

# The experiences of men receiving results of a prostate biopsy: a service evaluation

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## 1 Abstract

Cancer is a word that instils fear and uncertainty; therefore how a cancer diagnosis is communicated is paramount. This thesis is an evaluation of a service that enables men to telephone for the result of their prostate biopsy. The service has evolved over time initiated by patients need to know quickly whether or not they have cancer.

Current guidance recommends that a cancer diagnosis should be explained face to face. Evaluation of the service in 2007 by postal survey provided some evidence of support for our practice. However we wanted a deeper understanding of our patients' experience of using our service.

Using qualitative methods of enquiry with semi-structured interviews we purposively sampled patients who had undergone a prostate biopsy and were willing to share their experience of receiving the result. Interviews were recorded, transcribed verbatim and analysed thematically.

We interviewed 26 men, 22 of these had cancer diagnosed. Of those 19 had telephoned the uro-oncology nurse specialist (CNS) for the biopsy result. Our analysis generated 7 main themes; "I just wanted to know as quickly as possible", 'Preparation', 'Disposition', 'Service', 'Cancer=Death', 'Choice' and 'Support'.

The key message was speed. Patients want to know their results and quickly. It is important to them that the person explaining the results is knowledgeable in the subject. It is important that they are told the facts with sensitivity and kindness. Being told face to face is not essential.

We aim to tailor services to the individual needs of patients whilst keeping our practice evidence based. Our findings suggest that for some men explaining a prostate cancer diagnosis over the telephone is not only acceptable but preferable.

Our findings challenge the recommendations that a diagnosis of cancer should always be given face to face. Our 'expert' patients do not always concur with 'expert' opinion.

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### **3 Introduction**

The following thesis is an evaluation of a service that provides results of prostate biopsies to men over the telephone. It was a service initiated by patient demand. This practice goes against the recommendations and expert opinion for how to deliver a cancer diagnosis well. It is recommended that a cancer diagnosis is ideally given face to face and not over the telephone.

We wanted to explore the experiences of men receiving prostate biopsy results by different modes, telephone or face to face and to answer the following questions;

Is it acceptable to our patients to be told the results of their prostate biopsy over the telephone even if those results show cancer?

Is this choice of results delivery still wanted by our patients, i.e. should we still be offering this service?

Can we make any recommendations to improve our practice?

We begin by introducing prostate cancer, the incidence and mortality rates and the tests men have to go through to diagnose the disease.

We define what we mean by 'bad news' and the recommendations for breaking bad news. The literature looking at patients experiences of a cancer diagnosis, followed by the scant literature exploring patients' experiences of receiving a diagnosis of prostate cancer. We review the evidence or rather lack of evidence published supporting explaining a cancer diagnosis over the telephone. We introduce our service and explain how it has evolved over time describing the service as it is today.

We describe the methods used to evaluate our results service, followed by our findings. We present our findings and discuss these and the limitations of this evaluation with recommendations for future study and our overall conclusion.

## 4 Background

In order to appreciate the intricacies surrounding our telephone service it is important to have a basic understanding of prostate cancer, the vast numbers of men it affects, the tests the men have to go through to get a diagnosis and the background to why and how our results service evolved.

### 4.1 Prostate cancer incidence and mortality

Prostate cancer is one of the most common male cancers and has become a significant health problem worldwide (Lintz et al 2003). The number of men diagnosed with prostate cancer in the UK increased by 49% from 1998-2008 (Office for National Statistics [ONS] 2011). In the UK alone 37,000 men are diagnosed with the disease every year and 250,000 men are living with the disease (CRUK 2011). It makes up almost 25% of new diagnosis of malignant cancers in men in England and Wales. Prostate cancer accounts for the second highest number of deaths of men with cancer, second only to lung cancer (ONS 2011).

From the age of 50 incidence increases linearly with age, the biggest increase noticed in the 65-69 age groups (NICE 2008). It is estimated that about 50% of all men in their fifties have histological evidence of prostate cancer, which increases to 80% of all men by the time they reach 80 years of age. In the 1970's less than a third of men diagnosed with prostate cancer would survive beyond 5 years, only 20% would survive 10 years. Today more than three quarters of men newly diagnosed with prostate cancer will survive 5 years; nearly 70% will survive 10 years (CRUK 2011) and only 1 in 26 men will die from prostate cancer. Much of the increase in incidence can be accounted for by the increasing ageing population (ONS 2011), the Prostate Specific Antigen (PSA) blood test and increased public awareness.

Prostate cancer is common. It is common to the male population. It is *not* common to the individual patient. A man will only receive his diagnosis once.

### 4.2 How is prostate cancer diagnosed?

Prostate cancer is diagnosed with digital rectal examination (DRE) (Table 1), the PSA blood test (Table 2) and trans-rectal ultrasound scan and needle biopsy (TRUS/P). It can also be diagnosed following transurethral resection of the prostate (TURP), performed for relief of symptomatic benign enlargement of the prostate (BPH).

There is no national screening programme to detect prostate cancer which remains controversial (Barry 2008, 2009). Increased awareness of prostate cancer both nationally and locally including campaigns for men to have a PSA test has resulted in an increase in referrals and subsequent biopsies (Chapple et al 2002).

Many asymptomatic men will have the PSA test with little information about the implications of the test (Olliffe 2006) encouraged by their wives, friends and the media to have the test (Chapple et al 2008). A PSA blood test alone (unless above 100ng/ml) is insufficient to diagnose prostate cancer. A raised PSA does not necessarily mean the presence of cancer; a normal PSA does not mean the absence of cancer.

The UK Prostate Cancer Risk Management Programme (Department of Health 2001) states that;

“if your PSA is definitely raised, a prostate biopsy is required to determine whether cancer is present”.

Histology will also determine whether the cancer is high risk and needs treatment or if it can be safely monitored. Prostate cancer is graded using the Gleason grading pattern. The higher the Gleason grade the higher the risk of the cancer behaving aggressively (Table 3). Once a definite diagnosis is made further tests are needed (bone scan +/- MRI scan) before treatment can be discussed and planned.

<b>Clinical stage on DRE</b>	
T1	Prostate feels normal. Cancer localised to the prostate and can only be seen under a microscope
T2	Cancer can be felt but contained to the prostate
T3	Cancer can be felt through the capsule, will feel firm, may feel extension into seminal vesicles
T4	Cancer can be felt, prostate hard and irregular, spread to other organs, bladder neck, rectum, pelvic wall.
Further tests will be required to accurately stage the cancer with bone scan +/- MRI scan depending upon Gleason grade, PSA and treatment intent	

**Table 1: Tumour stage**

<b>Normal PSA level for age</b>	
Age	PSA
50-59 years	Up to 3ng/ml
60-69 years	Up to 4ng/ml
70 + years	Up to 5ng/ml

**Table 2: PSA**

<b>Gleason grade</b>	
Gleason 6 or less	Low grade and the cancer is less likely to spread
Gleason 7	Moderate grade
Gleason 8-10	High grade, cancer more likely to grow quickly and higher risk of spread.

**Table 3: Gleason grade**

### **4.3 Breaking bad news**

We will look at the evidence surrounding breaking bad news at the diagnosis end of the cancer trajectory as this is the area of interest with this service. Giving ‘other’ bad news over the telephone for example disease progression or moving from active treatment to control of symptoms can and should arguably only be done face to face so these studies have been excluded.

#### **4.3.1 What is bad news?**

Bad news for the purpose of this service evaluation is

“any information that produces a negative alteration to a person’s expectation about their present and future” (Buckman 1984:1597).

The determination of what news is bad news constitutes a subjective judgement in the mind of the receiver. Ptacek and Eberhardt (1996) describe that bad news is where there is feeling of no hope and a risk of upsetting established lifestyle or where there is a threat to physical or psychological well-being. They have suggested that bad news is bad because it results in cognitive, behavioural or emotional deficits in the person receiving the bad news that goes beyond the bad news encounter. Bad news needs also to be taken in context of what is happening in a person’s life at that time. Yet it is generally agreed that receiving any diagnosis of cancer is bad news (Fallowfield et al 1995, Maguire 1998, Baile et al 2001, Barnett 2002, Tobin & Begley 2008).

“to receive a diagnosis of cancer is a dramatic life event. It is a special challenge for a person’s resources to deal with the transformation of the view of oneself from being a healthy person to being a person affected by cancer” (Salander et al 1996).

This is important to remember. It is pertinent in relation to prostate cancer as often there will be no symptoms, the man will feel well and it is often a challenge for him to believe that he has a cancer diagnosis. Salander (2002) concluded in his analysis of 138 written narratives that bad news was better described as a process rather than an event. Subsequently we will discuss that seeing the diagnosis of prostate cancer as a process *may* aid men with the preparation for their diagnosis even if the initial shock cannot be totally removed.

In general most people equate cancer to death (Powe & Finnie 2003, Maliski et al 2002). Any cancer. Health Care Professionals (HCP'S) working within the field of prostate cancer do not necessarily see prostate cancer as a death sentence but rather as a slow growing disease which often does not cause death; an indolent disease of the aging population (Wall & Kristjanson 2004). Because of this disparity of understanding and the fear of death that any cancer causes, how this diagnosis is disclosed is of utmost importance.

No two people will respond in the same way to the same news, but the way in which the news is given can seriously influence their emotions, beliefs and attitudes towards the HCP and how they view their future (Fallowfield 1993, Fallowfield & Jenkins 2004). It is important to get it right and guidelines have been established to support professionals in the delivery of bad news (NICE 2004, Baile et al 2000, Garg & Buckman 1997).

If we agree that prostate cancer is bad news and that communicating this bad news badly can have a devastating effect on a person's coping and acceptance of their disease, what guidelines exist to steer professionals when giving this bad news and what evidence is this guidance based on?

#### **4.3.2 Recommendations**

In response to concerns from both hospital staff and patients that the way a diagnosis of cancer was delivered was often less than satisfactory a study was published by the Kings Fund (Walker et al 1996) which aimed to set up some auditable guidelines for consultations in which patients were given a diagnosis of cancer. The evidence for these guidelines was obtained by Qualitative research methods using patient semi-structured interviews (n10), focus groups (4) and feedback from consultants (n27). *All diagnoses were given face to face* by a surgeon. Although this study was conducted 16 years ago, and the National Health Service (NHS) has undergone many changes in that time, some of the issues remain pertinent today. Their findings acknowledged the 'shock' of a cancer diagnosis, made worse by lack of preparation or false reassurance. The language used was important and how the news was delivered regarding attitude and a caring manner. The telephone was not used and frowned upon by both patients and consultants for giving a cancer diagnosis. Based on these findings guidelines were published and have been used to inform both National and local guidance for delivery of a cancer diagnosis.

Four years later the National audit office conducted a large national survey of cancer patients' experiences and opinions involving responses from 65,000 patients (Department of Health [DOH] 2002). This survey provided a baseline on which to publish guidelines and improve access to health care (DOH 2000).

### 4.3.3 National and local guidance

NICE Guidance for Improving Outcomes in Urological cancers (2002) and Improving Supportive and Palliative care for adults with cancer (2004) report that patients and carers highly value *face to face* communication and recommend that

“A diagnosis should be communicated honestly to a patient with the minimum of delay. This information should be given in a comfortable quiet area with privacy and without interruption, ideally in the company of a close friend or relative (if the patient so wishes) and in the presence of a specialist nurse where possible.” (3.17 p58)

NICE guidance (2002, 2004) suggests that the guidelines outlined in the report *Breaking Bad News* (Walker et al 1996) might be followed.

The National Cancer Alliance (NCA) undertook a small scale exercise to enable patients with urological cancer to input their views into the NICE guidelines (2002). Qualitative methods were used in the form of a discussion group. The issues highlighted were not dissimilar to those reported by the Kings Fund (Walker et al 1996). The later published NICE guidelines “Prostate Cancer; diagnosis and treatment” (2008) endorse the above principles regarding communication of the cancer diagnosis.

Current local recommendations for delivery of bad news provide an 11 step approach to breaking bad news based on national guidance and expert opinion (Appendix I). It is recommended that ideally bad news should be given face to face and not over the telephone.

The CNS team providing the telephone results service have many years of experience looking after men with a diagnosis of prostate cancer and are very aware of the clinical significance and treatment options available for each stage of the disease. We are also very aware of the impact of a cancer diagnosis and the sensitive communication required and individual approach needed. We have all completed advanced communication skills training. The CNS explaining results of a biopsy over the telephone or face to face will always introduce herself by name; the word cancer is always used once to avoid uncertainty of the diagnosis. The patients who choose to telephone decide who is present with them at the time of diagnosis as they initiate the call.

In short National guidance based on some patient involvement with the use of surveys supports face to face delivery of a cancer diagnosis. Local guidance, although acknowledging the telephone, also recommends face to face delivery of a cancer diagnosis. Our service challenges these recommendations.

We continue to deliver cancer results by telephone. National guidelines and local guidance condemn this practice. What evidence exists, if any, to support our practice?



#### 4.3.4 What does the literature say?

Breaking bad news is a routine but difficult task for Health-Care Professionals (HCPs) and remains an emotive subject for all involved (Girgis & Sanson-Fisher 1995, McPherson et al 2001, Barnett 2002). There may be a dearth of evidence for giving a diagnosis of cancer by telephone but opinion articles regarding the best way to deliver a cancer diagnosis are plentiful (Paul et al 2009). SPIKES, a six step protocol for the delivery of bad news (Baile et al 2000) is often referred to in the literature and in guidance for the delivery of bad news. Here again the recommendation for face to face delivery of bad news is the expert opinion. Whilst some steps described may be useful to structure the bad news consultation and opinion articles may be of interest, we are focusing on the opinions and experiences of the bad news receiver rather than the opinions of the bad news provider.

A review of the existing evidence for breaking bad news to patients identified 4 RCT's, 27 descriptive studies, 2 case reports, 4 reviews, 25 opinion articles, 14 letters and 47 unclassifiable (Walsh et al 1998). The authors of this review concluded there was limited empirical data to assist HCP's in meeting the challenges surrounding the communication of bad news. Following on from this review Paul et al (2009) examined the literature published since 1995 to establish what progress had been made regarding the evidence base to guide clinicians when breaking bad news to patients with cancer. The review included 245 publications relevant to breaking bad news. Of these, 136 provided new data which consisted of 88 descriptive studies, 41 intervention studies and 7 measurement studies. Of the 41 intervention studies only 4 included patient psychosocial outcomes which involved measurement of anxiety and depression, distress, satisfaction and quality of life. The authors concluded that with only 1.6% of the published studies in the field of breaking bad news to patients with cancer providing an evidence base for practice, that current practice and training cannot be regarded as evidence based until there has been further research in this field. Fujimori and Uchitomi (2009) concurred that the literature for breaking bad news contained mostly descriptive evidence.

It is recognised there are significant challenges to developing empirical evidence in this field due to the complexities of communication and it may also be seen as unethical to randomise patients at such a vulnerable time, when waiting for a result that could show cancer (Thorne et al 2009, Parker et al 2005, Schofield et al 2003).

In the past many studies examining patient preference have concentrated on the information preferences of patients and how much information is wanted (Cassileth et al 1980, Lind et al 1989, Degner et al 1997, Meredith et al 1996, Fallowfield et al 1995, Butow et al 1996). Parker et al (2001) developed the Measure of Patient Preferences (MPP) questionnaire to assess patients' *preferences* for communication when receiving bad news about a cancer diagnosis or recurrence with the aim of focusing the bad news interview on the preferences of the patient rather than those of the clinician. Others have found this tool useful to assess patient preferences relating to a cancer diagnosis (Davison

et al 2009, Mauri et al 2009). Although this may be helpful for assessing patient preferences it does not help us to understand the experiences of patients hearing they have a diagnosis of cancer so that, as Health Care Professionals (HCP), we can learn from these experiences. More recently Cox et al (2006) carried out a quantitative study by survey of patients' experiences of information received and information needs and preferences. Disappointingly the 'what' is told rather than the 'how' it is told is reported.

With our service evaluation although we want to know if the telephone option is still wanted, and if it is preferred then why, we are also interested in the *experiences* of patients using our results service, in particular their experience of receiving their results over the telephone, as this practice is not recommended. The type of in-depth data needed to represent patients' experiences is best served by qualitative methods rather than large quantitative surveys. The numbers in the studies are smaller but offer a richer insight into the patient experience (Mason 2002, Liamputtong 2009).

#### **4.3.5 Patient experience**

Findings from studies using qualitative methodologies describe the mixture of shock, relief, disbelief, resignation and vulnerability felt by patients on hearing the diagnosis of cancer (Yardley et al 2001, McWilliam et al 2000, Randall and Wearn 2005). Receiving a diagnosis of cancer is arguably a process not a one off event (Tobin & Begley 2008). This emphasis that bad news is a step on a journey not an isolated event was a main finding of a small qualitative study examining the experiences of 15 patients receiving bad news (Randall and Wearn 2005). The above mentioned studies include patients with varied diagnoses; lung cancer (Yardley et al 2001), breast cancer (McWilliam et al 2000) and haematological cancers (Randall and Wearn 2005) yet their findings are very similar. 'How' the diagnosis is communicated is important, the language used (Yardley et al 2001), a sensitive and caring manner, creating hope without false reassurance, giving enough information but not too much, knowing the person giving the bad news (McWilliam et al 2000). The feelings of shock experienced at diagnosis and the feelings of vulnerability and lack of control which continued when the communication was not good were described. It is important to get it right.

All patients in the above studies were given their diagnosis face to face, not by telephone. A diagnosis of lung cancer has a high mortality rate, only 7-9% of patients will be living 5 years post diagnosis, for prostate cancer the 5 year survival is 77% (CRUK 2011). A significant difference and a strong argument for explaining a diagnosis of lung cancer face to face. None of the patients in the above studies had prostate cancer. Is a diagnosis of prostate cancer any different? What are the feelings and communication issues with our men?

### **4.3.5.1 The experience of receiving a diagnosis of prostate cancer**

#### **4.3.5.1.1 Emotions**

Studies focusing on receiving a diagnosis of prostate cancer are scarce. Yet recently there has been new interest in exploring men's experiences with prostate cancer. Some mention the diagnostic period reporting common themes throughout. The *shock* of the diagnosis was reported (Gray et al 1999, Oliffe 2004, Nanton et al 2009, Wallace & Storms 2007, Harden et al 2002). Men describe the *disbelief*, not ever having had a day's sickness and the *realization of mortality* (Oliffe 2006). The diagnosis phase is described with emotions such as '*shock*', '*fear*', '*anger*' and the association of *cancer and death* (Wallace & Storms 2007, Harden et al 2002). Managing the *uncertainty* was a major focus of two studies (Harden et al 2002, Nanton et al 2009) and related to the participants need for information which is supported elsewhere in the literature (Sinfield et al 2008, Maliski et al 2001). The feelings described at diagnosis by men with prostate cancer are no different to the ones described by patients with other cancer diagnoses.

#### **4.3.5.1.2 Communication**

Nanton et al (2009) reported on the aspects of the communication of the diagnosis and confer with national guidelines where *maintaining eye contact* and appearing *unhurried* were important to the men. Demonstration by the consultant that he had *expertise and knowledge* of the disease and treatments gave the men confidence and feelings of *trust* and *hope* for the future (Nanton et al 2009), alleviating feelings of anxiety and despair (Papadopoulos & Lees 2003). Appreciation of the consultation was further increased if the men were given a *point of contact* at the hospital for any further questions or concerns (Nanton et al 2009). Harden et al (2002) highlight the *need for information* and the *lack of knowledge* about prostate cancer reported by participants prior to the diagnosis.

The overall message from the literature is that a diagnosis of prostate cancer is bad news. It instils emotions such as fear, shock, uncertainty, anger. Cancer is associated with death; lack of knowledge impedes coping; fear thwarts ability to absorb and process information, if it is available. With the aforementioned studies the cancer diagnosis was given face to face. With the reported risk of long-term maladaptive psychological impact of being told a diagnosis badly it is important to get it right (Faulkner and Maguire 1998). In the main expert opinion appears to concur with the patient experience studies; a cancer diagnosis should be delivered face to face.

So what are we doing providing our service? We will now explore the literature relating to receiving a diagnosis of cancer over the telephone; as expected the evidence for delivering a diagnosis of cancer over the telephone is scarce.

#### **4.3.6 Review of the literature for delivering a cancer diagnosis by telephone.**

A search of the databases CINAHL, MEDLINE, PsycINFO was performed using the following search terms; neoplasm/truth disclosure/ communication/ Diagnosis/ Patient Satisfaction/ adult /or aged/ or middle aged/ young adult/ Truth Disclosure/ Professional-Patient Relations/ truth telling/ breaking bad news. The search was restricted to papers published in English, duplicates removed and studies selected on the following criteria. *Adults, receiving a diagnosis of cancer, by telephone.* Observational studies were included not interventional studies. We were only interested in patient experience or preference *not* HCP opinion. A manual search of the references cited in the articles was also conducted.

Following the inclusion criteria and including the manual search 11 articles were identified.

##### **4.3.6.1 Methods used**

Mainly quantitative methods were used in these studies which included 7 studies via postal questionnaire (Loge et al 1997, Azu et al 2007, Mauri et al 2009, Schofield et al 2003, Fujimori et al 2007, Davison et al 2004, Figg et al 2010), and 2 by telephone survey (Baumanis et al 2009, Purnell & Arnold 2010). The remaining two studies used qualitative methods; written narratives (Salander 2002) and semi-structured interviews (Thorne et al 2009).

Only one paper focused specifically on receiving a cancer diagnosis by telephone (Purnell & Arnold 2010), the other 8 studies only commented on this mode of delivering a cancer diagnosis in their results or discussion. Due to the dearth of evidence in the literature we have also included a survey by Baumanis et al (2009) exploring patients' experiences of receiving a genetic test result for breast cancer by telephone.

##### **4.3.6.2 What did the results show about patient preference for receiving their results?**

Patient *preference* for receiving a cancer diagnosis was reported by Mauri (2009), Fujimori (2007) and Davison et al (2004). Davison et al (2004) used the Measure of Patient Preference (MPP) questionnaire. This quantitative tool developed by Parker et al (2001) asks patient to rate 32 items on a 5 point Likert scale to examine their preferences for receiving a diagnosis of cancer. Davison et al (2004) used it to survey men attending for a prostate biopsy. Being told in person rather than over the telephone did not feature in the top 16 most important aspects of receiving their diagnosis. The overall content of the message was more important than the supportive aspects of the communication. In stark contrast the same MPP tool used by Mauri et al (2009) found that the number one most important item by patients was being told face to face. This patient sample also included those who had a recurrence of their cancer or progression of their disease. It would be hard to argue against the importance of having a conversation face to face where disease progression or recurrence is the subject of discussion and this may be reflected in those findings. Fujimori et al (2007) reported that

90.7% of patients *preferred not* to be told their diagnosis over the telephone, and only 2.7% stated that they would prefer the telephone.

#### **4.3.6.3 What did the results show about patient satisfaction/experience with receiving results by telephone?**

Of the seven surveys by postal questionnaire higher *satisfaction* of face to face delivery of results was reported by Loge et al (1997) where 19% (n90) were told their diagnosis by telephone. Figg et al (2010) reported 18% (n79) were their told diagnosis of cancer over the telephone. Patient satisfaction with delivery of diagnosis reported those receiving their diagnosis in person had a significantly higher mean satisfaction score than those who received their diagnosis by telephone. Four examples of very poor communication by telephone were cited. On all occasions the doctor had called the patient at home with no prior arrangement to do so. One doctor left a message on the patient's answerphone to say he had a lymphoma! The authors conclude that the diagnosis should be given face to face rather than by telephone; the consultation should take longer than 10 minutes and the discussion should include more than just the diagnosis. Azu et al (2007) reported that 40% of the patients in their survey received their diagnosis by telephone but no further comments or analysis were made other than that 66% said eye contact was important. It isn't made clear if this 66% includes some or all of those who received their diagnosis by telephone. Schofield et al (2003) looked at patient preferences and experiences. All 131 respondents had received a diagnosis of melanoma; 42 were told their diagnosis by telephone, 89 face to face. The satisfaction with communication of the diagnosis was similar with both modes of delivery, 64% (face to face), 63% (telephone). The authors do not comment any further on the telephone delivery so we do not know if the telephone delivery of their result was agreed with the patient first.

Thorne et al (2009) reported on particularly unhelpful communication of the diagnosis which included 25 of the 60 patients in their study. How many patients received their diagnosis by telephone is not reported but for some who did, it signalled that they deserved the information as soon as possible and alleviated the anxiety of waiting, whilst for others it showed a distancing mechanism by the HCP and a failure to individualize communications. Findings demonstrated that 1 year later 7 of those 25 patients who encountered the early difficult diagnostic experiences still recalled this as being a problem and this had appeared to affect their relationships and trust of HCP's along their journey; illustrating how important it is to get the communication right at the start of the cancer journey.

Salander (2002) used written narratives from 138 patients describing the delivery of the bad news from the patients' perspective. Telephone delivery is not the focus of the paper but 20% had received their diagnosis by telephone. Few openly scorned the use of the telephone; one patient complained that the telephone *hadn't* been used as he was expecting a cancer diagnosis and had a long distance to travel to the hospital. Salander (2002) argues that it isn't just the means of communication but the

status of the relationship that is important. If the patient is prepared to receive the call and there is a mutual agreement that the diagnosis will be received by telephone, the patient is satisfied. Equally, if there is no preparation and a call is unexpected the result may be catastrophic. To emphasize again, our patients initiate the telephone call, the CNS would *never* call a patient without specific prior arrangement to explain a cancer diagnosis. For results of a prostate biopsy the patient *always* initiates the call.

Only one study identified concentrated solely on the telephone as a mode for results delivery. Purnell and Arnold (2010) surveyed perceptions of women receiving breast biopsy results by telephone. A 50.4% response rate was reported (n66). Of these, 39 women had a benign result and 27 had cancer. The results were delivered by a nurse who had met the women at the biopsy clinic and it had been agreed that the results would be explained over the telephone. The women were offered a choice to either telephone the nurse or that the nurse will telephone them. The most important factor identified for these women was speed of getting results, followed closely by the results being delivered by someone who can interpret the results. Whilst the results of this survey clearly point to speed as being most important, no comparison is made with face to face delivery as this is not an option for these women. The authors identify the need for further research in this field to look at patient understanding and long-term psychological outcome after receiving breast biopsy results over the telephone.

Due to the paucity of evidence exploring patient experience of receiving cancer results by telephone the following study has been included. Receiving a result by telephone of a positive BRCA 1/2 gene test can have far reaching consequences for the patient and can be described as bad news as the result can have a serious effect on how one views his or her future (Buckman 1992). Mutations of the BRCA1 and BRCA2 genes result in an increased lifetime risk for developing breast cancer by 50-80% and 1 in 3 carriers will develop ovarian cancer by the time they reach 75 years (CRUK 2011).

Baumanis et al (2009) surveyed patient satisfaction of receiving BRCA1/2 genetic test results by telephone. Of 137 women, 51 had received their results by telephone, of those 5 would have preferred face to face; 82 received their results in person, of those 11 would have preferred the telephone. Those who received their results within a week of knowing the results were available were significantly more satisfied than those who had to wait a month or more for their results. Significantly higher satisfaction was reported in those women given a choice of results delivery than those given no choice. No significant difference was reported in satisfaction with telephone compared to face to face delivery. The majority of counsellors reported that they would encourage their patients to come to clinic to receive results face to face. The authors suggest that speed of results delivery is most important and offering a choice to patients of results delivery is desirable.

#### **4.3.6.4 Were there apparent gender differences in the findings?**

Does gender play a part in patient preference for communication based on the differences in the way men and women communicate and interact? Men often display a more information orientated approach and women a more emotion orientated approach, although this in reality is far more complex (Andersson et al 2008). This question was based on the grounds that the experts recommend face to face communication, but patients having a prostate biopsy say the telephone is the acceptable and sometimes preferred mode of communication, these patients being men. Davison et al (2004) surveying men attending for prostate biopsy would back up these initial inclinations with face to face delivery of results not featuring in the top 16 out of 32 most important factors when receiving a cancer diagnosis.

The survey by Mauri et al (2009) completed by 153 women and 57 men show entirely opposite findings to those of Davison et al (2004) in that face to face delivery was the number one most important factor. Mauri et al (2009) do not report on the gender split for each response. With Thorne et al (2009) the sample of female respondents was predominantly higher than male but there is no report of patient preference only experience. Azu et al (2007) included an all-female sample with a diagnosis of breast cancer and Loge et al's (1997) sample included 76 female and only 14 male, with both of these surveys face to face was reported to be the preferred mode of delivery. Yet we cannot presume that men are more prone towards telephone communication especially in view of the more recent findings by Purnell & Arnold (2010) and Baumanis (2009) where only women were included in their sample. It is suggested that researchers should not focus on gender in isolation of other factors such as age ethnicity and nationality which may correlate with behaviour, beliefs and perceptions (Street 2002).

#### **4.3.6.5 Did age, ethnicity or nationality influence the findings?**

The mean age for all the aforementioned studies did not differ greatly and ranged between 56-62 years, slightly younger than our average patient population.

The included studies were all published in English but covered a wide range of cultural diversity including Australia (Schofield et al 2001), Canada (Davison et al 2004, Thorne et al 2004), America (Baumanis et al 2009, Purnell & Arnold 2010, Azu et al 2007 Figg et al 2010), Norway (Loge et al 1997), Sweden (Salander 2001), Italy (Mauri et al 2009) and Japan (Fujimori et al 2007).

Where receiving a cancer diagnosis by telephone was reported strongly as not being the preferred option, the studies were carried out in Japan and Italy and may be based on cultural differences (Uchitomi & Yamawaki 1997, Karim 2003, Surbone 2006). The two studies that challenge current thinking about the best way to deliver a cancer diagnosis or test results that can be classified as bad news were both carried out in America, which again may have cultural significance (Purnell & Arnold 2010, Baumanis 2009).



In summary there is a lack of research looking specifically at explaining a diagnosis of cancer over the telephone. Where the telephone has been mentioned in the literature, this has been mainly in a negative light with patients reporting experiences where telephone calls had been received unexpectedly and without previous agreement or, it has been reported as not the preferred method of communication (Loge et al 1997, Azu et al 2007, Mauri et al 2009, Fujimori et al 2007, Figg et al 2010). Most of the included studies concur with both expert and patient opinion that face to face communication of a cancer diagnosis is preferred and seen as best practice. This is reflected in published guidelines for delivering bad news (NICE 2002, 2004, 2008). Yet, the only study we identified that has explored patients' experiences of receiving a cancer result over the telephone challenges the current recommendations (Purnell & Arnold 2010). The important finding from this survey was that the women were prepared and had agreed to receive their biopsy results over the telephone. Although they were not given an alternative, i.e. to receive the result in person, the women were given a choice of initiating the call or being telephoned by the nurse who they had met at the clinic. Speed of receiving results was important to the women and that the person explaining the results could interpret them. In the survey conducted by Baumanis (2009) women did have a choice of receiving results by telephone or face to face and having this choice increased their satisfaction as did receiving results quickly. To our knowledge there have been no studies looking specifically at patients' experiences of receiving prostate biopsy results over the telephone; or indeed any studies exploring patients' experiences of receiving any cancer diagnosis over the telephone using qualitative methods of enquiry. This service evaluation addresses both these issues.

We will now revisit the question we posed before we reviewed the literature. Why are we explaining a diagnosis of prostate cancer over the telephone? Reassuringly it wasn't a kneejerk response to the cancer targets (DOH 2000) to ensure patients moved quickly along the pathway. So, if it wasn't in response to targets how did we find ourselves in this position, of providing a service to patients with no evidence to support this practice, indeed going against recommended best practice for communicating a cancer diagnosis?

The answer, at least to that question is simple; patient need. The patients' need to know their results-quickly.



## **4.4 Receiving results of a prostate biopsy, the evolving service.**

### **4.4.1 Prior to the telephone service; what used to happen?**

Biopsy of the prostate would take place under local anaesthetic (LA), with antibiotic cover and ultrasound guidance. The results reported in 5-10 days, an appointment then sent to the patient for the results. Results are either normal (benign), suspicious (sometimes requiring repeat biopsy) or show cancer when a grading will be reported (Gleason grade). The appointment to receive the results varied from 3 weeks at best to 12 weeks at worst. Waiting for results of a test that could confirm or deny a cancer diagnosis is widely acknowledged as a stressful period in the patient's cancer journey (Thorne 1999, Padgett 2010, Leydon et al 2002). It has been suggested that the uncertainty of waiting to know is worse than the actual knowing cancer is present with patients reporting the moment of diagnosis as upsetting but, on reflection, seeing it as the point at which coping begins as they are able to regain control of the situation and move forward (Walker et al 1996, Wong et al 2000 Gaston, Mitchell 2005). This anxiety of waiting led some patients to ask to telephone the CNS for their results; to know quickly. We acknowledge bad news, given badly, can have a profound effect on the patient's acceptance and ability to cope with their disease with lasting negative psychological impact affecting ability to cope with future treatments (Faulkner and Maguire 1998). We did not proceed to meet the request of patients to telephone for their biopsy results without careful consideration and higher authority.

Agreement was reached within the Trust and urology department that the CNS could explain biopsy results over the telephone if asked to by the patient; on their understanding the result could show cancer. This practice was unusual at that time. As numbers of referrals increased so too did the number of men telephoning for results. Some would only wait 2 or 3 days before telephoning, although asked to wait a week. Patients with benign results would be telephoned to end the anxiety of waiting. The numbers telephoning for results increased in a very ad hoc fashion. The patient would be prepared to receive the result as they had initiated the call yet the CNS was not always primed to deliver the result in this way. With the patient knowing their result, they were keen to move forwards. Staging scans were booked and the consultant appointment rearranged for after the scans. This appointment was deemed to be more productive as the patient had overcome the initial shock of the diagnosis and was ready to hear the plan of treatment following the staging scans (McGlynn 2004). The added benefit was the patient pathway was swifter enabling national cancer targets to be met, at a time when demand outstretched capacity. Although we (CNS's) could see the benefits both to the patient, easing the anxiety of waiting and the resulting benefits to the oversubscribed clinics we had concerns this practice had snowballed without any existing evidence to support it. Indeed this practice, although patient led, was contraindicated to recommended best practice for breaking bad news (Walker et al 1996, NICE 2002, 2004). We had concerns that patients were feeling pressured

into using the service and it was no longer patient led but seen more as a necessity for meeting ever increasing demands.

In response, we audited the telephone service by anonymous postal survey in 2007. We hoped to gain evidence to either disband or support this practice. The delivery of bad news recommendations are in the main based on expert opinion (Paul et al 2009). Whilst we can argue that the experts have experience of delivering bad news to patients and may be best placed to set the guidelines, we could also argue that our patients are the experts with the experience of waiting (NICE 2004). On the other hand it is often the patient's first experience of waiting for results or receiving a cancer diagnosis, so others would argue they are far from expert. The argument could go on. Suffice to say the audit showed overwhelming support for the service and patients were keen for it to continue. We (CNS) felt a little more at ease with delivering the results by telephone. The post biopsy information sheet was updated and the telephone service established as a choice for all men undergoing prostate biopsy under LA.

#### **4.4.2 The results service post audit**

Improvements to the service included changes to written information. It is clearly explained the biopsy is to look for cancer; the results will be available in a week; they can telephone for the result if they wish (appendix II). A 2-3 hour period and date is printed on the post biopsy advice form with the CNS name who will be answering the telephone. Options for receiving results are explained at the biopsy clinic. If a clinic appointment is preferred this will be arranged; realistically this is at best 2 weeks post biopsy. Some men request the result is faxed to their GP. The time slot enables the CNS' to have dedicated time to deliver the results. A prostate cancer booklet is posted and a summary of the call. Staging scans are requested by the CNS to protocol. The patient is prepared for the possible results and always initiates the call; the CNS is prepared for the call with the patient's notes and results ready. The histopathology department are made aware when the patient will be told their results and endeavour to have the results reported in that time; it is rare for the results not to be ready.

Despite positive feedback with patients expressing gratitude for the opportunity to telephone quickly to know 'one way or the other', and being slightly more at ease with the service provided, we still had reservations. The numbers of patients using the telephone results service was ever increasing; it had become the 'norm' rather than the exception. We wanted to know more about their experience. Was offering to explain results over the telephone acceptable to patients? Was this choice still wanted? Could we make further improvements to the service that would make a difference to our patients' experiences?

Questions remained that could not be answered in the depth we needed by a postal survey. An opportunity arose to apply for some funding for a small research project from the East of England

Strategic Health Authority. Funding was granted and the following pages report on our service evaluation using qualitative methods of enquiry.

## 5 Methods

### 5.1 Population

The population for the service evaluation included men referred for and who proceeded to Trans-Rectal Ultrasound guided biopsy of the Prostate (TRUS/P) under local anaesthetic (LA) in the urology outpatient department of a NHS Hospital in the East of England from 17<sup>th</sup> August 2010 to 31<sup>st</sup> December 2010. The biopsy is performed to obtain histological evidence of suspected prostate cancer.

#### 5.1.1 Sampling

We aimed to recruit men receiving both positive (cancer) results and negative (benign) results. The intention was to inform how we could improve delivery of results for *both* groups of patients by exploring their experiences. All men were telephoning for a *result*, they would not know if the biopsy was benign or cancer. We wanted to understand in particular how the results were received if they showed cancer. With this in mind we aimed to recruit 30 patients, 5 with benign results and 25 with cancer results who had received their prostate biopsy results by telephone or conventional method (face to face). We wanted a more in-depth understanding of patients' experiences and felt that any greater number of participants would reduce the quality of the analysis (Patton 2002). The sample size was adjusted as data saturation was reached. Although the response rate was high (85%) with our audit in 2007, this was a survey via anonymous postal questionnaire. With the proposed service evaluation we were asking participants to be interviewed and recorded at an already anxious time, and we were uncertain what the response rate would be. We wanted to include the experiences of men from all age groups and grades of disease. The clinical stage, mode of results delivery and demographics were assessed as data collection progressed and then we purposively targeted specific groups if absent from the data sample. Demographic details were recorded.

#### 5.1.2 Exclusion criteria

Names were taken from the patient attendance list of the TRUS/P clinic. Patients were excluded with known metastatic prostate cancer (clinically diagnosed but having biopsy for histological purposes only). These men are telephoning for the Gleason grade not to find out if they have prostate cancer. The numbers of men undergoing TRUS/P for histological confirmation are small. Patients were excluded if they had significant communication difficulties; dementia, psychosis, non-English speaking and dysphasia. Access to a telephone was required. Men with impaired hearing are given all the options, *if* the patient requests and it has been agreed to discuss the results with his wife or significant other, so were not excluded. This agreement is documented.

## **5.2 Ethics**

Ethics opinion was sought from the NHS Ethics committee at the Local NHS Trust and was approved as and classed as a service evaluation (Appendix III). Written approval was gained for the service evaluation to proceed from the clinical director, ethics committee and Caldicott approval was obtained. Although seen as a service evaluation as the interviewer I was mindful that I was asking men to reflect on what could be a painful experience for them, and although not wishing to cause distress, I realised the potential distress we could cause. The participants were being interviewed at a vulnerable time and facing many uncertainties, not only about their future but also treatment uncertainties (Nanton et al 2009), and for some they had many more choices to make. Free counselling services were available if participants felt they needed additional support we were unable or not qualified to provide. The protection of patients' confidentiality and anonymity were central to the process and the ethic of non-maleficence (Beauchamp & Childress 2001) was paramount in the practice of collecting and storing data.

Prior to commencing the interviews the information sheet (appendix II) was checked through with the participant to answer any questions or concerns. Written consent (appendix V11) was obtained prior to commencing the interview and the dictaphone. I also ensured the participant understood the recording would be transcribed word for word by a third party. The recorded interview was password protected prior to sending for transcription. No patient details were recorded, the recorded file was identified by participant number only. Verbal consent was obtained prior to switching on the dictaphone and only when the participant had given written and verbal consent to all the aforementioned issues, and that he indicated he was ready, did the interview begin.

Anonymity was maintained by the patients' identity being known only to the interviewer. I am bound by my own professional code of conduct, performance and practice (NMC 2008), Data Protection Act (1998) and by the NHS Code of Practice on Confidentiality (DOH 2003), which incorporates the Caldicott principles. Transcripts and demographic details were coded by number and any names used were removed at the earliest opportunity. The code book had the patients identity number and initials and was kept in a locked drawer in the CNS office on the hospital site and only accessible to me. This was the only access to the patients' identity. The code book will be destroyed in line with Good Clinical Practice (GCP) Guidance.

## **5.3 Recruitment**

One week after receiving results either by telephone or face to face consultation a letter of invitation (Appendix IV) patient information sheet (Appendix V) and an expression of wish form (Appendix VI) was posted to the patients selected from the clinic list. We asked that they returned the form regardless of whether or not they wished to participate. If no response within 2 weeks I planned to telephone the patient to see if the letter had been received or enquire if they minded saying why they

did not wish to take part. A log book of recruitment letters sent and returned was kept; non responder details recorded. The timing of sending invitations was debated with the steering group. We wanted to capture views before the initial shock of the diagnosis was over; the experience still fresh in their minds. The response rate had been high in our previous audit of the service (85%); questionnaires had been posted a week after the results were received. We could have waited 6 months but felt the trauma of the event could have subsided, sealed over, so we would not get a true picture. The advantage of waiting 6 months would have allowed the men time to reflect on their experience and see it in a different light. With the benefit of hindsight they may have given different opinions. Overall we agreed we wanted an account of their experience as close to the event as possible so invitations were sent a week after results were received aiming to interview within 6-8 weeks of receiving the biopsy results.

## **5.4 Location**

I telephoned those willing to be contacted to answer any questions, check they had understood the interview would be audio recorded and that they were still happy to participate. If still willing, the interview was arranged at a mutually convenient time and venue to suit the participant; at home or hospital. Those who preferred to come to the hospital were ideally interviewed in the Cancer Information Centre, in the hospital grounds but away from the clinical environment. This provided a more relaxed atmosphere was less prone to interruption and privacy and confidentiality was respected as conversations could not be overheard. The alternative plan when a room was unavailable was the nurse office or a clinic room in outpatients, although the clinical environment was less than ideal with the risk of interruption.

## **5.5 Consent**

Written consent was obtained prior to interviewing (appendix VII). The original consent form was kept in the code book, a copy in the patient's notes with study identity code removed. I went through the patient information sheet (appendix V) prior to interviewing, checking the participant understood and was happy to proceed with the interview.

I acknowledge in my role as an uro-oncology nurse I am in a position of power. The participants either had a diagnosis of prostate cancer or, if benign, may need further biopsies in the future. Still under our care they may not have felt able to say no or change their minds. I made it clear that their care would not be affected either adversely or favourably by consenting to take part in the service evaluation; yet they were in a vulnerable position and I was asking for their trust. To influence their care, favourably would not be ethical and would breach my professional code of conduct (NMC 2008) but I acknowledge participants may have seen this as an advantage of 'helping' with the service evaluation. Alternatively, if the participant was seen as 'unhelpful' or not giving the 'right' answers, or unhappy with the service I could influence their care adversely; not something I would do but I

acknowledge these are thoughts that could have gone through participants' minds when considering taking part. Others may have had altruistic motives and been keen to give something back if they have had a good experience or to report a bad experience to prevent this happening to someone else. What was important was that I was aware of my own and others possible agenda's and ensured that there was an understanding that taking part would not affect their care either way. Consenting to being interviewed and audio-recorded does not mean consent to whatever questions we wanted to ask (Mason 2002). As part of the consent process I made it clear to the participants they could refuse to answer a question or stop the interview for whatever reason.

## **5.6 Data collection**

The interview meeting was arranged as close as practically possible to the time of receiving their biopsy results, at the patients chosen venue. We chose semi-structured interviews. This method of collecting data allows structure with the interview, focusing the interviewer and the interviewee but without being too rigid to enable the questions to be addressed (Liamputtong 2009). This method enabled us to capture the experience in the patient's own words and the process is based on the existing skills of conversation which most people possess and it also requires minimum specialist equipment (Taylor 2005, Low 2007). There are drawbacks to this chosen method that we acknowledge. Although I am used to 'interviewing' patients in the clinical setting I am a novice interviewer in this environment and may not have elicited the in-depth information and quality of information needed to answer our questions and understand their experience of our service.

We could have used other methods. Postal survey via a questionnaire would have given the patient greater anonymity avoiding the face to face encounter and the possible pressure of the interview whilst being audio-recorded. Yet we wanted to get beneath the 'satisfaction with the service' reported from the audit (2007) and explore patient experiences of receiving results in more depth. We wanted to enquire what had influenced their choice; if they felt they had a choice; with the benefit of hindsight would they have made the same choice. We wanted to explore how their diagnosis was received, what that experience was like and how we could improve the service or even if it was a service still wanted by our patients. We did not feel we would get this depth of information from a postal survey by questionnaire.

We could have used unstructured interviewing and allowed the patient to focus on the issues important to them. With this method we would have risked not getting the answers we needed to evaluate the service and answer our fundamental questions. We needed some structure to maintain the focus of the interview whilst allowing participants to cover areas they wished to explore (Liamputtong 2009).

Salander (2005) maintains that written narratives as a method may be an advantage when dealing with 'controversial and loaded topics' (which we are clearly doing) as they put participants under less

interaction pressure. He noted that the men often wrote shorter less personal accounts of their experience compared to the women. Written narratives rely on the writing skills of the participants and are dependent on participants having the language to describe their experiences. This may have been an obstacle to some participants in our study and using semi-structured interviewing enabled those participants to take part.

An arguably robust method for investigating patients' experiences would have been focus groups. Focus groups have been widely used to explore the experiences of patients with cancer (Wagner et al 2010, Kazer et al 2011, Carter et al 2010). It is argued that people with similar health experiences are more likely to talk openly with each other because of their shared experiences (Liamputtong 2009). Our sample certainly had shared experiences; of TRUS/P biopsy and receiving the results. One of our concerns related to gender, would men openly discuss their experience in a group of strangers? It has been suggested that focus groups are particularly good to elicit information from people who are seen as 'difficult subjects' i.e. men. Rubin (2004) used focus groups successfully when exploring men's attitudes to Viagra and others have successfully used focus groups when exploring men's experiences with prostate cancer (Wallace & Storms 2007, Harden et al 2002, Kazer et al 2010). We have a locally established prostate cancer support group, the members of which are always keen to assist us. Men involved with the support group are willing to talk openly about their diagnosis and experience of treatments; not an argument to disregard focus groups as a method. When the purpose is to identify areas where practice can be improved canvassing support group members can be useful as they are used to talking openly about cancer and exchanging ideas (Walker et al 1996). We were evaluating our service and wanted to hear patients' experiences as close to receiving their results as possible. At this early stage they may not be in contact with the group and not ready to disclose their diagnosis to others, still coming to terms with their own diagnosis (Gray et al 2000). Recruitment may have been more of a challenge. If men agreed to focus group participation it would be assumed they were keen to share their experience with others. This could prove an obstacle to men who were not able to talk about their diagnosis to strangers, on the other hand as previously argued it may have helped them with the acceptance and feelings of isolation they may be experiencing. Another perceived problem would have been arranging a time to suit all, within the timescale, and may have excluded those men still working. Importantly to get the best out of a focus group we would ideally need an experienced researcher not a novice to be the moderator for the group.

Although some of the other methods discussed could have been used for this service evaluation and may be appropriate for future evaluations in this field, for the present project with the novice researcher, the timing of events, the need to explore experiences with the aim of evaluating the existing service and seeing if it was an acceptable choice for patients, semi-structured interviews as a method was the most fitting.



The interviews were carried out by me. As previously mentioned the participants were and are still under our care and may not have felt comfortable making any criticism. As I am one of the service providers the men may have been reluctant to find fault with the service and be honest with their views. Alternatively because of my intimate involvement with the service we could argue that I was in the best position to interview them as I could empathise and relate better with them during the interview with this inside knowledge of the service.

To begin I explained the aims of the service evaluation and the background. I checked they had understood the patient information sheet and were happy to consent to audio-recording. If a participant had changed their minds about being recorded I would have asked if they were happy for me to take notes; in practice this didn't happen. Once written consent had been obtained I asked the participant if he was happy for the recording to commence before turning the dictaphone on.

We had a pre-prepared list of questions, devised following review of the literature and in collaboration with supervisors. There were certain questions we wanted answers to, e.g. perceived choice for receiving biopsy results; we wanted to know if it is acceptable to patients to telephone for their biopsy results even if they could show cancer. Was it acceptable to offer a choice? What influenced men's decision regarding mode of results delivery? We were interested in both positive and negative experiences, to make improvements to the service of receiving prostate biopsy results based on the patients' perspective. Had the information received been understood? What impact the loss of face to face communication had if any? A list of questions was peer reviewed, amended, and then agreed with the steering group which included a patient representative. The final list of questions was typed on one page only, one for each participant. This would enable me to take notes during the interview which may assist with the analysis and interpretation of the data (Liamputtong 2009).

We started with an opening question with the aim of allowing the participants to talk at length "can you tell me about how you received your biopsy result?" This allows the participants to choose which part of the subject they want to emphasize and even more importantly where they wish to start (Kvale 2007). In practice this was not always the case, as some participants were not quite sure what I meant to start with, particularly in the earlier interviews. Further questioning was designed to encourage participants to elaborate on their answers. Additional questions addressed issues we wished to explore (appendix VIII).

## **5.7 Audio recording**

We decided audio-recording would be the best way to capture the discussion. Alternatively we could have recorded the interview manually. Yet we would not have been able to capture tone of voice, tapings of irritation, utterances and the speed at which notes would need to be taken may have rendered them illegible. Notes were taken but knowing the interview was being recorded enabled me to concentrate on the interview allowing it to flow more freely. Disadvantages to audio-recording

interviews are that it can inhibit responses; the interviewer needs also to feel comfortable and confident using the equipment. There is the potential for user error, equipment failure and batteries to run out. Minimizing this was achieved by lots of practice, becoming familiar with the device prior to using it 'live', taking spare batteries, checks prior to interviews. Post interview the recording was downloaded and stored in a password protected file. The dictaphone recording deleted. During the interview, once permission was gained and consent form signed the participant was at liberty to ask the recorder to be stopped at any time and on occasions when a man became emotional I asked if he was okay to continue or if he wanted to pause with the interview. In practice I found that most of the men forgot about the machine even if the interviewer didn't.

## **5.8 Transcribing**

The recordings were sent securely the same day for transcription. On return the transcription was checked for accuracy against the recording and any names of people or places removed to protect the identity of the patient, family and HCPs. Often with qualitative research the analysis begins with the transcription, the researcher becoming absorbed in the data whilst transcribing (Liamputtong 2009). I can be criticized for employing a third party to transcribe with the risk of the recordings not being transcribed accurately and pauses and utterances, tone of voice not being noted. Transcribing an hour long interview can take an experienced transcribe up to 6 hours (Liamputtong 2009). This is not a valid argument for employing a third party, yet transcribing verbatim is a skill that I do not possess and felt with the importance of accuracy it was better left to a trained professional with expertise. Anxious not to miss anything I checked each transcript against the recording as soon as it was received, prior to sending to the patient, for accuracy of the transcription. I immersed myself in the data by listening to each recording on at least 2 more occasions, making notes and noting tone, emotions, using my field notes also to prompt my memory of the interview. Reading and re-reading the transcripts made me very familiar with the data set.

After the interview the participant was asked if they would like a copy of the transcript to check accuracy and add any further comments. The transcripts were posted with a letter of thanks (appendix IX) and a pre-paid return envelope enclosed asking for the return of the transcripts within a week. A record of transcripts sent and received kept in the locked drawer.

Throughout data collection I read through the transcripts looking for any patterns emerging. Some changes to the service were made along the way in response to patient feedback and interview questions tweaked.

## 5.9 Analysis

Thematic analysis is a method for identifying, analysing and reporting patterns within the data (Braun & Clarke 2006) through careful reading and rereading of the data. We planned to use this approach as not only is it understandable to the novice researcher, it also offers a flexible approach to analysing the data with the potential of gaining a rich and detailed account of patients' experiences which is what we sought to achieve (Braun & Clarke 2006). Thematic analysis is broadly similar in its techniques used for analysing data as grounded theory but the main difference is that grounded theory includes theoretical sampling and thematic analysis does not (Liamputtong 2009). Grounded theory aims to generate, develop, or construct a theory out of what has been learnt from participants. The methods used for data collection are often in-depth interviewing, written narratives and ethnography (Charmez 2006, Corbin & Strauss 2008) and as we have argued we wanted to maintain a degree of focus which semi-structured interviewing allowed. With Grounded Theory the theory generated is 'grounded' in the data from the participants experiences (Cresswell 2007, Charmez 2006). Although we wished to explore our patient's experiences of our results service we also wanted answers to specific questions about whether or not this service should be offered and if improvements could be made, we were not aiming to construct a theory, hence Grounded theory was discarded.

We explored using the Framework Approach analysis which has been developed for policy relevant research and hence increasingly used in health-care research where there is often a need to link the analysis with quantitative findings (Pope et al 2000). Framework analysis is highly structured and although we were asking set questions we wanted to explore issues as they arose. Therefore with the use of semi-structured interviews, audio recorded and transcribed verbatim, using a thematic approach to the analysis allowed emerging themes and patterns within the data to be expanded upon. Thematic analysis as described by Braun & Clarke (2006) guided the analysis.

Braun & Clarke (2006) propose 6 steps; 1) Familiarizing yourself with your data by transcribing the data, reading and re-reading the data, noting down initial ideas. 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes: generating a 'map' of the analysis; 5) Defining and naming themes; 6) Producing the report: - the final opportunity for analysis.

Thematic analysis starts from the moment data collection begins. Analysis of the data began immediately post interview guided by Braun & Clarke (2006). Notes and memos were written during the process to ensure impressions, ideas, reflections and observations made were not lost. The recordings were then transcribed verbatim. Transcripts were checked initially for accuracy against the recordings; tones of voice (emphasis, anger, quietness, sadness, thoughtful) were then noted on the transcript (step 1). Initial observations (codes) were made and noted on the transcripts. Throughout the period of data collection, reflection on the interviews continued, initial ideas noted, and questions

tweaked as prominent themes were noticed, to explore these in more depth during subsequent interviews.

When no new subjects or nuances could be elicited from the interviews it was deemed that saturation point had been achieved and data collection ceased. All transcripts were reread; identifying interesting patterns, themes, powerful statements (step 2). Sections of the data were copied and pasted into separate documents with common patterns, or saying similar things, initially, along with the notes and observations made. However we needed to see the picture as a whole and in the end all common themes, powerful statements, codes, were written onto large sheets of paper enabling us to see the patterns emerging and links between the codes. Each large piece of paper had a main theme and codes related to each theme (step 3). The main themes were discussed throughout with the initial supervisor experienced in research and thematic analysis. This provided a valuable opportunity for the robustness of the emerging themes to be challenged and ensured that the themes and patterns could be supported by the data. The main themes and sub-themes were agreed, following our discussion, with the data to illustrate and support each main theme and sub-theme (step 4 thematic map). Each transcript was read through again and colour-coded with highlighters to ensure there were no important omissions from the analysis, defining and refining the themes (step 5). These themes were then organised into word documents with extracts from the data to support the themes for ease of reference when writing up the results (step 6).

As the interviewer and provider of the service I had an in-depth familiarity with the participants' world and others could argue, with reason, that this would affect my interpretation of the data. The supervisor would also be familiar with this world, although to a lesser extent, and we could be criticised for only reporting what we wanted to see emerging from the interviews and transcripts. To try to dispel concerns and to ensure validity of the themes a selection of transcripts were independently reviewed by another experienced researcher who joined the project towards the end of the data collection period, before any of the themes had been discussed with her. Her independent analysis generated themes of 'Choice', 'Time' (I wanted to know as quickly as possible), 'Control' (Preparation), 'Anxiety'. Several further discussions about the analysis and themes followed and we came to a consensus agreement of the themes, for example we agreed that anxiety, emotional responses, control and the beliefs men held were all sub codes of an overarching theme of 'Disposition'. Arguably had this been a qualitative research study rather than a service evaluation we could have summarised the findings and sought the views of the participants to assure credibility known as member checking (Lincoln & Guba 1989, Holloway & Wheeler 2002). We asked the participants to read through their transcripts to check for accuracy and that the important points had been made. Only 4 patients did not wish to read their transcripts. I didn't feel entirely comfortable asking participants to review the preliminary themes, not because I was misrepresenting them but because I had not prepared them for this and was loathe to yet again asking them to relive the

experience of receiving their diagnosis when many of the participants would have moved along the trajectory and been involved in their treatments. We did not feel it was appropriate to bother them again. A report of the findings overall will be sent to the participants on completion of the project.

Following the above methods of enquiry we will now report our findings.

## 6 Results

### 6.1 Population

Recruitment commenced the week of the 24th August 2010. In the first 3 weeks 21 letters of invitation were posted, 20 replies received; of those 16 agreed to participate, 4 declined. In total 40 invitations were sent from 31<sup>ST</sup> August 2010 to 21<sup>st</sup> December 2010. Overall response rate was 85% (n34). Of these, 26 men agreed to participate, 8 declined. The letter of invitation and information sheet said we would call patients up who did not respond. In practice we did not do this. Demographic and clinical details were recorded and reviewed as data collection progressed. Clinical details of non-responders and those who declined were recorded (Tables 4, 5, 6).

<b>Age of patients invited to participate in the service evaluation</b>			
Age	Number of Participants (26)	Number of Non Responders (6)	Number who declined (8)
40-49	0	1	0
50-59	3	0	1
60-69	12	2	2
70-79	6	3	4
80+	5	0	1

**Table 4: Age**

<b>PSA values of patients invited to take part in the service evaluation</b>			
PSA	Number of Participants (26)	Number of Non Responders (6)	Number who declined (8)
≤10ng/ml	11	3	3
11-20ng/ml	8	1	0
20.1-30ng/ml	2	1	2
30.1-40ng/ml	1	1	0
>40ng/ml	4	0	3

**Table 5: PSA**

<b>Histology of participants invited to take part in the service evaluation</b>			
Histology	Number of Participants (26)	Number of Non Responders (6)	Number who declined (8)
Benign	4	0	3
Gleason 6	2	1	0
Gleason 7	13	3	3
Gleason 8	1	0	0
Gleason 9	5	2	2
Gleason 10	1	0	0

**Table 6: Histology**

## **6.2 Mode of results delivery**

Of the 16 men who agreed to participate in the first 21 invitations, all except 1 had telephoned the CNS for their results. For the remaining interviews men who had received their results face to face were targeted. This proved challenging as 87% of patients having prostate biopsies under LA had received results by telephone or letter (see Table 7). A further 10 interviews were arranged; only 2 of these men had received their results face to face. Recruitment ceased 4 short of the target of 30 due to 1) data saturation for patients receiving results by telephone and 2) inability to identify any further patients receiving results face to face in the required time scale. The last participant interviewed was recorded as having his results received in outpatients but he telephoned for his results prior to this appointment so he was prepared for the consultation.

<b>Patients biopsied under local anaesthetic (LA) during recruitment period 17/8/10-21/12/10 (n=320)</b>	
<b>Mode of results delivery</b>	<b>Number (%)</b>
Telephone	158 (49%)
Letter (benign only)	121 (38%)
<sup>1</sup> * Face to face consultant	22 (7%)
* Face to face CNS	9 (3%)
GP	10 (3% <sup>2</sup> )
<b>Histology during recruitment period</b>	
Cancer n=177	Benign n=143

**Table 7: LA Biopsy results**

In total 23 participants received their biopsy result by telephone, 3 face to face. Of those 3 men, 2 were in outpatients and 1 on the ward (Table 8).

<b>Mode of delivery of result to participants</b>	<b>Number of participants with a Cancer result (22)</b>	<b>Number of participants with a Benign result (4)</b>	<b>Total (26)</b>
Telephone	19	4	23
Face to face	3	0	3

**Table 8: Participant results**

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<sup>1</sup> \* Of these 31 patients receiving results face to face 12 had either metastatic disease or needed treatment commencing based on clinical findings at TRUS, 3 were not able to communicate by telephone



### 6.3 Demographic characteristics

All 26 men who agreed to participate were interviewed, recorded and the interviews transcribed verbatim. The participants' ages ranged from 58 years to 85 years (mean 69.9 SD 8.7) and were representative of the age we would expect to see within this group of patients (CRUK 2011). All patients were Caucasian living in Norfolk with a range of educational background (table 9). Most men (n18) were retired; some were still working (n8). All were either married (n22) or widowed (n4).

<b>Educational background</b>	
No Formal Qualifications	13
Secondary level certificate	5
Higher level certificate	2
Degree level or above	6

**Table 9: Education**

#### 6.3.1 Clinical characteristics of participants

Clinically, 4 men had benign histology, 22 prostate cancer with a Gleason pattern ranging from 6 to 10. Clinical stage T1 –T4 was represented. PSA ranged from 4.7-82.4 (mean 18.9 SD 19) (table10). One patient was excluded from the evaluation as he had known metastatic disease; biopsy was for grading rather than diagnosis. At the time of interviews only one invited participant was found to have bony metastases, this was after the interview had been arranged, he was keen to participate. Participants recorded anxiety level prior to receiving their results ranged from 0- 9 (mean 4). (Table 10).

<b>Participants clinical details and anxiety scores</b>						
<b>Participant (P)</b>	<b>Age (Years)</b>	<b>PSA (ng/ml)</b>	<b>Gleason Grade (6-10)</b>	<b>Mode of results delivery</b>	<b>Clinical Tumour Stage (T1-T4)</b>	<b>Anxiety level prior to receiving results (range 0-10)</b>
1	83	54	9	Telephone	T4	2-3
2	68	13.4	9	Telephone	T2	8
3	58	6	7	Telephone	T2	8-9
4	68	8.6	10	Telephone	T2	0
5	64	13.2	7	Ward	T3	0
6	64	27	7	Telephone	T2	2
7	77	7.3	6	Telephone	T1	5
8	73	9.3	7	Telephone	T2	2
9	61	53	8	Telephone	T3	5
10	59	5.5	7	Telephone	T2	4-5
11	60	4.8	Benign	Telephone	Benign	4
12	60	17.6	Benign	Telephone	Benign	9
13	82	30.8	7	Telephone	T2	0
14	65	13.3	7	Telephone	T3	8-9
15	78	6.9	Benign	Telephone	Benign	3-4
16	59	5.1	Benign	Telephone	Benign	8
17	68	20.8	7	Telephone	T3	2
18	66	5	7	Telephone	T1	3-4
19	78	10.4	7	Telephone	T1	2
20	75	12	9	Telephone	T2	1
21	83	17.3	9	Telephone	T4	3
22	72	13.6	7	Telephone	T3	8
23	81	9.1	9	Telephone	T3	2
24	66	82.4	7	Outpatients	T3/4	7
25	85	40.8	7	Outpatients	T3	0
26	65	4.7	6	Telephone	T1	3-4

**Table 10: Anxiety scores**

All participants except one had undergone TRUS/P under local anaesthetic (LA).

## 6.4 Data collection

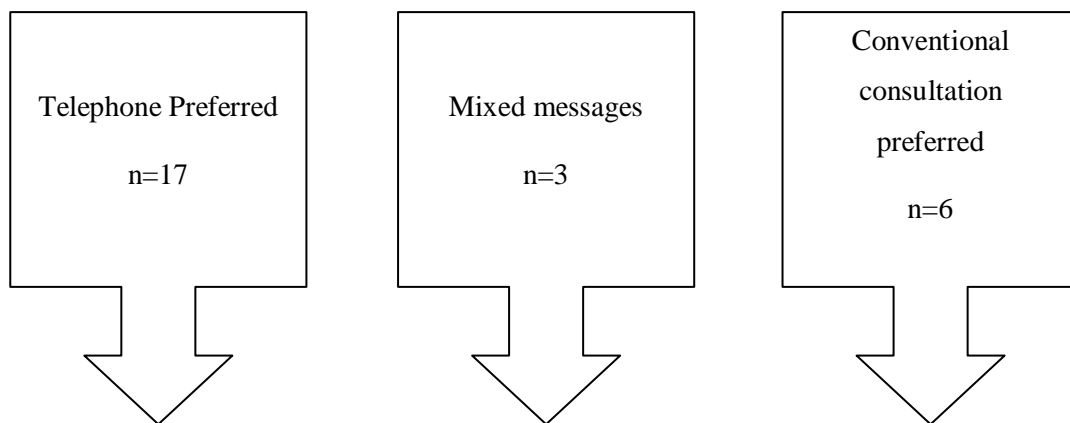
Interviews were conducted in the patient's own home (n11), the cancer information centre (n12), the CNS office (n1) or outpatient clinic room (n2). Average time from receiving results to interview was 5 weeks, range 3–10 weeks. Interviews lasted 7-61 minutes (mean 30). Men receiving results by telephone waited 7-10 days for their results (mean 8 days). Men receiving results in outpatients waited 9 and 14 days to hear their results.

Prior to the interview the pre-interview checklist was followed (Appendix X). Some participants attended alone through choice (n10); others accompanied by their wife (n5). Where interviews were conducted in the patient's own home; sometimes the wife was present (n6) at other times absent (n5). Written consent was obtained and only when verbal consent was also gained did the recording and the interview commence. No participant declined being recorded. Although I emphasized when arranging the interview it would be taped, I also made it clear at the interview they could change their minds. We were mainly interested in the experience of the participant yet it was also valuable to hear the wife's opinions; often this would prompt a further response from the participant.

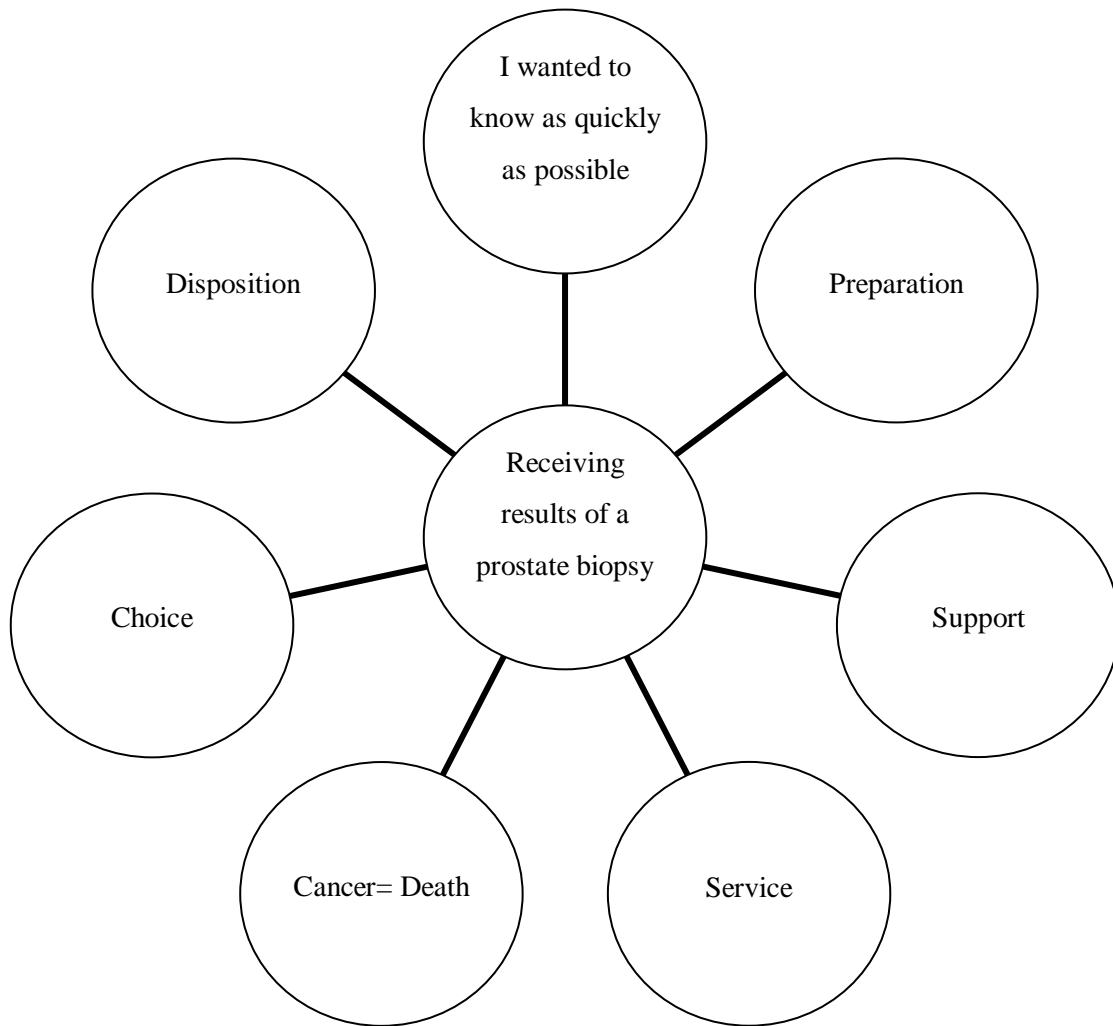
Limited notes taken during the interviews were added to post interview when reflecting on each experience. On completion of the interview I thanked each participant and asked if I had missed anything that was important to them. Nearly all participants had questions regarding treatment. This in itself was identified as a common theme throughout and coded as *moving forwards* within the main theme of *Choice* which we will report shortly. Participants were asked if they wanted to check the transcript for accuracy and make any further comments. Most men wished to review their transcripts but 4 declined (P9, P10, P16, P23). All transcripts were returned within the specified time. A post interview checklist was kept to track data (appendix X).

## 6.5 Findings

Throughout data collection the overwhelming message was that speed of results delivery was paramount. Mainly positive experiences of the service were reported but negative experiences were also described. We found for most participants delivery of their biopsy results by telephone was an acceptable mode of communication whether the results were benign or cancer. For others it was not their preferred option and some men gave us mixed messages. Within these 3 main groups we identified 7 themes which emerged during data collection and further analysis. Within these 7 main themes we found sub themes which we coded as such (see maps). We will now report each theme individually, supported by the words of our participants.

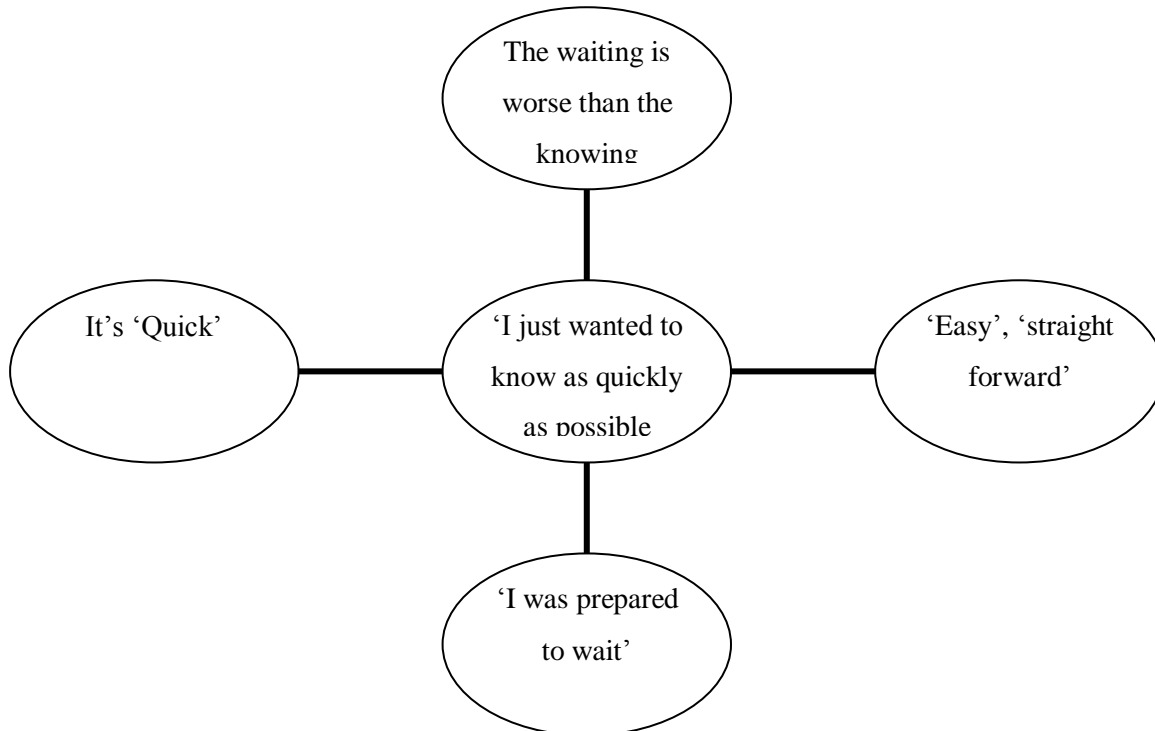


**Diagram 1: Main groups**



**Diagram 2: Main themes map**

### 6.5.1 Theme: 'I just wanted to know as quickly as possible'



**Diagram 3: Theme map**

*I think you should tell people what they want to know. so I would give them the information regardless because ...people want to know the results of things, well I think most people want to know the results of things as soon as possible and they just want to know kind of where they stand really in fact (P26, GL6, PSA 4.7)*

Our men just wanted to know their results, and quickly. The speed in which the results were received was more important than the mode of delivery and for most was the driving force behind phoning. The strength of this theme would be hard to contest as every participant (excluding participant 25) interviewed commented about the importance of the speed in which results are received. Men wanted to know as soon as possible. This main theme was sub coded into the language used to describe what was important to the men about receiving their results quickly.

#### 6.5.1.1 'The waiting is worse than the knowing'

*The anxiety of waiting is pretty tremendous. ...I just had to know really.....At the time the waiting is the thing that is frustrating and annoying and worrying thing (P16, 59yrs, benign)*

*Because at least you know where you stood then don't you? ....because if you've got the waiting bit it's the bit that is hard, the waiting, that's the – that's the hard bit, you know. It gives you some sleepless nights and things like that (P22, 72yrs, GL7)*

*I was very pleased that I phoned.... And I would have phoned earlier., if they'd have said two days I'd have phoned two days ....., I'd have phoned as soon...I couldn't wait to phone and that is*

*the truth. I, I kept thinking, oh you know, tomorrow I can phone. And I kept saying... to my wife, you know, I'll be able to phone tomorrow. And I just wanted to know....., even if it was bad news, I still wanted to know (P6, 64yrs, GL7)*

*.....I didn't want to hang around for two or three weeks for an appointment to have a face to face meeting. I wanted to be getting on, finding out if there was anything..... It's hanging about which...it's the timescale which...I was anxious to avoid (P19, 78yrs, GL7).*

### **6.5.1.2 'It's quick', 'as quickly as possible'**

Many men used the word 'quick' when describing why they used the telephone to hear their results;

*..the crux of the matter is did I have prostate cancer or didn't I? And I think it was good that I was able to find out so quickly (P14, 65yrs, GL7)*

*I think as quick as possible for the results but..., within a time as quick as possible (P16, 59yrs, benign)*

*Yeah, so I found out nice and quick rather than hanging about, thinking about it (P18, 66yrs, GL7)*

*the important thing was that I should be told as quickly as possible (P21, 83yrs, GL9)*

*Basically... I decided to phone up because I wanted to, to know the results quicker than waiting to see the doctor (P6, 64yrs, GL7).*

### **6.5.1.3 'It's easy', 'straightforward'**

Some men described receiving their results as 'easy' or 'straightforward' when using the telephone to find out their results;

*... it's a lot easier to just pick the phone up and just get the results over the phone.....whichever direction they go in,...you can't change things can you, so that's just an easy option to get it over the phone (P11,60yrs,benign)*

*...as far as I was concerned that was straightforward job, I wanted to know what was going on, wanted to know the extent of it and then we go away from there. So from my point of view – that was no concern at all (P23, 81yrs, GL9)*

*I've got no problem at all with the phone call Wendy, at all, that's quite straightforward, quite open and I've got no, no problems or no faults with that at all,...I found it quite good and easy (P4, 68yrs, GL10).*

#### **6.5.1.4 'I was prepared to wait'**

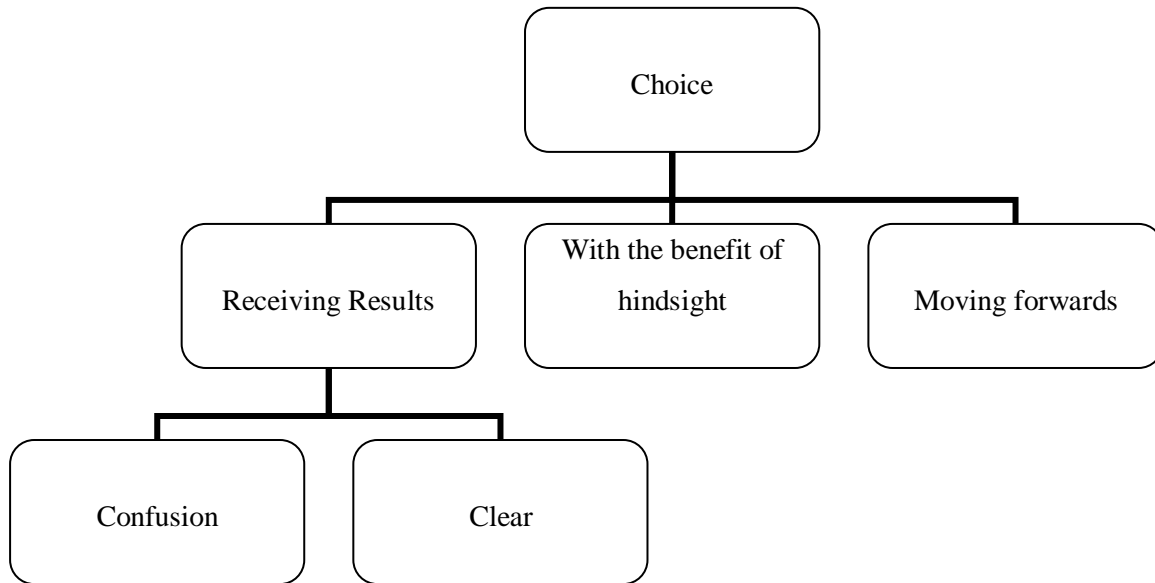
In contrast participants 24 and 25 were prepared to wait for the results to be delivered in the conventional way. We should note however that for participant 24 the wait was only an extra 2 days, for him that was bearable, for most men in this evaluation knowing those results were available, they would not have been able to wait the extra 2 days. For participant 25 he did not like communicating by telephone as his hearing was impaired and his preference was always for face to face consultations.

*the results would have been available sometime on Tuesday... But we only had to wait then Thursday and Friday and then we came in and like this it was a consultation..... So two days..... It was worth waiting, yes. (P24, 66yrs, GL7)*

*I'm not very good on the phone. ...if you have it come through on a letter you can recap as many times as you like. ...so that's what I said...– I never wanted a quick phone; I waited until the letter (appointment letter) came through....I think that came through in reasonable time. (P25, 85yrs, GL7).*



## 6.5.2 Theme: Choice



**Diagram 4: Theme map**

Choice was a strong theme throughout. The men had many choices to make. We sub-coded this theme into choice *receiving results*, choice with *the benefit of hindsight* and choices ahead - *moving forwards*. There appeared to be much confusion for some not only about how to get their results but also the treatment choices once the diagnosis had been made. Post biopsy the strength of this theme may have been in part due to the questioning and our focus on men's perceived choices to receive their results. We were anxious to know if they thought that they had a choice or if they felt pressured into making the telephone call. Not one participant admitted to feeling any pressure from the HCP but the confusion was evident. We were also interested to know if the men would make the same choice with the benefit of hindsight.

### 6.5.2.1 Post biopsy, receiving the results

#### 6.5.2.1.1 *Perceived choice poor*

Some men did not realise they had a choice, or couldn't remember there being one (P7, 77yrs, GL6) so they telephoned as instructed at the biopsy clinic.

Some patients had interpreted the choice as waiting for a letter versus telephoning (P9, 61yrs, GL8; P16, 59yrs, benign)

*You could wait to receive a letter. Or you could telephone earlier for the results (P16)*

Others interpretation was to wait for the results to go to their GP versus telephoning;

*I didn't look on it as a choice, it was that if I wanted to do so I could...if not I could have always waited for my doctor or, made an appointment with my doctor, no, I didn't see it as that's the only way you can do it (P17, 68yrs, GL7)*

Some participants (P18, P20, P6, and P12) had understood that they had a choice but didn't see coming to outpatients as one of those options. They had selected to use the telephone above seeing their GP; again this may have been due to speed.

#### **6.5.2.1.2 Perceived choice clear**

Some men were quite clear about the options for receiving their results and chose to telephone...

*..., they gave me the fact sheet and the nurse then said you can phone up or you can make an appointment to come up.....I can't see the difference myself. It makes no difference to the facts. (P10, 59yrs, GL7)*

*Well when the biopsy was done I was given the option of either it could be conveyed to me face to face or I could ring up and I opted to ring up. (P19, 78yrs, GL7)*

... or chose to come to clinic

*We were given the option of either having it over the telephone or face to face and my wife and I would prefer to have it face to face with the consultant ... (P24, 66yrs, GL7).*

#### **6.5.2.2 With the benefit of hindsight**

Having noticed confusion of how to receive the biopsy result, particularly in the earlier interviews, and with speed appearing to be the driving force behind telephoning, we were keen to know if the men would make the same choice again, with the benefit of hindsight, if the timescale was equal. Or, were other factors also influencing their decision? Many of the men said they would make the same decision in the same timescale; some qualify this with practical reasons for using the telephone.

Participant 10 (59yrs, GL7) said he would still have phoned explaining that he uses the phone and email all the time at work for communication and that to him the important thing is “*clarity, understanding and knowledge*”.

Participant 15 (78yrs, benign) would use the telephone again and remarks that it's not being “*philosophical*” but “*facts are facts*” and if the results are there “*it's not going to change*”

Some men describe the “*hassle*” of coming to the hospital (P23, 81 years, GL9) as their reason for using the telephone given the same timescale. Others, with the distance between their home and the hospital meant it was “*easier*” (P11) to pick up the phone;

*I'd choose is phone first, doctor's second and then come up to the clinic last. (P11, 60yrs, benign)*

*I personally would have still gone for the phone option because it's such a pig's ear to get up here. If I'd lived round the corner then perhaps I would have said yes, I'd like to come in, come in and see you, but I'm perfectly happy with the system because it, it saved me a 60 mile around trip and god knows how many hours in the parking fee. [laughs] (P14, 65yrs GL7)*

For some men the telephone afforded them some *control* at a time when there is so little they can control with regard to the results. Control over environment, control over the time, and control over who is with them;

*...it's getting the answer in a time that suited me...in a location, being where I wished to be, who I wished to be with, rather than any coming to the hospital, speaking to somebody, strange surroundings anyway, which you anxious in coming up, so I could, so I could work it to suit me. (P16, 59yrs, benign).*

Whilst we had previously been concerned that some men may feel under pressure to phone some cited 'less pressure' as the reason for making the same choice;

*...I can't see anything difference in calling and speaking to someone on the phone as there is to going in and seeing them. You know. It's probably less pressure actually. ...if you've got to go and sit there and they're behind and you're sitting there waiting and you just get...whereas on the phone you pick it up, phone, and you're straight through and you get your result. But you might have to go and sit there 10 or 15 minutes before you get in and then you're worried about, you know, what you're going to be told when you get there. But no, I thought the phone was quite good, that suited me anyhow. (P18, 66yrs, GL7).*

For others it was the suggestion of some degree of *anonymity* afforded by the telephone which appealed and being able to display emotion without it being witnessed by others that influenced their choice;

*Well I think it's not so impersonal.....from my point of view I think I prefer to pick the phone up to be truthful because if you meet someone face to face, obviously when they want to tell you something bad it – it sort of comes a bit difficult, you know, you don't know how to react. You know, and as I told you earlier I'm quite an emotional person because I get worked up about things and you think, you don't realise you're getting worked up, but you do. And it then becomes a bit...and you make a fool of yourself (P22, 72yrs, GL7).*

Participant 21 (83yr, GL9) and his wife both commented that they felt as it was prostate cancer it was perfectly reasonable to phone as they viewed this as non-life threatening a 'good cancer' (Maliski 2002); however for something 'more serious' it could be catastrophic.

As illustrated above there were many participants with the benefit of hindsight that felt they had made the right decision to phone and with the benefit of hindsight and an equal timescale would make the same decision.

This was not always the case. Others with the benefit of hindsight would have made a different choice;

*if ...they'd have said you can come up in a week's time to find out I'd have probably chose to come up. Because .....on the phone I tend to come off the phone and think oh, I should have said... and I think of things as I'm talking to somebody. So I would always rather meet face to face in any situation, so definitely ...thinking about it now, more deeply, I would have definitely come up and met somebody (P6, 64yrs, GL7).*

Participant 9 would rather have telephoned if it was the same timescale but acknowledges that this is “a hindsight view” and at the time would have probably said “oh, we'll do it over the phone”. “But it's, it's after the event I think when it bites a little bit more” (P9, 61yrs, GL8). He also acknowledges that he is giving a “mixed message” in that;

*I chose to ring and that was my decision and I don't regret having done that. But a lot of people I could see being much better off actually going to the personal touch....And me on reflection would probably have been better having the personal bit (P9, 61yrs, GL8).*

He comments on the impersonal aspect of the telephone; not us being impersonal but the mode of communication. Other participants were very clear that if the time scale was equal they would have preferred to come to clinic;

*The timescale is not an issue? .....Oh I think I would have taken the opportunity to come up and be told face to face (P19, 78yrs, GL7).*

### 6.5.2.3 Moving forwards

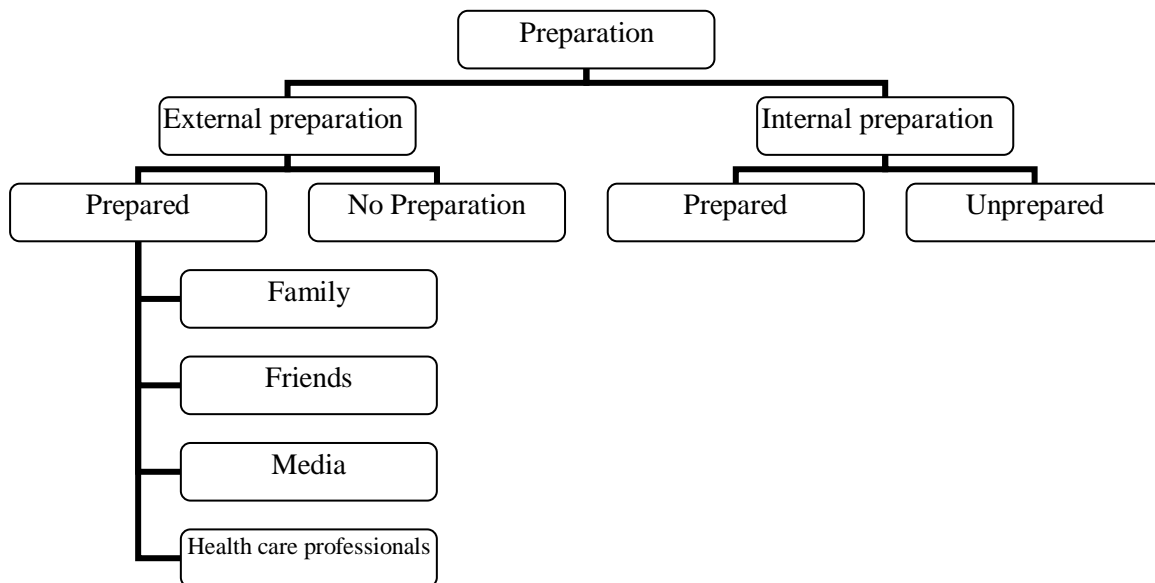
Having received a diagnosis of cancer the men were now faced with more choices. Confusion was evident regarding the next step of the journey, whether that was choice of treatment for early disease or understanding the complexities of commencing hormone deprivation treatment. There was confusion for some (P5, P2) as to why they had seen an oncologist and not a surgeon..... “*I was confused....it's a lot to take in*” (P5). The intent (curative/palliative) of treatment was not always clear with some believing that hormone treatment was the best option, that surgery or radiotherapy was not such good treatment;

*...he was saying you'll probably just have a course of hormones..... But obviously since then I've found out it's a little bit worse than I thought....I've been told now that it's either going to be removal of the prostate or radiotherapy (P6, 64yrs, GL7).*

These conversations were not often captured on tape but rather discussions that took place at the end of each interview which were included within the analysis as the confusion was so evident.

### 6.5.3 Theme: Preparation

Having made the choice, or not, of how to get their result we noticed that how prepared the men were to hear their result seemed to affect their acceptance of this result in whichever way it was communicated. We observed that some men were well prepared for a diagnosis of cancer, whilst others were not. We found that there were many ways in which men had prepared themselves for a potential cancer diagnosis. Within the main theme of preparation we coded into two further categories, internal preparation and external preparation and sub coded further into well prepared or unprepared. With the sub code of external preparation we noticed that the sources of information had calming effects for some and increased anxiety for others.



**Diagram 5: Theme map**

#### 6.5.3.1 Internal preparation

##### 6.5.3.1.1 *Prepared*

All men were given the same written and verbal information about the biopsy and knew the test was to look for cancer but some had accepted ‘it could be them’ whilst others had not.

Most of the men had prepared themselves mentally that they could receive a cancer diagnosis. We called this *internal preparation*. Some men had little insight at diagnosis to prostate cancer *but* the fact that they had prepared themselves mentally seemed to be enough;

*I knew I had the biopsy done and there was going to be something on it and because the PSA readings I'd been getting I thought well, there's going to be something wrong here and I didn't bury my head in the sand and try to push it behind me and think well, no, it isn't going to happen to me. ...it's going to be somebody else, it won't be me, I'm going to be okay. I didn't do that, I prepared myself that there is something there and that is how I dealt with it (P4, 68yrs, GL10).*

Participant 9 had a “*broad understanding of what prostate issues were about*” but admitted he had not researched into prostate cancer prior to his biopsy but he had prepared himself mentally;

*I know the PSA test is not truly indicative but it's a pretty fair bet and if the norm for a man my age is about four and it comes out at 53, there's obviously got to be some fairly big issue underlining the thing as well. So that's really where I felt fairly sure in my own mind it was going to come out to be, to be cancerous, yeah (P9, 61yrs, GL8).*

Participant 14 had little insight into prostate cancer and admitted to being “*a little stunned*” when he received his result but again he had prepared himself *mentally* for a diagnosis of cancer;

*... it was more or less yes, you've got cancer, or no you haven't got cancer (P14, 65yrs, GL7).*

Some had prepared themselves mentally for a cancer diagnosis and had some insight into prostate cancer through external sources for example the internet, written media, and friends but still it was the acceptance that the result could show cancer, they had the notion;

*...from the beginning ...I thought yes it could be cancer..... (P7, 77yrs, GL6)*

*...I was kind of quite ready to make the call... and I kind of managed to convince myself that the result was going to be positive.....and therefore the worst that could be said to me was the result is positive (P26, 65yrs, GL6)*

*I was just anticipating if it was bad news I was ready for that bad news (P16, 59yrs, benign).*

#### **6.5.3.1.2 Unprepared**

Some men had not prepared themselves *mentally* for the possibility of a cancer diagnosis; the result was less well received;

*.....Until I had the biopsy result I didn't even...hardly think I had..... The reason I say that because that would all be psychological cos I still had in my mind that I hadn't got it so it's hard to talk about something if you don't really want it..... (P8, 73yrs, GL7).*

He still had in his mind that he hadn't got cancer. He knew why he was having the test but didn't think it would apply to him.

Participant 5 had understood why he was having biopsies. It was his 4<sup>th</sup> set of biopsies over a period of 4 years; all previous biopsies had been clear so in his mind although his PSA was rising, it wasn't that unusual for him and he didn't really think this set of biopsies would show cancer either, he was *mentally unprepared* for a cancer diagnosis;

*Well I think I was a bit blasé about it really because like I said the other three were negative and I think you half, even the surgeon..., he said I expect this one to be...clear as well. So you become slightly in that mind-set .....oh, they're clear so this one will be clear,.. so.....It was a little bit of a shock. I didn't have any indications from anybody that anything other than it was clear.... (P5, 64yrs, GL7).*

Participant 20 (75yrs, GL9) had a repeat PSA but “*didn't really think anything then*”, he had noticed he needed the toilet more often but put that down to his age and even being sent for a biopsy he “*really didn't think too much about having cancer*”

*. ...and even now I find it difficult to, to really not accept, I think I've accepted that yes, I have got cancer, but really to take it on board. .... I was going to be given the results of the biopsy..... I'm going to be told that I've – the biopsy is a negative or a positive result. I've either got cancer or I haven't because that's basically what was going to come out of it. **But at the back of my mind I was still quite reasonably confident that I didn't have cancer**, basically (P20, 75yrs, GL9).*

### **6.5.3.2 External preparation**

Some men had more preparation than others via external sources. By this we mean through their own research, via friends, family, HCPs. Sometimes this had a positive impact at other times a negative impact on their experience.

#### **6.5.3.2.1 No external information sought**

We asked the men what information they had found out prior to receiving their results. Participant 17 (68yrs GL7) had not looked for any information about prostate cancer before his diagnosis, neither had participant 14...

*Not a lot because I'm one of the sort of people that thinks, you know, I've got something nasty, do I really want to know all the ins and outs of it or do I just want to have to sorted out? And I'm the guy that I don't want to know too much information, just sort me out please (P14, 65yrs, GL7).*

... but both men, despite their lack of research into prostate cancer, had *mentally prepared* themselves for a cancer diagnosis.



### 6.5.3.2.2 *External sources of preparation*

Some men were prepared for a diagnosis of cancer by their GP;

*he told me that was more than likely cancer, and so I was prepared (P25 ,85yrs, GL7).*

*my GP she was quite good at explaining things and she made it sound as if that was probably cancer anyway. I mean I thought right from the very start that that was going to be cancer...(P6, 64yrs, GL7).*

Others had also been reassured by comments such as the high PSA is a sign of prostate cancer but this is a “none life threatening cancer” (P24, 66yrs, GL7) and “you will die with it not because of it” (P17, 68yrs, GL7).

For those that had been well prepared by their GP, the process of transition from a state of good health to the realisation that their health may be challenged by cancer had begun.

There was also evidence that the preparation by the doctor prior to the biopsy (P9) or at the biopsy clinic (P6) aided the discussion/ acceptance of the results for some;

*... he was up front ..... very factual and he got my wife in as well and said look, this is what he thought the score would be. But you know, it's never sure until it's sure. But not to worry because there's all this and that and the other things we can do. And I thought that was very good. I was very impressed .....he did it in a very factual, non-threatening sort of way (P9, 61yrs, GL8)*

*...when he done the biopsy ... he obviously thought that was cancer. He didn't make any pretence about that, he didn't say that that was serious or life threatening but he did make it quite clear that,.....in his view he thought that was cancer, so the telephone call didn't come as a shock..(P6, 64yrs, GL7).*

*... he said there's definitely cancer there, and he said like a man your age I expect to get it, you expect to have some form of cancer there or limited amount of cancer and when I'm your age he said I'll have it. So of course that was reassuring (P23, 81yrs, GL9).*

Not everyone appreciated this honest ‘upfront’ approach at the biopsy clinic;

*...I've always been very fit all my life, I've never had any illnesses or been into hospital for anything at all, touch wood. So obviously when someone mentioned the word cancer to you that do come as a bit of a shock. ..., I can remember going home thinking oh, I wish that doctor hadn't said that word cancer until I'd had the tests and then been told (P11, 60yrs, benign).*

#### **6.5.3.2.2.1 Family history**

A family history of prostate cancer seemed to influence how prepared the participant was for his results. If the man had a close relative with prostate cancer they almost expected to have cancer themselves, therefore they were more prepared;

*I knew that there was an hereditary factor.... And I said well, I said my father died of cancer, prostate cancer, years ago and I said I realise there's a genetic connection (P15, 78yrs, benign)*

*I mean it's not nice knowing you've got it. I had a guess, a thought, because my dad died of it. So I thought to myself well I'm more likely to get it than not get it I suppose (P18, 66yrs, GL7)*

*..... I found out that my father had prostate cancer and I found out that my younger brother has prostate cancer. ....I told the GP that and he said well actually that quite dramatically increases the chance of you having prostate cancer..... So when I had the biopsy and I had the results of the biopsy I was kind of mentally ready for it to be a bad result .... I think I would have been quite a bit more shocked had it come completely out of the blue. But I was kind of expecting it to be a bad result because of my family history (P26, 65yrs, GL6).*

#### **6.5.3.2.2.2 Friends**

The shared experiences of friends with prostate cancer had both a negative and positive impact on patients' own experience. Some were able to talk openly with friends and learnt 'a little bit more' (P24, 66yrs, GL7) from meeting others with prostate cancer 'in the village' (P24) or 'at the golf club' (P14, 65yrs, GL7). This willingness to discuss prostate cancer with friends and also family members encouraged participant 14 to have a PSA test.

In contrast, participant 8 did not discuss prostate cancer with others but was present when prostate cancer was being discussed; these discussions only perpetuated his belief about cancer;

*There's a chap I used to work with because...a group of us we meet up every, once a month, about 20 of us ....work colleagues and people I used to work with..... we were at the meeting and someone said, this chap's ..... got prostate cancer..... he's got to go up the hospital and by the time we finished that day I thought, ....to myself the way they're talking he's finished, he's had it, that's it.....So I thought I don't want people to know because if they know they'll think I'm going to die in a couple of weeks time. And I don't feel I am. (P8, 73yrs, GL7).*

#### **6.5.3.2.2.3 Written Media**

*'it's the biggest killer of men'*

Newspapers, like the internet, were found to be unhelpful with information reported about prostate cancer. There were no reports of helpful news articles in this evaluation. The message being received loud and clear is that prostate cancer kills.

*...I did know it was, ... or is, it's the greatest killer of men should we say and more so than breast cancer for women.....where did you find that out? .....Just reading the newspapers. The Daily Mail. [laughs] (P7, 77yrs, GL6)*

*.....sometimes the newspapers and the media I suppose they've got to sell papers I suppose.... they say, you know, oh, that's the biggest killer of men but is it? (P18, 66yrs, GL7)*

As one man said as soon as he was diagnosed with prostate cancer there seemed to be reports everywhere, he didn't elaborate on how helpful or not that was;

*But when you read that it's one of the biggest killers for men, this type of cancer, I have read this several times,..... there's been a lot in the papers and everything about it, it wasn't something I was looking at but – and certainly since I started having various tests and that the papers seem to be filled with it.....(P20, 75yrs, GL9).*

#### **6.5.3.2.2.4 The internet**

The internet is a powerful source of information. It can be very useful and many of the participants searched for more information about the prostate and prostate cancer. Men searched for information at different times, sometimes the information was helpful at other times not.

Some men looked for information before receiving their results;

*The internet is a dangerous thing because you can go on the internet and you can read lots and lots of things. And sometimes it's a dangerous thing, you know...I read an article.... I don't recommend it (P12, 60yrs, benign).*

Some men searched for information after they had received their results;

*I hadn't gone into it in any great depth prior to finding out if there was a problem really. So once I actually had got it, well I knew what the score was, I started actually getting into a bit more detail, then of course a lot of information can be horrendous actually. You start reading and you think Jesus! [laughs] This is the end of the line coming, you know, very quickly. I mean you've got to sort of...there are so many websites out there with dis-information almost, giving you the horror stories, that you tend...and your mind because of the way things are, your mind tends to home in on the bits that are the worst rather than on the more positive issues (P9, 61yrs, GL8).*

Some men found the internet helpful;

*..... I have a computer. And in anticipation of getting a result I'd already done a bit of research....I knew what the Gleason scale was and I had a rough idea of what the way things were and without being an expert on the subject I could take a judgement on whether or not it was...good, not so good [laughs] or bad or terrible (P19, 78yrs, GL7).*

*because I'd read into prostate cancer already.....And I knew that there was a fairly extensive range of treatments for it. So even though it was, you used the big 'C' word on it, I knew that if you had to pick a choice it was the one to have if you understand.....So I was less distressed than perhaps people thought I should be (P10, 59yrs, GL7).*

Some would have appreciated information about helpful sites for information;

*...I mean it tends to come up quite quickly once you put in prostate cancer .....a lot of American stuff on the internet is crap actually,..... it tends to lead you in all kinds of different directions and ultimately it just became a kind of lots of people's experiences which I found didn't particularly relate to me, I just wanted hard information, I didn't want to know the soft stuff at that stage. I wanted to know what's hard data and what's not hard data and..... the prostate cancer charity one was pretty good on hard information (P26, 65yrs, GL6).*

In contrast others found the American sites helpful;

*I tend to go for the information sources on the Net, mainly because it's more direct and you can get quite a breadth of stuff, and I've hit some sites in America as well, you know, to get the full gamut. Not that I don't value the conversation here but I'm conscious of the fact that you...are seeing windows ...So I'd rather see the broad spread side, I can get informed as I need it (P10, 59yrs, GL7).*

Use of the internet did not appear to be related to age or previous employment;

*I knew that I had the biopsy because the possibility of cancer to remove segments to analyse..., I read on the internet, so I mean I know they just can't look at you. So I was aware of that they would take bits and pieces and they would check it out.....(P23, 81yrs, GL9).*

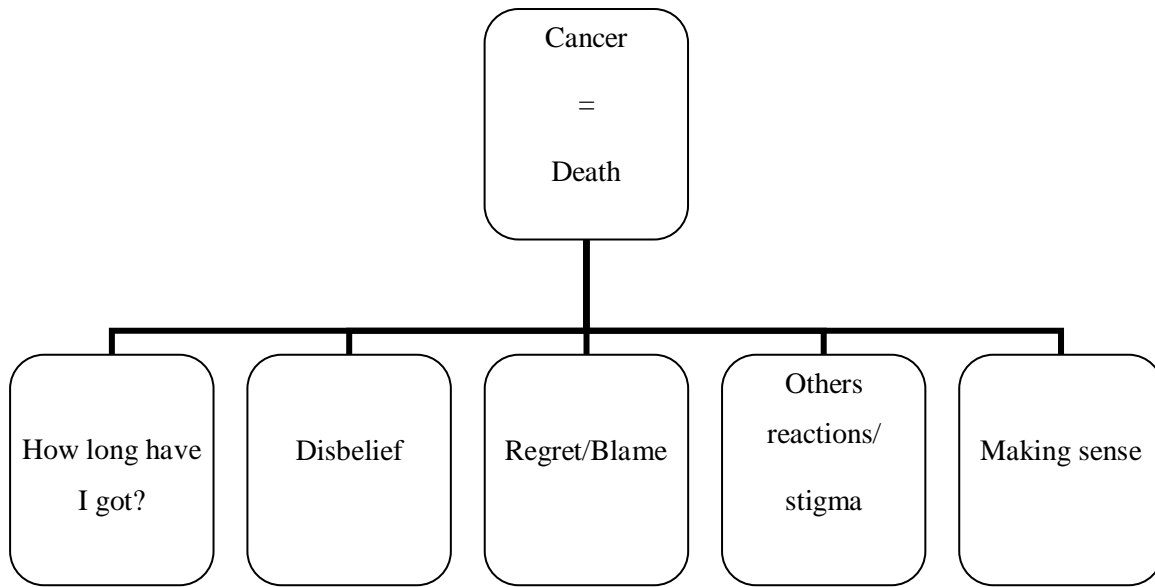
Some found the internet both frightening and reassuring;

*And I also looked it up...on the internet as well..... scared myself to death when I looked at that lot on there but if you've got a fairly open mind about it, you can put your mind at rest a lot by knowing. I'm a person who'd like to know anyway ..(P11, 60yrs, benign).*

In summary, men were prepared for their results in many different ways by as many different sources. Sometimes the sources of information were helpful. At other times unhelpful. An important finding was whatever external sources of information the men were exposed to if they hadn't moved themselves mentally from being a man without cancer to a man who may have cancer the results were less well received. This takes us forward to the next theme, what the word 'cancer' means to most people.

### 6.5.4 Theme: Cancer = Death

With the media portrayal of prostate cancer as a ‘killer’ it should not come as any surprise that many of the participants also viewed the diagnosis of prostate cancer as a death sentence. This theme was strong throughout and sub-coded further into the feelings voiced by our participants or interpreted through the analysis (see map).



**Diagram 6: Theme map**

#### 6.5.4.1 ‘How long have I got?’

*he gave me the letter to take to the GP’s and I saw on there that said erm injections sort of for three years, I thought well perhaps I have got three years instead of three months (P2, 68yrs, GL9).*

These feelings are expressed by the following participant;

*That sounds a bit pathetic but in a way the, at the point, the 24 hours afterwards you are a bit pathetic actually. [laughs] sort of feeling sorry for yourself, worried about the family, what are the implications, and strangely enough Wendy, one of the things that went through my mind and I know it's irrational and I know prostate cancer is not a killer immediately, but my immediate thoughts were how long am I going to be here, Christ, I'd better start getting this sorted out, that sorted out, what am I going to do with my wife, what about the kids, you know, it was that type of thing. So your mind starts building up the pressure of all those issues. When in practical terms, unless it was sort of, unless it's got me with a vengeance, which it clearly hasn't yet, I've got plenty of time to work, to sort those sorts of things out. But that's how the mind works, or my mind works anyway (P9, 61yrs, GL8).*

*.....that's probably a reaction that most people have with that word isn't it? It's got that horrible connotation to it... in some respects I'd rather have what I've got than Alzheimer's or something like that. ....I mean it sounds silly but you can deal with this one way or the other. .... But at the time...ooohhhh. It's all about how long have I got? [laughs] I know it's very silly (P9)*

*It's not silly. (interviewer)*

*It's totally irrational actually. Because...I'm far from being stupid, I'm not saying I'm the world's brightest but I'm by no means intellectually thick and I'd read the details, and I know what the score is and I knew that ..there's a long time potentially before things really rocket up, but you don't think about that actually. You sort of, you are irrational almost at the point ...irrational and emotional I think is a weird combination, well it's not a weird combination, but it is a combination that's, can be quite debilitating actually....but it didn't take me long to get over it. [laughs] (P9).*

Other participants used the word 'terminal' when talking about their diagnosis;

*I mean I don't care if it's, they say it's terminal or anything like that you know I mean there's times I mean like this morning, I think I'm gonna die. I get this feeling, all of a sudden, that I'm not going t' make it, you know and that's what's a bit upsetting because err... pauses.....crying..(P1, 83yr, GL9).*

*... unfortunately cancer always goes with the other word, terminal. So I thought to myself crikey, you know, what do I do? I didn't know whether I was supposed to then rest up because I was ill, because I certainly didn't feel ill. And do I take it easy...that was the worst thing. I didn't really know how ill I was. And ...so then it gets in your mind and whatever you do you can't get it out. No. And that was my first reaction. Well I suppose I was frightened in a way. Not frightened of cancer but I, I wish I'd have known more about it. Maybe it's my own fault that I didn't. But that's the thing what hit me worst....I thought, you know, so how long have I got? (P8, 73yrs, GL7)*

The pre biopsy patient information sheet (Appendix II) clearly explains why the biopsy is being done i.e. to look for prostate cancer. All the participants in this evaluation had understood what the test was for. We know the word cancer instils fear and uncertainty but we had thought the message that prostate cancer is often either curable or chronic in its nature was getting across; this wasn't always the case and as the interviews continued this theme became quite prominent. For those patients with benign disease we decided to delve a little deeper and ask what the word cancer meant to them; the findings were consistent – it meant “Death” (P11, 59yrs benign),..”unpleasant death” (P15, 78yrs, benign).

*...I also know quite a few people that have died from cancer, so...that's, that's the worry to it.  
(P16, 59yrs, benign)*

Some acknowledged the fear;

*.....cancer is a word which inspires people with worry; fear anyway (P21, 83yrs, GL9).*

Some had experienced personal loss due to cancer which had an impact on their beliefs about cancer. Participant 12 was not probed, his comments came freely. He had not only lost his wife to cancer and sister in law but also his new partner's husband had died of prostate cancer;

*...basically once I had the PSA and then got the results then the cancer started appearing. ...  
cancer's all around you....and you hear about all the good cases but .....a lot of people  
die.....it causes death, it's linked with death. ....to me cancer is death..(P12, 60yrs, benign).*

#### **6.5.4.2 Disbelief**

A further observation during the interviews and analysis of the data was this feeling of disbelief. Prostate cancer in its early stages does not generally cause symptoms. In locally advanced disease symptoms such as difficulty voiding or a change in voiding habits may manifest; in late stage or advanced prostate cancer retention of urine, bone pain, bowel symptoms or renal failure may be the presenting symptoms. If a man is being investigated for prostate cancer on the basis of a slightly raised PSA test only, he will feel well and often have no symptoms to suggest there is anything wrong with him. The association with cancer is not only you will die but you should also feel ill. Therefore if you feel well how you can possibly have cancer? This paradox leads to feelings of disbelief for some men;

*... if I'd been in severe pain or had symptoms....., I probably would have been concerned  
but seeing I feel the same now as I did a year ago,..... it's unbelievable that I've got cancer  
there.... it was only, what, three months ago when I was getting up in the middle of the night,  
other than that all my life I never had to get up in the middle of the night. So that's why I left it  
for a month or so... – I thought it was just a habit I'd got into. So.....if I was in severe pain and  
had a lot of symptoms I would be more concerned .....I'm fortunate in the sense that I feel  
the same now as what I done the last 50 years, so you know, touch wood.....so consequently  
that may be why I maybe sort of blasé about it because if – don't think there's nothing wrong  
(P23, 81yrs, GL9).*

Participant 2 (68yrs, GL9) seemed surprised that he still had an appetite “*it hasn't put me off my food*” and still felt well and could carry on as usual, racing his granddaughter and “*still out in the garden*” despite having been diagnosed with cancer.



The feeling of “*jogging along thinking I was 100% fit*” not knowing he was “*ill*” by participant 8 (73yrs, GL7) again illustrates the belief that cancer and feeling ill go hand in hand and therefore makes it difficult to believe or accept the diagnosis of cancer.

Participant 20 (75yrs, GL9) and his wife repeated several times during the interview this difficulty of matching the diagnosis of cancer with feeling so well and the difficulty accepting that with no symptoms he could possibly have prostate cancer, “*I don't feel unwell*”. He had played sport all his life, football until age 45 and then squash until the age of 63, he had always been “*quite fit*”, his sister in law had cancer, his brother in law had prostate cancer but it never “*occurred*” to him or his wife that he could have cancer “*it still seems unreal*”. This sense of disbelief was felt very strongly throughout the interview; because he felt so well, he couldn't have cancer.

#### **6.5.4.3 Regret/blame**

For some with the diagnosis of cancer came feelings of regret and self-blame. For participant 25 (85yrs, GL7), his wife encouraged him to see his GP as he “*couldn't hold my water*” but he “*blames*” himself for not going sooner, regret that he hadn't acted sooner, that they had ignored possible symptoms. Participant 24 (66yrs, GL7) and his wife also expressed “*regret*” that he didn't go to the doctor earlier.

Participant 1 (83yrs, GL9) had similar regrets; his cancer was advanced at diagnosis with bone metastases, again he said he had felt well in himself but there is a sense of regret and feeling that he may have been ignoring symptoms. He realised he “*should have gone t' GP, well long time before I did*” but he “*felt alright in me self so...I just carried on*”.

Participant 2 was fairly pragmatic in his approach but there is still that hint of regret of not having acted sooner and the air of uncertainty that often goes hand in hand with a cancer diagnosis;

*....I've got it. it's not going to go away on its own. I've got to learn to live with it. However long that might be..... it's no good thinking oh, if only I'd have gone to the doctors five years earlier, I might have known five years earlier that might not have been so aggressive.....there's no good dwelling on,...(P2, 68yrs, GL9).*

#### **6.5.4.4 Other people's reactions**

Some men described the stigma still associated with a cancer diagnosis....

*If – if a person – well my – my close friends I tell them, I said I've got prostate cancer. 'Oh!!!'They say. 'Whatever are you going to do?' (P25, 85yrs, GL7)*

*I say what do you mean? I said deal with as it comes And 'oh, whatever will you do?' This was round about Christmas. I said 'meet – meet every day as it comes along'. And that's what we do” (P25).*



He appears to cope with this reaction quite well almost mocking them with his tone of voice as he describes their reaction. Interestingly the following gentleman (P2) also mimicked the reaction of some people when they found out he had cancer using a pathetic tone of voice and he sounded almost irritated by their reactions;

*But I really sort of try and do things to take my mind off it...if I'm busy I'm not thinking anything about it..... It's only if somebody starts 'oh dear, you didn't want that did you?' And you think oh, why don't...? You know, just, just leave it. Let me get on with it...because some people can be a bit sort of pathetic....a couple of people have been round ours, well, not been round, one of them phoned me up, was my cousin, and she is so pathetic. 'Oh my dear, what are you going to do?' Oh....I can do without that. You know, let's get on with life (P2, 68yrs, GL9).*

This reaction of others although almost certainly well-meant appears quite unhelpful to those on the receiving end. Participant 10 who had appeared unemotional and matter-of-fact in his own approach to his diagnosis, found the reaction of his brother to his diagnosis unsettling. Once more this goes to illustrate the stigma associated with cancer;

*I personally was informed. I mean when I told my brother, you know, he was really shaken by it.... in fact he upset me, his reaction.....again I had to go and refresh myself with, well the position I had in my own head (P10, 59yrs, GL7).*

This reaction from others and cancer being viewed as a death sentence can hinder any potential support available outside of the hospital environment. This feeling of not wanting to be pitied by others was described;

*I didn't want people...I suppose to feel sorry for me. I, I didn't want other people to know. ....I thought I don't want people to know because if they know they'll think I'm going to die in a couple of weeks time. And I don't feel I am (P8, 73yrs, GL7).*

#### **6.5.4.5 Making sense of their situation, irrational thoughts and feelings**

The overwhelming sense of fear that comes for many when told they have cancer was articulated by some of the men;

*And ...so then it gets in your mind and whatever you do you can't get it out (P8, 73yrs, GL7).*

For others they tried to make sense of their situation or had irrational thoughts or feelings. Participant 4 understood that he had the “aggressive type” which led him to fantasize about the “spores” escaping “into the system” during the biopsy when the needle was withdrawn “did any escape?” This question is not uncommon following diagnosis. He also tried to make sense of how his cancer was the aggressive type by attributing it to previous experiences of shock in his life;

*Does shock bring these cancers out in people? I think they do. I think they do. And I think that's what's happened to me to be quite honest (P4, 68yrs, GL10).*

He attributed the rise in his PSA as “*too much of a coincidence*” when it started to go up following his sister-in-laws diagnosis of cancer which both he and his wife were shocked by. This couple also described previous tragedy early in their married life and spoke at length about this after the interview, wondering if this could have played a part in his diagnosis, trying to make sense of it all whilst feeling so well.

With others their thoughts had moved on quickly to accepting they had cancer but how bad was the cancer? Had it spread outside the prostate?

*.....then it was whether it was contained. ..or is it elsewhere? .....well all right, I got it, now I need to know, it's like have I got it? Yes I have. Now I need to know where it is. We know it's there but has it gone anywhere else? (P3, 58yrs, GL7)*

*the worst bit for me I think was the bone scan thinking if it's got to my bones it is really serious (P2, 68yrs, GL9)*

*You know, the fact that you'd got it, that's treatable, but you know, how far down the line have you progressed? ..... (P10, 59yrs, GL7)*

Participant 5 sums up the feelings of many diagnosed with prostate cancer;

*.....it suddenly hit me oops, you know, this is it. I mean it's, it can be a serious problem but a lot of men live with it for years don't they?..... But it kills 9,000 men a year they reckon. Which is, you know, quite a few. And I don't want to be one of them 9,000 (P5, 64yrs, GL7).*

### 6.5.5 Theme: Disposition

We observed that wanting to know results quickly; choosing the method of delivery; how prepared the man was to hear his results and what the word cancer meant to him also appeared to be related to his character, personality and outlook on life in general. We named this theme disposition and broke it down further into 'beliefs', 'control', 'horses for courses', and 'emotions'.

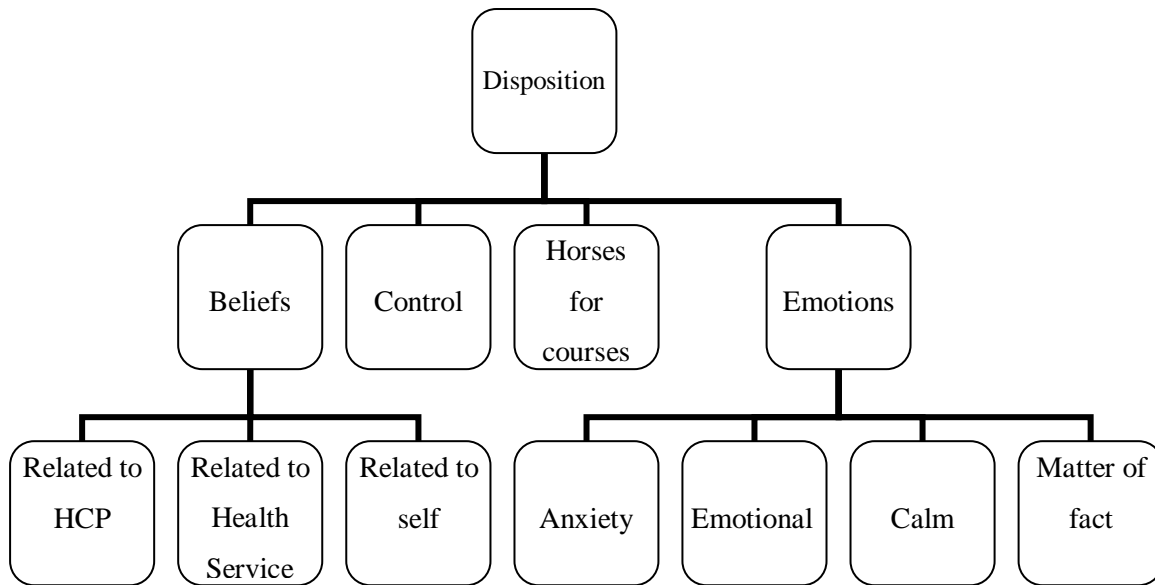


Diagram 7: Theme map

#### 6.5.5.1 Beliefs

By *beliefs* we mean the views or beliefs held by participants about HCPs, beliefs and expectations about the health service, and the trust placed with the doctors and nurses.

##### 6.5.5.1.1 *Beliefs related to health-care professionals*

Some of the participants held firm beliefs regarding the roles of doctors and nurses and for some, what nurses were 'allowed' to say to them;

*unless I was coming here to see....., a consultant or something like that with their results I would think well, I'm just going to be given the result, I won't be able to talk to the nurse because the nurse won't tell me anything, that's before I knew how this worked (P20, 75yrs, GL9).*

We found that those men who had more conventional beliefs on roles and hierarchy often leant more towards face to face consultation;

*...I do like to see the head honcho or whoever and be told rather than letters or phones really... (P5, 64yrs, GL7).*

*I would prefer to have it face to face with the consultant so that we could ask questions and could also put my wife at ease (P24, 66yrs, GL7).*

For some there was this sense of trust in the HCPs to look after them;

*...the rest of it is in the hands of the consultants and you people to sort me some treatment out and I accept that. I don't need to look elsewhere and burden myself down unnecessarily with complications of trying to get too much information in my head. I want to keep it as simple as I can for me to understand it and this is what I've done (P4, 68yrs, GL10).*

*....I put myself in your hands (P23, 81yrs, GL9).*

*...you just have to take a deep breath. Like (wife's) brother says, you know, let them decide what's wrong with you.....This is the treatment. Take the treatment, get on with your life (P24, 66yrs, GL7).*

*.....but often what you read in books leave a lot to be desired.....But the professional, he's the person who knows and can give you sound advice (P25, 85yrs, GL7).*

In contrast others put the onus more on themselves, to look after themselves rather than rely on others;

*.... well from my point of view ... nobody looks after you like you do.....nobody's going to come and say oh, Mr (name), because you're getting 72 you ought to have a prostate biopsy, it's only because through your persistence, or not from your persistence...(P22, 72yrs, GL7).*

#### **6.5.5.1.2 Beliefs and expectations of the health service**

Some men had no preconceived expectations of the health service; they appeared to be accepting of the care they received (P25, P2, P8). The fact that they were offered to telephone for their results did not appear to matter much to them;

*I would have accepted however the, the results came (P2, 68yrs, GL9)*

*..the phone call...that was as much as I could expect (P8, 73yrs, GL7).*

Whether this was down to personality or how they viewed life experiences in general is not possible to say.

Some men described themselves as “lucky” (P2, P3, P4, P9, P24) or “fortunate” (P15, P20, P23). We could interpret this as the men having low expectations of the health service so when good care is received they feel ‘lucky’ or ‘fortunate’ to have received this care rather than seeing ‘good’ care as the norm. Remarks such as “lucky” to have a “cracking doctor” (P3) or “lucky” that the hospital can “process me in that way” (P24) were made.

Some related this feeling of good luck to their diagnosis of cancer, participant 2 (68yrs, GL9) felt “*lucky*” that the cancer was only found on one side and hadn’t spread, also commenting that it “*was just luck I went to the local GP’s*” (P2). Participant 8 (73yrs, GL7) had experienced good health all his life only seeing his GP for blood pressure so felt “*lucky*” the cancer had been found early.

Others appeared to have low expectations of the health service in general and described previous experiences that may have formed or confirmed their beliefs. Participant 20 (75yrs, GL9) remarked that there was never enough time to talk to the GP “*you get 10 minutes, that’s all*” and “*they want you out of the door as quickly as they can*” (P20).

Participant 22 (72yrs, GL7) described a previous experience at a hospital appointment when the doctor was “*absolutely horrible to me*” and “*he sort of roared at me*”.

It was common for men to describe the hospital, the nurses, and the doctors as “*busy*” (P2, P3, P9, P12, P20, P22, P23). This sense of how busy the hospital and staff appeared seemed to influence their use of the service in that many described not wanting to waste our time and some appeared to trivialise their cancer diagnosis;

*.....I thought no, you're going to be busy. There's enough things to do without me ringing up on something as daft as this really because at the end of the day it didn't seem to be...I know it sounds silly again, it doesn't sound...to you, you've got lots of people to deal with, there's only, what, four or five of you dealing with god knows how many people (P9, 61yrs, GL8)*

*... mainly because I think that the pressures which doctors, nurses, what have you, consultants, that's better to do it like this rather than me going to waste someone’s time for quarter of an hour waffling on and –.....I thought rather than going up there and ...wasting time, if that was it.....(P23, 81yrs, GL9)*

*...like I say the reason I haven’t phoned in too much it's because you're so busy, there's people out there,..... that are far worse than I am. I know I've got it, and no matter how many phone calls I make it's not going to change it ..... I've been very well informed, considering how busy you are (P2, 68yrs, GL9)*

*..I felt that you were rather busy, I apologised to this lady, (nurse), for troubling her, and she said oh no, it's my job. She said I want to help you, you know... (P22, 72yrs, GL7)*

*.....to me to come up here is putting more extra burden on you, yourselves,.... That’s how I look at it,...I know hospitals are very busy, under staffed sometimes,.... (P12, 60yrs, benign)*

*....the hospital is just busy, no matter what time you go up there, everybody’s, you know, there's always somebody there isn't there, it's not as though it's empty, there's always somebody there ... (P3, 58yrs, GL7).*

### 6.5.5.1.3 *Beliefs related to self/ageing*

For some there was also an acceptance or maybe expectation that as they get older their health will be challenged by one disease or another;

*the GP said .....there's a possibility that you have non-life threatening prostate cancer, I thought oh, well that's the cross I'm going to have to bear. Because at some stage in your life you're going to come up against something.....somewhere around there's a cancer that might get you (P24, 66yrs, GL7).*

*I've been aware of prostate cancer and...but I haven't feared it but .....having the enlarged prostate for a number of years that I would need some treatment at some time or another, I knew I couldn't go on taking the finasteride indefinitely, something might happen sooner or later, which it has (P4, 68yrs, GL10).*

However in contrast others did not expect to have their health challenged as they had felt so well and had experienced good health all their lives;

*..... I wasn't expecting that sort of reply basically. Because as I say I've always been reasonably healthy, I only take some blood pressure tablets (P20, 75yrs, GL9).*

### 6.5.5.2 **Control**

A dictionary definition of 'Control' is 'exercising constraint or direction over; to dominate, to command' (The Concise Oxford Dictionary). References to control in healthcare are many especially in relation to stress, coping and adaptation (Walker 2001). Wallston et al (1987) defines perceived control as;

*"the belief that one can define one's own internal states and behaviour, influence one's own environment, and/bring about desired outcomes"* (Wallston et al 1987:5).

In health psychology there are references to perceived or personal control, locus of control, self-efficacy, learned helplessness (Walker 2001). The theory of control is beyond the scope of this thesis so for the purpose of definition what we mean by control here is the perceived control men had, the threat to the feeling of being in control and the disabling effect it can have when control of a situation is felt to be lost; helplessness.

The men cannot control the results of their biopsy; however they can control how their results are received. Being able to maintain a sense of perceived control at a time of much uncertainty, or taking some control over the situation, appeared to be valued by some (P10, P11, P16, P18, P26).

*So for me phoning up I was fairly sanguine about doing it all along in fact I found it, it saved me the travelling up and the hanging around. So I preferred that, I got the answer when, when I actually was ready to, ready to find out. (P10, 59yrs, GL7)*

*...I'm not a person to ....sort of sit there, sit back and wait for things to happen. If I can make them happen myself by just a simple phone call or something like that.... (P20 75yrs GL9).*

Some men spoke about being able to choose the surroundings in which they heard their results;

*...it's getting the answer in a time that suited me, ..in a location, being where I wished to be, who I wished to be with, rather than any coming to the hospital, speaking to somebody, strange surroundings anyway, which you anxious in coming up, so I could, so I could work it to suit me. (P16, 59yrs, benign).*

Others appreciated being able to choose who was with them or choose to be on their own;

*....my wife said can I, can I be here this morning? I said no, I said I'm the one with it, you know, you...I will tell you everything you need to know about it, you know (P17, 68yrs, GL7).*

Participant 23 described why he chose to be alone;

*...I didn't want to have my daughters here while – while the phone call was coming on in case I was going to shall we say be distressed or something...(P23 81yrs GL9).*

This need to be able to react to the bad news in the privacy of their home, was appreciated by participant 22 (72yrs, GL7) also describing himself as “*an emotional person*” and not wishing to “*make a fool of yourself*”.

Participant 5 whose preference was for face to face consultation was not expecting his results when he was told during his hospital admission post biopsy. He describes the feeling of the need to control his emotions in front of strangers when he was told he had cancer, but being unable to control these emotions when he saw his family;

*I didn't want to get upset in the ward, sort of...I said, you know, let's go. And I thanked, you know, I thanked the staff etc. and I just couldn't hold it, you know, I sort of let go and of course you don't get upset for nothing do you? (P5, 64yrs, GL7)*

### **6.5.5.3 Horses for courses**

We know that people are heterogeneous in their needs and preferences for information. One size does not fit all, in the same way when communicating results one method of delivery will not suit all patients;

*“it's another horses for courses situation I'm afraid” (P26, 65yrs, GL6)*

This finding was clearly demonstrated by the men in this evaluation; although some men said they were satisfied and didn't see a problem for themselves they also recognised that it wouldn't suit everyone to receive results by telephone;

*...there's something very personal and private about that, you know the information that will come to you and only you can deal with it how you are as a person. Some people are quite mentally strong and they can handle it. And some people ... that would just disintegrate them. (P11, 60yrs, benign)*

*Less pressure on the phone. Well to me.....But no, phoning in was, as far as I was concerned, was all right, I know as I say a lot of people wouldn't want to would they?.....But we're all different (P18 66yrs GL7)*

*I personally – I think that – that's all to do with the person you're dealing with. Like the person who's suspected cancer, if he's a – a nervous person,..highly strung person, and one thing and another, I think that could probably have a profound effect on him but.....– I thought it was a good idea and I ...couldn't see any problem (P23, 81yrs, GL9).*

Others expressed their preference for face to face consultation, again personal preference;

*I don't mind being told things on the phone but I'm a little bit of a...I like face to face. You know, that's how I am as a personal opinion (P5, 64yrs, GL7).*

Some men had no extreme preference either way, just deliver the results;

*So for me it's, it makes no difference, it's more important for me to have the knowledge so that I can actually start thinking about courses of action ... (P10, 59yrs, GL7).*

#### **6.5.5.4 The emotional experience**

Some men described themselves as anxious, some emotional. In contrast others portrayed a calm and relaxed demeanour and at times demonstrated a very matter of fact approach to receiving their results.

##### **6.5.5.4.1 Anxiety**

“anxiety is commonly experienced as a state of physiological arousal associated with unpleasant feelings, ranging from unease to panic” (Walker 2001 p.153)

These feelings of anxiety were expressed by some of the participants (P3, P9, P8, P12, P16, P22, P26). Many described the anxiety of waiting. Some described themselves as anxious people or described situations that increased their anxiety;

*I was anxious for the result. ....The anxiety of waiting is pretty tremendous....I just had to know really (P16, 59yrs, benign)*

*I was fairly anxious.....I'm a shocker for actually thinking the worst before I get to somewhere and I can get myself really wound up before all these sort of procedures....even down when I was having the.. scans, .....I was really strung up tight as a bow. .... for no reason, I knew they weren't going to hurt me or anything like that, but it's the anticipation and*



*also I think the, the worry about what the end results are going to be all the time. ..(P9, 61yrs, GL8).*

*You know, you worry about things, well I do anyway (P22, 72yrs, GL7)*

*And it's been on tenterhooks. I mean we all have, we've all been just sitting and waiting and trying to carry on as normal....and I think that bit is difficult to do until you know.....you know, you, you're still thinking about it all the time, it's worse when you're relaxing (P3, 58yrs, GL7).*

*...I was anxious. ..I wasn't – I mean by nature I tend to be an anxious person... that's the way I'm actually, you know, hard wired, I've got relatively high anxiety levels generally. ...but on that particular issue I was just anxious, I wasn't kind of, you know, thinking oh, I can't make the call kind of thing. I was, you know, I just knew I was going to make the call and that would be it (P26, 65yrs, GL6).*

#### **6.5.5.4.2 Emotional**

Some men admitted to being more emotional than others (P3, P4, P5, P6, P9, P11, P12, P13, P16, P20, P22) and some were able to express or describe this emotional side during the course of the interview;

*....this is surprising really because I'm finding this ...more emotional than I thought it would be. Because the results that I have are suggesting that I don't have cancer.....So that's a relief but just even talking about it brings this sort of emotion out. (P16, 59yrs, benign)*

*I am quite an emotional person anyway....(P6, 64yrs, GL7).*

#### **6.5.5.4.3 Calm**

Others described themselves as not being particularly anxious when calling for their results and came across during the interview as having a calm demeanour (P4, P6, P7, P13, P17, P18, P19, P21, P23, P25);

*Not at all. (anxious)...., I haven't been ever since. (P13, 82yrs, GL7)*

*I wasn't really anxious at all. No.... my son, he tells me off for it because he thinks that I should be worrying a lot more about it. I said well, what do I do, go and stand in the corner, put my head in the sand or, you know, no, I can't see any point. (P17, 68yrs, GL7)*

*...my wife was more anxious than me.....No, I was all right.....I just carried on doing my jigsaw puzzle (P18, 66yrs, GL7)*

*I was fairly...not resigned to it but as it went through I just read further into the information. So even now I'm relatively relaxed about it (P10, 59yrs, GL7).*

#### **6.5.5.4.4 Matter-of-fact**

A pragmatic approach often went together with calmness (P7, P10, P15, P18, P23, P25, P26);

*I'm fairly down to earth on this, I'm, I am a problem solver and fixer. So I'm not that bothered so much about the problem as are there solutions to it.... (P10, 59yrs, GL7)*

*.... as I say, if that's the way it's going to be, that's the way it's going to be. The die is cast now, it's done, the results are on the books, you know... nothing I say is going to change it. So might as well get on with it. I've tried to be sort of philosophical about these things in life and that's, that's the way I saw it (P15, 78yrs, benign)*

*from my point of view ....I'm glad to have the information given to me....I've got no qualms about that. ...I don't want to put my head in the sands and that. I would just – I just accepted that the – it – I mean that isn't your fault I've got it, your fault or the consultant's fault that I've unfortunately got it and the mere fact of not knowing isn't going to help the job at all (P23, 81yrs, GL9).*

### 6.5.6 Theme: Support/Social network

Results showed varying degrees of support available to participants. We observed that the level of support available appeared to affect how the men coped with receiving their results. We noted that those who were ‘cared for’ i.e. looked after by their wife or partner (P13, P21) took the news of their results better than those who ‘cared for others’, i.e. the participant had a wife or partner who was dependent upon them due to ill health (P1, P20). Some men in this evaluation demonstrated concerns about the future of their loved ones when faced with a diagnosis of cancer. This appeared to act as a barrier to feeling supported although the supporting relationship was potentially there.

We further coded *Support* into support in relation to *immediate family*, in relation to *friends and others*, in relation to *health-care professionals* and *potential barriers* to support. We observed that support was strongest when the participant was involving their family and communicating openly about their diagnosis with them. We perceived support to be weaker where the man was for one reason or another ‘putting on a brave face’ or keeping the information to themselves i.e. not openly communicating with others.

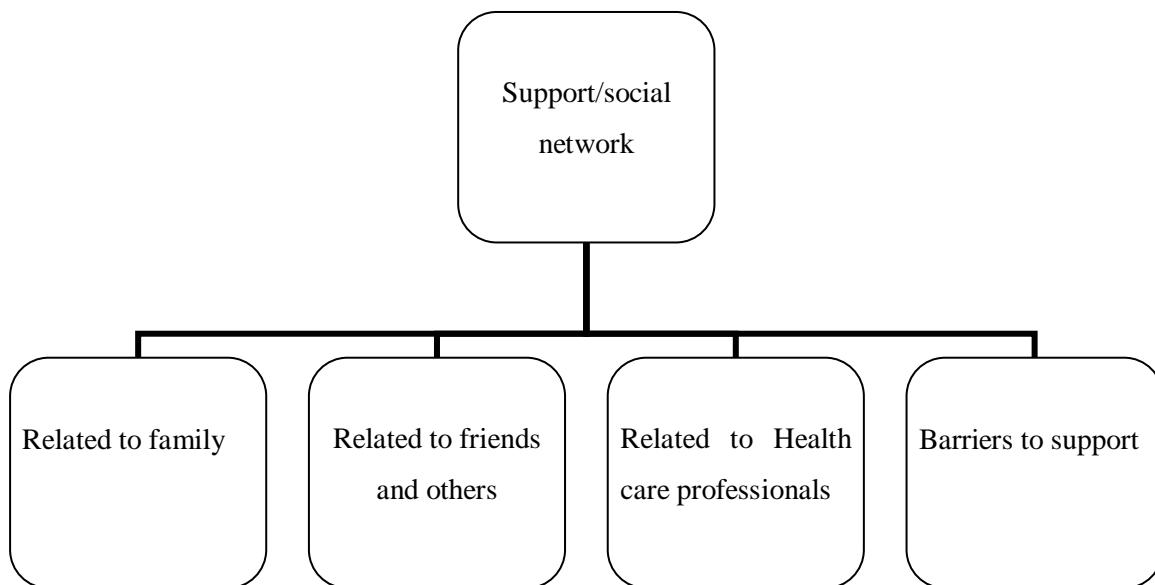


Diagram 8: Theme map

#### 6.5.6.1 Support in relation to immediate family

Wives and partners were most often mentioned in relation to support for their husbands. When receiving their results 10 participants had their wife or partner present through choice. Of note those that scored high on the anxiety scale (>7) were more likely to have their wives present at diagnosis (n7);

*.....and she's (wife) been with me, she didn't come the first time actually but she came all the other times ...we share everything anyway so it was, it's nice that she was here when, when it happened, when you told me (P3, 58yrs, GL7).*

*I've got a new partner, ....but unfortunately, she lives in (place name) and she said to me you're not going to be on your own, .....come down and stay until the Thursday and then...once you get the results then we'll go from there, ....I'd gone, as my partner wanted, she wanted to kind of protect me, she wanted me to be in people's company, not on my own, in my own house. ...That would be worse, being on my own, that would have just blown my mind completely. You just need somebody to talk to you and change the subject ... (P12, 60yrs, benign)*

*but I think if you've got a loved one there with you who's either making the call or, and then they can tell you, you've got that reassurance..... and it's a hug isn't it? If it's your wife or your partner, or your mum or your dad, that's a hug. Where, you know, there's someone there for you (P11, 60yrs, benign).*

Other men chose to make the call alone but their wife or loved one was present in the house (n7) or in the outpatient waiting area for participant 25;

*I was on the phone upstairs and my wife was downstairs.....She might have just crept in behind me sort of half way through the call I think, I'm not quite sure. It seems quite a long time ago now (P14, 65yrs, GL7)*

*I was taking it in my, in the separate room, in my study, my wife could hear me sort of talking in there but when I went back afterwards I was a bit upset..., sat down. She said oh I thought it was, what did they say, I thought it was bad news because, you were on there sort of quite a while sort of thing.....obviously we discussed it after that and started looking into stuff and we phoned my daughter that evening and told her (P20, 75yrs, GL9).*

There were also those men who were alone 'by choice' (P17). One made the call whilst at work (P10). Some men made the call when they knew their wife or partner would be out or had refused the offer of a family member being present when the call was made (n8).

*.....Like this morning my wife said can I, can I be here this morning? I said no, I said I'm the one with it, you know, you...I will tell you everything you need to know about it, you know. .... it's just the way I want to deal with what I've got. (P17, 68yrs, GL7)*

Other family members were also valued as support. Participant 4 (68yrs, GL10) talked "quite openly about it" with his granddaughters and participant 20 (75yrs, GL9) remarked how both his son and daughter "delve into sort of things" and were "Googling everything" demonstrating his willingness to discuss his diagnosis with his family and the supporting relationship.

## 6.5.6.2 Support in relation to others

### 6.5.6.2.1 Friends

Some men were able to talk openly with friends about their experience and cancer diagnosis and found it helpful to “*talk to somebody that's had it done*” (P3, 58yrs, GL7). Participant 14 (65yrs, GL7) discussed surgery with his cousin who had “*just recently had the operation*” and also spoke to “*a couple of the guys at the golf club had been through it*”. Participant 26 describes why he finds it helpful to talk to others he knows about their experiences, but not people he doesn't know;

*...It's easier to talk to people you know about this kind of thing than people you – you don't know because you also know a bit about the person if you're talking to someone you know and you know what their general kind of demeanour is and the way they react to things and so on so you could kind of tailor their response more to the way you feel about things (P26, 65yrs, GL6).*

Others purposely kept the information to themselves and did not find it helpful when present in social gatherings where prostate cancer was the topic of discussion. Participant 8 illustrates this as although he was willing to discuss his diagnosis with his immediate family he was not ready or willing to share this information with his wider social network and explains why;

*at the time I just didn't want anyone to know.....I didn't want people...I suppose to feel sorry for me (P8, 73yrs, GL7).*

This association of cancer with death within his social network prevented him from discussing his diagnosis with friends;

*There's a chap I used to work with .....a group of us we meet up every, once a month, about 20 of us .....we were at the meeting and someone said, this chap's name is (name)....they said he's got prostate cancer.....and by the time we finished that day,...I thought to myself the way they're talking he's finished, he's had it, that's it. That's final you know. And that before he even knew I had anything to do with prostate. And that's just what stick in my mind, you know. So I thought I don't want people to know because if they know they'll think I'm going to die in a couple of weeks time. And I don't feel I am (P8, 73yrs, GL7).*

Whilst some kept the news to themselves others were motivated to inform others and educate others to “*get tested*”;

*The blood test, yeah. I mean everyone that I knew, I know now the fifty age group who I talk to, I tell them, you know, just, just go to ask your GP for the blood test for it (P11, 60yrs, benign)*  
*there's a lot of people of my age in the place I work, and of course I'm telling them you need to get down there, mate, take that PSA test (P10, 59yrs, GL7).*

#### **6.5.6.2.2      *Spiritual***

Some men mentioned the church as a source of support;

*And we also have a friend who's an Anglican priest and his wife is a Macmillan nurse.....and they occasionally ring through just to say hello and how are you...which is supportive as well... (P24, 66yrs, GL7).*

*there again (wife) was with me and I think that is essential that you've got someone with you. And we wandered about and we had a meal and this and that and then we found a little chapel or a place of worship I suppose and we were looking there and the lady said you can go in if you like. And (wife) and I went in there and had a quiet sit down. We found that was most helpful. Yeah. (P25, 85yrs, GL7).*

#### **6.5.6.2.3      *Work***

Participant 3 (58yrs, GL7) felt fortunate that his employer was very understanding and he felt supported by his colleagues who phoned him frequently during the time he was on sick leave to see how he was coping.

### **6.5.6.3 Support in relation to health-care professionals**

#### **6.5.6.3.1      *The GP***

Some men reported positive experiences valuing the support from their own GP;

*.....we've got a cracking doctor..... there's no rush and, you know, sit in the surgery and you think oh, 20 minutes late. But when you get there it's exactly how you want it to be, answering questions like. So he was good and then I went back to see (GP 1), but (GP 2) was brilliant... (P3, 58yrs, GL7)*

*...the receptionist, opened it (the letter to start hormone deprivation treatment) and she said oh, it's only a prescription. She said I'll get that processed for you and then you pick it up on Friday. Well subsequently I had a call this morning to say that Dr. (name) wanted to see me on Monday, because obviously she – she wants to explain things to me. So both (wife's name) and I are going down on Monday at 10 o'clock (P22, 72yrs, GL7).*

*We have a very good GP too. And we have a very good relationship with him (Wife P21, 83yrs, GL9).*

Others did not find the same level of support from their GP. Participant 14 described how his GP tried to put him off having a PSA test;

*...he tried to talk me out of it, and then he tried to frighten me out of it by telling me all the nasty things they were going to do to me.....turns out that I have got prostate cancer, if I'd listened to him...it would have probably been too late to do anything about it when they found out, so I think that is despicable from my GP (P14, 65yrs, GL7).*

Participant 1 felt his GP lacked understanding and was 'shocked' when his GP told him he had cancer without any warning;

*.....I thought there might have been ...like some enlightenment or something like that ... you know but I never expected that.....I was a body ball... (P1, 83yrs, GL9).*

### **6.5.6.3.2 The CNS**

Our main role as nurse specialists in uro- oncology is to provide support and information for men with urological cancers, many men did report that they felt able to access that support or felt supported saying that they felt it was;

*...quite easy to phone and if I'd a question and ...I wouldn't have hesitated to phone up (P6, 64yrs, GL7)*

*...would have no hesitation in phoning your department.....in fact I think you know I'd phone you rather than phoning the GP or anyone else (P20, 75yrs, GL7)*

*..., you know, it's either there at the end of the phone or the end of a 20 minute drive if I want to speak to somebody. You know, it's...as simple as that (P17, 68yrs, GL7).*

For others the CNS being there as a source of support was not felt or demonstrated to them;

*...I phoned up once because obviously, I wanted to find out what the sequence of events were... I left a message, I didn't get an answer but the next day it's happened that the, one of these appointments popped through the letterbox. You know, so...I think twice I've left messages on the answerphone and not had a response (P10, 59yrs, GL7).*

#### 6.5.6.4 Barriers to feeling supported

We have already mentioned the association of cancer as a death sentence, which could be seen as unhelpful and a barrier to social support. The ‘busyness’ of the hospital or CNS service could also be seen as a block to potential support. The other factor that appeared to get in the way of feeling supported was whether or not the participant was a ‘carer’ or ‘cared for’.

Both participants 1 and 20 were the main carers for their wives which appeared to intensify their concerns at diagnosis;

*....I don't feel unwell fortunately because you know I've had to look after you (referring to his wife) for [laughs] for the last 12 months. I mean not saying that in a bad way but I mean we've been unfortunate as I say, she's been in and out of the hospital, I mean she's spent eight weeks in here early this year .....so it's been fairly traumatic and then as I say to have this sort of hit us on the back end on, I just think, I'm just hoping that I'm going to be all right to keep on looking after her and the house and everything....(P20, 75yrs, GL9).*

This sentiment was echoed by participant 1; both participants became emotional when talking about this worry during the interview;

*it's not me..... I'm concerned about the wife.....that's all my worry is... if I lived on me own it would be different. It's her I bother about cos she can't really look after herself to that extent she.... can't really get around very well and things you know and she has to be helped in one or two things and.... that's the problem.....that's the problem (P1, 83yrs, GL9).*

In contrast participant 13 and participant 21 were more dependent upon the good health of their wife for day to day living i.e. ‘cared for’ and appeared less anxious about their diagnosis than participants 1 and 20.

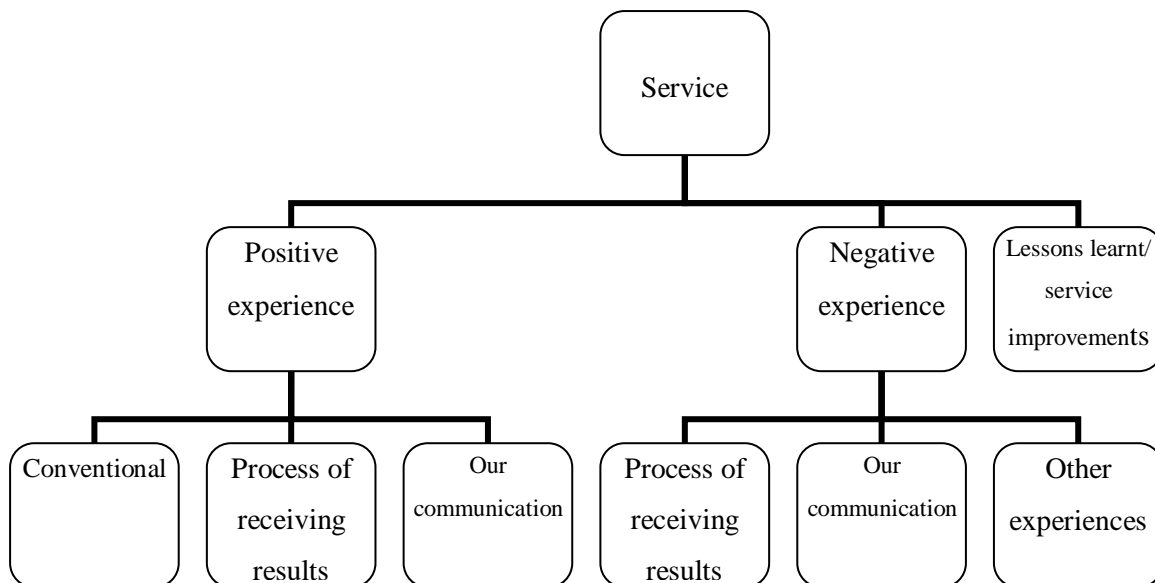
Despite recommendations that a cancer diagnosis should not ideally be communicated over the telephone and we were going against these recommendations, what did our patients think of the actual service we were offering?



### 6.5.7 Theme: Service

This theme is arguably at the heart of the service evaluation. Do we provide a good service for delivery of prostate biopsy results for our patients? How can we make it better?

Within the theme *Service* we sub-coded into *positive experiences* (satisfaction), *negative experiences* and *lessons learnt* (service improvement). We will begin with the reported positive experiences of receiving prostate biopsy results by telephone, then face to face. We will then report the negative experiences of patients and the lessons we learnt following patient feedback. With patient experience surveys patients have a tendency to report satisfaction with the service provided. This was frequently the case with this service evaluation. We have already acknowledged the potential for bias as I conducted the interviews. With this in mind we will first report the positive experiences and satisfaction with the service.



**Diagram 9: Theme map**

#### 6.5.7.1 Positive experiences ‘I was quite satisfied’

There were many positive experiences reported. We further sub-coded experiences of the service into the *process* of receiving their results and how the *communication* was perceived using the words of the participants.

##### 6.5.7.1.1 *The process of receiving results*

Men described the process of getting their results as “*straightforward*” (P21, 83yrs, GL9 and P15, 78yrs benign). Others found it “*easy*” to get in touch and ask questions (P6, 64yrs, GL7 and P4, 68yrs, GL10). The “*timeframe*” given in which to call for the results was seen as “*excellent*” (P6, 64yrs, GL7 and P23, 81yrs, GL9) being given a date to call and time slot of 2-3 hours in which to make the call if they wanted to. As participant 17 (68yrs, GL7) put it “*It done what it said on the tin*”.

Some men already had a lot of information through their own searching, others hadn't. Many found the prostate cancer booklet we post to men after they have telephoned for their results helpful, describing it as "*quite a nice concise ...short reading*" (P10, 59yrs, GL7), "*it's not gone out to ...complicate the patient too much*" (P4, 68yrs, GL10) and "*I think that's sort of quite well explained in there*" (P2, 68yrs, GL9). Following the telephone call a letter is also sent summarising the conversation. This was found to be helpful for most and acted as an aide memoire when explaining the results to others "*it goes between the two of us, and what (husband) remembers or doesn't remember, and then if you've got confirmation here you know exactly where you are. Oh yes, I think that's important*" (Wife of P21, 83yrs, GL9). Some men were unfortunate to get the answer phone but didn't report it as a problem as they left a message which was responded to (P4, 68yrs, GL10). Men appreciated being given the option to telephone;

*I thought it was quite good actually (P17, 68yrs, GL7)*

*....Well I was pleased that we were able to call (P21, 83yrs, GL9)*

*...it's nice to, for someone to say if you want to know, phone this number. That was great. (P6, 64yrs, GL7)*

*Even though it's potentially cancer? (Interviewer)*

*Yeah, especially because it's potentially cancer.... (P6, 64yrs, GL7).*

#### **6.5.7.1.2      *Our communication of the results***

We found that men frequently described not only the process of receiving the results but also described positive experiences of how the results were communicated. Being given their results in a "*kind*" (P13, 82yrs, GL7) and "*caring*" manner was appreciated (P2, 68yrs, GL9).

*... I was told...if you want to talk to us please either phone us or come in and see us, please don't hesitate. Which I thought was rather nice..., that was it really, it wasn't a long conversation by any means. ...it was to the point, ..it was caring, whoever it was. Obviously, you know, you could tell that she was caring about it. ...no I thought it was quite good (P17, 68yrs, GL7).*

The way in which the results were explained were described by some men as "*very well explained*" (P2, 68yrs, GL9) and with "*understanding*" (P1, 83yrs, GL9). The "*tone of voice*" used by the nurse explaining the results over the telephone was described as "*perfect*" and "*the way it was phrased was ideal*" (P7, 77yrs, GL6). The nurse was sometimes described as "*up front and very polite and sympathetic, she wasn't ...abrupt or anything*" (P22, 72yrs, GL7). Although participant 6 said he usually put off phoning people he commented that he "*would have phoned anytime he wanted*" as he wasn't made to feel like he was "*being a burden*" and described the nurses as "*quite friendly*" (P6, 64yrs, GL7). Others found everyone;

*really helpful- And that's a genuine comment; I'm not just saying this for your research.....so the good side is clearly you as a group of people if you like (P9, 61yrs, GL8).*

Participant 20 (75yrs, GL9) described how pleased he was to get a call the following day describing it as “*thoughtful*”. This call was made as he had sounded so shocked when he received his results over the telephone. His wife went on to explain that they weren’t used to that kind of “*pastoral care*”.

Some men described the way in which the results were given as “*pretty factual*” but they appreciated the “*upfront*” approach as they were the type of person that would rather “*know the score*” (P9, 61yrs, GL8). Participant 6 (64yrs, GL7) described how he felt that the nurse was “*reading my reactions even on the phone*” and goes on to explain this further;

*...even though you can't see people, body language, etc., you can gauge how they're taking things. I mean my work is not, you know, nothing like yours obviously, but at the same time I can tell whether, you know, people can take a joke, whether they can see the funny side of things, whether they're very serious, whether they're very straight to the point, and that's how I felt on the phone. I felt that, because I laughed when, when I was told that I was young, you know, I sort of laughed and, and there was a reaction to that, you know, so I felt whoever was talking to me was talking to me on my level (P6, 64yrs, GL7).*

Participant 26 (65yrs, GL6) described the “*professionalism*” of the nurse and the “*accurate way*” in which his questions were answered with “*no attempt to soften the blow*”. He saw this as a “*real positive*”, and commented that he felt this is how most people would want it not “*wrapped in cotton wool*”.

Participant 14 (65yrs, GL7) was under the impression that he would just be given the result then he would “*hang up*” and was surprised that the nurse had “*so much time for me*” and was “*so reassuring*” also commenting about the length of time with him on the phone as “*you don’t tend to get at hospitals too often*”.

The following excerpt is quite lengthy but I have included it as it demonstrates that not all face to face communication is better than telephone communication. Participant 6 had telephoned for his result whilst he was on holiday with friends, because he wanted to know;

*...as I said this was all done nice and slowly, gradually, not sort of rushed into... so I had time to take in each piece of information. ...then she went onto to say that ... I was relatively young ...which we joked about, but..., she gave me obviously the, the bad news, and then enlightened me on the various other aspects of what I had and I felt that was done, you know, really well because there's no way you can make it sound like good news, but I always find that ...I mean we went to the doctors, my GP, just the other day and ...although he's a good GP he, he just ran on through things and I came away not knowing really what he'd said. But I must admit*

*that conversation that day, considering that was where it was and in the circumstances it was I came away remembering every word that was said, I could relay it to my wife almost word for word which is unusual because I'm not that good at gathering information. ...and that become more apparent later when, when we were able to talk, because I couldn't tell her straightaway. I just told her that that was cancer and whatever, but that wasn't until that evening which was about five or six hours later that I could relay the whole conversation and I could actually relay the whole conversation, you know, which was, you know, quite good really (P6, 64yrs, GL7).*

Participant 4 explained that he was usually a “great worrier” but felt he was taking his diagnosis “in my stride”. He attributed this to the communication with us;

*...your, little department, your little team, has been informing me as to what's been going on.... I'm sure that's what it is, of being informed correctly. I know what the score is and you've told me all what's going on and what can be done. And I'm, I'm happy with that. So therefore I'm...not unduly worried about it (P4, 68yrs, GL10).*

Others described feeling “well informed” (P6, P2) and “quite satisfied” with what they had been told (P4). Participant 18 (66yrs, GL7) stated that “couldn't have been no better if I'd have been sitting in front of her really”. Participant 7 (77yrs, GL6) agreed with this sentiment saying “I don't think you could better it”. Participant 21 (83yrs, GL9) also remarked “I couldn't think of any way which it could have been improved”.

As previously acknowledged positive experiences have to be treated with some caution as there is a genuine risk that some participants were only comfortable to report good experiences. Particular care should be exercised in interpretation where I had been the nurse delivering the results.

For those men that were reportedly happy with receiving their results over the telephone we were interested to know what their thoughts were regarding expert opinion, having received results in a way that isn't recommended by the experts. Most of the men didn't see a problem with it and were pleased to be able to phone. Participant 14 cited reasons such as “it wasn't a problem as” the nurse “was so good.” He also described the service as “most essential” as having someone to talk to with experience, knowing “how men like myself react and what we want to hear and what we don't want to hear”.

Participant 23 (81yrs, GL9) describes the telephone service as “ideal” citing reasons such as he likes to know “what's going on” rather than “just wandering up there”.

### 6.5.7.2 Positive experience of conventional consultation

As previously mentioned recruitment of men who had received their results face to face had proved more difficult as the numbers were significantly smaller (table 7). Of the 3 men who had been given their results face to face, two had received their results in outpatients and one during an unplanned admission post biopsy. Only positive experiences were reported in this group.

Participant 24 (66yrs, GL7) described the doctor as having a “*good bedside manner*” and again the “*reassuring*” aspects of the communication were commented on. Participant 25 was pleased to be “*attended to*” on time and felt he “*got on with*” the doctor. Again, the participants focused on the communication aspects of the results delivery; the how.

Participant 5 remarked that he was “*extremely happy with my experience*” despite being admitted with septicaemia post biopsy *and* being told his results in the ward dayroom with very little warning!

### 6.5.7.3 Negative experiences

Although positive feedback from participants was often reported, there were those who did not have such a good experience. Some of those bad experiences we can learn from and try to ensure they aren't repeated for others. Yet we have to be realistic and acknowledge that one size does not fit all and we have to do the best we can with the resources available. Some of the excerpts go a little way to negate the argument that participants weren't comfortable to tell me the bad things about our service. Some of it was quite hard to hear; as we will now illustrate.

#### 6.5.7.3.1.1 The process of receiving results

The answerphone was a particular problem for some. Patients are given a 2-3 hour period to call. This is to enable them to pick a time to suit them, when they feel prepared, they are in control. The risk of this, which we readily acknowledge, is that if the CNS is already taking a call the answerphone clicks in. The patient will be telephoned back as soon as the other call has ended. Participant 6 (64yrs, GL7) was “*disappointed*” to get the answerphone not because he felt we were “*not running the show properly*” but because he had to “*wait a little bit longer*” to hear his results.

Participant 12 describes the intense anxiety felt prior to making the call only to get the answerphone click in;

*Basically... waited for Thursday...Half past one, I rang, I got the answerphone. You can imagine...you know when you build yourself up, that probably last half, probably half hour, to an hour, was really horrible. And I got the answerphone. And I just thought oh no, you know, like I don't want an answerphone. I want to talk to somebody, you know? So I left a message and sat there and sat there, it wasn't that long, I can't remember, ten minutes, I can't remember, I can't remember the exact time, but you know, it's just like you know...it was hours, if you can*

*understand that. Anyway, so I got the result and it was clear. Fine, you know, everything just, you know, as you say, everything comes back to normal, your life comes back to normal (P12, 60yrs, benign).*

In the past this wouldn't have happened as we used to telephone patients whose results came back as benign to relieve the anxiety of waiting. Participant 12 believes we should still do that. Participant 16 would not have appreciated an earlier call with a benign result –he would rather pick the time and place to make the call...

*Even if they were normal, to actually have that call earlier would have been a worry to me initially (P16, 59yrs, benign)*

... illustrating the diversity of patients' needs and opinions.

Our aim for general enquiries that are left on the answerphone is to respond within 24 hours, that was clearly not the experience for participant 10 (59yrs, GL7). He likened his experience to feeling like "you're on a bit of a treadmill" and that twice he had left messages on the answerphone and "not had a response". He describes the system as "just trundled down its way" and "thought it was a touché impersonal there".

#### **6.5.7.3.2      *Our communication***

It wasn't always the case that patients only told me the good bits when I had been the nurse delivering the results. This contrast is illustrated by the following excerpt from participant 8 who had spoken to me on the telephone for his results.....we (I) didn't always get it right;

*I think that was probably the worst thing, the only thing I knew when I was, when I had, I wanted to receive it, don't get me wrong, that...but I, I didn't have a clue what that was all about. Except the only thing I knew after the phone call was that I had cancer. So .....the medical terms didn't mean too much to me. I knew the word cancer..... But I didn't know much about all the other stuff. And I wish that you'd have told me that I was... that was treatable (P8, 77yrs, GL7)*

This gentleman did not feel reassured. He only heard the word cancer and did not understand the explanations given. I had not picked up on this during the telephone call; valuable feedback.

#### **6.5.7.3.3      *Other negative experiences***

There were other bad experiences described. However these were in relation to previous outpatient appointments or experiences with their GP. We will not go into these in too much depth as it is not direct feedback of our results service. Still, these previous experiences are important to note as they may have deterred the men from face to face appointments and may have influenced their choice of

results delivery so as not to have a repeat of the bad experience. It may also have increased their level of satisfaction with our service if they were measuring it against these previous experiences.

Participant 22 was “*made to feel foolish*” at a previous appointment and the doctor “*he sort of roared at me*”.

Participant 4 “*was rushed*” and “*if they run late then you don't expect, I suppose you don't expect to be treated quite so gently as you would do if you'd been on time*”

The wife of participant 13 described the doctor as “*arrogant*” and was upset when they were told prior to the biopsy that her husband had cancer, again no preparation or warning shot fired, he had gone to the appointment with a hydrocele and come away with a diagnosis of cancer and told “*but not to worry about it*”!

All these men were very complimentary of our service but this may have to be treated with further caution given previous bad experiences at outpatient appointments.

Participant 14 described his experience of an appointment; although this was following his diagnosis, when he attended to discuss his treatment options, the experience may have made him report our service more favourably;

*I found him a bit abrupt.....I could have been anybody, I wasn't an individual to him. I was just somebody [wiping or clapping hands] with prostate cancer, you know, here's another one sort of thing..... (P14, 65yrs, GL7)*

he also reported how his GP tried to advise him against having a PSA test;

*he tried to frighten me out of it by telling me all the nasty things they were going to do to me..... it turns out that I have got prostate cancer, if I'd listened to him...it would have probably been too late to do anything about it when they found out (P14, 65yrs, GL7)*

again this could have contributed to him seeing our service in a more favourable light.

#### **6.5.7.3.4 Service improvement- what can we do better? What lessons have we learnt?**

We asked the participants what we could, as a team, do differently to improve our service for future patients. The following feedback was received:

##### **6.5.7.3.4.1 Information pre biopsy**

In this account participant 15 describes very well the actions of some men; they want the information but don't want anyone to see that they are looking for information. Our cue to ensure information is easily accessible, maybe placed around in the waiting area rather than men having to get up and walk over to an information stand, so information can be reached unobtrusively;



*Only a bit I picked up in the ...area, you know, the waiting room area, the big clinic area where they're all pushing and shoving, coming and going, sitting down. That, there was a table with bits of paper on it, ambled across to that, looked, noticed it, made sure no one was looking, I'll have that, have a quick shifty and mmm...that's...oh...right, that's...right...I'll have one of those sheets and folded it up and put it in my pocket. I'll look at that later. That's all, that's the only information I had (P15, 78yrs, benign).*

#### **6.5.7.3.4.2 Information post biopsy**

Participant 10 describes his experience post biopsy as “*leapfrogging into the dark*” as he didn’t feel he had enough information about the sequence of events and timescales of these events with regard to further tests and treatment options.

This feeling of not knowing what to ask was felt by others too (P22, P20) and participant 9 remarks that;

*...the biggest problem I think is, is in a way the lack of information about, to be able to ask people like yourself the right questions at the right time (P9, 61yrs, GL8).*

There is always the risk of too much information but clearly what our patients are saying is they need more guidance, more information and more direction so we have a duty to respond to this and to provide it.

Some men made recommendations about the post biopsy information regarding receiving a negative result;

*That's the only thought, maybe one thing that could be added that if you do get a negative result, because I had a negative, you know, that this time, or that the point is made that this isn't forever, you know (P15, 78yrs, benign).*

One man did not like to be told to prepare himself for bad news;

*Like I remember reading that and thinking oh, prepare yourself for bad news. So you're really winding the mind up to...do you see what I mean? (P11, 60yrs, benign).*

We explored this view with later participants and no one who was asked agreed with this opinion, the consensus is a warning shot needs to be fired. Patients need to understand what it is we are looking for, what the results may show; again this takes us back to information, and knowledge about prostate cancer, as explained by participant 18;

*...you've got to tell people that could be like that. It's...when you ring that's what you, you know, you expect whatever they have found to be told don't you? It's no good ringing up and then sort of going crazy because they tell you the bad news. If you don't want to do that you*



*don't bother ringing, you wait until you see your GP or something don't you? .... (P18, 66yrs, GL7)*

Some of the participants commented that it would be helpful to be directed to further sources of information participant 24 remarked that;

*all the information is out there if you want to find out but just go to this site,..... you just need to know the basic facts and the support that is available (P24, 66yrs, GL7).*

Participant 26 commented that it would be helpful to have been pointed to the useful sites of information at an earlier stage. Referring to the websites he comments that;

*I dare say there are good ones there, it's just that there are so many bad ones there that, you know, you can't really kind of see the wood for the trees almost (P26, 66yrs, GL7)*

*But certainly – certainly the prostate cancer charity one was a good one..... (P26).*

#### **6.5.7.3.4.3 The delivery by telephone - putting a name to a face**

Participant 22 commented that it would be nice to have met the nurse giving the result. We strive to do this and as there are now 4 CNS' involved, more often than not the results are communicated by the same nurse in attendance at the biopsy clinic. This also makes it easier for the CNS explaining the results as she has made an assessment of the patient prior to the call.

#### **6.5.7.3.4.4 Reassurance when the results are delivered;**

Participant 11 comments on the importance of “reassurance” at the time of receiving results;

*...to make people aware that that's, that's not the deadliest of things that could happen to them, ...if it's caught on time. (P11, 60yrs, benign)*

This feeling of reassurance being important was also felt by participant 8;

*...as soon as the word cancer used...that was what done it. If you'd ...have said to me, you know, we're now very, very advanced on prostate cancer and we can cure it, ... I think them words would have been superb (P8, 73yrs, GL7).*

Participant 9 commented that it would have been helpful to have a call the next day;

*now again I appreciate you've got so many people, and so many things to do, and it, but it might just have been the sort of the friendly voice at the other end of the phone, how are you? I'm sort of all right-ish sort of idea but.....Is there anything else you need to know or can I help at all? (P9, 61yrs, GL8).*

Participant 9 did make several calls to us over the weeks, but at the time of diagnosis he didn't know what to ask. This is another example for the argument for provision of information, and where to search for more.

#### **6.5.7.3.4.5 To have a choice**

*I think just to give them both options, both choices. Some people no doubt would prefer to come to discuss it face to face. I think if you can just give the two choices I'm not sure what more you could do (P16, 59yrs, benign).*

#### **6.5.7.3.4.6 Reduce the waiting**

*I would preface my comment by saying that I've had nothing but kindness and care from the doctors in my surgery and those I met at the hospital. , the one thing that could be done is to shorten the timescale of....Waiting for the results (P19, 78yrs, GL7).*

*At the time the waiting is the thing that is... frustrating and ...annoying and worrying thing (P16, 59yrs, benign).*

#### **6.5.7.3.4.7 Be there to pick up the telephone**

There were men included in this service evaluation who telephoned and either got the answerphone or our secretary. This was due to circumstances beyond our control but illustrates the importance of being there when they call. This was a one off occurrence which will not be repeated but those men were not excluded from the evaluation.

*Just that little bit of waiting. And you've got to wait...you had your biopsy and that and you've got to wait but at least I knew when I got off the table she said ring Wendy on the 3<sup>rd</sup> of whatever it was. I don't know whether it was the 3<sup>rd</sup> or later. But, you know, then I thought oh okay, that's Friday week. .... So, fine. But it's when you pick up the phone and you get Wendy's not there. What? (P3, 58yrs, GL7)*

#### **6.5.7.3.4.8 For those with benign results**

Some would have liked to be telephoned as soon as the results were available and not waited for the agreed date and time;

*That's what I'm trying to say, you know, so that way if you can give people good news, without...what's the word, you know, penalising the people with the bad news,.... Can that be done? I know it's ...labour intensive because you're making phone calls...But that would be nice if it could be done (P12, 60yrs, benign).*

As we will discuss this has been an issue of resource, but one we should try to address.

We have heard the experience of our results service from the patient's perspective. Have we been able to answer our original questions? Is it acceptable to explain biopsy results that show cancer over the telephone? Is the choice still wanted and should we even be offering this option to telephone for biopsy results? The overall message received loud and clear is that most men want the result of their biopsy as quickly as possible, delivered by someone who knows what they are talking about in a sensitive, kind and caring way, in language that is easy to understand. They want reassurance but honesty. Prostate cancer to many men means death. Information and education can go some way to diminishing this belief but the shock of the diagnosis, however well prepared they may be, cannot be diluted. Yet the telephone is not necessarily the problem but can for some be the solution *if* used appropriately. It seems that 'how' the results are told is important, not where and by whom.

Are we offering a good service? Maybe, but it can be improved. We will now discuss our findings.

## 7 Discussion

Our Audit in 2007 by postal questionnaire showed overwhelmingly that patients were satisfied with our telephone service providing limited evidence to back up a service that evolved in response to patient need. A diagnosis of cancer is bad news. The breaking of bad news is a complex process. National, local guidelines and expert opinion denounce the use of the telephone for delivery of bad news. Our patients continue to challenge this opinion.

### 7.1 Speed

The key message from our findings is speed. Patients want to know the results of the biopsy as soon as possible in whatever way is quickest. If that means hearing by telephone that is acceptable to most. Even if the results show cancer. The pressure of the anxiety of waiting to hear if the results show cancer or not cannot be underestimated. Does that make it acceptable for men to telephone to hear that news? In some instances yes, because as some literature suggests and as our service evaluation found the anxiety of not knowing is greater than the knowing they have cancer. Speed is paramount. Once the results are known coping can begin, they can move to the next step along the trajectory. This replicates the findings from our survey in 2007 showing that men wanted to be informed quickly. The anxiety of waiting is too great for some. As previously discussed Purnell and Arnold (2010) surveyed the perceptions of women *after* receiving breast biopsy results by telephone. Both benign and malignant groups ranked hearing the results quickly as the most important aspect of communication and hearing the results in person as the least important. This study was a large scale quantitative survey by telephone but supports our findings that patients '*just want to know as quickly as possible*' and would suggest this is not gender specific. These women were not offered a choice **but** an arrangement to receive results by telephone had been agreed and akin to the service we offer the nurse has met the patient at the biopsy clinic; observations regarding character and understanding have been made. A relationship has been formed; a face can be put to a name. The importance of this relationship with the HCP and the agreement regarding explaining cancer results over the telephone is also supported by Salander (2002). The difference with our service is the patient initiates the call maintaining some degree of control. Most appear to be satisfied.

The critics may suggest that patients are better to wait to be given a cancer diagnosis face to face rather than to be told 'quickly' over the telephone. Our patients disagree. This suggestion makes the assumption that face to face communication is better; our participants revealed this assumption isn't always true.

Uncertainty and the anxiety of waiting was one of the issues highlighted in the National patient survey conducted prior to development of the Cancer Plan (DOH 2000). The implementation of the two week wait targets and 32 and 62 day pathways for patients with cancer was to reduce those waits and

periods of anxiety between the steps on a cancer journey. Waiting is described in several studies as the period of most anxiety (Yardley et al 2001, Padgett et al 2001) the information vacuum often being filled by imagined worst case scenarios. Providing the option of being able to telephone the CNS for the prostate biopsy result a week later helps to reduce that wait and period of anxiety for some.

## 7.2 Preparation and process

We observed that receiving a diagnosis of cancer is not a one off event. It is a process of events that patients worked through leading up to their results. Different patients experienced different journeys that had an effect on how prepared they were to hear their results. This process of receiving a cancer diagnosis has more recently been described in the literature (Tobin & Begley 2008, Salander 2002) and our findings would support this view. In some cases the patients experience leading up to the biopsy prepared them well for the diagnosis of cancer, for others the process did not prepare them well, quite the reverse. False reassurances, lack of knowledge of prostate cancer, a 'head in the sand' approach hindered some of the patients preparedness for a cancer diagnosis and made the receiving of their results by telephone more difficult. Arguably a face to face appointment to hear the results would have not changed their lack of insight but face to face communication affords the non-verbal cues that are essential when explaining a cancer diagnosis to someone who is mentally unprepared to hear it. Preparing patients well by education and provision of accessible information is important for any mode of results delivery but essential for those who chose to use the telephone service.

The preparation we observed begins even before they see their GP with, for most, a notion that there could be something wrong. For others there was no thought of cancer, they were fit and well, so the possibility there could be a cancer present was not foremost in their minds. With cancer you should feel ill. The GP sometimes provided this first step of the preparation for a diagnosis with the PSA test, explaining that it *could* be a sign of a prostate cancer. For some their GP approached it with reassurance that most prostate cancers are indolent, '*non-life threatening*', and some men found this reassurance helpful. For others false reassurance lent them into a false sense of security which made hearing the word 'cancer' more shocking as they were not prepared, their fears had been unrecognised or dismissed. This finding was affirmed by Sinfield et al (2008) looking at the experiences of men with prostate cancer. Others support this finding that good intentions of false reassurance can be more damaging when a suspected diagnosis is eventually confirmed (Tobin & Begley 2008). To explain a diagnosis of cancer over the telephone we found that men who were prepared to receive bad news of a cancer diagnosis appeared to receive the news better than those who were not well prepared, this corresponds with others findings (Sinfield et al 2008). Having some knowledge helped. This is also the case for face to face delivery of a cancer diagnosis (Schofield et al 2003). In short receiving a diagnosis of cancer is not a one off event (Salander 2002, Tobin & Begley 2008). It is a process which for some begins before they are even in touch with any HCP. For others this process begins in primary

care. Wherever it begins it is important for us to ascertain for individuals when we meet them in secondary care the point they are at along this information journey; moving them carefully to the next step; preparing them for confirmation of, or removal of, the suspicion of a cancer diagnosis whether this is face to face or by telephone.

### **7.3 Information needs**

Patients' information needs are diverse and our findings show that in line with the literature (Jenkins et al 2001, Meredith et al 1996, Leydon et al 2000) our men want information about their cancer. Information is a powerful tool in aiding men to come to terms with their diagnosis and future treatments. We found that information sources varied. Some men used HCPs as their sole source of information to meet their needs and placed a great deal of trust in them. This *trust* in HCPs was a finding from a qualitative study exploring the information and support needs of older men with prostate cancer (Bungay & Cappello 2009). For some men in our study this trust was given and appeared to negate the need for patient expertise, lack of trust signals the need to become expert (Bungay et al 2009) and this was certainly in keeping with our findings. Nanton et al (2009) described similar findings in that the older men with prostate cancer placed more trust in the HCP's and sought out less information than the younger men. Yet caution must be heeded and no assumptions made on the basis of age as our findings demonstrated, with one of our octogenarians routinely using the internet as one of his main sources of enquiry and two of our participants in their early sixties relying solely on information provided by HCPs.

Other men in our study searched tirelessly gathering as much information from as many sources. Sources of information included written media, the internet, family and friends. The information gained was in the main helpful but at times overwhelming and unhelpful. Being guided to reliable sources of information was reported as an improvement that could be made to our service. The information provided after the diagnosis was helpful but for some it came too late. This brings us back to the provision of information, at what point is it most beneficial? The diverse needs of men mean that we have to accept we will not get it right all of the time. One man found the mere mention of the word cancer too alarming and did not appreciate its use even at the biopsy stage. We would argue that the lack of understanding about prostate cancer increased this participant's anxiety and providing information prior to biopsy would benefit most. Wallace and Storm (2007) suggest that information is wanted about prostate cancer long before a diagnosis is made with information about prevention giving men opportunities to change their lifestyle. By the time a man gets to the point of biopsy it is often too late for preventative measures but knowing our patients search for information and where aids us in providing and directing them to the best sources of information for them at this stage. Wallace & Storms (2007) support our findings demonstrating that men will search the internet for information to try to regain some control by trying to understand their diagnosis and treatments available. Developing a sense of control by searching for information is acknowledged as one way

some cope with the threat of a cancer diagnosis (Zeibland 2004, Pollock et al 2008, Cegela et al 2008). We found men valued factual, clear information from sources such as the Prostate Cancer Charity but also trusted the opinion of experts working with prostate cancer patients. Pollock et al (2008) support this finding suggesting that patients value verbal information from HCPs with continued trust in the information they provide. Being given the time over the telephone to talk through the diagnosis and the provision of information from the CNS was helpful for most. This concurs with others findings that time spent explaining the diagnosis is important (Figg et al 2010) and our findings demonstrate this is achievable over the telephone. Yet for others the shock of the diagnosis hindered their ability to absorb any further information and on at least one occasion it was reported that we provide *too* much information in the telephone call. We could argue that harm was done by providing results via telephone to this participant. The anxiety of waiting for him was too great; the lack of understanding about prostate cancer evident; cancer to him meant death; he described the stigma of a cancer diagnosis; all in all a recipe for causing harm. Arguably he would have had the same reaction during a face to face consultation; nonetheless, face to face would have afforded the CNS the opportunity to pick up the non-verbal cues of distress that were not identified in the telephone conversation, on this occasion. A sound argument for face to face communication of prostate cancer. Can we learn from this and prevent a repeat of this experience? Possibly by careful assessment of the patient at the biopsy clinic, assessing their information needs, sources of and existing knowledge. Offering face to face results or telephone results in the same timescale with factual information about prostate cancer focusing on the numbers of men that *live* with the disease rather than focusing on the numbers of men who *die* of the disease. Acknowledging fears but also providing hope and helping men to find a way forward (Thorne et al 2009) could reduce the risk of harm when giving the results whether communicated face to face or by telephone. The need for reassurance and hope at the point of diagnosis was described by Nanton et al (2009). Reassurance that the cancer can be treated and hope for either a cure or an ‘extension of their lives’ was described by their men and replicated by some of ours. It is important to get the information balance right though as needs are diverse, too much information at diagnosis can lead to increased anxiety levels causing as much harm and anxiety as too little information.

## **7.4 Communication**

### **7.4.1 How, rather than by whom**

Breaking bad news, i.e. news of a cancer diagnosis is a complex process which was demonstrated within our findings. Most of the literature and guidance recommends that the Breaking of Bad News should ideally be done face to face (Baile et al 2000, NICE 2002, 2004, Walker et al 1996). Our findings did not always support these recommendations. We found that patients appreciated being



able to talk about their concerns and have their suspicions confirmed even if it was over the telephone. Our findings imply that face to face communication is not as essential as expert opinion suggests.

The argument that all non-verbal communication is lost over the telephone sounds a logical one for not supporting telephone diagnosis. Yet the men in our study, despite the lack of non-verbal communication, were able to connect with the bad news giver and talk through their problems and concerns. For some the lack of non-verbal communication was seen as a positive aspect. Not having to risk a public display of emotion. To react in the privacy of their own home. To have met the nurse prior to telephoning for their results helped some men, others were still satisfied with the communication despite having not met the nurse. This finding replicates those of Purnell & Arnold (2010). Being able to communicate effectively is crucial in the whole process. Communication of the results can be done well or badly regardless of whether it is face to face or over the telephone. The *how* the results are delivered rather than the *where* and by *who* was found to have greater importance for some of our men.

Some studies have shown that receiving a cancer diagnosis by telephone can do a lot of harm (Thorne et al 2009). We would agree that in those reported cases in the literature the harm is very evident as the patients in these studies were unprepared for the call; it came 'out of the blue'. Even if the patients knew what the test was for, an unexpected call to receive their results was not appreciated and for some was damaging. The telephone call had not been agreed with the patients. We know *how* the bad news is given can have a lasting damaging effect on the patient and we know it can harm future relationships with HCPs (Thorne et al 2009). We are anxious to get it right more often than not. A minority of studies confirm our findings, that an expected call, agreed with the patient can be seen as the patient being important enough to telephone, to relieve the anxiety of waiting (Thorne et al 2009, Salander 2002). For others, unprepared for a telephone call this is not the case. We would argue that with our service the patient initiating the call places them in the position of control, certainly over their environment and who is with them. The *result* is out of their control, other factors need not be.

We found that patients appreciated being told their diagnosis by someone "*who obviously knew what they were talking about*". For most, experience and expertise in the subject appears to be more important than who is giving the news, this is supported in the literature (Davison et al 2004, Figg et al 2010, Purnell & Arnold 2010). Again we demonstrated it is the *how* they are told the news rather than the by *whom*. Being told with sensitivity, kindness, being given time to express their concerns and to have these concerns responded to was important to the men in our evaluation. This caring and sensitivity was felt over the telephone despite the lack of non-verbal communication. Others appreciated the matter of fact approach by the nurse delivering the news, with "*no attempt to soften the blow*" and we could argue that despite the lack of non-verbal communication that in the main the nurses giving the results were reading the men correctly. We were getting it right more often than not. Having a telephone number to call was also appreciated. This is in keeping with recommendations



from the literature (Harden et al 2002, Nanton et al 2009). Yet not all our participants favoured the telephone. Some prefer to receive their diagnosis from the “*head honcho*” this being the consultant. Being seen by the consultant can signal that they have something serious, a warning sign that bad news is approaching (Pollock et al 2008). Our concern is, being given the option to telephone; does that give the opposite signal? The cancer isn’t serious? Or worse, does it qualify that their cancer is not important, or indeed they are not important? Are we affirming commonly held beliefs that men’s health is not as important as women’s health by even offering this as a service?

#### **7.4.2 What is told**

We found most men in our evaluation were able to recall *how* they received their results. They were also able to give an accurate account of *what* they were told. It is well reported that when someone is told they have cancer that they remember little else of the conversation once the word cancer has been used (Walker et al 1996). We may have speculated that delivering a diagnosis of cancer over the telephone, with the lack of face to face communication, this would be a greater risk. We found the opposite. Most of the men who had telephoned for their results had recalled the conversation accurately and the details of their diagnosis. This *may* partly be due to the information booklet we send out with written confirmation of the phone call and next steps. But some reported remembering the specifics of the conversation word for word before the information had arrived.

Most knew their Gleason grade and understood to some extent the significance of this. This suggests that the telephone can be used to deliver results not only sensitively but also accurately. We are mindful that although this was true for most men it wasn’t always the case. Shock can impede the amount of information absorbed and lack of understanding and preparation can also hinder the information retained. The importance of clarity of information at the time of a cancer diagnosis has been described by Thorne et al (2007) as it ‘reduces the fear of the unknown’ and dispels the state of confusion and doubt that is often felt around this time.

### **7.5 Cancer and death**

Our study demonstrated the association between cancer and death. This is not a novel finding, far from it but it is a stark reminder for HCPs, many who may not see prostate cancer as the death threat it is to patients (Maliski et al 2002). Knowing this or being reminded enables us to bring prostate cancer into perspective for patients, to reframe their diagnosis (Nanton et al 2009). Caution must be applied though as some men do have a disease that will eventually kill them. We need not necessarily focus on this at diagnosis as providing hope is important (Nanton et al 2009) but, to be aware of it in the periphery as honesty is arguably the best approach for a trusting relationship to be fostered and maintained. We demonstrated the belief men held, that the cancer would almost certainly kill them and some expressed surprise at treatment plans that mentioned 3 years ahead. Providing this reassurance and information can arguably be carried out face to face or by telephone. Some may argue

that with face to face communication it is easier to read the non-verbal cues when someone has heard enough. Over the telephone the skill of listening and careful questioning, pauses to allow the information to be absorbed, but not for too long, asking the patient to summarise what has been heard and understood, using the same skills but with heightened listening to tone and utterances. Still we did not, and do not, always get it right but our findings suggest that we get it right more often than not.

The shock of a cancer diagnosis cannot be disputed. Our findings suggest that patients can be prepared for cancer but the initial shock will remain. This is a common finding in many studies relating to receiving a diagnosis of cancer, prostate cancer included (Kelsey 2004, Sinfield et al 2008, Harden et al 2002). So we cannot remove the shock but can we prepare men better? Our findings demonstrated even where men were well prepared, almost expecting to have cancer due to their age or family history or preparation by a HCP, the shock was still very evident and reported as such. This concurs with the findings of Nanton et al (2009) that even those men who expected to be told they had cancer still experienced shock, and the uncertainty of not knowing turned into the uncertainty of the implications of the diagnosis, the 'how long have I got' scenario. The shock experienced following diagnosis whether told face to face or over the telephone is arguably no less or no more, "*it depends where you want to take the hit*" as one of our support group members so eloquently put it. His preference was to telephone.

We found the shock of the diagnosis often went with disbelief. The disparity of feeling well and having a prostate cancer diagnosis led some men to find it difficult to accept, also described by Maliski et al (2002). This finding is not necessarily of significance to telephone delivery of prostate biopsy results. It is significant for HCPs giving the results by whichever mode to be reminded of in order to prepare men for the next phase along the trajectory.

## **7.6 One size does not fit all**

We know that one size does not fit all; this was clearly demonstrated in this study. Men's needs are individual and diverse. We found that personality appears to contribute to these different needs. Those that were by nature more anxious appreciated the option of being able to telephone, to regain some control in a situation of uncertainty. The uncertainty of the not knowing only heightened the already present anxiety. The uncertainty of waiting has been described by others (Thorne et al 1999, Yardley et al 2001, Tobin & Begley 2008) and the ability to exercise some control over the situation was helpful for some of our men. Others who were less anxious and took a more matter of fact approach to the situation again were pleased to be given the opportunity to telephone so the problem could be 'dealt with' and the next step in the 'process' could be taken.

We found that for some men the option of hearing bad news in the comfort and privacy of their own home had its advantages. For some the anonymity afforded by the telephone and the lack of non-verbal communication had its benefits. Not having a display of emotion in front of a stranger, being

able to react in private and when composed to then see the consultant, ready to take in the next step of the journey was advantageous for some men. This finding may not sit comfortably with the HCP who may naturally want to reach out to a patient in distress but at present we are focusing on the opinions and experiences of the patients.

The literature suggests that some patients appreciate having another person with them when hearing the bad news (Girgis & Sanson-Fisher 1995, Fallowfield 1993). The advantages of this are cited as another pair of ears, when in a state of shock being unable to absorb all of the information presented or for transport home. However as we keep reiterating patients' needs are very different and some prefer to be alone (Schofield et al 2003, Yardley et al 2001). Our findings confirm this.

## **7.7 Support**

We found some men valued the support of their wives and ensured they were with them when the results were received, whilst others excluded wives from any appointments or receiving of results whether by telephone or face to face. Some men sought support from male friends or acquaintances that had personal experience of prostate cancer whilst others avoided mentioning their cancer to anyone other than their wife or immediate family. Some kept the information to themselves because of the stigma associated with a cancer diagnosis and not wishing to be pitied. Our findings suggest that those men who felt well supported and communicated openly about their cancer appeared to cope better than those who did not openly communicate about their cancer, did not seek support from others or if that support from friends and relatives was just not available. This is in agreement with another study that found some men were keen to disclose their diagnosis to others and felt support and gained information by sharing their experiences, others however chose to keep the information to themselves and carry on as normal (Gray et al 2002). In relation to receiving prostate biopsy results is this finding of significance? We think it is, as by offering this service we place more control in the hands of the patient. He can control not only his environment but also who he is with. As HCPs we cannot assume that because a man is married that he wishes to involve his spouse in matters regarding his health. Although for most men in this evaluation the support of their spouse is important the need to have control over what their significant other is told must be respected and has been reported by others too (Boehmer & Babayan 2005). We acknowledge this is not a strong argument for providing a telephone service however it should be considered as it does afford the patient control over who hears the information and who is present when it is heard. The opposing argument is that a face to face consultation enables both parties to hear the same information at the same time *if* this is the patient's preference. We acknowledge this is only possible by telephone if the patient has two handsets or the ability to receive the call on loudspeaker which some of our men who use our telephone service do. Still, for those who don't have this available to them we offer to speak to their wife or partner, this is sometimes accepted at other times not. This inability in some instances to speak to both patient and

wife or partner at the same time is a valid criticism of the service and was reported by one of our participants.

Our findings demonstrated that having a dependant appeared to make the diagnosis more upsetting for those men. We don't believe this finding is of significance in isolation but rather a contributing factor to a complex process. The implications of the diagnosis and fear of dying was greater with the thought of leaving their dependant with no one to look after them. This is relevant when offering a telephone results service to all men as although the need to know is overwhelming we could argue that the delivery of results face to face would serve these men better as the support from the HCP may be felt more with the non-verbal elements a face to face consultation affords. Having said that the two participants whose wives were dependant on them for their everyday needs did feel the support from the CNS delivering the result despite the telephone method of delivery BUT with the benefit of hindsight one of those men would have rather had a face to face consultation. The other participant would have made the same choice but *I* felt he would have been better off with a face to face consultation for his results. Maybe I am falling into the trap of the professional knows better than the patient and I should delete this argument from my discussion?

In contrast we found that those men who were well supported by their wives, even to the point that their wife arranged to make the call to receive the results, appeared calmer, more accepting and appeared to take it in their stride.

## **7.8 Men are different to women**

Our findings suggest that our patients find our telephone service acceptable. All these patients are men. Does gender have a part to play in the acceptability of the service? Men are different to women. Real men do not make a fuss over their bodies (Gray et al 2002). Men are different; they in general treat their health differently making fewer trips to the GP than women, and have less involvement with health-care providers' in general (Salander & Hamberg 2005). Men see things differently, are less emotional (in general) and those who are emotional wish to hide this from outside in line with the hegemonic expectations of society (Gray et al 2002, Chapple & Zeibland 2002). Men have a tendency to minimize the impact of illness and need for support (Gray et al 2000), are we just helping them to do that? Are we endorsing the characteristics of hegemonic masculinity expected by society by offering this service? Is the telephone *more* acceptable for men? I don't honestly think we can say that, it isn't that simple, personal preference must be the guiding factor whether male or female and certainly the findings of Purnell and Arnold (2010) would not support gender as an issue. Indeed Wall & Kristjanson (2005) suggest that when the experiences of men with prostate cancer are being investigated the findings are often presented in a less complex form 'men after all are just men'; their words not mine. Yet our service does afford the men an aspect of control which was found to be important to some of our men and in line with the findings of Gray et al (2000). Some men in our

study had a very matter of fact approach to receiving their results whether or not they showed cancer. It was not worthy of much discussion. Are these men trying to lessen the impact of their diagnosis on their lives, minimising the impact of their illness with a low perceived need for support and maybe fear of stigmatization as suggested by Chapple & Zeibland (2002)? Are we just supporting this worthlessness or are we enabling some men to cope with the impact of the diagnosis the only way they know how? Are there those who just accept their lot in life or see it as the process of aging and carry on without giving it too much thought? This was demonstrated by some of our participants.

## **7.9 The service**

### **7.9.1 Busy**

The men in our evaluation described the hospital, doctors and nurses as '*busy*'. This is not unfounded and a common view described by others (Harden et al 2002, Leydon et al 2002). Did this affect the acceptability of the service? Were we seen as too busy to be offering an appointment 'just' for a biopsy result so they thought they had better telephone and not waste our time? We believe that for some men this may be the case and for those men they were also accepting of the care they received, not seeing it as a problem or even 'quite good'. This is not a valid reason for offering results by telephone but an observation of why some men may have 'chosen' this method of finding out their results; the busyness of the hospital and HCPs may have contributed to this choice.

### **7.9.2 Expectations**

Our findings demonstrated that previous experiences with HCPs appeared to have an effect on patient's satisfaction with our service. Those men who had experienced previous poor communication with a HCP lent more towards the telephone service and were satisfied. We could argue that their expectations had been exceeded as the expectations were so low following previous bad encounters. I don't believe this is a strong argument for offering delivery of biopsy results over the telephone in isolation however these findings demonstrate that telephone communication performed well surpasses face to face communication executed badly. Some men expected to be just told the result over the telephone, 'a quick call' yes it is cancer or no it's not, and were pleasantly surprised that this wasn't the case, that time was taken to explain the results and questions were answered. This again may have made these men more complimentary of the service as their expectations had been exceeded. Ziebland et al (2010) found this to be the case in a qualitative study exploring lymphoma patients' experiences of NHS care. These patients described many positive experiences but attributed this to 'luck' indicating that they didn't expect to receive good care under the NHS. Zeibland et al (2010) comment that low expectations are unlikely to end in disappointment and may lead to pleasant surprises if the care received is good, yet their findings suggested that patients expectations were 'unrealistically low'. Our findings concur with these. Many of our men reported feeling "lucky" to be "processed"

quickly and “lucky” with the care they received even when they had telephoned for their biopsy result and it had been cancer.

It is suggested by Bungay and Cappello (2009) that as awareness of prostate cancer increases and attitudes change the next generation of patients may become more expert and have higher expectations. This in turn may have an impact on their satisfaction with services provided.

### **7.10 Choice, should it even be offered?**

Choice is generally regarded in health care as a good thing (Walker 2001). But is it? Choice in the NHS is the latest buzz with choice of appointments, choice of hospitals, choice of surgeons, putting the patients in control (DOH 2007). In reality these choices are often paid lip service to and no real choice exists. Should we be offering a choice of hearing cancer results over the phone? We are certainly in vogue by offering a choice but are we providing too many choices for patients when they have little understanding of the implications of the decisions they are making? Or, are we treating men with the respect and dignity they deserve? Handing over some of the power to the patient? Giving back some sense of control in a situation where they may be feeling vulnerable and out of control? Or, by offering this choice are we adding to their confusion, increasing their anxiety, making them more vulnerable?

Our findings suggest that some men do not want a choice; they will just do as they are told. Others were surprised to be offered the opportunity to telephone for the results and some appreciated the option seeing it as “essential” for the choice to remain. We should remind the reader that in the beginning this option of telephoning was patient choice, not the choice of the CNS, not implemented as the sign of the times. As the service has evolved and the changes to the delivery of cancer care have been implemented within the NHS, the option of face to face communication of results has been more difficult to deliver, certainly in the same time scale.

Our findings demonstrated confusion for some around the choice of results delivery. One man commented that at the time of the biopsy he was so anxious about the biopsy that he couldn't really recall having any choices of results delivery explained and he was anxious to leave. Yet often the first question asked after the biopsy is ‘when will I get the results?’ The time of the biopsy is reported as an anxious one with the uncertainty of what to expect, the anticipation of pain, anal penetration and the implications of what might be found (Olfiffe 2004, Chapple et al 2007). This arguably is not the best time to be offering a choice of how to get the results of the biopsy. Or for others does it give back some control over the situation, decreasing feelings of vulnerability?

Maybe we are able to answer this question of whether or not a choice should be offered for results delivery. With the benefit of hindsight most men said they would make the same choice of how to get their results, they appreciated being able to telephone. There were others though who with that benefit

of hindsight would have preferred to come up and receive their results face to face. If we are providing a choice it should be a comparable one, the same time scale for both options.

### **7.11 Benign results**

Some of the men in this evaluation did not have cancer. Often these results are available sooner than the cancer results. To reduce the number of calls to the results line and lessen the risk of a man with cancer getting an engaged tone we write to the gentlemen to tell them no cancer has been found on their biopsies. Historically we would have telephoned the men also to relieve their anxiety. It is reported that high levels of ‘tension-anxiety’ are felt by some men, not only at the biopsy but also following the result of a negative biopsy (Macefield et al 2010), although most men in their study coped well. As the demands on the CNS service increased we have had to prioritise our workload and those men without cancer are only written to as this is less time consuming. Our findings suggest that men would appreciate being telephoned as soon as a negative result is available, to reduce that anxiety. This wasn’t always the case but in the main we found that a call ‘out of the blue’ with good news would be well received.

### **7.12 Treatment choice confusion**

Once the diagnosis was known many of the participants were then faced with the confusion over the treatment choices available for prostate cancer. Some had few or no options but many would have liked to have known more about prostate cancer prior to receiving their diagnosis. This is in keeping with findings in the literature (Wallace & Storms 2007). The men who had either started hormone deprivation treatments with or without radiotherapy intent did not have a good understanding of their treatment and side effects. Possibly one of the hardest choices men have to make is regarding their treatment options post diagnosis and staging investigations (Kelsey et al 2004). Prior to treatment men often feel well, some find it incredible that they have a diagnosis of cancer and struggle to come to terms with the fact they not only have cancer but are then being offered emasculating treatments which will have a huge impact on not only their lives but their whole being. All the participants had questions at the end of their interview regarding treatments for their cancer. These large gaps in their knowledge should arguably be filled by the CNS when the patient attends to discuss their treatment with the consultant. What has this to do with delivering results by telephone? With one hand we have reduced the anxiety of waiting for a cancer diagnosis; with the other we have taken away the support that used to be more readily available at the consultant clinic. The provision of a results service has not single-handedly depleted this support but it has contributed as the results service consumes 2-3 whole sessions of CNS time a week. The benefit of the telephone service is that it frees up consultant time for more clinic appointments and complex treatment choice discussions, but these clinics are busy and often the patient, as we have demonstrated, leaves confused. This confusion surrounding treatment choices following a diagnosis of prostate cancer is well reported in the literature (Harden et



al 2002, Wallace & Storms 2007, Sinfield et al 2008) and this bewilderment is arguably best resolved by the CNS (Sinfield et al 2008, DOH 2005).

We know that men with prostate cancer do not get as good a deal as patients with other cancers (DOH 2005). We know that the number of cases per CNS in urology is almost double that of cancer CNS' in other specialities (NICE 2008). If we turned back the clock and all men were given their results in clinic and we concentrated our efforts solely on providing information and support to those with a diagnosis or suspected diagnosis of a urological cancer, would that be a better service for our men? Possibly, for some. Yet in reality if we now abandon the telephone results service the effect could mean more waiting or worse an unexpected call with a cancer result by other HCPs when clinic appointments are stretched.

Breaking bad news is a complex process.

## **7.13 Strengths and limitations of our service evaluation**

### **7.13.1 Recruitment**

Recruitment was dependant on patients' willingness to meet me for interview. Hence, the patients who did participate were all willing and able to voice their thoughts and opinions. They were able to describe the way in which they received their results and their experiences. We found that some of our participants were more able to articulate their feelings than others. It is suggested that those who respond to patient surveys are not representative of the larger population of patients with prostate cancer as those who respond are more able or more willing to express their opinions (Gray & Philbrook 1999). We found our participants representative of patients with prostate cancer on clinical findings and age. The high recruitment may partly be due to the confusion felt regarding future treatments and participating may have been seen as an opportunity to discuss this. Others may suggest that only those who were happy with the service responded and those that were less happy chose not to. This may be the case for some and we acknowledge that those with more negative feelings about the service may have been less likely to participate and may be underrepresented in our findings. Yet we did recruit those who were able to criticise the service and the service provider. We also found those who had not accepted their diagnosis who may have responded for cathartic reasons. We can only surmise as to why some men did not respond as we did not feel it justifiable to contact them with our high response of those willing to take part.

The number of men recruited following conventional consultation for results delivery was low so it was not possible to make comparisons with face to face delivery.

We acknowledge there is a lack of ethnic and cultural diversity within our patient sample. This is mainly due to the population of the catchment within Norfolk and the catchment area covered by the hospital. Therefore our findings cannot be assumed to be generalizable across the whole population of



men with prostate cancer. As we previously reported patient preferences are diverse with cultural differences having an impact on information and communication preferences (Uchitomi & Yamawaki 1997, Karim 2003, Surbone 2006, Fujimori et al 2007).

### **7.13.2 Interviewing and analysis**

We demonstrated that the use of semi-structured interviews can provide rich data with most participants describing their experiences giving us some depth of understanding as to why the service was used. A criticism may be that a professional transcription service was used as arguably transcribing is an important part of the analysis. Yet the process of analysis was thorough with constant reading and rereading of the transcripts and checking and cross checking across the data set. We were anxious to do justice with the analysis and interpretation of the data, for the men's experiences and opinions to be heard. This may have been achieved with fewer participants with an experienced researcher. But as a novice interviewer I acknowledge the earlier interviews were not so good and certainly as my confidence grew so did the quality of the interviews. Although unfazed by interviewing patients in a clinical environment it is entirely different in their own homes. I was in a very privileged position, invited into participants' homes and seeing the impact of their diagnosis in 'real life' as opposed to the clinical setting which affords us some protection from the reality of living with a cancer diagnosis.

### **7.13.3 Interviewing as service provider**

As the service provider I can be criticised for interviewing the patients. Some may not have felt they could be entirely honest with me, although I can assure the reader some felt very comfortable being honest about the service, as we illustrated, it wasn't all good. We acknowledge that the men were in a vulnerable position, still under our care and not wishing to jeopardise future relationships with us or the hospital. There had to be a certain amount of trust and safety felt, to enable them to criticise the service. It may have been useful for a more experienced researcher, not a provider of the service, to conduct some of the interviews to see if this would have any effect on the responses received. This wasn't possible but conscious of my intimate involvement with the service peer debriefing was valuable throughout data collection and the on-going analysis to check the interpretation of the emerging themes.

### **7.13.4 Gender & Bias**

We have discussed gender in relation to the acceptability of the service but it may also have influenced participant responses, being interviewed by a female. This could be viewed as a positive aspect as the men may have felt more comfortable expressing emotion and feelings to a female interviewer than a male one (Oliffe and Thorne 2007). On the other hand the men may have limited their comments due to embarrassment with a female interviewer (Wallace and Storms 2007). The

analysis was also at risk of bias as I am one of the service providers. I have my own bias. Explaining the results of a prostate biopsy that is benign is one of my better jobs. Explaining the results of a biopsy that is cancerous is not one I look forward to each week. The service commenced in response to patient demand. As numbers using the service escalated I became less comfortable with it. I do not like the lack of non-verbal communication the telephone affords. Yet it is a service we provide, in response to patient need, and I may have unwittingly noted mainly the positive aspects of the responses and ignored the less positive feedback. Aware of this potential for bias and my own ambivalence possibly steered me more in the opposite direction, certainly the bad was reported. The analysis was also carried out with an experienced male researcher not involved with the provision of the service and bias was explored during the process of analysis. The themes validated by a second experienced researcher.

### **7.13.5 Trustworthiness**

The processes in place to ensure validity of the findings should be evident throughout any studies using qualitative methods of enquiry (McBrien 2008). The opinion of the ethics committee was that this project came under the umbrella of service evaluation. There is a fine line between service evaluation and research; I felt we were very close to that line. The ethic of non-maleficence (to do no harm) was central to the project throughout. Member checking has been argued to be one of the most robust mechanisms for ensuring credibility in qualitative enquiry (Guba & Lincoln 1989). Yet Angen (2000) disagrees that relying too much on member checking does not enhance the validation process. The transcripts were sent to the participants to check for accuracy and for them to comment with any further thoughts. In retrospect we could have sought permission from some of the participants to review our preliminary themes which arguably would have added further credibility to our findings. In practice we did not wish to inconvenience or trouble these men any more than we already had at a time when most were now faced with the uncertainties that come hand in hand with a diagnosis of prostate cancer.

### **7.13.6 The service provider**

To provide an all-round evaluation of the results service we should arguably have explored the perspectives of the service provider also. This had been the intention prior to commencement of the project. We discussed this with the steering group and with the size of this project we felt this may be a recommendation for future enquiry. Our priority was to understand the patients experience of the service and in order to do this justice we concentrated our efforts on the patient's perspective alone.

### **7.13.7 Generalizability**

Qualitative data by design has limited generalizability (McBrien 2008). The purpose of this service evaluation using qualitative methods was to gain more depth of understanding of our service from the

patient's perspective, whether or not it was an acceptable service to them, whether there were factors other than speed that influenced their use of the service. Whether we were doing more harm than good and how we could improve the service for them. The extent to which are findings can be generalized to other populations is questionable and recommendations of this kind should be cautious ones.

## **7.14 Small Changes made to the service along the way**

### **7.14.1 Information sheet**

As data collection progressed it became clear that there was confusion around the choice available to men to receive their biopsy result. A small change was made to the post biopsy information sheet and more emphasis placed on the options available at the biopsy clinic, they don't have to phone, appointments are available.

### **7.14.2 Dedicated results line**

We also noted the frustration felt by some participants, not getting through straight away when they telephoned. At the start of this project 2 years ago we had one telephone for all calls received, results and enquiries. Following the feedback from participants we now have a dedicated results number which goes through to a separate phone. This number is only given out to those men telephoning for their prostate biopsy results, to lessen the risk of not getting through first time. We explored alternatives to this, for example having a set time to phone but those men we asked liked the flexibility of the 2-3 hour period to make the call.

### **7.14.3 Reflection and reassurance**

We noted the need for reassurance at diagnosis with many of the participants and fed back to colleagues. The bad news cannot be made good news but hope can be fostered. We like to think that we do offer hope and reassurance at the time of a cancer diagnosis but it didn't hurt to be reminded that sometimes the word 'cancer' is the only word heard, the importance of reframing their cancer at diagnosis, making it more manageable for them to cope with and to offer hope in the face of more uncertainty.

### **7.14.4 To have met the nurse delivering the results**

Following patient feedback we endeavour to have the same nurse at the biopsy appointment delivering the results. This is beneficial both to the patient and the nurse, putting a name to a face for both parties. The nurse having assessed their general demeanour and understanding prior to the call makes the conversation easier. A follow up call is made the next day for those who we feel are in most need of it. We have always offered a follow-up face to face appointment for those who wish to attend after they have heard their results. This offer is rarely taken up.

### **7.14.5 Changes to be made**

Our findings suggested that for most, information and understanding can have a reassuring effect and enables men to reframe prostate cancer. The written information given to patient's pre and post biopsy is under review with the aim of providing more information about prostate cancer in general and direction to more helpful sources of further information for the men who seek it. Information needs, like our patients, are diverse. We will strive to get the balance right and with the help of our prostate cancer support group members reviewing the re written information we hope to get the balance right for the majority. We acknowledge we will not get it right for all.

These are small changes that we hope will improve the experience of the service we offer. There are further changes we would like to make that will not be so easy to do. To offer a real choice of results delivery, in the same time scale. The problem with the implementation of this is resource at a time when the hospital is looking to make huge savings and telephone results delivery has come to be seen as the norm and acceptable way of ensuring cancer targets are met. Yet we must strive to achieve this to meet individual needs as one size does not fit all.

### **7.14.6 Recommendations for future**

Our results would suggest that receiving a cancer result by telephone isn't as dreadful as it first seems. Yet our findings cannot be recommended to be generalizable across the whole population of men undergoing prostate biopsies to diagnose prostate cancer. For telephone results the patients understanding of what they are phoning for is pivotal to the whole process. The nurses explaining the results must have expertise not only in the subject but also advanced communication skills.

We would recommend that further studies could look at the long-term effects of receiving a cancer diagnosis by telephone. Further service evaluation should also include the service provider and link with primary care. Re-evaluation of the service, once the recommendations have been implemented, may be able to answer whether or not improved information equals improved acceptance and lessens the shock of a diagnosis of prostate cancer; whether if the choice was equivalent in waiting time to hear results the telephone service would still be used as often.

## 8 Conclusion

“Involving service users in the evaluation of services is fundamental to ensuring patient-centred provision” (NICE guidance for Supportive and Palliative Care 2004).

We set out to evaluate a service that provides the option of receiving results of prostate biopsies over the telephone. We sought after a deeper understanding of men’s experiences of using this service. We needed to know if communicating results that show cancer over the telephone was acceptable to our patients and if the choice was still wanted. We wanted to know what improvements could be made to the service. There is little point involving patients in the evaluation of services if the health-care providers continue to think they know best, despite the feedback from patients.

Our participants told us that the worst experience is the waiting; the waiting to know if they have cancer or not. The key message is that they want to know the results of their biopsy as quickly as possible. Despite the dearth of evidence in the literature, for most of our men the telephone was an acceptable way to communicate biopsy results to them, even if those results show cancer. For some the telephone was preferred. The need to know quickly undoubtedly overrides the need to be told face to face. To be told bad news well does not necessarily mean being informed face to face. An agreement with the patient about how they want their results communicated is essential for telephone delivery. Relieving the uncertainty of not knowing, filling the information vacuum is the outcome.

We found that information and understanding is pivotal to explaining cancer results over the telephone. We affirmed the findings of others that a diagnosis of cancer is not a one off event but rather a process leading up to the diagnosis. We demonstrated that men went through different processes to reach their diagnosis. Preparation for the results was part of this process and was influenced by a wide range of sources encountered in day to day living including friends, family, acquaintances and the media. The vicarious knowledge obtained through these sources had both negative and positive effects on the participant’s preparedness to receive his results. We found despite these external influences affecting their insight or knowledge of the disease, what was of significance was their own internal preparation. We found that many men wished they had known more about prostate cancer before their diagnosis. We suggest that written information pre and post biopsy may improve this readiness to receive the results but whether or not this will have an effect on their internal belief is more complex.

We demonstrated the trust felt by many in the experts. We noted that for some on receiving a cancer diagnosis the need to become expert led them into a flurry of searching and confusion. Our findings supported those in the literature that patients are heterogeneous in their needs for information and information delivery; we confirmed that men who search for information appreciate guidance to

reliable factual information to complement that provided by the HCP. Changes to our patient written information will be keeping with these findings.

We confirmed that prostate cancer is associated with death. We demonstrated the disbelief that was felt by some with the disparity between feeling well and having prostate cancer. We affirmed there is still stigma associated with a cancer diagnosis. We found this stigma has an impact on potential sources of support. We suggest that information and increasing awareness of prostate cancer as an indolent disease *may* aid to lessen this stigma of the diagnosis. This suggestion comes with a cautionary note as there are those who die from the disease not with it and we would not wish to trivialise any cancer diagnosis. Yet, is it this indolence of prostate cancer and men's need to know that in a sense makes the telephone service a little more palatable? I'm not sure, maybe.

We demonstrated the importance of getting it right, but also that this isn't always going to be possible. Our findings suggest that most of the time we do get it right, but at times we do not. This is not exclusive to telephone communication. We found that some men appreciated having met the nurse that gave the result, for others it didn't make a difference. We demonstrated that most appreciated the service we offer but also believed that the hospital, the doctors, the nurses are busy. For others expectations of the health service were low, and some felt 'lucky' to have the service.

We found that choice for some is good, for some it causes confusion and for others it is not wanted. To offer the option of telephoning for results of a biopsy that shows cancer is responsive to some patients need to know and to know quickly. This choice allows patients to maintain some control over the environment in which the results are communicated but others will accept however the results come. We demonstrated that patients' needs and expectations are very different.

The risk of doing harm by giving a cancer diagnosis badly cannot be contested. We reviewed the recommendations and evidence to support the communication of bad news. The recommendations denounce the use of the telephone to explain a cancer diagnosis. Our patients challenge these recommendations. Bad news is bad news, you can't make it good news but how it is told can make a difference. The communication style must match the recipient. To be given the facts but with sensitivity and kindness was appreciated. Our findings challenge the assumption of experts and fellow colleagues that being told a cancer diagnosis over the telephone is wrong. Communication of a cancer diagnosis can be communicated well by telephone. We demonstrated that guidelines are just that. The experts do not always know best.

Can we recommend this practice to others? I would like to say yes but if I did it would be a very cautious yes. We have to listen to our patients, otherwise what is the point of asking for their opinion? But we have to be responsible with our recommendations. If the patient is unprepared, a diagnosis of cancer will not be well received face to face or over the telephone but, if the patient has really understood the results could be cancer, if they have understood that prostate cancer isn't necessarily a

death sentence, if it is their preference to telephone, they make the call, they choose where they are and who is with them, it is reasonable. This is on the provision that the HCP explaining the results has expert communication skills and undertaken advanced communication skills training. It is vital that they also have expertise in the subject and the implications of each diagnosis.

In short we confirmed that breaking bad news is a complex process. Waiting for results is an anxious time and patients want to know results as quickly as possible. How they are told is significant. Preparation is vital for all cancer diagnoses but especially so for telephone communication with the lack of non-verbal cues. Assessment of where the patient is in their understanding is important. An established relationship with the CNS giving the results by telephone is ideal but not vital. The option of the telephone for communicating results of a prostate biopsy is still wanted by our patients; even if the results show cancer. It is essential that an agreement has been made with the patient first.

If the news is bad, the telling of it need not be.

## Appendix I: Trust Guideline for the Management of Breaking Bad News to Adult Patients



Norfolk and Norwich University Hospitals **NHS**  
NHS Foundation Trust

### A clinical guideline recommended for use

<b>In:</b>	All clinical areas
<b>By:</b>	Medical and Nursing Staff
<b>For:</b>	All relevant patients
<b>Key words:</b>	Breaking bad news for adults
<b>Written by:</b>	Dr. Nicola Holton, Consultant in Palliative Medicine Julie Noble, Specialist Palliative Care Nurse
<b>Supported by:</b>	Sally Legge Lead Cancer Nurse
<b>Assessed by:</b>	<b>Professional Protocols, Policies &amp; Guidelines Committee (PPPG)</b> <span style="float: right;">_____ <u>20/06/2011</u> Dated</span>
<b>Ratified by the:</b>	<b>Clinical Guidelines Assessment Panel (CGAP)</b> <span style="float: right;">_____ <u>27/07/2011</u> Dated</span>
<b>Approved by the:</b>	<b>Clinical Effectiveness Committee</b> .....Dated <b>Clinical Governance Committee</b> .....Dated
<b>Guideline issued:</b>	June 2011
<b>To be reviewed before:</b>	June 2014
<b>To be reviewed by:</b>	Author
<b>Guideline supersedes:</b>	B31/ CA2021 Version 2
<b>Guideline Reg. No:</b>	B31 / CA2021 Version 3



**Breaking Bad News Flow chart -The McMaster Technique (Garg, Buckman, 1997)**

**Step 1**

**Preparation**

Check the patient's notes and talk to the team.

Check who should be present.

Set the time.

Set the scene and ensure privacy.



**Step 2**

**What does the patient know?**

*"What do you understand about your illness and tests so far?"*



**Step 3**

**Is more information wanted?**

*"Your test results are available. Would you like more information about the results?"*



**Step 4**

**Give a warning shot**

*"I'm afraid it looks more serious than we had hoped".*



**Step 5**

**Allow patient to refuse information at this time**

*"It must be very hard to accept this?"*



**Step 6**

**Explain (if requested)**

A narrative of events can be useful, using pauses between each event for emphasis.



**Step 7**

**Elicit and listen to concerns**

*“What are the main things that you are worried about?”*



**Step 8**

**Encourage ventilation of feelings**

*“How does this news leave you feeling?”*



**Step 9**

**Summarise and plan**

*“Your main concerns at the moment seem to be.....”*

Offer to discuss any treatment options if this is wanted.

Give written information if wanted.

**Step 10**



**Offer availability and support**

Give follow up appointment/give contact numbers.



**Step 11**

**Communicate with the team**

Document in the notes your discussion.

Write and inform the GP

**Objectives**

The aim of this policy is to provide guidance for any healthcare professional having to break or give bad or significant news to an adult patient and/or family. Bad news can be defined as “any information which adversely and seriously affects an individuals view of his or her future” Buckman (1992)

The aim is to ensure the news is imparted in an appropriate environment, in a well structured and sensitive manner, with adequate support for the patient and family/significant other/s. Any information given to relatives of a competent adult should only be done so with the patient’s consent

## **Rationale**

The manner in which bad or significant news is given can have a huge impact on the individual/s receiving the news. It can affect anxiety levels, comprehension of the information, satisfaction with care, level of hopelessness and subsequent psychological adjustment.

It is acknowledged that breaking bad news is one of the hardest tasks healthcare professionals have to do. The majority of healthcare professionals at some time in their career will have to break bad/significant news. Ideally it should be broken face to face and not over the telephone. The psychological sequelae of breaking bad news in an abrupt or insensitive way can be devastating. Ideally bad news should be given by a senior clinician who has expertise in the disease and treatment options.

The following recommendations for breaking bad/significant news is to ensure a standard approach is achieved. They are not profession specific; however, it is important that any professional using these guidelines does so acknowledging the limits of their own competence and skills and acts within the governance of their own profession.

Any healthcare professional breaking bad/significant news requires certain key skills:

- The ability to elicit the patient's main problems; their perceptions of these and the emotional, physical and social impact on the patient and their family
- The ability to tailor information to the patient's needs. Particular care needs to be taken when breaking any bad/significant news to cognitively impaired or learning disabled patients. The hospital has a Learning Difficulties Liaison Nurse who can be contacted via switchboard.
- To be able to ensure the patient's understanding
- The ability to elicit and explore the patient's reactions to the information given
- To be able to determine how much the patient wants to participate in decision making
- The knowledge and ability to discuss treatment options (or lack of) so the patient understands the implications of the discussion
- The ability to identify, offer, discuss and signpost relevant further support that the patient and family may find beneficial.

## **Broad Recommendations**

*“The cardinal rule is to reveal gradually. The key is to slow down the speed of the transition from a patient’s perspective as being well, to a realisation that he or she has a life-threatening disease. A rapid or bald disclosure can provoke either psychological illness or pathological denial”, (Maguire and Faulkner, 1988).*

All staff (band 6 or above) who have to deliver bad or significant news in cancer care or life limiting illnesses should attend and complete the Connected Advanced Communications Skills Course (staff working with cancer patients) or the End of Life Advanced Communications Skills Course (for staff caring for patients with life limiting illnesses).

### **STEP 1: Preparation**

- **Know all the facts**  
Before seeing the patient, check the patient’s notes first and also speak to other members of the team so that the information to be discussed is clear
- **Who should be present**  
It is often best for a doctor and a nurse to see the patient and relatives together. Ensure there are enough chairs in the room for everyone to sit comfortably and that tissues are available.
- **Ensure privacy**  
Before starting, try to create the right setting. Set time aside and avoid interruptions. If a private room is not possible then simple measures to ensure privacy should be undertaken e.g. drawing curtains around a bed. Introduce yourself and check that the patient can hear you. The breaking bad news interview should ideally take place sitting down with the doctor being at the same level as the patient to allow appropriate eye contact.

### **STEP 2: Finding Out What The Patient Knows**

It is important to find out what the patient already knows about their condition. Ask questions to elicit what the patient has understood of what they have been told e.g. *“It would help me to know what you understand about your illness - how did it all start?”*

*“What happened next?”*

*“What have the previous doctors told you about your illness?”*

*“What have you made of the illness so far?”*

These questions will help you to get an understanding of how close the patient's ideas are to the reality of the situation.

### **STEP 3: Does the patient want more information?**

The key task for the health care professional is to establish the patient's information needs e.g. *“Would you like me to give you more detail about your illness?”*

If a patient expresses a wish not to discuss information, then this decision must be respected as forcing unwanted information on patients can be emotionally distressing. Even if a patient wants to know everything it is still best to impart the information gradually. Giving the patient control over how much and what information they want increases their trust in you.

The level of information the patient prefers can be clarified before results are available by asking questions such as: *“If this condition turns out to be serious, are you the kind of person who likes to know exactly what is going on?”*

Fear can sometimes prevent people asking for information therefore further appointments should be made available and the patient made aware that they are free to request more information later.

### **STEP 4: Giving a warning shot**

The warning shot lets the patient know that you have difficult information to give them. It alerts the patient e.g. *“I'm afraid it looks more serious than we had hoped”*

Pause after this sort of phrase to allow time for the information to sink in before proceeding with more information. Allow time for the patient to ask questions.

### **STEP 5: Allow patients to refuse further information at this stage**

Some patients will not want any more information at this stage. This form of personal protection or 'denial' should be respected as a coping strategy and is not necessarily maladaptive.

It is important that the patient knows that they can always ask for information in the future if they change their minds.

### **STEP 6: Explain further if requested**

Give basic information simply and honestly. Avoid using jargon and use language which is appropriate to the patient's intelligence. If you are unable to answer a question be honest with the patient.

Do not give too much information too early as this can be overwhelming. Give information in small chunks and repeat important points.

Relate your information to the patient's framework.

Watch the pace and check repeatedly for understanding and feelings as you proceed.

A narrative of events can be a useful technique when breaking bad news e.g. *"When you had a cough your GP arranged a CXR for you. This showed a shadow. The shadow looked suspicious which was why a sample was taken from it. I'm afraid the results of the tests are more serious than we had hoped. The tests unfortunately show that the shadow on your lung is in fact a cancer."*

This narrative illustrates the use of the hierarchy of euphemisms recommended by some. It is an alternative way of imparting bad news gradually. It is however important to pause after each phrase to allow for the patient's reaction.

### **STEP 7: Elicit concerns**

After breaking bad news it is important to elicit all the patient's concerns e.g.

*"What are the main things that you are worried about?"*

Having identified all the patient's specific concerns, offer help by breaking down overwhelming feelings into manageable concerns

### **STEP 8: Encourage expression of feelings**

Encourage expression of feelings and give early permission for them to be expressed e.g. *"How does that news leave you feeling?"*; *"I can see that the news I've given you has distressed you"*.

Respond to the patient's feelings with acceptance and empathy. Verbalising feelings is therapeutic and can also help explore underlying reasons for the patient's distress.

### **STEP 9: Summary and plan**

Having identified the patient's concerns it is helpful to summarise these and prioritise the fixable from the unfixable e.g. *"Your main concerns at the moment seem to be....."* *"Have I left anything out?"*

Making a plan involves listing the patients concerns and combining this with the health care professional's knowledge of the options available. Identify a plan and timeframe for what is to happen next.

### **STEP 10: Offer availability and support**

It can be helpful to ally yourself with the patient so that the patient understands it is a partnership e.g. *“we can work on this together”*. It is important to give hope tempered with realism and emphasize the quality of life e.g. *“preparing for the worst but hoping for the best”*

An early follow up appointment is important as most patients need further explanation after being given bad news; offer contact details and written information if appropriate. Identify support systems and involve friends and family. Offer to see/tell spouse or other relatives.

### **STEP 11: Communicate with the team**

It is important to communicate with the rest of the multidisciplinary team including the patient's GP. Document details of the conversation in the patient's notes

### **Clinical Audit Standards**

Due to the sensitive nature of this policy specific standards are not easily identified.

To ensure practice is compliant with the above standards, the following monitoring processes will be undertaken:

- A review of patient notes for documentation of the process and information given
- Practice can be reviewed by appraising complaints and PALS reports with feedback to the clinical area
- Patient satisfaction surveys e.g. Patient Experience Tracker
- Direct observation in the clinical setting by Managers and Peers

Any healthcare professional giving bad or significant news to any patient or family should document this episode of care in the patient's notes. Therefore



there should be 100% adherence to this standard in patients' notes where they have been given such news.

The audit results will be reviewed by the relevant Department Head who will make recommendations for further action.

### **Summary of development and consultation process undertaken before registration and dissemination**

The authors have drafted this guideline on behalf of the Hospital Specialist Palliative Care Team who has/have agreed the final content. During its development it has been circulated to Ward Sister/Charge Nurses, Paula Balls, Practice Development and Education Facilitator.

*This version has been endorsed by the Professional Protocols, Policies and Guidelines Committee.*

### **Distribution list/dissemination method**

Practice Development and Education Department

Trust Nursing Policies and Guidelines folders (Bereavement section)

Trust Intranet

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## **Appendix II: Patient information pre and post prostate biopsy**

(On Hospital Trust paper)

### **Prostate Scan & Biopsies**

#### **Commonly asked questions**

##### **Why am I having an ultrasound scan of my prostate?**

The two most common reasons for having this done are an abnormal feeling prostate gland and/or a raised PSA blood test result.

##### **How is the scan and biopsy done?**

An ultrasound probe will be placed into your back passage. This is a small instrument that uses sound waves to produce an image of the prostate on a computer screen. It helps to find out if there is anything wrong with your prostate gland, and what the problem is.

The scan also helps the doctor to decide the best areas of the prostate to biopsy.

##### **What is a prostate biopsy?**

This is the removal of tiny pieces of prostate tissue under local anaesthetic. A number of biopsies are taken and sent to the laboratory for testing. The biopsy needle makes a click when it takes the sample; this is normal, do not be alarmed. This test can confirm or exclude the presence of prostate cancer. The whole procedure takes about 15 minutes.

##### **Do I need to do anything before the scan?**

Yes, because the biopsies are taken through the back passage, there is a risk of infection. In order to try to prevent this, you will need to take a short course of the antibiotic Ciprofloxacin; this will be provided by the hospital, along with instruction of when to take it. Do not take if you are allergic to this antibiotic, please call the Urology specialist nurses on 01603 289845.

You may eat and drink normally before your scan. We do not need you to have a full bladder, so please empty your bladder before your scan. If possible bring someone to the hospital with you; they do not need to be with you for the actual biopsies. Most men will feel able to drive home after the procedure, but it is sensible to have a few minutes rest and a drink before leaving.

## **Are there any after effects?**

It is normal to see blood in your urine or with bowel motions for a few days after the scan and biopsy. Blood can also be present in the semen and may persist for several months.

**If you are taking Warfarin or Clopidogrel (Plavix), please call the Urology specialist nurses on 01603 289845.**

## **Getting the results**

The biopsies need to be very carefully analysed, results are usually available 7 to 10 days after your biopsies are taken.

You will be contacted by the Urology Department as soon as possible to discuss these results. Your GP should receive the results within 2-3 weeks.

If you have any concerns or worries please contact a urology nurse specialist on 01603 289845, during office hours. Written information is available each time you come for a hospital appointment. If you are not given this, please ask

(On Hospital Trust paper)

## Transrectal ultrasound scan

### What to expect after your biopsy

It is normal to see blood in your urine or with the bowel motions. This may last for 2-3 days, occasionally longer. Drinking plenty will help flush the blood away in the urine. You may also find blood in your semen for up to two months.

### Possible complications

You have been given antibiotics tablets (Ciprofloxacin) to take as there is a risk of infection. This is because the biopsy has been taken through your back passage. A course of antibiotics will reduce the chance of this happening, so it is important to take the tablets as directed. Begin taking the 3 day course in the evening after the biopsy. Unfortunately, a few men still get an infection following a biopsy. If infection does occur, it can be like a bout of flu and make you feel quite unwell.

If you get a temperature, pain or a burning sensation when you pass urine soon after the biopsy, you may have a urine infection despite the antibiotics.

Difficulty in passing urine is a complication but is uncommon

If you experience any of the above symptoms, please contact your GP as you may need more antibiotics. Occasionally admission to hospital is necessary.

### Things to avoid following the biopsy

Strenuous exercise and sexual activity for 3-4 days.

Long journeys for 1 week.

### Results

Primarily this is a test to find out if you have prostate cancer or not.

Occasionally results are inconclusive and a repeat biopsy may be required

Because the analysis needs to be very carefully carried out, results are not usually available for 7 – 10 days.

If your result shows cancer cells, it will be graded (Gleason grade 6 - 10) which can help us decide, with you, if you need treatment and if so which treatment is best for you.

Some men find waiting for results stressful, you may if you wish telephone the urology nurse specialists Sallie Jermy, Rachel Matthews, Helen Walker or Wendy Baxter on **01603 288835**, who will be able to inform you of your results and what will happen next. *If you choose to telephone for your results please be mindful that you may be given bad news.* If you wish to ring the best time is between 2pm and 3.30pm on .....

If you choose not to telephone, the Urology Department will usually arrange an outpatient appointment for you. Your GP should receive the results within 3 weeks.

If you have any concerns or worries please telephone the Urology Nurses on 01603 289845, during office hours.

## Appendix III: Ethics opinion

### Norfolk and Norwich University Hospitals NHS Foundation Trust

Ref: KA/2010UROL01

Wendy Baxter  
Norfolk and Norwich University Hospitals  
NHS Foundation Trust  
Colney Lane  
Norwich NR4 7UY

Research & Development Office  
Medical Education Centre, Room 032  
Level 3, East Block  
Norfolk and Norwich University Hospital  
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direct dial: 01603 289819  
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E-mail: [kathryn.andrews@nnuh.nhs.uk](mailto:kathryn.andrews@nnuh.nhs.uk)  
Website: [www.nnuh.nhs.uk](http://www.nnuh.nhs.uk)

24/8/2010

Dear Wendy

**Re: R&D Ref 2010UROL01- Service evaluation of receiving prostate biopsy results.**

Thank you for sending through information regarding the above service evaluation. . As this study is a service evaluation it does not require Trust approval as a research project . As it has been approved by the Caldicott and Information Governance approvals group and has directorate support the evaluation can start when convenient.

With regards



**Kath Andrews**  
Research and Development Manager

## **Appendix IV: Patient letter of invitation**

(On Hospital Trust paper)

Dear Mr .....

We understand you have recently received the results of your prostate biopsy. This may have been by telephone or at the hospital.

Your urology team is interested to hear how this news was given to you to see if we can make any changes to improve our service and our communication with patients.

We understand this may be a difficult time for you and would not wish to add to any strain or anxieties you may be feeling at this time. However, if you would be willing to talk to us about your experience and feel you could spare an hour of your time, we would be extremely grateful.

Any information received would remain anonymous and would not affect your care in any way.

Please find enclosed further detailed information which you may like to look at before deciding whether you would be willing to take part.

If you are willing to take part in this review of our service or would like any more information please return the enclosed form in the stamped addressed envelope or contact Wendy Baxter, Uro-oncology nurse specialist, on 01603 289845.

If we do not hear from you Wendy will call you 2 weeks later to check you have received the information.

Yours Sincerely

Mr Robert Mills

Consultant Uro-Oncologist

Wendy Baxter

Uro-oncology Nurse Specialist

## **Appendix V: Patient information sheet**

(On Hospital Trust paper)

### **Patient Information sheet for the following study:**

**Title: A project to investigate the experiences of men receiving prostate biopsy results by telephone or conventional consultation.**

We would like to invite you to take part in a review of the results service that we offer to men having a biopsy of their prostate. Before you decide you need to understand why we are looking at this service and what it would involve for you. Please take time to read the following information carefully.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

If you agree to take part you would be free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

We cannot promise that taking part will help you directly but the information we get from men who have had experience of our service may help improve the communication of results to men having prostate biopsies in the future.

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

### **The purpose of this review.**

The purpose of this review is primarily to find out if we can improve the way in which we communicate the results of prostate biopsies to patients. Wendy Baxter, nurse specialist, is undertaking this project with the aim of achieving an MSc at the University of East Anglia. She is working as part of a team including academic supervisors and lay advisors that advise and inform on the conduct and interpretation of the evaluation.

Some men choose to telephone for the results of their prostate biopsy others prefer to attend an out patient clinic to have the results explained face to face. We are interested to hear about your experience whether good or bad.

If you decide you would like to take part Wendy will arrange to meet with you to ask some questions which will take about an hour of your time. The interview will be recorded. This can take place at the hospital or your home whichever is most convenient for you.



All information received would remain anonymous and would not affect your care in any way, now or in the future.

The following are some questions you may need to know the answers to before you decide whether or not to take part.

### **Further Information**

#### **Why have I been asked to take part?**

You have recently had a biopsy of your prostate to look for evidence of prostate cancer.

We are interested to hear about your experience of receiving the results of your prostate biopsy. We aim to talk to 30 men who have had a biopsy of their prostate recently.

#### **What will it involve for you?**

You will be interviewed by Wendy Baxter at the hospital or in your home, this is your choice.

If you choose to come to the hospital your travel costs will be met.

The interview/conversation will be audio recorded (taped). This should take no longer than an hour of your time.

Any information which could be used to identify you will be deleted from the recording.

The recorded interview will be typed up word for word and then returned to you to check that it is an accurate account of the conversation.

If there are any changes you wish to make, you can then make them before returning the report.

The corrected report will then be returned to you again (if you wish) for checking and agreement that it is a true account of the discussion that has taken place.

We will provide a stamped addressed envelope and ask that it is returned within the week of being received.

#### **What happens to the information then?**

The anonymised report will be read carefully and compared with other men's experiences to see if any themes emerge, i.e. are there things we are doing badly

that can be improved on? Or are there things which we are doing well but could also be done better?

Wendy in collaboration with the team will write a report of all the findings and you can have a copy of the report if you wish. The results may be published to inform others and change practice for the better. No one will be able to identify you from the report.

**What happens if I change my mind during the interview or after the interview?**

Participation is entirely voluntary. You can withdraw from the study **at any time**. This will not affect your care in any way.

If you choose to take part but then change your mind prior to the interview taking place you will be removed from the study. However if the interview has taken place anonymised information from the interview will be retained in the service review.

**How do I know the information I give can not be traced back to me?**

Wendy Baxter will interview you and will make sure that all identifiable information will be removed from any written work. For example you may be known for the purposes of anonymity as Mr A. We will not record your address or date of birth. We will need to record your age and results of your biopsy but this will not be able to be traced back to you. Wendy Baxter's interview with you will be the only access to your identity and she will keep this confidential and is bound by her professional code of practice, the Data Protection Act 1998 and will follow the Caldicott Principles. The identifiable information will be destroyed 6 months after completion of the work (estimated at July 2012)

**What happens if I get upset during the interview?**

Being asked questions about your experience of receiving your results, especially if these results showed cancer, can be difficult for some people whether their experience was good or bad. If you find you get upset and wish to stop the interview that is ok. If you find after the interview that you have further areas you wish to explore that Wendy is unable to deal with or resolve for you, she will make the appropriate appointments or referrals to help to address these areas of concern.

**Complaints**

If you have any complaints about how the interview or study was conducted you can contact Mr R Mills, clinical director and consultant urologist on 01603 286772.

If you have any complaints relating to your care that you feel have not been addressed adequately please contact PALS (01603 289036)

If you are interested in taking part please complete the enclosed expression of interest form and return in the Stamped addressed envelope. Wendy will contact you by telephone to arrange a convenient time with you for interview.

Thank you

Yours sincerely

Mr R Mills

Consultant Uro-oncologist.

## Appendix VI: Expression of wish form

(On Hospital Trust paper)

**A project to investigate the experiences of men receiving prostate biopsy results by different modes; telephone or conventional consultation.**

### Expression of interest form

1. I have read the enclosed information sheet and would like to be contacted to be involved in the service evaluation
  
2. I have read the enclosed information and would like to be contacted to ask some more questions before deciding
  
3. I have read the information sheet and do not wish to take part

If you have answered yes to 1) or 2) please write your name and contact number below.

If we do not hear from you a reminder will be sent in 2 weeks. If you don't wish to take part we would be grateful if you could please tick box 3 and return the form in the enclosed stamped addressed envelope.

Thank you

Yours sincerely

Wendy Baxter

Uro-oncology Nurse Specialist

## Appendix VII: Consent

(On Hospital Trust paper)

### Department of Urology

Patient Identification for this service evaluation:

### Consent Form

Title: A project to investigate the experiences of men receiving results of their prostate biopsy by telephone or conventional consultation

Please  
initial  
box

I confirm that I have read and understand the information sheet for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my taking part is entirely voluntary and that I am free to withdraw at any time without my care being affected in any way.

I understand that any information collected about me and my experience during the project may be looked at by members of the team involved with the study in the urology department at the Norfolk and Norwich University Hospital and the University of East Anglia but that all information will be anonymised prior to this. I give permission for this to happen.

I agree to take part in the above service evaluation

Name.....Signature.....Date.....

Name of person taking

consent.....Signature.....Date.....

## **Appendix VIII: Questions for interviews**

### Receiving Prostate biopsy results- telephone (T) v conventional(C) consultation

#### Interview questions (T)

1. Tell me about receiving your diagnosis of cancer/biopsy results.
2. What options/choices did you have about how you received your cancer diagnosis/biopsy results? Can you tell me about that choice?
3. How clear was it that when you telephoned the hospital you were phoning for your diagnosis/result?
4. When you received your result and it showed cancer how comfortable were you in asking questions about your diagnosis and treatment?
5. What questions would you like to have asked when you got your cancer diagnosis but did not feel able to ask?
6. Who was with you when you got your diagnosis?
7. Did you feel pressurised into telephoning for your biopsy result? If yes, where did you feel the pressure was coming from?
8. What were you told about your cancer that you would rather not have known about or did not want to know? (also is there anything you have since discovered about your cancer that you feel you should have been told at the time of discussing your results?)
9. What information had you found out or already knew about prostate cancer before you received your diagnosis?
10. At what point did you think that you could have cancer?
11. Had you met the person previously who told you your results?
12. What do you think your treating team (doctors and nurses) could do differently when they give patients their results/diagnosis?
13. If you were in the same situation again would you choose to have your diagnosis/results in the same way? (why is that?)

(If you told after your biopsy you could either telephone for the biopsy results or attend a hospital appointment to receive them in the same time scale i.e. 7-10 days, what would you chose?)

14. Is there anything else you would like to tell me about your experience, good or bad?

## Receiving Prostate biopsy results- telephone v conventional consultation

### Interview questions (T-neg)

1. Tell me about receiving your biopsy results.
2. What options/choices did you have about how you received your biopsy results? Can you tell me about that choice?
3. How clear was it that when you telephoned the hospital you were phoning for your result?
4. When you received your result and it didn't show cancer how comfortable were you in asking questions? (how did that feel?)
5. What questions would you like to have asked when you got your results but did not feel able to ask?
6. Who was with you when you got your results?
7. Did you feel pressurised into telephoning for your biopsy result? If yes, where did you feel the pressure was coming from?
8. What information had you found out or already knew about prostate cancer before you received your results?
9. At what point did you think that this could be cancer?
10. Had you met the person previously who told you your results?
11. What do you think your treating team (doctors and nurses) could do differently when they give patients their results?
12. If you were in the same situation again would you choose to have your results in the same way?
13. Is there anything else you would like to tell me about your experience, good or bad?

## Receiving Prostate biopsy results- telephone v conventional consultation

### Interview questions (c)

1. Tell me about receiving your biopsy results.
2. What options/choices did you have about how you received your biopsy results? Can you tell me about that choice?
3. How clear was it that when you attended the hospital you were attending for your diagnosis/result?
4. How anxious were you leading up to the appointment?
5. When you received your result and it showed cancer how comfortable were you in asking questions about your diagnosis and treatment?
6. What questions would you like to have asked when you received your cancer diagnosis but did not feel able to ask?
7. Who was with you when you received your diagnosis?
8. What were you told about your cancer that you would rather not have known about or did not want to know? (also is there anything you have since found out about your cancer that you feel you should have been told at the time of discussing your results?)
9. What information had you found out about prostate cancer or already knew before you received your diagnosis?
10. At what point did you think that you could have cancer?
11. Had you met the person previously who told you your results?
  
12. What do you think your treating team (doctors and nurses) could do differently when they give patients their diagnosis?
13. If you were in the same situation again would you choose to have your diagnosis/results in the same way?
14. Is there anything else you would like to tell me about your experience, good or bad?



## Receiving Prostate biopsy results telephone v conventional consultation

### Demographic information

1. Patient number
  
2. Has the patients name been entered in the code book?
  - a. Yes
  - b. No
  
3. What is the patient's age?
  
4. Ethnic background
  - a. Black
  - b. White
  - c. Asian
  - d. Other  (specify) \_\_\_\_\_
  
5. Is the patient currently
  - a. Married
  - b. Living with a partner
  - c. Living with significant other
  - d. Living with parents
  - e. Living alone
  - f. Other  (specify) \_\_\_\_\_
  
6. What is the patients highest level of academic attainment
  - a. No formal qualifications
  - b. O'level or equivalent
  - c. A'level or equivalent
  - d. Degree or above
  
7. Current job
  - a. Employed  (specify) \_\_\_\_\_
  - b. Unemployed
  - c. Retired  (job before retirement) \_\_\_\_\_

## Receiving Cancer Diagnoses

### Clinical information

1. What is the patients' Gleason Grade?
  - a. G1 6
  - b. G1 7
  - c. G1 8
  - d. G1 9
  - e. G1 10
  
2. What is the patients PSA level?
  
3. What is the patients' clinical Tumour stage?
  - a. T1
  - b. T2
  - c. T3
  - d. T4
  
4. Has the patient ever had cancer before?
  - a. No
  - b. Yes (within the last five years)
  - c. Yes (within the last ten years)
  - d. Yes (more than ten years ago)
  
5. How does the patient travel to their hospital outpatient appointment?
  - a. Car (driven by patient)
  - b. Car (driven by other)
  - c. Public transport
  - d. Walk
  - e. Other  (specify) \_\_\_\_\_
  
6. Where did the patient receive their diagnosis?
  - a. Telephone
  - b. Outpatient clinic
  
7. How anxious was the patient before receiving the cancer diagnosis?
  - a. Score out of 10

8. Does the patient have a history of depression?

- a. Yes
- b. No

9. EQ-5D (quality of life)

• MOBILITY

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

• SELF-CARE

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

• USUAL ACTIVITIES (e.g. work, study, housework family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

• PAIN/DISCOMFORT

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

• ANXIETY/DEPRESSION

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

10. If the patient meets any of the following criteria we will not involve them in the study

- a. Is profoundly hard of hearing
- b. Has dementia
- c. Has psychosis
- d. Has known metastatic cancer
- e. Does not speak English
- f. Has profound communication difficulties

11. Date the patient consented? [dd/mm/20yy]

- a. / /20

## **Appendix IX: Letter of thanks**

**(On Hospital Trust paper)**

Dear Mr .....

Thank you for agreeing to talk to me about your experience of receiving your prostate biopsy results.

I have enclosed the transcript for you to read and for you to correct any inaccuracies or make any further comments.

I would appreciate it if you could return the transcript in the enclosed stamped addressed envelope within the next week.

Once again thank you for giving up your time to participate in this evaluation and for sharing your thoughts and experiences.

If you have any concerns please do not hesitate to call me on 01603 289845.

With Best Wishes

Wendy Baxter

Uro-oncology Nurse specialist.

## **Appendix X: Interview checklist**

### **Pre interview- checklist.**

**P**

#### **Date and place of interview:**

Patient address, directions and telephone number.

Consent form

Demographic and clinical details form

Interview questions

Dictaphone

Spare batteries

If at patients home, have you arranged check in with colleagues?

Mobile phone- charged!

Expenses form if patient coming here

**Would patient like a copy to check Y/N**

### **Post Interview checklist**

Transcribed

Checked against recording

Date sent to patient:-

Date returned:-

Amendments made

Consent filed- notes  
Code book

## Appendix XI: Further evidence from the data to support the themes

### Theme: “I just wanted to know as quickly as possible”

Didn't want to wait. Wanted to know soon as possible. I wanted to start treatment as soon as possible (P1)

Well I could either phone or come to hospital face to face really but like I said I wanted to know as quick as possible really.....(P1)

well that's the quickest way you see (p1)

I probably would looking back. Erm...just to put my mind at rest, that little bit earlier. Erm...yeah I think possibly I would because I...it's a bit of concern when you don't know but at the time I looked at it was better if there was anything really serious I would have had a phone call from here to say, you know, quite serious, it's best you get back up here (p2)

and you think sooner is better (p3)

... and as I say it's a waiting game (p3)

That would be about ten days, which was you know...(p3) *Interviewer-It felt a long time?*  
Well, it's just, it's just not knowing.(p3)

, it is the wait. Not knowing. (P3)..... But it's getting there.

Now I'm waiting to find out what they're going to do.(P3)

that little bit of waiting. And you've got to wait...you had your biopsy and that and you've got to wait but at least I knew when I got off the table she said ring (*nurse name*) on the 3<sup>rd</sup> of whatever it was.(p3)

all I'm going to say are all the good things about how...[sighs]...and the speed of which that's all been taking, taking place.(p4)

.... I thought what's the point of waiting...I didn't want to stand about there two or three hours waiting for my family to arrive knowing that I'd got some bad news, because you don't get somebody in, I've got some news, you know, I'd like to discuss something with you. I'm, I'm not that naive, you know. [laughs] So I guessed that was bad news and er he explained.(p5)

you know, it's one of these things, you have to, you know, get on with it. Get it sorted. Because I, I hate waiting around, I hate standing about doing nothing, I want some...once I know something I like action.(p5)

, there always seems that delay from when you have a blood test and you get a result, that...it seems to go on forever (p5)

Once I know something I want something, I want something to happen, I don't like sitting about waiting, you know, I like action (p5)

it's a personal thing. I, I don't like waiting. You know me. I'm impatient. When I know something I want something to happen.(p5)

. I mean let's put it like this then, if, if I, if I wanted to be told or I needed to be told something and it was quicker to do it on the phone and then I would rather know on the phone than wait weeks to see the man face to face, if you like. Can I put it that way? (p5)

I decided to phone up because I wanted to, to know the results quicker than waiting to see the doctor.(p6)

it's quickest and I don't have to come to (name of )Hospital. [laughs] (p7)

, I like to think, get things done, finished and over with.(p7)

, the choice you want to know as soon as possible. I, I can't argue with that. Whatever the result I, I think you, you need in your own mind to know as soon as possible. And er that's what happened to me. I phoned up and got the result. (p8)

I was right glad I did phone up, yeah. I can't argue with that, that's by far...because that was going to be the soonest I knew. And that's what, unfortunately that is what you want to do. Well, me personally,(p8)

as I say my option was to phone, because it was earlier, which I did. (p8)

, that's the thing what that done away, that done away with the waiting and I knew. [laughs] (p8)

, I'm the sort of person that actually would much prefer to know what the score is than to sit and wait.(p9)

...fact I chose to ring and to find out what the results were as quickly as I could basically which was a week afterwards (p9).

Because of needing, wanting to get the results as quickly as I could (p9).

I need to establish the facts, I'll establish them quite quickly and I'll make a decision and run with it. They don't have to be 100% all there before I make the decision. But that's the way I'm built. I won't wait and wait and wait. I need to do something, I need to actually make it happen (p9)

half past nine on the nose I rang. [laughs] (p9)

...I see no point in having another week delay, for me.(p10)

She (wife) was really anxious to get the news that day and that was the easiest, quickest way to do it.(p11) *his wife made the call whilst he stood next to her*

It's quicker, easier. You know, it's a lot quicker, you know, you're just picking up, the answer's there isn't it? (p11)

So of course, it's like anything, your mind's saying look, you want to know as soon as possible (p12)

that is something I wanted to find out as soon as possible really. (p14)

. I don't think men are very good at waiting..... we tend to be I want it, and I want it now. (p14)

the crux of the matter is did I have prostate cancer or didn't I? And erm I think it was good that I was able to find out so quickly.(p14)

although knowing it could be bad news I would still like to know early. (p16)

, I was waiting for the day to come. I was anxious for the result.(p16)

The anxiety of waiting is pretty tremendous. Erm...I just had to know really (p16) ,

I think I would have still gone with the telephone call but erm my main decision probably was because I wanted to know rather than wait. Well I would have still been probably happy to go the telephone call in my environment. (p16)

At the time the waiting is the thing that er is er frustrating and annoying and worrying thing.(p16)

I think as quick as possible for the results but erm...well, within a time as quick as possible. But for me it was so much being able to pick the time that suited me. Very much.(p16)

Because even waiting a week is erm...you're still worrying and anxious about it.(p16)

I suppose like most people I wanted to, I wanted a result one way or the other. .... And the quicker, as far as I was concerned, the better. And that to me was excellent that erm I only had to wait a week. Wait a week. (p17)

. *Is there anything that you think we can do differently when we're giving results to men?* Erm speed I think is the only one.(p17)

Yeah, I found out early. Rather than waiting for the doctor, it would have been another, as I say it might have been another week or so mightn't it? (p18)

, so I found out nice and quick rather than hanging about, thinking about it. (p18)



*And what made you take that choice about telephoning? For what reason did you? erm I didn't want to hang around for two or three weeks for an appointment to have a face to face meeting. Erm, erm, I wanted to be getting on, finding out if there was anything.(p19)*

*The timescale is equal ..... Oh I think I would have taken the opportunity to come up and be told face to face (p19)*

*we talked about this and I said well I'd sooner find out and I'll ring erm which I did.(p20)*

*when it came to sort of finding out yes, I wanted to know as soon as possible so if there was any problems we could get things started sorted out as quick as possible (p20)*

*, I'm not a person to sort of perhaps erm sort of sit there, sit back and wait for things to happen. If I can make them happen myself by just a simple phone call or something like that. You know, if I need to do something I want, I'm the sort of person that I'll do it now rather than leave it, generally.(p20)*

*. I didn't find anything negative in the idea of phoning up and getting the results as soon as.(p20)*

*I don't mind at all, the important thing was that I should be told as quickly as possible.(p21)*

*at least you know where you stood then don't you? you know, because if you've got the waiting bit it's the bit that is hard, the waiting, that's the – that's the hard bit, you know. It gives you some sleepless nights and things like that. So there we are (p22)*

## **Happy to wait**

*But the time factor is important. And we are grateful that we have been just rolling over gently, that we've been – first one week we have an erm an appointment then the next week we have the results, then another week we have the appointment and the next week we have the results. So we're quite happy with that but we do think that er – erm – it would be difficult if it was a long period of time.(p24)*

*It was worth waiting the extra two days to know and then be told in such a way and then you had your bone scan and...(wife p24)..... Yes and you gave us the results over the phone which was fine because they were clear(p24)*

*– I never wanted a quick phone, I waited until the letter came through. and I think that came through in reasonable time.(p25) *happy to wait**

## Theme: Choice

*so if you were in the same position again would you make the same choice about making that call? Phoning? Yeah. Absolutely. (p3)*

*the results in the same time scale..... and I said no. I said I'll have it by phone. Er, not knowing where I was going to be on that Friday anyway, and I just thought right, I can ring you up and it's easier for me. She said well if you ring on a time I'll ring. Strike of nine o'clock I rang. So...yeah, but no, she did actually say that, I forgot about that, she did say that, she said if you need to come in or, or by phone. I said no, I'll have it by phone. Just...(p3)*

She give me the paperwork, she said (*name*) if you want them ring us up if you want your results you can ring (*nurse name*) up that day. And I went yeah, fine. Didn't think any more of it. That was it. (p3)

I mean really it doesn't matter whether I get it over the phone or in letter but it's a bit more personal if somebody actually speaks to you on the phone than sort of suddenly getting a letter come through the post. I mean for an appointment that's totally different, but when somebody actually sort of explains it to you, yeah, I found that was sort of better for that. (p2)

*so if you were in the same situation again would you telephone for your results?..... P1:*  
I would, yes

: I would have preferred face to face actually (*if given the same time scale*) (P1) *you would?*  
P1: yeh, you know, but I thought that would take some time you see.....:.. and err like I said I thought phoning would be quickest (p1)

I found in the phone call was a lot easier than by a letter. That was, that was a lot better. Having like a personal contact er that was far easier for me. (p4)

*can you remember what the choice was? Or if there was one (p4)*I can't really remember to be honest. Erm...I don't know...*No?* what I felt really.(p4)

only choice he gave me did I want my family there and of course, [laughs] you know, I thought what's the point of waiting...I didn't want to stand about there two or three hours waiting for my family to arrive knowing that I'd got some bad news, because you don't get somebody in, I've got some news, you know, I'd like to discuss something with you. I'm, I'm not that naive, you know. [laughs] So I guessed that was bad news and er he explained.(p5)

I'd most probably say I'd speak to, oh I'd like to just see the man or the whoever. That's just me, that's just a personal, little personal thing. But not essential. You know. Rather have it that way than the other. But that's me in life in general. I don't like dealing with people on the telephones, whatever it is. I'm an old fashioned git.(p5)

I can't remember but that said quite clearly that, you know, you can wait for the results but if you want to know quicker you can phone, you know, phone up. And it did say on there that, you know, be aware that you can receive bad news. Which I thought was a good thing because obviously some people are in a sort of dream world, but erm, yeah, it did actually say quite clearly that er be aware that you can receive bad news. Yeah, so I felt I had a choice, yeah. (p6)

*..... your results will be available in a week, you can either come up and see somebody face to face with those results or you can telephone for those results, which would you have gone for do you think in hindsight? I probably would have come in.(p6)..... to be honest..... if it was the same timescale.(p6)*

my wife said to me we'll be on holiday when we get the call. And she said you could leave it until we come home and see the doctor. And I said no, I said I'm going to phone and she said well, we'll be with er (*names*), our friends. And I said well, you know, hopefully that will come when we can get away a bit. Erm, but I'd have phoned whatever. I'd have phoned if I'd had to take it at the, the dinner table. You know, I would have definitely phoned. And that's the best thing for me, was that option to phone. I'd have hated not to have that option. I wouldn't have known obviously, but now, if you now said you're going to do the same again, but this time there's no phoning, I would hate it. Yeah, I'd hate it. (p6)

, if I'd have been at home, and they'd have said you can come up in a week's time to find out I'd have probably chose to come up (p6)

. So I would always rather meet face to face in any situation, so definitely you know thinking about it now, more deeply, I would have definitely come up and met somebody.(p6)

, I think that was an equal er either to make the call or see my doctor, I think that was just a 50/50 thing that I felt was down to me. I didn't feel that I should have done one or the other. I just thought just instinctively I want to know quickly. No, I didn't feel any pressures to make that call at all. (p6)

obviously the best thing about it is that you get the option to, to find out a week earlier than you would if you went to see your doctor. That is absolutely fantastic for me.(p6)

Oh I just can't remember now. But I, I did...I think I was asked if I wanted by phone or not, you know, I can't remember details of that..... it was my choice I think to have by phone (p7)

*you can telephone us in a week or you can come and see us face to face in a week. What would you choose?* Phone. (p7)

, the choice you want to know as soon as possible. I, I can't argue with that. Whatever the result I, I think you, you need in your own mind to know as soon as possible. And er that's (p8)

*did you have a choice about phoning or not phoning?* Yeah, because they would send the results. *You felt that the option would be to send the results to you?* Yes. *Not an appointment?* Yeah. I couldn't...no, I think it might have been an appointment. I can't remember now. I'm sorry. (p8)

*... be told face to face or you can pick up the phone and call, same day, what would you do?* I, I'd come up here. *You would come up here* Yes, I would have done, yes. *And had it face...had that conversation face to face?* Yeah, yes. (p8)

, I had the option of either waiting for it to come through by post or by ringing one of your colleagues.(p9)

, **I chose** to ring and that was **my decision** and I don't regret having done that.(p9)

And I think it was very clear it was going to be a couple of weeks I'd have to wait until the results were sent through to the doctor. So in fact I chose to ring and to find out what the results were as quickly as I could basically which was a week afterwards.(p9)

The paperwork that I had was indicative that you could either ring if you wished or wait for the results to come through.(p9)

*.....same time frame, what one do you think you'd have gone for?* I'd have probably gone for the latter actually..... *coming up to the hospital?.....* Yeah. But that's a hindsight view, now. Erm, probably at the time I'd have said oh, we'll do it over the phone. But it's, it's after the event I think when it bites a little bit more. (p9)

went through the, er, the process, erm they gave me the, er, the fact sheet and the, the nurse then said you can phone up or you can make an appointment to come up. Well, to be quite honest it's...I can't see the difference myself. It makes no difference to the facts (p10)

*same timescale.....* Erm I would have probably, I would have probably still phoned.(p10)

*when you left the clinic were you given a choice or what choice were you given about how you received your biopsy result?* he did say to me you can either ring in erm or you can go

and see your GP or erm...I think you can come back up the hospital and get them, you know, on a result basis I think were the three options (p11)

*And you chose to telephone?* I thought it would be easier for everyone rather than come up the hospital and it's a lot easier to just pick the phone up and just get the results over the phone..... whichever direction they go in, there's...you can't change things can you, so what's...that's just an easy option to get it over the phone.(p11)

*if you were given the same choices again, .....you can ring in a week's time and gave you a time to ring, or you can come up in a week's time and gave you an appointment to come up, or you can go to your GP and have your results in a week's time, so the same time scale for all three options, which one do you think you'd go for? Phone. You'd go for the phone? Definitely. Even though they're doing the biopsy for, to look for cancer cells? Phone. (p11)*

It's quicker, easier. You know, it's a lot quicker, you know, you're just picking up, the answer's there isn't it? You don't have to do any travelling to get here and that sort of thing. But the options I'd choose is phone first, er, doctor's second and then come up to the clinic last.(p11)

Well I had the biopsy..... I think it was the Thursday week when I had to ring up for the results, after half past one..... Right, I accepted that. Or alternatively go to the doctors in three weeks time, or it might take three weeks for the results to get to the doctors.(p12)

*If you had been given the choice of you can ring up in one week's time, or you can come up and see us in one week's time, or you can go and see your GP in one week's time for your result, so same time scale, but different choices, what would you have chosen?* I think the GP. *Would you?* Well, in normal circumstances I would say the GP because if you're with a GP you probably know your GP a lot better than you do the consultant, yourself, you know, erm and they might not give you what you want to know but at least you know yes or no straightaway. (p12) *perception that quicker to see GP*

*what choices were you given about receiving your results?* Either you had the option of ringing the hospital didn't you? (wife of p13) Oh yes, yes.(p13) Or waiting for your doctor to tell you which could be up to three weeks. (wife p13)

*if you were in the same situation again and we said to you right, you can telephone us in a week, and we'll tell you what the results are. Or you can come up and see us in a week, and we'll tell you what your results are, what would you choose do you think?* Probably telephone.(p13) Yeah. It would have to be a spur of the moment though.

I was given the choice of sort of waiting for a week or so or, no I think it was a bit longer than that. er, or being able to phone up I think it was a couple of days later or something like that.(p14).....I was concerned and I, I wanted to know what the situation was. And so having given, been given that choice I phoned up and spoke to one of you lovely nurses and erm got the results. Which er, unfortunately, weren't very good.(p14)

*If we had said to you okay, erm your results will be available in a week's time, you can come up to the hospital and speak to one of us and we will tell you your results, or you can pick up the phone and call us and we'll tell you your results, which would you have chosen with the same timescale?* I personally would have still gone for the phone option because it's such a pig's ear to get up here. If I'd lived round the corner then perhaps I would have said er yes, I'd like to come in, come in and see you, but erm I'm perfectly happy with the system because it, it saved me a 60 mile around trip and god knows how many hours in the parking fee. [laughs] (p14)

*Did you feel any pressure at all to call us?* Oh no, no. It was purely my choice. (p14)

the chap gave me the form, give me the paper and said oh, here's the number, so and so, it's Thursday, you'll see there it's after two o'clock, I think it was after two on Thursday, with a date on it, if you'd like to give us a call and so.... I can't think, I wasn't conscious of...maybe there was some other alternative offered, I don't think there was. No, I think it was straightforward. (p15)

*If you were in the same situation again, I've probably asked this already, but just to make sure, would you make the same choice..... Of picking up that telephone to find out whether or not it was cancer or not?* Oh yes. Yeah. *You would?* Oh yes. Yeah, definitely. (p15)

*what choices did you feel you had about receiving your results?* Erm I don't recall, I mean er I suppose when it's explained to you it's all a bit worrying, it's all a bit of a shock, you're not quite...and you maybe don't absorb everything that people are telling you. So erm I don't recall that there were perhaps other options. I mean it may have been explained to me but I don't recall that there were (p16)

*If we'd have said to you erm, or if it was in print on the letter, if we'd have said you can erm call us in a week at this given time or you can come up in a week and we will tell you your results face to face. Which do you think you'd have gone for?* I think I would have still telephoned... *Why?...* Because erm it's probably in your own surroundings, rather than in a strange surroundings, erm and you choose your time and who you're with and exactly where you are. (p16)

*would you do the same thing again?* Yes.(p16)

I think it was, it's getting the answer in a time that suited me, erm...in a location, being where I wished to be, who I wished to be with, rather than any coming to the hospital, speaking to somebody, strange surroundings anyway, which you anxious in coming up, so I could, so I could work it to suit me. (p16)

I think that's how I remember it. You could wait to receive a letter. Or you could telephone earlier for the results. (p16)

*Is, is there anything you, you think that we could do differently for men having their biopsies and their results?* I think just to give them both options, both choices. Some people no doubt would prefer to erm come to discuss it face to face. Er I think if you can just give the two choices I'm not sure what more you could do. (p16)

, to be able to pick my time suited me...(p16)

But for me it was so much being able to pick the time that suited me. Very much.(p16)

But I would still like to pick that time slot for the result. (p16)

*So if you were in the same position again would you make the same choice?* Yes, I think I would go the same way.(p16)

*what choices were you given about how you got your results?* One really, and that is erm you can phone next week, I had it done on the Tuesday, and if you, if you want to you can phone next Wednesday to get the results. That was all, I wasn't given anything else (p17) But I was quite happy with that (p17)

I didn't look on it as a choice, it was that if I wanted to do so I could. (p17)..... if not I could have always waited for my doctor or, you know, made an appointment with my doctor, no, I didn't see it as, you know, that's the only way you can do it. (p17)

*You thought that was okay?* No, I thought it was quite good actually. (p17)

*If you had, if we'd have said to you, when you came up for your biopsy, okay, you can have your results in a week, you can either come up and see one of us or you can give us a telephone call in those two hours, what would you have done?* Yeah, phoned. *You would have still phoned?* Yeah. (p17)

he said if you want he said ring in on Wednesday between half past nine and half past 12 I think it was, something like that, he said and you can get the results then..... , I could have waited until they sent it to the GP..... , I thought I might as well find out now as to find out later. You know. But I had a, you know, I had an idea like I had got cancer. (p18)

I was er, er given the option of erm either it could be conveyed to me er face to face or I could ring up and I opted to ring up. (p19)

Yes, most definitely. Yes most definitely. And I think anyone, as long as they're...I won't say strong enough but I mean I think that I was possibly you know sort of – I wanted to know one way or the other erm and I would certainly sort of well given that sort of – I won't say opportunity or chance because I don't want that chance again, but I would – I would do the same thing. I didn't find anything negative in the idea of phoning up and getting the results as soon as.(p20)*when asked if would make the same decision again about phoning*

I think we were told that if you wish you could – you could phone up and that we would be told in specified time within quite a short space of time. I can't remember whether it was a week or not (wife of p21)

*Did you feel there was another choice or not really?* Well I think I wanted to.....*You wanted to?* Yes. Oh yes, I wanted to make sure, I wanted to be definite about it, but then again when that happened, when I rang up you erm answered the phone, you know, and this lady (*nurse's name*) spoke to me on the phone and she said, you know, told me how it was and I just sort of said, oh okay, you know, because you do don't you? You don't sort of...and then you think about it afterwards.(p22)

I couldn't see nothing wrong with that. I mean they said ring up, I rang up and she was there, erm and erm, you know, so that was 100% as far as I could see. I couldn't see you do any more. That was either a case of doing that or wait until, well I don't know, wait until – I don't know how else you would have known (p23) *perceived choice- none!*

Well we were given the option of either having it over the telephone or face to face and my wife and I would prefer to have it face to face with the consultant so that we could ask questions and could also put my wife at ease.(p24)

, I was told that er I could phone through or erm wait for a letter and I give them the option of erm waiting for a letter. (P25) *perceived choice*



## **Theme: Preparation**

a little bit of a blow to start with but I was, I was well prepared for that. Erm...(p4)

I don't fear the worst, but I prepare myself for the worst of anything.(p4)

....so then it doesn't come as too big a shock then, that's how I prepared myself for it.(p4)

I didn't try to...I knew I had the biopsy done and there was going to be something on it and because the PSA readings I'd been getting I thought well, there's got, there's going to be something wrong here and I, I didn't bury my head in the sand and try to push it behind me and think well, no, er it isn't going to happen to me. Erm...er...it's going to be somebody else, it won't be me, I'm going to be okay. I didn't do that, I, I prepared myself that there is something there and that is how I dealt with it. (p4)

that's at that point I went ah, they, they do need a biopsy, so this, this is for real.(p4)

....was at that point I, I knew that there was definitely something, something there to be investigated. (p4)

I had a fee...one of these, a gut feeling that yeah, there's going to be something there. Don't know what it was but I just had this feeling, ..... And there was. Just, just one, the one biopsy showed it up didn't it? (p4)

if there's anything come on the news and the newspapers with the word prostate in like a headline I do tend to prick my ears up and ah, I've got to read this. (p4)

I've been aware of prostate cancer and...but I haven't feared it but I've, I've always just been aware that through taking the tablet and having the enlarged prostate for a number of years that I would need some treatment at some time or another, I knew I couldn't go on taking the finasteride indefinitely, something might happen sooner or later, which it has (p4).

would you, would you like to come into this room...have a chat? So I said, what, have you got some bad news? No, sorry, he said would you like your family here? And I straightaway thought there's bad news. So I said no, if you've got some bad news let's get it over with, you know. So we went into the waiting room area and he said, you know, that it was er positive, the result of the biopsy. And he explained erm the procedure and what, what the options were and we had a chat about it, I was a bit upset [laughs]. You know, you would think about, because I'd had three previous biopsies and they were all clear and you half expect this one to be clear as well and when it wasn't I was a bit sort of taken back. (p5)

But I didn't really have any indication up till that Sunday morning that something, you know, wasn't right.(p5)

Well I think I was a bit blasé about it really because like I said the other three were negative and I think you half, even the surgeon when he was going to do it, he said I expect this one to be, you know, clear as well. So you become slightly in that mind-set if you know what I mean, oh, they're clear so this one will be clear, you know, so...(p5)

It was a little bit of a shock. I didn't have any indications from anybody that anything other than it was clear. Or I didn't have, well I don't think they indicated either way. Not particularly.(p5)

*had you done any reading about prostate cancer?* Not at all.(p5) (diagnosis made on 4<sup>th</sup> set of biopsies)

And to be absolutely honest from the first time I went to erm my GP erm she was quite good at explaining things and she made it sound as if that was probably cancer anyway. I mean I, I thought right from the very start that that was going to be cancer.(p6)

and I had read up about it on the er, on the charity website anyway about various things.(p6)

, I had the blood test and that was 27 point something, and er I was told that it was quite high..... and said you've got to come in and I said, I was going to make an appointment and she said no, you've got to come in today. So I thought it's obviously something fairly urgent so I went in, she said the blood count was high and she said I'm going to refer you to the hospital and I got a call the very next morning about twenty past nine er and I, I guess that they must have made me an appointment, I can't remember now, but erm so straightaway you think well, you know, there's a likelihood that it's going to be cancer. They obviously think that could be (p6)

when he done the biopsy erm he didn't say anything about what he'd seen, er, but he did sit me down and, and say that he thought that I would definitely have to have some treatment of some sort. Erm, so again everything pointed at...you know, he obviously thought that was cancer. He didn't make any pretence about that. Erm, he didn't say that that was serious or life threatening but he did make it quite clear that, I mean I don't know how much they know from what they see but he made it quite clear that in his view he thought that was cancer, so the telephone call didn't come as a shock. Obviously it can do to some people. But not to me. (p6)

when I went on the website and various other things they, you know, obviously told me that they do often leave it and, and that's another thing they've told me, when er, er the consultant or whoever he was, done the biopsy he said afterwards he said erm...you know, most men, or

I think something like eight out of ten men in their eighties have probably got some form of cancer of the prostate but erm they're such a slow growing thing they usually die of other causes before that actually takes effect. Erm, and he was, although I got the impression that I had cancer from him, I also got the impression that, that it weren't...or he didn't expect that it was very bad.(p6)

well I expected anything actually. Erm, from the beginning, you know, I thought yes it could be cancer, and that's it.(p7)

I always like to look at the black things first, you know, it's easier. (p7)

*Did you know anything about prostate cancer before you called us or before you...?* Er yeah, I have read some things about it, you know.(p7)

, just the general how it happened, what it is and so forth, you know, what it could be. Mainly (p7)

Just reading the newspapers. The Daily Mail. [laughs] (p7)

And unfortunately cancer always goes with the other word, terminal. So I thought to myself crikey, you know, what do I do? I didn't know whether I was supposed to then rest up because I was ill, because I certainly didn't feel ill. And er do I take it easy, do I do this, and that was the worst thing. I didn't really know how ill I was. And er...so then it gets in your mind and whatever you do you can't get it out. No. And that was my first reaction. Well I suppose I was frightened in a way. Not frightened of cancer but I, I wish I'd have know more about it. Maybe it's my own fault that I didn't. But er, but that's the thing what hit me worst. (p8)

He (GP) was the first one who give me the breakthrough that he told me there's, there's...they've advanced terrifically on prostate cancer. And that was curable. (p8)

, I think if you'd have said to me at the time you've got prostate cancer, but that is now er...you can now have...medical treatment to cure it. and I think even if it weren't going to I think them words would have made me feel a lot better at that time.(p8)

and he convinced me that, that they've advanced so far in the treatment of prostate cancer that...I should be possibly to have it cured.(p8)

I had the biopsy result I didn't even...hardly think I had (p8)

The cancer might have been life threatening,..... Because that's the first time I'd had anything to do with it and as I said as soon as the word cancer used...that was what done it. if you'd have been able to phone and you'd have said to me, you know, we're now very, very advanced on prostate cancer and we can cure it, er I think them words would have been superb.(p8)

I've been through this and I know now what prostate cancer is, I feel sorry for the bloke because they all think he's, you know...goodbye.(p8)

*before you called us, had you done any reading up about prostate cancer? (p8) No*

well, well obviously I did because that's why I had the test. That was a possibility. I mean...you know, I did know that people of my age it's very popular it seems to be anyhow, I don't know. [laughs] (p8) *when asked if he understood reason for the biopsy*

...it was fairly evident from when I first had the PSA test and the score that came through there was a problem. And after having seen the doctor prior to the biopsy he was pretty indicative that it was going to be a problem. Erm although in all fairness to him he was making it very clear that er, [coughs] excuse me, it wasn't sure until it's sure. Erm but I was fairly prepared for the end result, I think what I wasn't prepared for was the extent of the problem erm and that was perhaps more of a shock than I anticipated. (p9)

*what point did you think it could be cancer?.....* Straight after the PSA test, so that was before the biopsies....Erm and I know the PSA test is not truly indicative but it's a pretty fair bet and if the norm for a man my age is about four and it comes out at 53, there's obviously got to be some fairly big issue underlining the erm thing as well. So that's really where I felt fairly sure in my own mind it was going to come out to be erm, to be cancerous, yeah.(p9)

, I knew in my own mind but there's a difference between knowing in your own mind and having it confirmed, so yes, I was fairly anxious. But then equally if a piece of paper comes through the door erm with the hospital's name on it and everything you, you've got the same degree of anxiety when you open it up to find out as well. So I don't think it was any more, I was no more anxious by ringing than I would have been to wait for the er letter.(p9)

And to be quite frank didn't know enough about the problem erm to know, to ask the right sort of questions.(p9)

...but then I started getting a lot more information through er the internet obviously but also I think I said to you on the phone I'm very lucky in that I've got some extremely good contacts that are, or used to work for Astra Zeneca, on research on prostate and er so I had a long chat with him. And erm he has other contacts as well which have been very useful as well in terms of at least setting my mind at rest. Now I'm fortunate in that sense. A lot of people won't be. But I still don't have a problem with having rung.(p9)

Essentially it's been since, because it was really that was not a lot of point, I knew what was involved in the biopsy and I sort of had a broad vision of what prostate issues were about. And erm I hadn't gone into it in any great depth prior to finding out if there was a problem

really. Erm, so once I actually had got it, er well I knew what the score was, I started actually getting into a bit more detail, then of course a lot of information can be horrendous actually. You start reading and you think Jesus! [laughs] This is the end of the line coming, you know, very quickly. I mean you've got to sort of...there are so many websites out there with dis-information almost erm, giving you the horror stories, that you tend...and your mind because of the way things are, your mind tends to home in on the bits that are the worst rather than on the more positive issues.(p9)

I was actually phoned up from work, so, you know, I was, er, I'd already read up on the internet and the booklet you gave me, so I was er, I was fairly comfortable with it, the fact that I had erm a low PSA count and all the rest of it.(p10)

, because I'd read into prostate cancer already, er, funnily enough I'd seen some articles on the television about it as well, but because I know it's, it's a well-trodden path in it, I don't think it has the, for me anyway, it doesn't have the same connotations as having the other forms of cancer that are there. I mean I knew it could be, if push came to shove it could be chopped out.(p10)

And I knew that there was a fairly extensive range of treatments for it. So even though it was, you used the big 'C' word on it, I knew that if you had to pick a choice it was the one to have if you understand.(p10)

. I mean I was fairly accepting of that because obviously going for the biopsy I knew it was either yes or no and so obviously I looked for the worst scenarios, so I went and had a look online, Wikipedia and the rest of it to get the gen and to be honest I was, I was more reassured by that. And the book, the fact that I could see there were multiple options and it was relatively common. So I, I was less distressed than perhaps erm people thought I should be. (p10)

knowledge is everything.(p10)

again I'd informed myself of, of most of them (p10)..... I tend to go for the information sources on the Net, mainly because it's more direct and you can get quite a breadth of stuff, and I've hit some sites in America as well, you know, to get the full gamut. Not that I don't, erm, value the conversation here but I'm conscious of the fact that you, you are seeing windows, you know. So I'd rather see the broad spread side, I can get informed as I need it(p10)

to be quite honest I've been relatively relaxed all the way through, relatively speaking, erm because erm, because I was informed.(p10)

. I mean we knew a lot because of, about cancer generally, because of erm both our, my mother and my mother in law, and the mechanisms of it,(p10)

I had a lot of the sting took out of it for me by the doctor who done the biopsy..... he did indicate to me that I looked 75% erm good..... that put my mind a lot at rest when the doctor did say, you know, you look 75% okay to me anyway, just from the biopsies that we're taking, you know, and the ultrasound scan that you received. (p11)

I've always been very fit all my life, I've never had any illnesses or been into hospital for anything at all, touch wood. So obviously when someone mentioned the word cancer to you that do come as a bit of a shock. Erm, you know, I can remember going home thinking oh, I wish that doctor hadn't said that word cancer until I'd had the tests and then been told. (p11)

I had a couple of blood tests which erm showed up the markers for her erm but since then I've also checked on the internet and the markers that come in the blood can also be if you do a lot of physical exercise, that can raise the levels as well, so there was that in the equation as well.(p11)

*when you were referred up here you didn't have any thought about any cancer? Er, well obviously that's in the back of your mind but it's not prominent. (P11)*

I didn't expect in my mind to hear yes, you have got cancer cells there. I expected, you know, I thought I'm not a gambling man, but I thought 75% is fairly good. So you know that's why I say I was very reassured.(p11) *results were negative but what if they hadn't been?!*

I remember reading that and thinking oh, prepare yourself for bad news. So you're really winding the mind up to...do you see what I mean? (p11) *(talking about the post biopsy information sheet offering telephone for results service)*

everybody know in their own mind what they're here for. And they know that it's either going to be yes or no. (p11)

And I also looked it up, you know, on the internet as well to do with erm [17.42], well scared myself to death when I looked at that lot on there but if you've got a, you know, fairly open mind about it, and you can, you know, you can put your mind at rest a lot by knowing. I'm a person who'd like to know anyway. You know, I'd like to know fairly quickly. (p11)

*, before your wife called us, erm, had you done a lot of research into prostate cancer or looked it up? I spent about an hour on the computer just looking through the details and*

checking, you know, the levels in the blood and that sort of thing and what could cause it and what couldn't cause it and I had a fairly good understanding of it, yeah. (p11)

, not once did anybody say that, you know, there's a chance you'll die. She died.(p12) *talking about his experience with his wife, past experience contributing to his anxiety levels when going through his own experience or 'brush with cancer', although his results were ok, anxiety level prior to that call was 9*

as I said, to me cancer is death (p12)

you read the 'statistics' in the papers, they know this country's cancer results are not brilliant compared with other countries in the world, and I wonder why.(p12)

I think sometimes you need to protect yourself as well, you know. The internet is a dangerous thing because you can go on the internet and you can read lots and lots of things. And sometimes it's a dangerous thing, you know.(p12)

never been upset or worried in any way (referring to her husband p13) He's been through so much before, been through a lot worse.(wife)

I was pretty worried because erm a couple of the guys at the golf club had been or been through it, going through it, and also erm I saw my cousin first time in donkey's years in the spring and he'd er just recently had the operation, er he had radical surgery really it was my cousin that really prompted me to go to for the PSA test.(p14)

*So you were clear were you that, what you were phoning for when you called up that day?* Yes, it was more or less yes, you've got cancer, or no you haven't got cancer. And so that is something I wanted to find out as soon as possible really. (p14) *(in speed too)*

*had you done any reading up about prostate cancer?* Not a lot because I'm one of the sort of people that thinks, you know, I've got something nasty, do I really want to know all the ins and outs of it or do I just want to have to sorted out? And I'm the guy that erm I don't want to know too much information, just sort me out please. (p14)

I didn't go into sheer panic when I put the phone down or anything. A little bit stunned..... But I think I was probably expecting the worst from the high PSA result I got (p14)

I suppose I over compensated in that I thought it was going to be positive erm, my father died of cancer, er, prostate cancer (p15)..... So in that sense I was anticipating and philosophical about what it's going to be....(p15) My brother ....He's had the run in, he's had surgery and all the rest of it as well...(p15)

I had to just pick my time of the day to ring, I wouldn't ring first thing, I had to just be able to work up to it. (p16) *preparing self for the call ? maintaining some sense of control or choice*

I was prepared for this to be bad news and I think I would still do the same.(p16)

*how prepared did you feel for that call?* As prepared as I could be, I don't know how, how you can say how prepared you can be. I was just anticipating if it was bad news I was ready for that bad news. (p16)

I had been on the internet quite a bit to erm find out as much as I could because prior to going to the GP in the first place I didn't know what the prostate was, didn't know where it was, what it was. So...I like to find out as much as I could from there.(p16)

I wasn't really anxious at all... but I think the reason for that is when this all first started my doctor, Dr. (*name*), erm he said to me you will die with it, not because of it. And that's the attitude I've adopted all the way through now. (p17)

it was the doctor that measured it he said erm you realise you've possibly got cancer there? I said, oh! Oh, have I? Oh, oh! Oh! He said don't worry. He said you'll die with it not because of it. (p17)..... and as soon as he said that, that was it, I...it didn't bother me anymore. Whether it was erm part of his er patter for telling people, you know, I don't know, but it reassured me.(p17)

*before you telephoned us for the result had you done any reading about prostate cancer?* No. (p17)

it's not nice knowing you've got it. I had a guess, a thought, oh, because my dad died of it. So I thought to myself well I'm more likely to get it than not get it I suppose.(p18)

I had an idea like I had got cancer. (p18)

.....but I thought knowing my dad had it so I'll more likely get it than not get it.(p18)

I wasn't concerned because erm I think I'd rather got used to the idea that something would be erm found.(p19)

, I have a computer. And in anticipation of erm getting a result I'd already done a bit of research. Erm and in fact I had a fairly basic knowledge of what was involved from erm experience in the family (p19)..... *did you find that helped?*..... Yes, I knew what the Gleason scale was and I knew that erm what – er I had a rough idea of what the way things were and erm without being an expert on the subject I could take a judgement on whether or not it was erm...good, not so good [laughs] or bad or terrible.(p19)

You were stunned a bit because you didn't expect it.(p20 wife)..... I wasn't expecting that sort of reply basically. Because as I say I've always been reasonably health, I only take some blood pressure tablets.(p20)



, I was prepared, I was prepared for that. Yeah. But the thing is that erm I, I still was a little bit sort of shocked to get that reply because I wasn't expecting that but I had prepared myself that it could be. You know I'm, I've got enough sort of intelligence to know that yeah,(p20)

But I certainly knew what I was doing when I phoned up..... I knew what I was going to be expecting to hear, either one way or the other. Unfortunately it was the wrong answer I got.(p20)

when you read that it's one of the biggest killers for men, this type of cancer, I have read this several times, erm you know I do think about this and think well, I know there's treatments and you can control it more than perhaps ten years ago sort of thing, erm it's still, well am I the unlucky one that er it's sort of happen? (p20)

I don't think it, you know, really occurred to me that I could have cancer. Erm, and even now I find it difficult to, to really not accept, I think I've accepted that yes, I have got cancer, but really to take it on board.(p20)

the biopsy is erm a negative or a positive result. I've either got cancer or I haven't because that's basically what was going to come out of it. but at the back of my mind I was still quite reasonably confident that I didn't have cancer, basically.(p20)

I still hadn't resigned myself to the fact that I could have it. Erm so that's probably why it was a bit of a shock (p20)

....at the clinic prior to the biopsy he was very frank and erm the chap said it is very likely to be cancer, we don't know till we get the results back and come in for the biopsy and so – and then he went on to describe in detail what the treatment would be with er injections, erm with injections, possibly radiotherapy, you know, that's – that wasn't decided at that stage but then he went on to say the prognosis was very good and (*husband*) was much more likely to die of old age with prostate cancer than because of prostate cancer. And this is the thing that I translated that he understood. (wife of P21)

It's because we'd been told what – about the prognosis. I mean quite different to the examples I've been talking about with women..... because it had been explained so well at that interview, well call it appointment, before the actual biopsy we felt we knew where we were.(wife of P21)

One of my granddaughters who is a doctor said that prostate cancer is more of a nuisance than life threatening. And so that's all right.(p21)

– the thing was that the – this PSA, I don't know what it means but it's a number, and our GP said if it goes past 20 it is almost certain to be cancer. And the most recent test we had, it was 17.(p21)

, that appointment at the clinic before the biopsy was very helpful because..... I asked quite a lot of questions and I got straight answers. And that goes a long way, yeah. (wife p21)

– I felt sure that that was what it was going to be and cancer is a word which inspires people with er worry, fear anyway ...*Yes, it does*..... But in fact, as we've said we don't regard prostate cancer as being anything very terrible (p21)

that was just to determine whether there was any erm problems with the prostate, i.e. cancer. You know, I mean that had been in the back of your mind for some time. (p22) *when asked if he understood reason for the biopsy*

*had you done any research or looked up about prostate cancer before that call?* Well yes, I had. Yeah. I have – I have – I did look on the computer oh, ages ago, in the summer time (p22)..... , *what had you found out about it?* Well I sent for a toolkit. (p22) I looked on the internet and er got it and I got this toolkit from, you know, was giving you all the various options of treatment and the side effects and what have you.(p22)

I was expecting something like this erm ...because from the blood test results,(p23)..... so consequently I wasn't at all surprised and as I said he said that there was a cancer there (p23)

I was expecting that I – there was a possible cancer there. I was expecting that after having accessed the internet and, and went over that fairly in depth on there (p23)

I was expecting it anyway and so I didn't come as a complete shock erm when I came out and saw, and you know, and when the nurse asked me out. So it wasn't a complete shock. I didn't – I wasn't collapsing or anything..(p23)

he said there's definitely cancer there, and he said erm like a man your age I expect to get it, you expect to have some form of cancer there or limited amount of cancer and when I'm your age he said I'll have it. So of course that was reassuring.(p23) *at the biopsy appointment*

really I had a good idea what was going on .(p23)

we were sort of forewarned that there would be something and at 66, you know, you expect something to be happening.(p24)

my GP said that the results were high and because I read around about these things and also because I have a friend who, although he's only an acquaintance, who has a similar problem I was sort of forewarned that mentally I was I suppose prepared for something.(p24)

the GP said to me that you have – there's a possibility that you have non-life threatening prostate cancer, I thought oh, well that's the cross I'm going to have to bear. Because at some stage in your life you're going to come up against something. Because modern medicine is so good that it gets rid of the pneumonia, the old man's curse you know, that would take an old man away, and somewhere around there's a cancer that might get you. So you know...(p24) *and in making sense*

so when the doctor said only go on that site then that's what I did, I just went on the Macmillan site and found that that was reassuring, so if I go on the internet I go onto two sites, I go onto either the Macmillan or I go onto this prostate cancer site. I never go onto any other site (p24)

they had already inferred that it was cancerous so we were pretty – we were prepared.(wife p24) *when asked how anxious they were before coming to clinic*

I wasn't surprised because I went to see my GP .....And erm that er he told me that erm that was more than likely cancer. and so I was prepared. (p25)

I've been through this and I know now what prostate cancer is, I feel sorry for the bloke because they all think he's, you know...goodbye.(p8) *(in death doc)*

## **Theme: Cancer = Death**

the question I, I want to ask erm to me that's important is erm the biopsy, if I've got the aggressive type, when the biopsy was done it obviously causes some, some bleeding don't it? (p4).....if mine's the aggressive type having these spores whether they be...have, have they escaped into the system? ..... So er...that's the only thing I, I found a little bit complicated. Erm...because of the bleeding and that, that particular part of the prostate obviously which the needle took it from, obviously causes some bleeding, did anything escape from that contaminated part of the prostate? (p4) *irrational thoughts/fears*

Because of the bleeding, when that needle was withdrawn with a sample on which obviously the one with the positive cells in, did any escape? That's, just from a picture I had in my mind, that's all.(p4) *fears, irrational thoughts*

everybody has these cancers, is there any sort of underlying causes for them? I'm, I'm...I'm a firm believer that some kind of a shock brings these on because, because erm...I've got to explain this a little bit. (*wife's*) sister was diagnosed with a cancer er when her son committed suicide didn't he? (p4) *making sense*

IE2: Yeah.(wife p4)

IE: And I'm tracing, I'm tracing, I'm tracing my PSA back when it started to go up. Right? And my PSA levels started to go up roughly the same time as (*wife's*) sister was diagnosed with the cancer. Her cancer. Right. Now on that given day, we're talking about shock here, I, I was the one who actually went to where he was, rather than her going. I didn't see anything but the police were there and, and they were the ones who told me what he'd actually done. Right. and I think, I'm sort of piecing this all together Wendy, er, to me that's more than a coincidence. Does shock bring these, bring these cancers out in people? I think they do. I think they do. And I think that's what's happened to me to be quite honest. Is it an unfair question to ask? You said ask anything you like. (p4) *making sense*

What I'm getting at is had she been given some, something er to overcome the shock of this all, er because she's like mine, mine's aggressive, hers is aggressive. Very aggressive wasn't it? (p4)

IE2: Yeah.(wife p4)

IE: And, and to me that's too much of a coincidence. So, you know, what I'm saying is if anybody's...yeah coming to you in the future saying well, you know, I've had a bad shock

through erm a car accident or someone getting killed in a whatever it is, and they've been in deep shock, if, if patients were given something for the shock does that lessen the effect of the cancers? I don't know.(p4)

IE: I'm going mad.(p4) (*irrational thoughts and fears, making sense of what's happening*)

You know, the fact that you'd got it, that's treatable, but you know, how far down the line have you progressed? The, the most, erm...the bit that causes me to lose sleep was the fact that I stumbled across it. You know, that there's no screening for it. (p10)

Well, the fact that I could, I could in five years time find myself in deep pooh simply through ignorance and not knowing. So, as I said everybody now, because there's a lot of people of my age in the place I work, and of course I'm telling them you need to get down there, mate, take that PSA test.(p10)

Yes. Yeah. I, now I would certainly be an advocate for screening. Because it would tell me everything. The doc screened a load of things for me that my mother had. And it was just that tick on the...he went how old are you? (p10)

*Mmm. And you'd never had trouble with your waterworks or anything?*

No, I'm, I'm one of these irritatingly robust people. (p10)

*Are you?*

Yeah. I haven't had a day off sick from my time in the military, been ill and broken, got scars to prove it in various places, however I've, I've never been given sick leave.(p10) *?disbelief*

and I just happened to have stumbled on it at a time when it's erm, everything is, is relatively confined and erm, and there are more options. I would have certainly hated to be in this position in five years time and find that things have gone a bit pear shaped.(p10)

I personally was informed. I mean when I told my brother, you know, he was really shaken by it. You know, in fact he upset me, his, his reaction. Erm, but of course now he's more sanguine about it because again I had to go and refresh myself with, well the position I had in my own head.(p10) *other people's reactions to cancer*

Well, see I've always been very fit all my life, I've never had any illnesses or been into hospital for anything at all, touch wood. So obviously when someone mentioned the word cancer to you that do come as a bit of a shock. Erm, you know, I can remember going home thinking oh, I wish that doctor hadn't said that word cancer until I'd had the tests and then been told. (p11) *also in anxiety/disposition*

...the first doctor I saw who mentioned the 'C' word, he erm actually did tell us the erm results. Erm, you know, and providing that's caught early enough he said there's going to be a 95% chance of being cured. Erm, you know, which I thought was good. (p11)

*Mmm,*

Because on the other end of the scale, you know, if you have to have the operation and I think most people are aware that if they don't have it, you know, they're going to die anyway, so most people would go for that surgery to prevent the life. . (p11)

*So...what does cancer mean to you?*

Death.(P11)

*Death?*

And I think most people say that it's death. (P11)

I mean I've lost a stepmother to cancer, erm when I was 11, and several people through my life, you know, I've heard with cancer. (P11)

maybe a few more tests to be done, you know, something along that lines rather than just saying yeah, that's looking as if you have got cancer, you know. erm, a more softer approach to it because that's, it is a bit of a shock to your, to your mind, especially if you've been fairly well all your life, you know, to hear that word, cancer...(P11)

, oh that's cancer, he went. But don't go home worrying about it. I thought oh god...I've lost three of my friends with cancer and that's the last thing you want to hear. Especially with your husband. In that way....., it could have been anything. I don't know. It's just the way he come out with it. And he wasn't even sure whether it was that. Why mention the word cancer if you don't know? You know what I mean? (wife p13)

But I think I was probably expecting the worst from the high PSA result I got. It was erm...I saw a chart and somebody of my age should have had 4 or 4.5 I think it is and mine was 13.5 and I thought god, that sounds horrible, you know. I'm on death's door. Knock, knock, let me in. [laughs] (p14) *also in cancer =death*

*Can I ask you just... what the word cancer means to you?*

[sighs] Well...erm...unpleasant death I suppose. (p15)

*Right*

Yeah, unpleasant death that's what I basically...(p15)

*That's what it...?*

That's what it basically, at the end of the day it's unpleasant death.(p15)

.....not been conscious particularly of, of meeting people, having a lot to do with it. It just, to me it's oh, unpleasant death. You know. Unpleasant death. Not necessarily misery but unpleasant, you know. (p15)

*Can I ask, you don't have to answer, but can I ask what that word means to you?*

In many cases I know some people who have erm had successful treatment for cancer...(p16)

...erm although I also know people who have had cancer er treatment and it seemed okay and it's come back again. But I also know quite a few people that have died from cancer, so...that's, that's the worry to it. (p16)

*you felt a little bit anxious did you?*

Well, a little bit, but because as I – I felt sure that that was what it was going to be and cancer is a word which inspires people with er worry, fear anyway.(p21)

I wasn't surprised. Erm if – if I'd been in severe pain or had symptoms and this, that and the other, I probably would have been concerned but seeing I – I feel the same now as I did a year ago, that's unbelievable really to – that that don't. But – but it's unbelievable that I've got cancer there. but erm – but reading up and talking and one thing and another, that is a quite common thing apparently when you get to my age, er and I talked to people and I – and it was only, what, three months ago when I was getting up in the middle of the night, other than that all my life I never had to get up in the middle of the night. So that's why I left it for a month or so, I thought – I thought it was just a habit I'd got into. So I, you know, if I – probably if I was in severe pain and had erm a lot of symptoms I would be more concerned but being like this at the moment, that's erm sort level things out, that's all I can say.(p23) *disbelief?*  
*Association with cancer= illness, doesn't feel like he's got cancer therefore not concerned?*

I'm fortunate in the sense that I feel the same now as what I done the last 50 years, so you know, touch wood. But – so consequently that may be why I maybe sort of blasé about it because if – don't think there's nothing wrong.(p23)

The mere fact that I done it and – and erm I gone there and I don't feel – I don't feel any different now to what I'd did ten years ago, you know.(p23)

I mean it came as a bolt out of the blue. (p2) *Right*. It really did.(p2)

but since then I've accepted that I've got it, erm...nobody obviously knows how long, you know, it might be before it kills me (p2) , I felt a bit worse after Tuesday when I was told that erm the only option was radiotherapy because it might have got sort of further afield, which was a bit of a downer after knowing that my bone scan and my erm MRI scan was clear, I thought oh perhaps that is it after all.(p2)

, but apart from that I've coped with it sort of fairly well. I mean it hasn't put me off my food. Erm, well I've been off my food the last couple of days a bit, but you've now put, sort of put my mind at rest again. But really that's the only way that's sort of affected me. It hasn't slowed me down. Erm...like two weeks ago, just before the grandchildren went back to school, erm we had the two youngest grandchildren, little granddaughter, she's nine and a half I think, like a young antelope. [laughs] She said I'll race you down to the river granddad. No, I can't run down there. Come on, she kept going, so we raced down to the river, it must have been a good 50 yards, I beat her down there and I beat her back up and that was uphill. So that hasn't sort of stopped me doing those sort of things. I mean obviously my heart was racing a bit but at 68 you don't really want to run 100 yards. Erm, apart from that I'm still out in the garden...(p2)

the worst bit for me I think was erm the bone scan erm thinking if it's got to my bones it is really serious. Which was obviously quite a big relief, erm, I phoned in for something...Oh, I know, I'd had pins and needles in my leg and I felt a bit numb but I think that was leaning over the hedge, cutting the hedge, putting all the weight on one leg. Erm, I phoned in to see if it was anything sort of that had been done here or in the back of my mind I thought yes, it has got up to my bones (P2) *fears*

you know I think at first he said well it's sort of 50/50 chance that this will be successful that we'll kill it. Erm I thought it's not very big odds really. Erm, and then he said well, I'm offering you 60% chance so erm then, because when I, he gave me the letter to take to the GP's and I saw on there that said erm injections sort of for three years, I thought well perhaps I have got three years instead of three months. (p2)

I don't know, who knows? Erm, we don't know how, how long individual people have. I suppose the higher the Gleason score, the higher the PSA, erm, whether they're in good health or not, goes a long way to how long they might cope with it. Or how long it might be before, you know, it takes over. (p2)



I mean to be truthful erm I didn't how that might sort of...how long I might have, erm I realised that was quite serious when I knew it was Gleason nine.(p2)

But I really sort of try and do things to take my mind off it. Erm, if I'm busy I'm not thinking anything about it. Hasn't affected me really in any way like. It's only if somebody starts oh dear, you didn't want that did you? And you think oh, why don't...? You know, just, just leave it. Let me get on with it. Erm, because some people can be a bit sort of pathetic. Erm...a couple of people have been round ours, well, not been round, one of them phoned me up, was my cousin, and she is so pathetic. Oh my dear, what are you going to do? Oh...I can do without that. You know, let's get on with life. Hope I'm not sounding sort of too callous, you know. (p2) *stigma and association with cancer said in mimicky voice, pathetic voice and irritated*

*No, not at all. No.*

But I sort of erm...found that I've had to take that sort of erm outlook on it, I've got it. Erm, it's not going to go away on its own. I've got to learn to live with it. However long that might be. Erm can't change anything, it's no good thinking oh, if only I'd have gone to the doctors five years earlier, I might have known five years earlier that might not have been so aggressive. But...that's gone, and there's no good dwelling on, in the past. So...(p2) *?regret*

and I thought oh, perhaps erm the radiotherapy is not going to work and erm...this might be it sort of thing. But then when I read on the letter injections for three years I thought well, perhaps I have got another three years. So that sort of eased it a little bit.(p2) *treatment choice misunderstandings, also in death*

They obviously, that is a fairly successful way of killing the existing cancer. But no guarantee that it won't re-grow.(p2)

And then you, then you start thinking other things then.(p3) *missed cue*

So that was okay. So I didn't ask too much about that. And then it was whether it was contained. And that was, you know, or is it elsewhere? And that's your wait, that's where you're thinking, well all right, I, I got it, now I need to know, it's like have I got it? Yes I have. Now I need to know where it is. We know it's there but has it gone anywhere else? (p3) *also in anxiety and speed and moving on*

as I say it's not knowing and now it's thinking well, how long have I...how long have I got now, what happens next? (p3) *(uncertainty but with next step I think)*

. I mean the one thing that...two things I wanted to know, obviously I wanted to know whether it was cancer, but after that the one thing I wanted to know, obviously, er which everybody wanted to know, was how bad that was. How serious it was.(p6)

and it sort of sunk in, erm, and if you like the extent of the problem was bigger than I had anticipated, I sat down and you start thinking about things and thinking about the implications are and obviously the family get involved. And it was the following day that it really hit me when I actually became quite emotional actually. Erm had a few tears on the phone talking to one of my, one of my sons. Erm and I thought then this is just very silly to be like this, for goodness sake snap out of it, you know, and in a way I think if this is a positive comment and maybe I'm jumping the gun a bit by saying this, but I think what I would have appreciated actually was a follow up call the following day. (p9)

Erm, I probably would have benefitted from having a follow up call the following day. Erm, on hindsight I probably would have preferred to come in to see somebody in...and be able to ask the questions then. Because in a way it's the bit impersonal bit isn't it on the phone? It's not that any of you are impersonal people, far from it, erm, it's that personal touch that you sort of, does that mean I'm going to die in the next six months sort of...you know, it's that type of...I know that's exaggerating but it's that type of expression really. (p9)

Essentially it's been since, because it was really that was not a lot of point, I knew what was involved in the biopsy and I sort of had a broad vision of what prostate issues were about. And erm I hadn't gone into it in any great depth prior to finding out if there was a problem really. Erm, so once I actually had got it, er well I knew what the score was, I started actually getting into a bit more detail, then of course a lot of information can be horrendous actually. You start reading and you think Jesus! [laughs] This is the end of the line coming, you know, very quickly. I mean you've got to sort of...there are so many websites out there with dis-information almost erm, giving you the horror stories, that you tend...and your mind because of the way things are, your mind tends to home in on the bits that are the worst rather than on the more positive issues.(P9) *in disposition & death*

. Erm, so that, that was fine. Erm, but then you sort of...it's partly again about researching and looking at it and I suddenly thought, oh hang on a minute, if I've got...oh, and the Gleason score of eight, now that shocked me actually, I think that was the one that really got me, erm...and then I didn't ask the question of how's it split because I didn't know at the time. So that whittled me a bit until I found out how it was split. Because I understand that if you have one that's higher than the other then that can be indicative of more aggressive cancer and er than not. So these are the sort of questions that subsequently came up who I then...that's right,

so when I rang erm...that was when (*nurse's name*) rang me I think actually after having had the scans. (p9)

That sounds a bit pathetic but in a way the, at the point, the 24 hours afterwards you are a bit pathetic actually. [laughs] sort of feeling sorry for yourself, erm, worried about the family, what are the implications, and strangely enough Wendy, one of the things that went through my mind and I know it's irrational and I know prostate cancer is not a killer immediately, erm but my immediate thoughts were how long am I going to be here, Christ, I'd better start getting this sorted out, that sorted out, what am I going to do with my wife, what about the kids, you know, it was that type of thing. So your, your mind starts building up the pressure of all those issues. When in practical terms, unless it was sort of, unless it's got me with a vengeance, which it clearly hasn't yet, erm, I've got plenty of time to work, to sort those sorts of things out. But that's how the mind works, or my mind works anyway. [laughs] (p9)

*Is that, it's since you've heard it was cancer?*

Yeah, oh yeah. Yeah, that's right. And I think that's probably of course the erm...a reaction that most people have with that word isn't it? It's got that horrible connotation to it. Erm...yeah, in some respects I'd rather have what I've got than Alzheimer's or something like that. You know, I mean it sounds silly but erm you can deal with this, erm, one way or the other. And there are ways and things, ways and means of dealing with it and no doubt there will be new things come forward in the next few years that will actually help as well. So it's not all negative. Far from it. Erm...(p9)

*But at the time...you were told...*

But at the time...ooohhhh....yeah, yeah. It's all about how long have I got? [laughs] I know it's very silly.(p9)

*It's not silly.*

It's totally irrational actually. Erm, because I'm not, I'm far from being stupid, I'm not saying I'm the world's brightest but I'm by no means intellectually thick and I'd read the details, and I know what the score is and I knew that they've got, you know, there's a long time potentially before things really rocket up, but you don't think about that actually. You sort of, you are irrational almost at the point, erm, irrational and emotional I think is the, it's a weird combination, well it's not a weird combination, but it is a combination that's, can be quite debilitating actually. So erm...but it didn't take me long to get over it. [laughs] (p9)

Yeah, it wasn't, I wasn't expecting that sort of reply basically. Because as I say I've always been reasonably health, I only take some blood pressure tablets. And, you know, apart from

my knees, erm which have given way on me over the years, too much sport, erm...So I was a bit upset and I wanted to probably cut the call short erm (p20) *disbelief*

I'm the sort of person that I'll do it now rather than leave it, generally. Some things I leave a bit too long (p20) *regret?*

I've got one of the symptoms which is I'm up several times in the night and, and now during the day that, you know, going to the toilet, doing a wee, that is one of the symptoms of it but I, I don't think I had any other symptoms as far as I know.(p20)

You haven't felt ill have you? (wife p20)

I don't feel, I don't feel unwell fortunately....(p20) *association with cancer, should feel ill, disbelief?*

I think it's difficult because you don't feel ill so you're, you're not – it's not in your mind oh I feel terrible, I'm ill, I wonder what's happening. (wife p20)

But when you read that it's one of the biggest killers for men, this type of cancer, I have read this several times, erm you know I do think about this and think well, I know there's treatments and you can control it more than perhaps ten years ago sort of thing, erm it's still, well am I the unlucky one that er it's sort of happen? And also erm what sort of treatments? But that's, you know, I've, I've kept that to myself a little bit sort of thing, I don't want to worry (*wife*) or you know sort of well the children sort of too much. And I don't know really what to say to them, like I've got it, erm the tests show that, but it's only on one place according to the scans so perhaps I'm fortunate that it's caught, been caught before it's been able to spread. Because I don't know even whether it just spreads as a natural sort of follow on sort of thing if nothing's done.(p20)

...and that's probably where you get the erm the people that do die from it I suppose have left it too late before they...(p20)

I mean even to when he said well, erm we'll just send you for a biopsy erm I really didn't think too much about having cancer at that time. If I'm honest about it.(p20)

No, I don't think it occurred to either of us. (wife p20)

I don't think it, you know, really occurred to me that I could have cancer. Erm, and even now I find it difficult to, to really not accept, I think I've accepted that yes, I have got cancer, but really to take it on board. You know, I'm sort of...(p20)

It still seems unreal doesn't it, yeah? (wife p20)

Yeah, yeah. because as I say I've, really over – I know I go back but really over my lifetime I've had very little illnesses. I've been fairly healthy, as I say I've played football and I mean I played football till I was about 45 or something up and down the type of quality sort of thing, so I packed up football because of my knees were playing and I went to see the doctor and a squash club in the village opened that same year and I went down there and never played squash, never seen squash game and I joined the squash club and I played then until I was about 63. So you know I've always been quite a fit – the only thing I've got I'm overweight, I know that because I eat too much of the wrong food probably...(p20)

, I mean...yeah...it didn't hit, hit me really I suppose erm until they...

I don't think it still has really.(wife)

No, no. No. (p20)

It seems unreal, even when we told the nurse when they came round to dress my foot, erm it just seemed unreal telling them that you, you've got prostate cancer and...(wife)

Yeah because she came round sort of eight o'clock this morning because we told them we'd got to come here and they've been coming like Monday, Wednesday and Friday, and she said Wednesday I'll get someone to come at eight o'clock. And they were, they were – I'd just got out of bed, I'd put the alarm on, it was quarter to, I was awake, and I'd just got up, I was still in my pyjamas like, you know, and erm she came and er that was when, well, you told her.(p20)

I don't know why we shouldn't expect if sort of, shouldn't have expected somebody to get cancer because my sister has had cancer and my brother has got cancer. (wife)

He's got prostate cancer. (p20)

His sister has got cancer so why we should have thought it wouldn't touch us I don't know...(wife)

My mother had cancer. (p20)

No, but somehow we just did. Erm mainly I think because he has always been so healthy. Erm I think it still seems unreal. (p20)

I've hardly taken any tablets as I say. Tablet wise I'm, you know, my blood pressure that's all. And that controls it but I mean as I say I've played sport all my life sort of thing and been fairly fit in the garden and as I say my only thing is my weight. It's not a problem exactly I mean but I am overweight. I'm not obese I don't think but...(p20)

...Now that's one of the things we wanted to ask was how aggressive is my cancer? (p20)

I realised I should have gone to GP, well long time before I did but it's like I said, it's just one of those things you know, felt alright you know. I didn't have any problems really, I felt alright in me self so err..... I just carried on.(p1) *regret, no symptoms*

, it's still not, I know it's sunk in but at times you know I forget what it's all about, you know..... you grow old (?) and you forget about it.... you know then you get these little symptoms and things and it brings it all back but err it goes off (p1)*disbelief*

..... I would have liked to have known as to what extent it's got you know....I know I've had a bone scan and they've told me that err I've got a rib affected on this side (*pointing to area*) and there's something on this side as well (*pointing to the other side*) but what I don't know and err..... previously this week or last week I started getting pains again in the bottom of my stomach but they've gone off you know, they've gone off, but I would like to know how far it's advanced ...now because I like to know what's what, always have done (p1)

: *ok*

P1: I mean I don't care if it's, they say it's terminal or anything like that you know cos I mean there's times I mean like this morning, I think I'm gonna die. I get this feeling, all of a sudden, that I'm not going to make it, you know and that's what's a bit upsetting because err... *pauses..sighs.....crying..(p1)*

And unfortunately cancer always goes with the other word, terminal. So I thought to myself crikey, you know, what do I do? I didn't know whether I was supposed to then rest up because I was ill, because I certainly didn't feel ill. And er do I take it easy, do I do this, and that was the worst thing. I didn't really know how ill I was. And er...so then it gets in your mind and whatever you do you can't get it out. No. And that was my first reaction. Well I suppose I was frightened in a way. Not frightened of cancer but I, I wish I'd have know more about it. Maybe it's my own fault that I didn't. But er, but that's the thing what hit me worst. (p8)

*Okay.*

The word terminal. (p8)

*That had got, you'd got that word terminal?*

I couldn't do nothing about it. So I thought, you know, so how long have I got? (p8)

And six weeks prior to that I started having some blood pressure pills. So I'd got to go and see the doctor. Er, he hadn't contacted me about the letter, I knew he'd got, received the letter because I said...but he assumed it had come back to me, and when I asked him why he said

because he was waiting, he said because there's nothing I can do about it until you go for your MRI. And er so I thought well that's a fair enough comment but then speaking to him about it he was the first one who give me the breakthrough that he told me there's, there's...they've advanced terrifically on prostate cancer. And that was curable. (p8)

Which it might still be but what I'm saying is, and he convinced me that, that they've advanced so far in the treatment of prostate cancer that...I should be possibly to have it cured. So that made me...if I'd heard that when I heard, had the telephone call about my PSA and all this here, the, the medical terms didn't mean too much to me. I knew the word cancer.(p8)

I mean I had five one side and one the other from the biopsy, I assume cancer.(p8).....

I, I realise all that. But that didn't tell me that my health wasn't in danger as much as I thought it was. (P8)

but even now I still feel 100% fit, that's the annoying bit about it. not annoying, I mean that's, that's a good thing but...so I, I, because it's now gone on for quite a while without knowing I was ill, there's no doubt about that. So having the biopsy was the best thing that happened to me. And I think every man of my age should have a biopsy. Because without that I'd have still been jogging along thinking I was 110% fit. (p8)

Because that was what was in my head. And that...I, whatever you do you can't remove it, I mean because you've got to go to bed and you got to lay down and you got to sleep and er...but if I'd have had that in my mind, that that was...that I had something that was curable, and treatable, then I'd have felt a bit better.(p8)

Because maybe that was er self-inflicted because I, well...(p8)....I think it's like...like a toothache, I mean if you have it treated and that go away you forget about it. Uh. And er...I thought to myself...I don't feel ill, now that was the thing what kept me going mostly I think. But obviously I weren't, I was ill, you know. I can't say I've accepted it now because I, I don't want to accept it, I want to try and fight against it and not accept it if I possibly can but there's not much I can do personally, I've just got to...hope and rely on everybody else. Out of my hands. (p8)

I didn't want people...I suppose to feel sorry for me. I, I didn't want other people to know. Well, the two daughters and the wife knew. And the two son-in-laws. But apart from that, and in fairness to them they told nobody. Because I thought so I can't say that...because....There's a chap I used to work with because we have a, every month we...a group of us we meet up every, once a month, about 20 of us used to...work colleagues and people I used to work with. but one of the, we were at the meeting and er someone said, this chap's name is (*name*), I know I shouldn't use names, and they said he's got prostate cancer. And he's got to go up the

hospital and by the time we finished that day I thought, I thought to myself the way they're talking he's finished, he's had it, that's it. That's terminal you know. And that before he even knew I had anything to do with prostate. And that's just what stick in my mind, you know. so I thought I don't want people to know because if they know they'll think I'm going to die in a couple of weeks time. And I don't feel I am. (p8) *stigma, associations with cancer*

The reason I say that because that would all be psychological cos I still had in my mind that I hadn't got it so it's hard to talk about something if you don't really want it. So no, no, no, I think that how it happened, me personally, was, was all right, you know, that was what I wanted. But I wish I'd have known that that was...not as...(p8)

. It's not until it affects you that, you know, your mind goes into overdrive, after seeing how she died and everything, through cancer, what she went through, your mind goes overdrive, plays tricks with you, you know. So...that was that. And it was unnecessary, to me if I'd have known there was a possibility of a letter also, don't you think I'd have had people going in every day just to make sure there wasn't anything from the NHS? From the hospital site? Do you understand? (p12)

That was it, basically once I had the PSA and then got the results then the cancer started er appearing. You know. Then you start worrying. You know, I lost my wife two and a half years ago to cancer and my sister in law, she had cancer last year. You know, it's all around, you don't realise until something happens, cancer's all around you. You know. And it's...and you hear about all the good cases but there's a lot of cases that don't happen, the goodness it not there, they die, a lot of people die.(p12)

It does, it causes death, it's linked with death. My wife, my wife never, ever, ever, nobody ever said that should wouldn't survive it. Nobody, so she worked for the consultants here, she worked for the (*department*) here, when she first came up from London. She knew all the consultants, she knew all the cancer nurses, not once did anybody say that, you know, there's a chance you'll die. She died. [14.52] You know, you know, it's...as I said, to me cancer is death. You know. You read, you read the 'statistics' in the papers, they know this country's cancer results are not brilliant compared with other countries in the world, and I wonder why.(p12)



the only thing that we – we – we did query, and my wife queries particularly, is that I have blood tests every two or three years...(p24)

For your blood pressure.(wife p24)

For high blood pressure, well I have high blood pressure but at my age you have regular blood tests, it would have been helpful if that blood test had included a test for the PSA level. I know that there's a cost involved for that but erm if you – if you go to the doctors like I've had two blood tests recently, erm one – one said oh, you haven't had a blood test for a long time so we'll have a blood test. Er and – and I was told over the phone that's clear, you don't have to make an appointment with the doctor, so that's right. Then I went to the doctor erm with –with the problem that – that er he said well I think we'll have to er –erm do another blood test on you and check your PSA levels because of my habits of going to the toilet and the fact that I was having discomfort on my bike, er and then he – he told me that – that erm I'd got a problem. But if – if I'd had a – a blood test, the first blood test, if that had included a PSA test then that would have flagged it up a bit earlier. But erm, you know, I know that I've also read that some people say well some people can have a high reading and erm it doesn't indicate anything serious, other people can have a lower reading and have a problem, so the PSA test is not a reliable test. (p24) *regret? Making sense?*

His times of going to the toilet had increased because that's what it does. And I mean that's years now isn't it? So you know I'm thinking well should he go to the doctor because it could be prostate cancer or is it just his blood pressure tablets that make him do this? So thinking he had a blood test every year to 18 months I presumed that that was tested. And didn't realise that it wasn't. (wife of p24)

But having been told that the results were – sometimes do, sometimes don't, that did reassure me but I do wonder if perhaps we could have found it earlier had that been included in his blood test checks.(wife of p24)

I'm a little anxious about it. Because also my father died at 80 and I think he had had prostate cancer but of course it had gone elsewhere...(wife of p24)

Before – before they discovered it.(p24)

Erm so, you know, I have this thing, prostate cancer, he's going to die. (wife p24)

The only regret we have is that he didn't go to the doctor earlier. (wife p24)

Yes, yes. We should have gone earlier. Well I mean that's what they're saying on the television at the moment isn't it? That a lot of cancers in the UK, people don't go to the doc early enough. Slapped wrist. Yes. (p24)

*is there anything that you found out about prostate cancer that you wish you'd known at the time?*

Well, yes, that's a fair enough question. I feel if I'd went to my GP earlier and I'd been treated earlier I wouldn't be as bad as I am now. And I blame myself for that. (p25)

*You do?*

Yes, I should have went before when I found I couldn't erm hold my water normal. (p25)

*Okay.*

But erm I mean I've got no one to blame, only myself. I mean my wife(*wife's name*), she said to me why don't you go to the doctors? Well I **hate** going to the doctor but erm the time come so I – I went, good job I did. (p25)

If – if a person – well my – my close friends I tell them, I said I've got prostate cancer. Oh!!! They say. Whatever are you going to do? (P25)

*Right.*

I say what do you mean? I said deal with as it comes. And oh, whatever will you do? This was round about Christmas. I said meet – meet every day as it comes along. And that's what we do.(P25)

But till that time, till I was up here, that didn't really...it suddenly hit me oops, you know, this is it. I mean it's, it can be a serious problem but a lot of men live with it for years don't they? (p5) *looking for reassurance?*

*They do. Yes.*

But it kills 9000 men a year they reckon. Which is, you know, quite a few. And I don't want to be one of them 9000. (p5)

## Theme: Disposition

...a little bit concerned as to how I was going to take it but I've tried to be positive and take it on the chin as it were (p4)

So I, I weren't too unduly worried about it Wendy and...I'm still not too worried about it even at this moment. I know what I've got and you are all trying to help me and you explained it through your booklet all of, all the ins and outs of it, the treatments, and such like and I, I feel, I feel quite happy with the way that, that you've all been trying to helping me out here. And I'm, yeah, I feel very happy about it to be honest.(p4) *and in service and in preparation*

I feel okay about it, you know, I just felt I had the biopsy done and, and that was it.(p4) *acceptance*

, I've read your, your booklet, I think it's very good. (p4) ..... I've read it two or three times to make sure I've got it in my head. Erm, yeah, but apart from that, Wendy, no I haven't looked up anywhere else because I, I, I found I didn't need to.(p4) *also in service. Accepting.*

In other words I found...I don't need to worry myself unduly more than I should do. because I find, well...what you people have told me from the hospital and what they've done so far with the scans and such like, and what's in the booklet, for me there's enough information there to tell me all I need to know.(p4)

I: Right.

IE: That the rest of it is, is in the hands of the consultants and you people to, to sort me some treatment out and I accept that. I don't, I don't need to look elsewhere and, and burden myself down unnecessarily with, with complications of, of trying to get too much information in my head. I, I want to keep it as simple as I can for me to understand it and this is what I've done. (p4) *trust*

Because, because I appreciate that you've, you've got other people besides me to look after and, and perhaps phone up or who you're attending to, , so yeah, I, I...you weren't available, I left a message saying that I want to speak to you, you called me back the same day, so yeah, that's fine. (P4)*In service too.*

Well...[sighs]...if, if I'd received it by letter I know at the end of the letter you'd given me a phone number if I'm concerned about anything, then I can call, but, but that's not the same as, as you calling me initially with, with the news of whatever it may be. Because I'm, I'm

speaking to a person and, and that was you, and that's the easy part about it, that erm...shall I say a personal contact. I was talking to a person, first hand.(p4) *in choice and satisfaction*

if, if they run late then you don't expect, I suppose you don't expect to be treated quite so gently as you would do if you'd been on time sort, kind of thing. I might be wrong to say that, I don't know. Or do you expect to be treated exactly right?(p4) *expectations? Sense of worthlessness, not important enough. Is this the message we were sending loud and clear?*

And you know...yeah, I'm a great worrier. Yet funnily enough all this that's happening to me, I, I'm taking it all in my stride, quite...quite...quite okay. And, and I honestly do feel all right about it. and I think a lot of it is due to the way your, your little department, your little team, has been informing me as to what's been going, what is going on. No, I'm, I'm sure that's what it is, of being informed correctly. I know what the score is and you've told me all what's going on and what can be done. And I'm, I'm happy with that. So therefore I'm, I'm not unduly worried about it Wendy. (p4) *and in satisfaction*

*That, was that the main reason?*

Well yes, I like to think, get things done, finished and over with. (P7) *also in speed*

. I always like to look at the black things first, you know, it's easier.(p7) *in prep*

So for me phoning up I was fairly sanguine about doing it all along in fact I found it, it saved me the travelling up and the hanging around. So I preferred that, I got the answer when, when I actually was ready to, ready to find out.(p10) *?control, MOF, also in easy*

I'm fairly down to earth on this, I'm, I am a problem solver and fixer. So I'm not that bothered so much about the problem as are there solutions to it. So for me the MRI scan results were the more significant part of the process shall we say. (p10) *also in moving forwards/choice*

, I tend to go for the information sources on the Net, mainly because it's more direct and you can get quite a breadth of stuff, and I've hit some sites in America as well, you know, to get the full gamut. Not that I don't, erm, value the conversation here but I'm conscious of the fact that you, you are seeing windows, you know. So I'd rather see the broad spread side, I can get informed as I need it.(p10) *also in preparation*

*Okay. Was there anyone, was there anyone with you when you called?*

No.(p10)

*No, you were on your own?*

Yeah.(p10)

*Okay. And did you say you called from work?*

yes, I waited, I waited until it was quiet and I use a headphone anyway, so I called from there. (p10) *picked moment to suit him, could argue maintaining a sense of control at a time of uncertainty*

*is there anything that we told you that you'd rather not have known?*

No. But then again, that's me. I'd rather I had the facts and then, and then make decisions from that. (p10)

Because that's a fair way down the line. I think that would have been helpful because that's what I was phoning up for, er, really to find out, you know, right, what...it might just be me, I'm, I'm a manager of people so I like to know what's going on, I don't mind if the milestones are this apart, or that, providing I know enough and I can arrange my life. For example, I was meant to be on leave these two weeks, erm, I've rearranged it with my wife to leave this week free, erm, but it is rather random, the letter comes through the door, ching, and I know you're flexible in that they can go but erm if I'd had some sort of erm...timeline for it then I could have sort of taken big steps to arrange stuff, you know, for it. But that might be just my preference. I like to be organised. (p10) *lack of control?*

So for me it's, it makes no difference, it's more important for me to have the knowledge so that I can actually start thinking about erm courses of action rather than being...I see no point in having another week delay, for me. (p10) *horses for courses*

And to be quite honest I've been relatively relaxed all the way through, relatively speaking, erm because erm, because I was informed.(p10) *and in prep*

. I was fairly erm...not resigned to it but as it went through I just read further into the information. So even now I'm relatively relaxed about it.(p10) *and in prep*

it fitted in, it coordinated with what was in the book and what, what I'd read as well, so that was reassuring that it all fitted in. you know, it was comfortable to get the same sort of information.(p10) *mof and in service*

Well, see I've always been very fit all my life, I've never had any illnesses or been into hospital for anything at all, touch wood. So obviously when someone mentioned the word cancer to you that do come as a bit of a shock. Erm, you know, I can remember going home thinking oh, I wish that doctor hadn't said that word cancer until I'd had the tests and then been told.(p11) *also in cancer=death*

That was the doctor I saw who said that I'd be having an ultrasound and the...obviously they're trying to forearm you I suppose, you know, with something like that. But in my case I think it would have been probably better if he hadn't have mentioned it at all until I'd had the biopsy. (p11)

Until, until I had the biopsy and then the doctor who'd done the biopsy er said to me erm...I don't know whether, that's probably whether they can detect whether you're a bit stressed or something about it but he did say oh, erm...or I can't remember whether I did say to him did it look okay to you and he just said it looks 75% fine to me, erm that's just relying on, you know, on that. And I went away feeling a lot better. (p11) *in preparation too*

*Some of the experts say that when you're giving bad news to somebody over the phone you've, you've lost all the visual expression and, and all of that in the communication. Does that matter to you, does that affect you or does that make a difference?*

No.(P11)

*No?*

No, I don't think so. Erm...there's something very personal and private about that, erm, you know, the information that will come to you and only you can deal with it how you are as a person. Some people are quite mentally strong and they can handle it. And some people, you know, that would just disintegrate them. And that's really how the person...but I think if you've got a loved one there with you who's either making the call or, and then they can tell you, you've got that reassurance.(P11) *horses for courses*

. I'm a person who'd like to know anyway. You know, I'd like to know fairly quickly.(p11) *also in speed. Horses courses, disposition*

Well, erm, I think anything to do er with the downstairs department in men and women is very embarrassing and er some of it is quite painful. But erm...what alternatives have you got? And I think everybody realises that. That whatever you're going through is for a reason and you have to just go through it. That's part and parcel of life and everyone, you know, everyone gets these diseases and you have to have the tests and the treatment for them.(p11) *?accepting or just realistic*

*how anxious were you before you made that call?*

Not at all. (P13).. , I haven't been ever since.

If it's there, it's there. Do you know what I mean? (wife of p13)

But then that's us. Not everybody would react the same. Everybody is an individual. And (*husband*) been very good. And I don't say that he didn't cry a bit when he come off the

phone, I think a lot of that was just relief knowing more than anything, wasn't it (*husband*)?  
(wife p13) *horses courses*

Not for many...not for long. Just for a few minutes, that's all.  
(p13).....Then I forgot all about it. I forget all about it until something comes up that I've got to go up there or...(p13)

, I looked at it this way, or they probably did as well, if you've got the strength of mind and character to ring up and take that news over the phone, then you can take whatever they had to say. Do you see what I'm saying? (wife p13)

Else you wouldn't do it would you? (p13)

Yeah, I was pretty worried because erm a couple of the guys at the golf club had been or been through it (p14)

I'm one of the sort of people that thinks, you know, I've got something nasty, do I really want to know all the ins and outs of it or do I just want to have to sorted out? And I'm the guy that erm I don't want to know too much information, just sort me out please. (p14) *and in preparation*

*how anxious were you before you picked up that phone?*

Oh, difficult to measure. I, I would...(p15)

*On a scale of nought to ten, ten being the most anxious, nought being relaxed.*

I would say I was three or four, something like that, slightly anxious. But again as I say, if that's the way it's going to be, that's the way it's going to be. The die is cast now, it's done, the results are on the books, you know, it's not, nothing I say is going to change it. So might as well get on with it. I've tried to be sort of philosophical about these things in life and that's, that's the way I saw it. Straightforward, no trouble at all really. (p15) *mof*

Well it's all right being...it's not philosophical, it's not just being brave or anything, it's what I said, facts are facts, it's going to be...that's the way it is, it's a fact. If they've got results there with ah, yes, sorry, it's...you know, one or the other. It's not going to change is it? (p15) *Factual, horses and courses also in choice*

It's all down to either you are, it's either positive or negative.(p15)

Erm I don't recall, I mean er I suppose when it's explained to you it's all a bit worrying, it's all a bit of a shock, you're not quite...and you maybe don't absorb everything that people are

telling you. So erm I don't recall that there were perhaps other options. I mean it may have been explained to me but I don't recall that there were.(p16) *also in choice*

I think I would have still telephoned. (p16)

*Why?*

Because erm it's probably in your own surroundings, rather than in a strange surroundings, erm and you choose your time and who you're with and exactly where you are. (p16) *in choice too*

*On a scale of nought to ten, ten being the most anxious, nought being relaxed, how anxious were you when you picked up that phone? Or leading up to that call.*

Probably about an eight.(p16)

Surprisingly, this is surprising really because I'm finding this erm...more emotional than I thought it would be. Because the results that I have are suggesting that I don't have cancer. Although I still...erm understand that because it's not ruled out there's a possibility but at the moment they're saying it's not. So that's a relief but just even talking about it brings this sort of emotion out. (p16) *becoming tearful*

*After that biopsy and waiting, were you sort of waiting for that day to come or had you been able to put it to the back of your mind?*

No, I was waiting for the day to come. I was anxious for the result. (p16)

And in fact my wife was erm...we were at work, it was a work day so we were at work, and we work together, erm and she was trying to encourage me to ring earlier and I had to just pick my time of the day to ring, I wouldn't ring first thing, I had to just be able to work up to it. (p16)

*Would you do the same thing again? If you, if you...ever had to, if you had to make that choice again, or if you felt you had a choice, would you, would you pick up the phone?*

Yes.(p16)

*You would?.*

Yeah, yeah. (p16)

*Okay.*

I think it was, it's getting the answer in a time that suited me, erm...in a location, being where I wished to be, who I wished to be with, rather than any coming to the hospital, speaking to somebody, strange surroundings anyway, which you anxious in coming up, so I could, so I



could work it to suit me. (p16) *control, anxiety, arguments for telephone (also in choice) horses for courses*

*Okay, some of the experts say that erm you shouldn't give certainly cancer results over the telephone because you've lost all the erm non-verbal communication, you know, the eye to eye, face to face.*

Yeah, sure, yeah.(p16)

*What do you think about that view, for you?*

Erm, years ago, sorry, slightly different I'm going off the track slightly years ago I used to work in a bank and erm I do remember that the Chief Cashier, his wife was ill in hospital, and he got a phone call and he went to the phone and erm we just heard a big cry. So they'd obviously given him this very bad news, his wife had passed away, over the phone. Obviously that's a slightly different situation but that always sticks in my mind. Erm...I was prepared for this to be bad news and I think I would still do the same.(p16) *also in choice and preparation*

*Is there...did you feel any pressure from anywhere to pick up the phone?*

For the results? (p16)

*Mmm.*

Yeah, my wife. [laughs] (p16)

*Your wife, okay.*

Kept saying are you going to ring them yet? Are you going to ring them yet? No, it had to be in my time. (p16)

*Right, but you'd have still done that?*

Yes, yeah(p16)

*Without that pressure?.*

Yes. (p16)

The anxiety of waiting is pretty tremendous. Erm...I just had to know really.(p16) *also in choice and speed*

I was uptight because I think it, it would be stupid to say I wasn't bothered because clearly I was. Erm, yes, I knew in my own mind but there's a difference between knowing in your own mind and having it confirmed, so yes, I was fairly anxious. But then equally if a piece of

paper comes through the door erm with the hospital's name on it and everything you, you've got the same degree of anxiety when you open it up to find out as well. So I don't think it was any more, I was no more anxious by ringing than I would have been to wait for the er letter.(p9)

I think initially whilst it was there erm, I thought well, should I or shouldn't I? I thought no, you're going to be busy. There's enough things to do without me ringing up on something as daft as this really because at the end of the day it didn't seem to be...I know it sounds silly again, it doesn't sound...to you, you've got lots of people to deal with, there's only, what, four or five of you dealing with god knows how many people. Erm and I suppose in my own mind I was sort of thinking well, if I do ring up what do I ask them? Because I don't know enough about it yet. Now again on hindsight I could have rung in the sense that when you rang, erm, or when I sort of rang you, sorry, and you gave me some more information, that was just sort of dotting the I and crossing the T for me actually. Erm...yeah, so yes, I could have rung you, I chose not to do it and that's not because I, I didn't know you were there, yes, I did know you were there but I thought well it's a bit silly, maybe not, I shouldn't have done that.(p9) *trivialising*

Yes, I was sort of laughing about erm...it sounds stupid doesn't it when you're in a situation like that, I was making cracks like I bet he's a damned good shot at the er fairground on the guns. [laughs] But erm...yeah. No, because I mean the nerves kick in don't they and I mean you sort of...I'm a shocker for actually thinking the worst before I get to somewhere and I can get myself really wound up before all these sort of procedures. And even down when I was having the erm, the scans, which I know there was nothing involved, but I was really strung up tight as a bow. Erm, for no, for no reason, I knew they weren't going to hurt me or anything like that, but it's the anticipation and also I think the, the worry about what the end results are going to be all the time. But..(p9) *anxiety*.

Yeah, yeah, because I've said earlier I'm the sort of person that throughout my working life I've been the same where I need to establish the facts, I'll establish them quite quickly and I'll make a decision and run with it. They don't have to be 100% all there before I make the decision. But that's the way I'm built. I won't wait and wait and wait. I need to do something, I need to actually make it happen. So that's my internal drive if you like, is that erm, you know, I need to know what I'm dealing with, I want to know what I'm dealing with. I'm, I'm fine, but I, I have a decision process that I can go through depending on what the issue is. So yeah, but no, I'm the pressure. (p9)

*Is, is there anything you, you think that we could do differently for men having their biopsies and their results?*

I think just to give them both options, both choices. Some people no doubt would prefer to erm come to discuss it face to face. Er I think if you can just give the two choices I'm not sure what more you could do. (p16)

*Okay, in an equal timeframe would you say or...?*

I think it would be, yeah, if the timeframe could be brought forward rather than thinking you have to wait, erm, I think I would have still gone with the telephone call but erm my main decision probably was because I wanted to know rather than wait. Well I would have still been probably happy to go the telephone call in my environment. (p16) *horses courses, also in service improvement!*

At the time the waiting is the thing that er is er frustrating and annoying and worrying thing.(p16)

*Mmm. was it, was it okay to have erm...you said you had a morning slot to phone, would you have preferred an exact appointment to phone?*

No. No. That would have been worse, well, for me personally it would have been worse. To think that I had to aim for that particular time erm, to be able to pick my time suited me... (p16)

*To suit you?*

...when I sort of felt more suitable. It's a bit of a build up to it. So to say you have to be ringing at that precise time would be more of a build-up, more anxious, I think. (p16)

*And what, what if we called you at a precise time?*

No, I would prefer to ring, pick my time. (p16)

*Okay.*

No, I think I'd be on edge all of the while waiting for that to happen, as it was I was at work and able to do some work until I felt comfortable to make that call. Trying to, trying to keep it from your mind, instead of it dominating your mind, if I could work or do something reasonably normal, erm, it helped me remove that worry from my mind as regards the result. And it just enabled me to, when I thought I was ready, to pick up the call and go for it then. (p16) *also in service feedback*

I think as quick as possible for the results but erm...well, within a time as quick as possible. But for me it was so much being able to pick the time that suited me. Very much.(p16)

*Do you think that time frame of a week is reasonable?*

If it could be brought forward it would be better. (p16)

*Right.*

Because even waiting a week is erm...you're still worrying and anxious about it. But erm If it was able to, it's subject to the workload and so...but yeah, if it could be brought forward it would be better still. But I would still like to pick that time slot for the result. (P16) *also in speed*

*How anxious were you when you picked up that phone to make that call on a scale of nought to ten, ten really anxious, nought not so?*

Two I suppose.(p17)

*Really?*

I wasn't really anxious at all. No.(p17)

*why did you pick up the phone? Why did you make that call?*

Because I needed to, erm, I needed to find out on way or the other. Erm, just for my own piece of mind I suppose. Erm...did it frighten me? No, no, it didn't frighten me. Erm...like I said my son, erm he tells me off for it because he thinks that I should be worrying a lot more about it. I said well, what do I do, go and stand in the corner, put my head in the sand or, you know, no, I can't see any point. (p17) *also in speed. Sounding very calm and relaxed about things. MOF.*

*Who, who was with you when you called us?*

Nobody. (P17)

*Nobody, you were on your own?*

Yeah. (P17)

*Was that on purpose or...?*

By choice, yeah. (P17)

*By choice.*

Like this morning my wife said can I, can I be here this morning? I said no, I said I'm the one with it, you know, you...I will tell you everything you need to know about it, you know. erm, yeah. (P17)

*Right.*

It's not being, you know, macho or anything like that but erm it's just the way I want to deal with what I've got. (P17)

*So even, even knowing that this or you know you thought that it could possibly be cancer, erm how did that feel sort of picking up the telephone to find that out? How anxious were you?*

Not at all really. (p18)

*Weren't you?*

I think I was doing my jigsaw puzzle at the time. yeah, no, I wasn't really anxious about it mainly because erm there weren't no rush, you know, no one was in, you know, saying oh, this and all that sort of thing. and when I phoned her and spoke to her I mean she didn't say straightaway well you've got this and you've got that. She went through it all and then told me that's what it was and yeah, it was quite good. Well she was good I thought. (p18) *also in service satisfaction*

*On a scale of nought to ten, ten being really anxious and nought being really relaxed, where do you think you were when you called us?*

Well I suppose about three or four I suppose at the most, yeah. I think my wife was more anxious than me.( P18)

No, I was all right, yeah. It's no good, you know, sitting...I didn't did I? I just carried on doing my jigsaw puzzle. (p18)

No, you were fine weren't you? You're laid back about everything aren't you? (wife of P18)

Yeah, try to be anyhow. (p18)

You know, so no good being frightened of it and waiting too late. You know, I mean they haven't got to treat me at all and I've just got the PSA test in January and see how it's going then I suppose. It might have changed then, you don't know, I don't think it probably will. Just wait and see, yeah. They don't think it will, so you know, not that great. But we'll find out. Yeah.(p18)

You've just got to carry on with life and look after me I hope, that should do it.(p18)

So I think that's good, no, you've got to tell...you've got to tell people that could be like that. It's...when you ring that's what you, you know, you expect whatever they have found to be

told don't you? It's no good ringing up and then sort of going crazy because they tell you the bad news. If you don't want to do that you don't bother ringing, you wait until you see your GP or something don't you? But then that's another week or so I expect, I don't know how long it takes for those tests to go through to your GP. (p18)*horses courses*

You didn't get home until about half past 11 did you? So I didn't phone, I don't remember what time it was, about tennish? Half past ten, something, round about then wasn't it? I didn't phone straightaway at half past nine, I just, I thought well they've probably got loads of people phoning in, in those 3 hours. But yeah, I got through straightaway. So yeah, no problem. (p18) *sounding very calm and relaxed*

*So you were on your own at the time?*

Yeah, yeah, oh yeah. (p18)

*Would you rather have had someone with you?*

No, I don't think so. No.(p18) *also in support*

*If, if we'd have said to you erm, okay, your, after you had your biopsy, you can come up and see us in a week's time, at this time, or you can call us in a week's time, no difference in the time, what would you have done do you think?*

I'd have probably still called. .(p18)

*Would you?*

Yeah. .(p18)

*Why?*

Just I can't see anything difference in calling and speaking to someone on the phone as there is to going in and seeing them. You know. It's probably less pressure actually. .(p18)

*What?*

Less pressure on the phone. Well to me, but yeah. .(p18)

*In what way?*

Well if you've got to go and sit there and they're behind and you're sitting there waiting and you just get...whereas on the phone you pick it up, phone, and you're straight through and you get your result. But you might have to go and sit there 10 or 15 minutes before you get in and then you're worried about, you know, what you're going to be told when you get there. But no, I thought the phone was quite good, that suited me anyhow. I mean some people it might not I suppose. But phone is good enough for me. Yeah. .(p18) *also in choice and service*

You've got to think that we're the sort of people who do tend to face things head on aren't we? (p18 wife)

Yeah.(p18)

If there's bad news we need to know and then we can deal with it, if you see what I mean. So we're better that way aren't we? (p18 wife)

Oh yeah. .(p18)

Rather than, you know, sort of fiddling about round the outside we tend to, prefer to know, and then we can cope with it can't we? (p18 wife)

Well that's why I went and had the PSA test otherwise I wouldn't have bothered if I didn't want to know whether there was anything wrong. But people don't do they, they won't do these tests, it's like the bowel cancer test, we have that sent through the post and we do it. But some people won't do that even will they? Don't know, that's very strange why they're...because by the time they do it it's too late isn't it? .(p18)

But that's just our way of dealing with things though isn't it? Some people I suppose find it more difficult don't they? (p18 wife)

Yeah. .(p18)

We've always tended to face up to things. (p18 wife)

But no, phoning in was, as far as I was concerned, was all right, yeah. I know as I say a lot of people wouldn't want to would they?(p18)

No.

But we're all different.(p18) *horses for courses!*

I was told originally it was an enlarged prostate, well and in fact it er has turned out to be cancer, well, right, so be it.(p21)

we felt we were getting the best treatment there could be. (wife of p21) *trust*

*How anxious were you on a scale of nought to ten before you received your results? Ten being really anxious, nought not anxious at all.*

Say three. (p21)

*In same timescale*

Well I think I have been happy to have it over the telephone.(p22)

*You would?*

Yeah. Oh yeah. Oh yes. .(p22)

*Why is that?*

Well I think it's not so impersonal. I mean at the moment we're having a conversation which is quite personal and I'm getting a bit worked up, obviously, but at the end of the day when you're speaking to somebody on the phone you don't see them do you and you can say what you – say what you think can't you? Do you think? I don't know. .(p22)

*Yeah, no, some men have fed that back to me actually that they – it's different. Some, some men like that impersonal touch where you – you kind of lose that over the telephone, you lose the face to face and other people erm have said it's too impersonal over the telephone.*

I – I am quite an emotional person. When it affects myself and obviously your nearest and dearest, obviously, but that's how I am, you know, so if I can speak to somebody on the phone which I worked in local government for a long time, at (*place name*), and obviously you know the ups and downs I had with people on the phone, you get, you get blasé to it, you know, you get sort of – well you get used to it, you know, they can go at you but it – it does hit you a little bit but you don't, after you put the phone down it just goes away. .(p22)

*What goes away?*

Well you know, whatever they've been going on about, you know, you deal with it, but it doesn't – it doesn't sort of erm come back to you too much until you have to deal with, say write a letter to them or respond to it, do you know what I mean? .(p22) *horses for courses, extreme emotion affecting reason to call, so doesn't have to display emotion in front of strangers and previous bad experience at clinic*

*If we could just go back to the call, erm how anxious were you when you picked up that phone on a scale of nought to ten, ten being really anxious and nought relaxed?*

Er no, I was quite – I was quite relaxed when I picked the phone up because – but I couldn't get through at first you see, because you – you keep trying don't you and erm – and erm...(p22)

as I explained to you I am used to speaking to people on the phone rather than face to face because you do get a bit worked up, if you don't go to see the doctor on a regular basis because like a lot of people do, you – you – when you do go, because you only see say every once a year or perhaps every six months, you – you know you do get worked up because you don't like to trouble people do you, you, well I don't anyway. You – you just – you think well



you only go when it's necessary. But a lot of people go when – just – because they want to go, you know, because if they have an ache in their finger they go don't they? (p22)  
*?worthlessness*

*do you think if you had to come up to the hospital for your results you'd have felt more anxious?*

I think I would have been more anxious, yeah. Yes. I think I would have been. (p22)

*Because of...?*

The face to face erm – face to face consultation that as – I go back to last year, December, when I saw that other man he was absolutely horrible to me and I thought well do I really want this, you know? Which I didn't. But I mean I don't know who he was. You know, I mean he wasn't English, that's all I can tell you. but erm – but I think he was under pressure, you know, because they had a lot to get through and things like that but...there we are. And I ended up having a cystoscopy I think, that's what he put down for me to have and apparently I did go subsequently back and erm I think it was after Christmas wasn't it I had this cystoscopy, and I still had this catheter in and he sort of roared at me about that. so I thought – well, I said it's not my problem, I said I'm – I'm – I'm not a doctor. You're guided by what they do for you aren't they? And if the Dr ( *GP Name*) had said take the catheter out the district nurse would have come and took it out. But obviously she didn't. Uh. (p22)

Obviously there's lots of questions that we want to know. And you don't think at the time do you? (wife p22)

*No, did you feel you could call us – call us back if you – if you wanted to?*

Well I felt that you were rather busy, I apologised to this lady, (*nurse*), for troubling her, and she said oh no, it's my job. She said I want to help you, you know. And that was how we left it. (p22)

*Was anyone with you or who was with you when you called for the – called (*nurse*) for the results?*

Oh, well you were...(p22)

Well I was just in the house.(wife p22)

...just in the house, that's all. Yeah. But as I told – I said to you earlier, I'm used to speaking to people on the phone, you know, because of the – the job that I had. you know, I had to be a bit – well I had to be how I was, you know, how, you know, you don't pussy foot around if

you're dealing with people really, you have to get the information you want or you try and solve what their problem is. (p22)

*some men are saying they felt er a bit of pressure to call, erm, to pick up that phone call for their results, did...*

Oh I did feel a bit of pressure, yeah, oh yeah, definitely. But not...(p22)

*Did you? Where was that pressure coming from?*

Well it would make you feel a bit shaky, obviously, you know, I am a – I am quite an emotional person. (p22)

*Right. Did you feel that – that the hospital or us as a department was pressurising you to call rather than come in?*

No, no, not at all. Because I'd rather, you know, from – from our point of view, well from my point of view or from our point of view, you know, you – you – nobody looks after you like you do, you know, nobody's going to come and say oh, Mr (*name*), you're, you know, because you're getting 72 you ought to have a prostate biopsy, it's only because through your persistence, or not from your persistence, but you keep, you know, doing what they say, like having a PSA tests and waiting for to see the specialist gentleman who – Mr (*consultant*), who is in the chair.(p22)

*some of the erm experts say that telling somebody they've got cancer over the telephone erm isn't the right thing to do. How – how do you feel about that?*

No, I think that's very good that you offer that service because otherwise you'd have to wait three weeks perhaps, you know, because there's not – you're not the only person with the problem, you know, you're probably seeing – well I asked the chap who did the biopsy on me, I said how many do you deal with a day, well he said we do about 17 a day, you know, which is quite a lot of people. and if you've got 17 and you're doing that everyday well you start working that out er, you know, towards the end of the week there's quite a few people that, you know, having biopsies, so it's a lot to get through for, you know, because as I said with the job I had I know what it is about responding to people, you know, because if you could ring up and solve the problem over the phone and say what you're going to do, rather than write a letter, it's quicker.(p22) (*Horses for courses and in speed*)

*If we gave you the same choice again would you...or if we said to you come up in a week, so it's the – what I'm trying to get at is it just that time or - or is it you prefer to pick up the phone?*

Well from my point of view I think I prefer to pick the phone up to be truthful because if you meet someone face to face, obviously when they want to tell you something bad it – it sort of comes a bit difficult, you know, you don't know how to react. You know, and as I told you earlier I'm quite an emotional person because I get worked up about things and you think, you don't realise you're getting worked up, but you do. And it then becomes a bit...and you make a fool of yourself. (p22)

*That's what you think?*

Yeah. (p22)

*You'd make a fool of yourself?*

Yeah, yeah. yeah. (p22)

*Right, okay.*

You know, you worry about things, well I do anyway. But there we are.(p22) (*and in disposition*)

you know, then that would have, you know, if – if – because what I'm saying we have – I have been a bit in the dark with it. But when, as I say I referred back to Mr (*consultant*), he said that erm the – your team, his – well whether it's your team or the oncology nurse, would be in touch with me. You know, so I mean – but we haven't heard anything, not yet. (p22)

*Okay. What way have you felt in the dark?*

Well erm...when I say felt in the dark erm I just felt that it's quite a lot to take in and I think the time factor again, because I know we had an appointment on Tuesday erm this week at half past nine, well that meant that we had to get up early, which I mean we're up but (*wife's name*) is up but – and to drive up to (*hospital*), which we did, we left at quarter to eight, and of course we got there about ten past nine I think, which was fair enough, but we didn't see Mr (*consultant*) until half past ten, you had to wait, you know, because obviously he – he's obviously with the time span, I think he's got a lot to do, do you understand my meaning? I think – erm well, that's it. You know, I feel he – if I'd asked the questions I feel he would have answered them, but you're not always familiar with what you need to ask. (p22)

*Anxiety with face to face*

Yeah, yeah. I think that's more the gist of the tale, you know. And you obviously try and put a brave face on don't you? You try and sort of gather yourself don't you because you – you're sort of going – you know, it's like going for an interview and that really. (p22)

*What, going up to..?*

Oh, going to see the – the main man, you know. I'm not saying he was – he was very polite and better than the other man I saw in December last year. But I don't know who he was.  
(p22)

*is there anything else that you'd like to tell me?*

Well the only thing, I think that if I hadn't have – you see I was going down this morning to pick up my tablets and – but – or what the prescription – what Mr (*consultant*) had written for me. But, well I understood it was a prescription, but erm – but they rang up, I haven't got to go now, I'm going on Monday, so if you haven't got time I understand and I can wait, I'll wait and ask the doctor on – Dr (*GP*) when I see her, on Monday.(p22)

*I'm quite happy to explain it to you. (also in moving forwards, treatment choice confusion.*

I wasn't at all surprised, if the PSA – if the PSA test had been 1 or 2 and then that would have probably well not alarmed me more, it's no good getting alarmed, but of course so consequently I was satisfied with that, he was straightforward with it, and away(p23)

they said ring up at that specific time from half past one to three o'clock. So I rang up immediately, I think it was at quarter to two, er so I knew what were we were doing and erm and of course I got the information which she had available to give to me, and then erm – so I had that and I think 24 or 48 hours later I got a letter confirming what she'd said. Which I thought was all right. I couldn't see nothing wrong with that. I mean they said ring up, I rang up and she was there, erm and erm, you know, so that was 100% as far as I could see. I couldn't see you do any more. That was either a case of doing that or wait until, well I don't know, wait until – I don't know how else you would have known. And then of course they then erm arranged, she said straightway, fair enough, so you know what's happening, now I'm now going to arrange a bone scan which she did (p23) *and in choice and in disposition-accepting*

*So when you were making that call, when you were picking up the phone to make that call, how anxious were you?*

Oh I weren't anxious at all. (p23)

*You weren't. On a scale of nought to ten, ten being really anxious, nought not being...*

Oh, I was about two.(p23)

*Two. Okay.*

I, I wasn't shaking and that. I – I just accepted – I just accepted and I wasn't erm that – two, two, between nought and ten, if that really.(p23)

I knew that I had the biopsy er because the possibility of cancer to remove segments to analyse erm maybe because I know what my wife gone through, I read on the internet, so I mean I know they just can't look at you. er so I was aware of that they would take bits and pieces and they would check it out and erm I was – well, I wasn't anxious but that's – that's – I wasn't anxious, I just thought well fair enough, she said ring up, which I rang up and erm – and then I just rang up like I'm talking to you. And she told me and erm I didn't need to leave sort of go to bed or anything, I just carried on as normal, and erm and found that all right.(p23) *and in preparation*

Because I like to keep aware of what's going on. Erm and I like to – I like to know exactly what's going on and the best treat- obviously I put myself in your hands.(p23) *–trust also in speed and service*

*some of the experts say that, or some people as well, think that giving somebody results over the telephone is not a good thing to do or telling somebody their cancer results over the telephone is not a good thing to do because you've lost all the non-verbal communication that you get with face to face. what do you think about that?*

I – I personally – I think that – that's all to do with the person you're dealing with. like – like the person who's suspected cancer, if he's a – a nervous person, erm highly strung person, and one thing and another, I think that could probably have a profound effect on him but from my – but from looking at it from point of view I – I thought it was a good idea and I – and I couldn't see any problem, erm, you know, and I didn't – I didn't want to have my daughters here while – while the phone call was coming on in case I was going to shall we say be distressed or something...(p23)*control element? Horses for courses*

if I was that sort of person who would be distressed or worried, one thing and another, I would think I wouldn't want to have them here. I had one of my daughters here but as far as I was concerned that was erm straightforward job, I wanted to know what was going on, wanted to know the extent of it and then we go away from there. So from my point of view that – that was no concern at all. (p23) *horses for courses and speed*

I – I – mainly because I think that the pressures which doctors, nurses, what have you, consultants, that's better to do it like this rather than me going to waste someone's time for quarter of an hour waffling on and – and you know, I could – I could hear what she said then she sent it by mail and, you know, just going over it, what she told me, and I thought rather than going up there and erm wasting time, if that was it, perhaps this hospital, just wander up here, no problem at all, but that's so much hassle up there, so I – I personally think it's a good idea. I can't see no...with it, but I think really the – that would start off when the consultant or

the nurses who meet the erm – the patient, they could assess what sort of person they had, whether they would be able to erm get it on the phone, whether that would upset them, on the – erm on the phone. That's what I think. and I would imagine, I don't know, but I imagine if you have some, I mean I go up there and I see some of these poor old people up there, I'm sure that you wouldn't attempt to say to them look, you ring up and we'll tell you what's happening because you know they're in such a terrible state. So I think really that's up really to the nurse and the consultant, to – I mean they can make a quick assessment when you go in there and they say yes, he'd be all right, tell him, he'll – he'll accept – obviously he'll be concerned but at least he – but someone else with all of a shake well that would be a waste of time ringing them up.(p23)

Meaning to say that's up to – to – to the consultant and the nurse to get – have a word when we're gone out, to say what do you think about him? Well, he'd be all right, he – he can accept that all right. But the next person come in, he's all of a shake, what do you think about that? You say well I'm afraid he must come up here and we'll have to have a face to face talk, is that all right?(p23)

I think if I could have rung up for this I'd have rung up after the result of the bone scan and then – and then of course I got the appointment with him, then at least I should have had some idea what to talk to him about. but I shall go there now and he'll – and that – and well maybe it will be a shock in the sense that maybe I shall may be a bit confused and may not be able to answer – ask him the things which I should do because of the shock and then I shall come home and think well I ought to have asked him that.(p23) *lack of knowledge causing confusion. Likes to be prepared*

*Do you feel – when you – when you came off the telephone when you've rang for your results did you feel that you could ring us back if you wanted to?*

Oh yeah, yes. I – I had no problem, no problem, with it at all. Erm and they – they did tell me that you can ring up erm but I've had no cause to ring up because we go through the system. Whether that will alter after next Monday I don't know. But erm yeah, I – I mean I would have no qualms about ringing up if I was concerned about something. P23 *acceptance*

*Some men are saying they like that two hour slot that we give, how would you feel if we said you've got to phone at half past ten?*

I would do it.(p23)

*On the dot, you...*

I would do it because I think that's important from my point of view and important from the work you're doing and the pressures you're under erm, you know, if you say I'll be available for half an hour for you to ring up I should do it, I wouldn't just say well I'll ring up at my convenience. I would ring it up at your convenience.(p23)

No, no, no I just put it on my calendar, the same as I put on the calendar for you 11 o'clock this morning, I put it on my calendar and that was on there and then of course my daughters, they were ringing up within a couple or three hours, well what do you make of it, one thing and another, you see, and erm so there was no pressure. I – I – I knew that I'd got to ring up and the same as I knew that you were coming here at 11 o'clock this morning and erm, you know, it's as simple as that. I – you see I might be different to a lot of people, I don't know. (p23) *matter of fact*

from my point of view I – I – I'm glad to have the information given to me. I – I've got no qualms about that. Erm I don't want to put my head in the sands and that. I would just – I just accepted that the – it – I mean that isn't your fault I've got it, your fault or the consultant's fault that I've unfortunately got it and erm the mere fact of not knowing isn't going to help the job at all.(p23 ) *matter of fact*

like I say, no other symptoms whatsoever. And that was just luck I went to the local GP's, (p2) *lucky*

I don't like keep ring...I don't like ringing up because everybody up here is so busy, there's people up here sort of worse than me, so I didn't ring anymore and I think it was you rang me to erm say my MRI scan was clear erm and arranging that meeting which I had Tuesday. (p2)

No, I was, I was just sort of...I would have accepted however the, the results came. Erm, you know, like I say I'm not one for keep phoning up and saying have you got my results? Have you got my results? Because there's far better things, far more important things for you to do up there. (p2) *also in disposition, worthlessness/busy*

No, I didn't feel...I mean the reason...like I say the reason I haven't phoned in too much it's because you're so busy, there's people out there, especially over at (*department name*), that are far worse than I am. Er, I know I've got it, and no matter how many phone calls I make it's not going to change it. (p2)

So yeah, I've been very well informed, considering how busy you are. (p2)

*If...you were in the same position again, okay, would you phone up to find your results out?*

I probably would looking back. Erm...just to put my mind at rest; that little bit earlier. Erm...yeah I think possibly I would because I...it's a bit of concern when you don't know but at the time I looked at it was better if there was anything really serious I would have had a phone call from here to say, you know, quite serious, it's best you get back up here (p2)

*Right.*

Erm, but I mean I didn't worry unduly about it. But I suppose if I had phoned sort of those couple of days earlier or whatever, maybe my mind would have been at rest or, you know, a bit earlier.(p2) *also in choice and speed (disposition/expectations)*

I mean like I say I was not unduly worried because in the back of my mind I thought if it was serious I'm going to get a phone call. Erm, but I would have been a bit, perhaps, a bit more relaxed if I'd have phoned in sort of three or four days after I'd had it done and said can you tell me the result? Erm, maybe that's the only thing but like I said earlier I don't like to keep phoning places up because they've got far more important things to do than keep listening to my broad Norfolk accent on the phone. (p2) *So you don't feel that you can call us if you...Oh yeah, I feel I could call you but I don't want to waste people's time erm by keep phoning up about trivial things. I know this was not trivial but... It's not trivial, no, no.*

She give me the paperwork, she said(*name*), if you want them ring us up if you want your results you can ring (*name*) up that day. And I went yeah, fine. Didn't think any more of it. That was it. (p3)

*And...*

But then you wait for that day to come, hurry up, erm...And then when you, when you get there and they say well, Wendy's not here, and you think...ah...you know...But erm...and I just said oh okay, fine. I mean that, again, a bit more waiting. But when four o'clock come that was fine and I was just pleased to know what the hell it was, what it was.(p3) *anxiety but also relief and waiting worse than knowing*

But there's lots of people and you think wow, we're all getting through, you know, this quick and I haven't complained at all. I've just been there and thought yeah, okay, and as I say it's a waiting game. And I know you can't go any quicker because when you do the biopsies and then you've got to go and do your bit and then it comes back and that's fine. I thought, was it ten days, I think it might have been ten days, and I thought yeah, that's okay as well. I'll, you



know, if that's what you say I'll ring you on that Friday. That would be about ten days, which was you know...(p3) *and in speed*

So that was okay. So I didn't ask too much about that. And then it was whether it was contained. And that was, you know, or is it elsewhere? And that's your wait, that's where you're thinking, well all right, I, I got it, now I need to know, it's like have I got it? Yes I have. Now I need to know where it is. We know it's there but has it gone anywhere else? (p3) *also in cancer and speed and moving on*

But what, I mean I'm lucky, I'm one of the lucky ones. We are, the family, is lucky because we've got a cracking doctor.(p3) *and in support*

Yeah. It's the not knowing. It's...and then it's everything else that goes with it, work isn't as it should be. Er, not in my opinion anyway. So that's difficult, that stress level as well.(p3)

...I mean wouldn't it be great if I had it done at ten o'clock in the morning and I knew the answer at midday? [laughs] But that ain't going to happen because there's, there's thousands of other people all doing the same thing so you understand. if someone said to me is it busy and I went yeah, and that's exactly what it is, the hospital is just busy, no matter what time you go up there, everybody's, you know, there's always somebody there isn't there, it's not as though it's empty, there's always somebody there. And so I just take it that, you know, I've been lucky. As I said I've gone in and I've gone out, and I, the longest I've been in was I suppose the erm biopsy. Other than that it's been in and out within the hour. So I, you know, that, that's, I don't think, no, I don't think there is anything else you could do. Erm, I think it depends on how, how busy it is. And I'm always under the impression that if it was serious I'd have known.(p3)

And it's been on tenterhooks. I mean we all have, we've all been just sitting and waiting and trying to carry on as normal. Erm, and I think that bit is difficult to do until you know. and then it was...oh...And then you got to then sorry, I...because I said to my boss today, I've had enough of this, I'm going to come into work next week. I think it's time to get to work. But my doctor will say when you know what you're doing, when the surgeon tells you what's what then we'll go and send you back to work. And I'm sure that's what he'll say. And I suppose in a way there's no point in me, because it's, you know, you, you're still thinking about it all the time, it's worse when you're relaxing.(p3)

...I am quite an emotional person anyway and erm I think if, if I'd had time to think about it I would have felt a little bit sorry for myself. But I couldn't do that through the circumstances which was a good thing. Erm, but it certainly didn't come as erm a great shock to me.(p6)

*. How anxious were you when you made that call on a scale of nought to ten?*

Erm, not particularly anxious to be honest with you, no. (p6)

*You weren't?*

No. No. I mean on a scale on one to ten, probably only erm...probably two or three at the most. Yeah.(p6)

...even like now I'm obviously going to find out what sort of treatment I'm going to have, but I want to know so that I can plan around it, even in advance, do you know what I mean? I'm that sort of person that erm I want to sort of...it doesn't matter whether it's good or bad news as long as I know what's happening. I always like to know, you know, what's going to happen and how long I'm going to be out of action. Erm, I know it sounds sort of trivial and you know, you should, you know I probably should think well as long as I'm okay, then it don't matter but, you know, I, I think in a way it's good that I...I mean I was disappointed that that was an answerphone only because I knew that I had to wait a little bit longer.(p6) *also in just want to know*

, I don't think I was particularly stressed to be honest. Whether that's, you know, whether that's deliberate, whether...because erm...I had a, I had a bypass a couple of years ago, I had a heart attack 15, 16 years ago, and a bypass a couple of years ago, erm, and I'm only saying this because my wife was really stressed when I had the bypass because I was told that I was in a really bad way. Erm, and er the doctor or the surgeon who, who I saw before the operation was very pessimistic, too pessimistic. He really upset my wife. Erm, so she had that and then the next year my daughter got meningitis erm, a type of meningitis, and she was in a coma for a couple of weeks. So two years running my wife had erm a lot of stress. So whether I, I think now I tend to try to take the seriousness off things, so maybe that's why I don't think I get stressed. Maybe I, because I'm putting on an act for her, I'm not really sure. But there was...you know you're going back to when I got the phone call and you said were you erm, you know, were you upset or whatever with the phone call, there was a moment between walking from where I was phoning to the other people, that there was just a little bit of, you know, erm...not panic, I don't, I don't get panicked, and I get er, well, emotional, that's what I get. I get emotional. Erm, I feel sorry for myself, you know what I mean. Erm, even now I can tell you when I'm talking I, I feel a little bit sad and a little bit sorry for myself. Erm, and there was just a glimmer of that. How I'd have been if I'd have been on my own, I

don't know. Erm, it's a job to say really. But certainly at the time of the phone call and after the initial few seconds, there was no erm...glimmer of er...I was glad I phoned, put it that way. (p6)

, I'm the sort of person that actually would much prefer to know what the score is than to sit and wait.(p9)

...but it didn't take me long to get over it. [laughs] (p9)

*It didn't?*

Not really no, because actually again I sort of gave myself a good kick and thought this is stupid, you know, get yourself together and get find out a bit more and decide what the hell you're going to do. Erm, because there's no point feeling sorry for yourself, it's happened, it's there, you've got to deal with it. Erm, now get on with it. Which in, in a way I've done that. I mean I've had my ups and downs, I'd be the first to acknowledge that, I've had the odd day when I've been a wee bit depressed, you know. Erm, not for very long. Erm, in fact the most depressing thing was finding out I couldn't drink taking these tablets [laughs]. So, go on.(p9)

...So I was a bit upset and I wanted to probably cut the call short erm I was taking it in my, in the separate room, in my study, my wife could hear me sort of talking in there but when I went back afterwards I was a bit upset, erm, sat down. She said oh I thought it was, what did they say, I thought it was bad news because you, you were on there sort of quite a while sort of thing. To me it didn't seem all that long. So yes, I was a bit upset erm, a bit, I don't know how much, but, but I was glad that I'd phoned up and found out. So as far as I was concerned that was a good thing for me. Erm, obviously we discussed it after that and started looking into stuff and we phoned my daughter that evening and told her. I think it was that evening was it? (p20)

, I'm not a person to sort of perhaps erm sort of sit there, sit back and wait for things to happen. If I can make them happen myself by just a simple phone call or something like that. You know, if I need to do something I want, I'm the sort of person that I'll do it now rather than leave it, generally (p20)

I think I like to sort of get them out of the way and sort of get an answer for it. (p20)

I knew what I was going to be expecting to hear, either one way or the other. Unfortunately it was the wrong answer I got.(p20)

*Not the one you wanted.*

But at the time I think I accepted it. I mean that's the first time now that I've actually felt emotional about it since I was told. I've...(p20)

Well at the time I did in as far as I was asked do you have any questions? And I suppose thing is that it knocked me back so I really couldn't think of any questions to ask. I'd been told what I wanted to know basically. Erm, because that's all I expected when I phoned up, I was going to be given the results of the biopsy and I suppose the thing is the way I was looking at it was that erm yes, I'm going to be told that I've – the biopsy is erm a negative or a positive result. I've either got cancer or I haven't because that's basically what was going to come out of it. but at the back of my mind I was still quite reasonably confident that I didn't have cancer, basically. (p20)

Well to be honest we're not used to that level of careful thought from the medical profession, the doctors and everything that we go to see at the surgery, they never ask or very rarely do you see the same doctor so they don't know your medical history, any more than...I mean years ago they used to know your medical history, you'd see the same doctor all the time. Erm...(wife p20)

It was your family doctor.(p20)

But, but now you, you might, you might see, well I have done, three or four different doctors, erm over whatever your, is wrong with you. And they just look on the computer oh yes, yes, yes, they don't ask – concerned with how you're feeling. I mean they're just concerned with whatever's wrong with you but not how you're feeling about it. So as I say we're not used to that erm pastoral care I supposed you'd call it. (wife p20) *low expectations, also in service*

Well you go to see the doctor now unfortunately and you get ten minutes, that's all. You know, you've got that ten minute slot and if they want you out of the door as quickly as they can and I understand that, you know that's, that's how they work nowadays, the GPs, but you go in and see them and you, it never appears that you've got time to talk to them (p20)

Yeah, I had the biopsy, I then got the result and someone asked me whether I'd like a phone call erm when the results of the biopsy which would probably be through sort of on the Monday I think, if I'd like a phone call with the results and I said yes I would like that. erm I got the MRI scan which was arranged for the Thursday and as I say the bone scan was for the following Tuesday so everything was you know being dealt with, I couldn't expect any more than that, you know, sort of thing (p20) *expectations low*

Well I'm the kind of person who prefers to actually know...does know about something rather than not know about something. Erm I mean I'm not somebody who wants to say to

themselves well, you know, I'll just sort of let this kind of push me along and I'm not quite sure where I'm going to go and all that kind of stuff, I prefer to actually have some hard information about things than not. it just helps to make a better decision I feel, or a more informed decision if not a better decision. (p26)

*How anxious were you before you – you picked up the phone?*

Erm...I was anxious. Erm I wasn't – I mean by nature I tend to be an anxious person, erm that's – that's the way I'm actually, you know, hard wired, I've got relatively high anxiety levels generally. Erm but on that particular issue I was just anxious, I wasn't kind of, you know, thinking oh, I can't make the call kind of thing. I was, you know, I just knew I was going to make the call and that would be it.(p26)

*Okay, so nought to ten, ten being really anxious, nought not so, where would you put yourself before you called?*

Four. And no higher than four, possibly even three actually. Erm so I – I was kind of quite ready to make the call without erm – and I kind of managed to convince myself that the result was going to be positive. Erm and therefore the worst that could be said to me was the result is positive. (p26)

Erm I mean if – if – and I don't think it's ever going to be the case but erm – well no, I could see a situation where you could actually say to somebody the information will be available at, you know half past eight on Tuesday morning. Come up and see us at 9 o'clock. If you could do that that would be a better way of doing it but if that wasn't possible then over the phone is to me acceptable. But as I said I'm speaking with respect to somebody who was actually caught at quite an early stage. If it wasn't that I probably wouldn't be saying this to you now.(p26)

*No, no. Mmm.*

So it's erm – it's another horses for courses situation I'm afraid. (p26)

*when you phoned for your result did you feel you could ask questions?*

P1 no, no not really, I mean (*sighs*) that's my trouble, I'm not one for asking questions a lot really you know, I listen.....I take in what people say..... and I don't seem to ask questions, what I should ask really..... you know like now you know and I think oh, after I should have asked that. I just accept things you know.

I, I think the biggest breakthrough came, I was lucky, you know, I don't know whether the word is lucky, I, I got to go and see my doctor about blood pressure because er all my life I've been lucky I suppose in a way because I've had no particular illnesses.(p8)

I can't say I've accepted it now because I, I don't want to accept it, I want to try and fight against it and not accept it if I possibly can but there's not much I can do personally, I've just got to...hope and rely on everybody else. Out of my hands. (p8) *loss of control? Helplessness?*

The reason I say that because that would all be psychological cos I still had in my mind that I hadn't got it so it's hard to talk about something if you don't really want it. So no, no, no, I think that how it happened, me personally, was, was all right, you know, that was what I wanted. But I wish I'd have known that that was...not as...(p8) *anxiety, also in cancer and prep*

No, me personally, I, the phone call, I couldn't...that was as much as I could expect. (p8)

Erm...trying to think the best things, you know, to me to come up here is putting more extra burden on you, yourselves, you know. That's how I look at it, you know, I know hospitals are very busy, under staffed sometimes, you know, er GPs, sometimes need a bit more extra work, I'm sorry, that's how I feel at the moment, that's how I feel about GPs. Er, so to me to go to the GP would have been easier, you know, because I do know the GPs there.(p12)

Yeah, rather than sitting there waiting to pick that phone up at half past one and get that recording, that just don't...you know when you, you think I can't, I don't want this, I don't need this and you put the phone down and you think I don't need this, you know. And you're sitting there watching that phone, waiting for it to ring again, you know? (p12)

*on a scale of nought to ten, where ten is the most anxious and nought is relaxed about making that call...*

Nine, nine.p12

It would be a bit rude to suggest that er, er I doubted er the PSA blood test but at least erm, erm...I was pretty relaxed about it. (p19)

In September. Er, you know, erm and I – I – I was more uncomfortable than usual, I thought oh blimey, I hope I haven't got – got it, but if I have, well, you know I'm philosophical about it, I'm 66 and when the doctor said to me – the GP said to me that you have – there's a possibility that you have non-life threatening prostate cancer, I thought oh, well that's the cross I'm going to have to bear. Because at some stage in your life you're going to come up against something. Because modern medicine is so good that it gets rid of the pneumonia, the old man's curse you know, that would take an old man away, and somewhere around there's a cancer that might get you. So you know...(p24)

*if we can just go back to when you were told that you had prostate cancer, did you feel comfortable to ask questions at that point?*

Erm off the – off the GP yes, you know, because erm I think he probably thinks the same as I do, that hey you're 66 what do you expect? You know, if you're 36 it's a scream, if it's 66 you think deep breath, this is the cross I have to carry, you know, and – and I was all right with that.(p24)

*Trust/acceptance?*

And erm...you just have to take a deep breath. Like (*wife's*) brother says, you know, let them decide what's wrong with you...(p24)

This is the treatment. (*wife* p24)

This is the treatment. Take the treatment, get on with your life. As long as I can ride my bike I'll be all right. [laughs] (p24)

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TRUST

Erm you – you read a lot about it but often what you read in books leave a lot to be desired. I mean they reckon you – erm you can have cod liver oil tablets and you can have this and you can have something else. But the professional, he's the person who knows and can give you sound advice. (P25)

*how anxious were you?*

[sighs] I accepted them as they came along. (P25)

*Okay.*

I've erm – I've been through a lot in my life. I mean I've had – I've had erm – I've had cancer before. And erm so I knew what it was all about. Erm I had Hodgson's Disease in the 1980s. And erm that was worse than this because I had erm 20 sessions of radiotherapy and six months of chemotherapy. And erm that leaves a lot to be desired. Yeah. (P25)

you know, it's one of these things, you have to, you know, get on with it. Get it sorted. Because I, I hate waiting around, I hate standing about doing nothing, I want some...once I know something I like action. (P5) *also in speed*

I didn't want to get upset in the ward, sort of...I said, you know, let's go. And I thanked, you know, I thanked the staff etc. and I just couldn't hold it, you know, I sort of let go and of course you don't get upset for nothing do you? (p5)

I think I'd have been more upset if my family had have been there. I was better off on my own to be told actually I think. Rather than everybody standing around, because my son in law, he gets quite emotional and I was dreading telling him. Because I know he would, he was going to get upset, you know. And that makes, when other people get upset it makes you upset. So I don't really think...there's no other way of doing it, is there? (p5)

Once I know something I want something, I want something to happen, I don't like sitting about waiting, you know, I like action. (p5)

I don't mind being told things on the phone but I'm a little bit of a...I like face to face. You know, that's how I am as a personal opinion. (p5)

*Right.*

Some people don't mind. But I, I do like to see the head honcho or whoever and be told rather than letters or phones really. But that's just a personal...that's just me as a personal opinion.(p5)

*Yeah.*

You know, I think it depends what it is doesn't it? In a way. Depends how serious it's classed as. Some things you can discuss over a phone but some things I think need, it's nicer to be told personally, you know, face to face. I know it takes up like an appointment spot just to tell somebody, I don't know. Do you think that? Would...?(p5)

I think, if I'm talking to a professional person I think I like eye contact.(p5)



## **Theme: Support**

*Was anyone with you when you phoned?*

IE: Yeah, (*wife*), she was there. (p4)

I: *She was with you?*

IE: Yeah.(p4)

I'm very positive. I'm, I'm not feeling dooms as it were, I'm not down in the mouth about it at all. I talk to my, I've got two daughters, two granddaughters and I talk to them quite openly about it. How do you feel...do you feel ill granddad? No, I feel, I feel fine. And I do, I do feel...I feel okay. (p4)

they can tell you, you've got that reassurance.(P11)

You know, and it's a hug isn't it? If it's your wife or your partner, or your mum or your dad, that's a hug. Where, you know, there's someone there for you.(P11)

The blood test, yeah. I mean everyone that I knew, I know now the fifty age group who I talk to, erm I tell them, you know, just, just go to ask your GP for the blood test for it. (P11) *sharing knowledge, openly communicating, is that because he felt better having a little more knowledge?*

He's been through so much before, been through a lot worse. (wife of P13)

P13, supportive wife and cared for.

And so has our doctor, he's been very good. (P13 WIFE) *supportive GP*

And when you think of the pain he's been in, he's been on so much morphine and he had a hospital bed in there for 12 months when, before, when he had his legs done. He was dreadful. And then when his leg went gangrenous from the knee down well, I think if they hadn't have done it then he'd have died. It was poisoned, it was black and mouldy. Black from the knee. It was awful. But he's borne it all well, he's never complained once, and that's why I was so angry that's how we were treated that day. (wife p13)

*Was there anybody with you when you got your result?*

Erm...I was on the phone upstairs and my wife was downstairs.(p14)

*Right*

She might have just crept in behind me sort of half way through the call I think, I'm not quite sure. It seems quite a long time ago now. (p14)

*Was, was there someone with you when you called?*

There was, yeah.(p16)

*Who was with you?*

My wife. (p16)

*So you were on your own at the time?*

Yeah, yeah, oh yeah. (p18)

*Would you rather have had someone with you?*

No, I don't think so. No. (p18) *also in disposition*

That's right; there was no pressure on us to...because I went in the second time because I thought well, if we go together what one will forget the other one will remember. (Wife of p18)

*Husband's*) heard the numbers when he's talked to (*GP'S name*), the doctor, our GP, separately. And then if there's anything he doesn't understand because I know (*GP*) from [*place*] he rings me and says, you know, are you sure you've got this right? And this sort of thing. So what he tells me backs up and I wanted to know if he's given me a number, and I'm a mathematician, and on a scale and, you know, this so – then I feedback and we talk about it and we – we felt we were getting the best treatment there could be. (wife of p21) *supportive GP and wife!*

We have a very good GP too. And we have a very good relationship with him.(wife p21)

I would be interested. And he gave me a prescription for – to go and see my doctor, well I understood that's what he said to me, gave me a prescription to give to my doctor. But when I went to see the doctor – when I went down to surgery after we came back from the hospital, on I think it was Tuesday last week, my doctor was on – wasn't – no, did I ring up? Well she was on holiday anyway. And of course when you – when you get used to somebody you – you like to go back to them don't you? You know, because you're happy with them and that – and this lady which, my doctor is Dr (*name*), she's a charming sort of woman, and er she – I get on all right with her. And she's always been upfront and that sort of thing and er – but she wasn't there. And I could – and they said well you could see another doctor and I thought – then we thought about it and then we thought well perhaps not, it's only a prescription. And if

I – I was going to see the doctor yesterday, it was yesterday morning, I made an appointment to see her but it wasn't Dr (*name*), it was another doctor. I can't...(p22) *supportive GP (also in treatment choices moving forwards)*

the receptionist, opened it and she said oh, it's only a prescription. She said I'll get that processed for you and then you pick it up on Friday. Well subsequently I had a call this morning to say that Dr (*name*) wanted to see me on Monday, because obviously she – she wants to explain er things to me. So both (*wife's name*) and I are going down on Monday at 10 o'clock.(p22) *support GP*

when my daughter rang me up and said what they – I said well they had five biopsies and erm there's cancer in all of them they would have been concerned and I would have probably been a bit concerned but when they said it was only on two erm that appeared to me that there were caught at a relatively early stage, whether it is or not I don't know, we'll have to go to wait for that – we've got to wait for Monday. Know then. And erm – but I – I – as I say if they had said it was five erm – five – five of them, well I should have thought well the whole thing is – is cancer – the whole caboosh.(p23)

*Who was with you when you made that call? Can you remember? Just my wife. Your wife was with you was she? Yeah, yeah, yeah. (p2)*

she's on the net(*wife*), and jotting everything down and somebody else said that as well, if you want to find out anything just get on the internet, get on the Macmillan Nurse's thing, it's got a bit about what's what haven't they? (p3)*Also in prep*

But what, I mean I'm lucky, I'm one of the lucky ones. We are, the family, is lucky because we've got a cracking doctor.(p3) *and in support from GP and disposition*

Whereas, that's why I was saying, well, I think (*wife*) was saying ask this, because I think I asked you a couple of questions and she was asking me things and I said but I'm sure that we'll find out. It's like, I said come whatever it is, whenever it is, we'll go and we'll go together. So, and she's been with me, she didn't come the first time actually but she came all the other times. (p3)

And we're, you know, we...we share everything anyway so it was, it's nice that she was here when, when it happened, when you told me.(p3)

Well it better to talk to somebody that's had it done than it is to talk to somebody that's, it's like somebody telling me how to deal with stress, have you ever had it? No. It don't work (p3) *supportive friends and GP*

And my boss just phoned me up now and said are we coffee-ing this week because he couldn't make it last week and I said yeah. So, we're going to have a coffee together. (p3)

I was taking it in my, in the separate room, in my study, my wife could hear me sort of talking in there but when I went back afterwards I was a bit upset, erm, sat down. She said oh I thought it was, what did they say, I thought it was bad news because you, you were on there sort of quite a while sort of thing. To me it didn't seem all that long. So yes, I was a bit upset erm, a bit, I don't know how much, but, but I was glad that I'd phoned up and found out. So as far as I was concerned that was a good thing for me. Erm, obviously we discussed it after that and started looking into stuff and we phoned my daughter that evening and told her. I think it was that evening was it? (p20)

I don't feel, I don't feel unwell fortunately because you know I've had to look after you for [laughs] for the last 12 months. I mean not saying that in a bad way but I mean we've been unfortunate as I say, she's been in and out of the hospital, I mean she's spent eight weeks in here early this year and she's just lost her toe. Erm, so erm it's been fairly traumatic and then as I say to have this sort of hit us on the back end on, I just think, I'm just hoping that I'm going to be all right to keep on looking after her and the house and everything. So yeah, I mean...But I certainly knew what I was doing when I phoned up. (p20) *carer for his wife*

*Details re external stresses page 8-9 transcript patient 20 regarding wife and daughter*

But that's what I was trying to explain was that was why I'm feeling tired, it's nothing to do with the results of what I've received. Erm, and how I feel about that at the moment. Obviously I'm con- you know, I'm probably keeping it in a bit but I am concerned. I haven't spoken to my kids very much about it. And I've probably not spoken to you about it very much. (p20)

. And of course the trouble is my daughter especially, but (*name*) my son, they always say well what did they say about this? What did they...? And I said well I don't know we didn't ask this, you know, we didn't ask that. and they delve into sort of things and of course my daughter, she's straight on the – on the erm Google, she's Googling everything like finding out because she took biology, human biology, at university as her degree, so she knows all about the body although she's never gone...(p20)

Yeah. Well I think the information actually in the leaflets on side effects and, you know, what its after effects were is generally speaking pretty good, I mean I found that to be – it doesn't pull punches again, it just as this is what can happen, this is the percentage risk of it

happening and so on. And that's the way I kind of prefer it to be so I think I'll stay with that for the time being, I mean I'm not going to go to a support – I mean I may at some stage, I mean in six months time I could be giving a completely different set of answers to that kind of question but at the moment I don't feel the need to actually go to a support group. And there's a friend of mine I'm seeing actually in about two weeks time who I haven't seen for a couple of months and he actually had it five years ago and I'm going to talk to him about his experience as well. It's easier to talk to people you know about this kind of thing than people you – you don't know because you also know a bit about the person if you're talking to someone you know and you know what their general kind of demeanour is and the way they react to things and so on so you could kind of tailor their response more to the way you feel about things. (p26) *support from friends*

P1: I mean I don't care if it's, they say it's terminal or anything like that you know cos I mean there's times I mean like this morning, I think I'm gonna die. I get this feeling, all of a sudden, that I'm not going to make it, you know and that's what's a bit upsetting because err... *pauses...sighs.....crying..*

Interviewer: *are you ok, would you like me to stop?*

P1: no, I'm alright

Interviewer: *ok*

P1: it's not me..... I'm concerned about the wife

Interviewer: *yes?*

P1: ...that's all my worry is... if I lived on me own it would be different. It's her I bother about cos she can't really look after herself to that extent she.... can't really get around very well and things you know and she has to be helped in one or two things and.... that's the problem.....that's the problem

at the time I just didn't want anyone to know.(p8)

I didn't want people...I suppose to feel sorry for me. I, I didn't want other people to know. Well, the two daughters and the wife knew. And the two son-in-laws. But apart from that, and in fairness to them they told nobody(p8)

I've got a new partner, but I'm reliving my life, but unfortunately she's, she lives in (*place name*) and she said to me you're not going to be on your own, she come to me, up here, with me for the biopsy, she said you're not going to be on your own, come down and stay until the

Thursday and then, you know, once you get the results then we'll go from there, you know.(p12)

we both went. I mean I went with my husband for the biopsy as well because I felt he needed support, I think women are far more open about going to the doctor because you – if you've had children for goodness sake nothing horrifies you after that. Whereas for men it's not so easy. They haven't been through that and it's, you know, having somebody stick something down your throat or up somewhere else it's more difficult for men. I think. And I'm sure that is – is why. (wife p24)

And we – we also have a – a friend who's erm an Anglican priest and his wife is a Macmillan nurse. And I had to tell him because there are certain aspects, I'm a church warden, and there's certain aspects of my job I can't do because I don't want to stand up in front of everybody and say prayers for the sick and then sort of suddenly fold myself, so I – I felt I had to tell him and his wife's a Macmillan nurse. And she was also very helpful in counselling me and saying, you know, just take it step by step and the support's there should you need it and they occasionally ring through just to say hello and how are you er which is – which is supportive as well. So I think having a friend at the end of the phone is helpful.(p24)  
*support from friends and church*

*BUT*

Having – having had a friend who had er had this – his gland removed as well, he and been very open with us because he's quite a close friend, and you were able to talk to him as well weren't you? (wife p24)

Yes, yes. (p24)

So there are people who know but we haven't told our kids yet because we don't want them to worry until we've got all the information. When we've got all the results and all the information and what treatment is going to be then we'll sit them down and tell them about it..... Because it's this not knowing, your imagination runs riot. (p24)

mean (*wife*)there again (*wife*) was with me and erm I think that is essential that you've got someone with you. And erm we wondered about and we had a meal and this and that and then we found a little chapel or a place of worship I suppose and we were looking there and the lady said you can go in if you like. And (*wife*)and I went in there and had a quiet sit down. We found that was most helpful. Yeah. (P25) *support from wife*

## Theme: Service

### *Positive experiences*

#### *Asking about experience of receiving results*

I found it quite easy because, because the way you explained the results to me and what's got to be involved and what the next steps were going to be, I found in the phone call was a lot easier than by a letter. That was, that was a lot better. Having like a personal contact er that was far easier for me. (p4)

So I, I weren't too unduly worried about it Wendy and...I'm still not too worried about it even at this moment. I know what I've got and you are all trying to help me and you explained it through your booklet all of, all the ins and outs of it, the treatments, and such like and I, I feel, I feel quite happy with the way that, that you've all been trying to helping me out here. And I'm, yeah, I feel very happy about it to be honest.(p4) *and in service and in disposition*

, I've read your, your booklet, I think it's very good. (p4) ..... I've read it two or three times to make sure I've got it in my head. Erm, yeah, but apart from that, Wendy, no I haven't looked up anywhere else because I, I, I found I didn't need to.(p4) *also in disposition*

#### *Do, so you think you were given enough or too much information at the time?*

IE: No. No. I, I think, I think what's in, in that booklet, is exactly enough. (p4)

I: *Right.*

IE: Er you haven't...how the book is compiled it's not gone out to er...to complicate the patient too much. I'm talking about myself. That hasn't made it too complicated for me to understand er, although some of the bits need to be sort of gone over, over again. It's like er what does this bit mean? So I've gone back and, and read it again. Erm, once you've read it a couple of times then that's explained better. But no, it's, it's not, it's not gone out to...to complicated, well for me not too much anyway. I'm quite happy with that. (p4)

15. I phoned you and, and you phoned me back. (P4)

16. I: *Ah right. Okay.*

17. IE: Yeah. Because you were otherwise busy and you did call me back.

18. I: *How did that feel, that you called and there was nobody there to take your call?*

19. IE: Erm...if, if you mean when I called you and you...

20. I: *To get the results of the biopsy.*

21. IE: ...you, you weren't available at that time erm...that didn't make any difference Wendy.

22. I: *No?*
23. IE: Because, because I appreciate that you've, you've got other people besides me to look after and, and perhaps phone up or who you're attending to, , so yeah, I, I...you weren't available, I left a message saying that I want to speak to you, you called me back the same day, so yeah, that's fine. (P4)*In disposition too.*

Well I have known someone who was in hospital, you know, and the doctor stood there and he said oh Mr So and So, you've got cancer. (p7)

*Right.*

Mmm. Which is not quite er...your method. [laughs] (p7)

*what was my method?*

Oh you...you put it over the best way you could. Over the phone. I don't think you could better it. (p7)

the book was quite helpful as well.(p10)

*. Did you erm feel you were told enough information at the time?*

For me, yes. Erm, but that's because I, I already had a lot of information. This tidied it up, the little booklet, and I thought that was quite a nice concise erm short reading and I, I've been back to that a few times as I've needed to refresh myself.(p10)

*Was it helpful to have the letter as a follow up or did that not really...?*

Yes, no, no, it, I think it's always...erm because there all in here, you know, yeah, so yes I do, it's worth it, perhaps don't stick as well as it used to, so yes I do and that's why the booklet was handy. (p10)

But the mechanism phoning up, no, for me that worked fine.(p10)

, it fitted in, it coordinated with what was in the book and what, what I'd read as well, so that was reassuring that it all fitted in. you know, it was comfortable to get the same sort of information.(p10) *and in disposition*

Yeah, they were very, very nice. (wife of p13)

Very nice (p13).

Very nice. Very kind, couldn't have been nicer on the phone. (P13)

I think it was done just right. (wife p13)



Yeah.(p13)

They told us enough but not as to frighten you or to worry you, they just said it as it is and if we had, I looked at it this way, or they probably did as well, if you've got the strength of mind and character to ring up and take that news over the phone, then you can take whatever they had to say. Do you see what I'm saying? (wife p13)

Else you wouldn't do it would you? (p13)

Or else you wouldn't do it. And you have just enough information, she didn't go over the top. She just told us the basics and the things we should know. And she was very, very nice on the phone. Very nice.(wife p13)

It was just if you want to do it that way you can phone up next Wednesday. (p17)

*Okay, okay. And you didn't think that was – you thought that was okay?*

No, I thought it was quite good actually. (p17)

*can you tell me sort of a little bit about that phone call and how that went?*

Erm, I think more or less, erm, you know you've got two out of your ten biopsies erm were positive. And you've got a score of seven on one of the scales, I can't remember the name of it. Erm, how do you feel about that? Yeah, fine. And, you know, I was told, you know, erm if you want to talk to us please either phone us or come in and see us, please don't hesitate. Which I thought was rather nice. Erm, that was it really, it wasn't a long conversation by any means. Erm, it was to the point, erm it was caring, whoever it was. Obviously, you know, you could tell that she was caring about it. Erm, no I thought it was quite good. (p17)

*Did you, did you feel you were given enough information in that call?*

Erm yes. Because erm to an untrained mind a lot of information, I think, can cause you more problems.

That side of it, totally happy. Yeah. Erm...it done what it said on the tin. You know, erm you can phone next Wednesday, I phoned the next Wednesday and I got the results.(P17)

and phoned her and she just – well, she's quite good actually. You know, she just said I'd got it but I was still all right because that was erm three plus four something on the Gleason scale she said which was very, as I say a very mild cancer which is slow growing and all that sort of thing, yeah. So I had no, I weren't upset about it or anything. (P18)

*some people say that when you're erm, obviously on the telephone you lose all the non-verbal don't you in communication, how did that, how was that for you?*

That was all right. (P18)

*Not being able to see the person that is telling you that you'd got cancer?*

I didn't mind, no. That don't worry me, that don't. (P18)

*It didn't?*

No, no, not at all. No. (P18)

*Okay.*

No, I don't know if that...that couldn't have been no better if I'd have been sitting in front of her really could it? Still the same. She was good. Yeah. (P18)

so I just phoned up sort of 9, 10 o'clock in the morning and spoke to erm, I think it was (*nurse's name*). And she was very reassuring, she had plenty of time to talk to me. She was really good. I was very pleased with the whole thing apart from the result of course. (p14)

*Some people also say that when you're telling somebody you've got cancer and you're not doing it face to face, you obviously lose all the non-verbal communication, how did you find that?*

It wasn't a problem for me because er (*nurse's name*) was so good, she had so much time for me, you know, I thought she was just going to say oh yeah, you know, it came back something such and such, and hang up. But I spoke to her for what seemed like ages afterwards and she was just so reassuring and you just felt as though she had time. Which you don't tend to get at hospitals too often. (p14)

*Okay. Just back to the process of receiving results and, and telephoning, is there anything that we can do better with that do you think?*

No, I thought you were very good and you...(p14)

*Or anything that we could do differently to make it better?*

Erm...well apart from sending somebody round to my house, no. [laughs] No. Very pleased with you nurses. You've been brilliant. (p14)

*So you think that's quite reasonable to offer that choice to men do you or...?*

I would think it's most essential because it makes us feel so much better, you know to be...have somebody that seems to know what they're talking about, all right I know it's not the surgeon who should know everything, but you know you girls have obviously been in it for a good few years, you've, you've seen lots of people and you probably know how men like myself react and what we want to hear and what we don't want to hear. I don't know. (p14)  
*also in choice*

Yeah, well it was very straightforward, I, I obviously made a note of the date and time and to ring up and er took it from there. I, initially I was very, you know, uneasy about it and I thought well no, come on, it's got to be faced up one way or another. And er as it got closer to it, about eight, seven or eight days later, it was very straightforward, I had no misgivings particularly about it, well it's going to be one way or the other. Whatever happens you get the answer, so there you are and it was not – I didn't find it all off-putting or distressing at all, I thought it was very straightforward. It was, and it was very, very erm, you know, there was no hold up on the telephone when I rang up, went straight through. Don't know if I spoke to you or one of your colleagues. And it was, you know, straightforward, no trouble at all. I felt quite good about it all, all right I got a good result so maybe it colours it, you know, but er I don't know how I'd have felt if it was a bad result. No, I thought, I think it was, I felt that was all right. Mmm. I must say initially I thought that's rather strange isn't it, I thought they would tell you eyeball to eyeball, and I thought well why would they, what's the advantage if it's eyeball to eyeball? Unless it's putting an arm round your shoulder or something if it's bad news or whatever and tell you what the next steps going to be rather than you running to the door or whatever. But er, I can't, I found it very straightforward, very erm, you know, I didn't have any strong antipathy at all, it was very straightforward I thought. But again, maybe it's coloured because I had a positive result, you know. (p15)

*how did you find that letter? Was it – I know you've just said that it hit you more when you got it in the letter...*

Oh yes.(p22)

*...to confirm it. Erm was that unhelpful?*

No, I thought it was helpful. (p22)

*It was helpful?*

Yeah, very much so. Oh yes. I don't – I don't think erm – I don't – no, I don't see a problem with it to be truthful. Because at least you know where you stood then don't you? (p22)

she was, you know, up front and very polite and sympathetic, she wasn't erm...abrupt or anything (p22)

*some people feel that they get too much information in that call and other people feel they don't get enough, how, how did you feel?*

No, I felt that was adequate because either you have the problem or you don't. You know, when she said oh yes, you've – four – the four biopsies that were taken they all both – all show cancer. Prostate cancer. I mean I'll show you the letter if you want, or you've probably seen it. You don't need to see it do you? You know.(p22)

I mean it happened all so quickly, you know, I thought that was very, well, good, you know, they really did move, you know. When Mr (*consultant*) said – said about the biopsy, you know, that really did move when your colleague arranged for the, you know, she said it would be about a fortnight, well it was less than a fortnight before I had the bone scan and I had the bone scan on the Monday and then I had the MRI scan on the Wednesday. (p22)

*is there anything else that you'd like to tell me, sort of good or bad about how you got your results or your experience?*

No, I thought that everything was all right. Can't think of anything else. (p18)

Well (*nurse's name*) was very efficient wasn't she? (wife of p18)

Yeah, yeah, I thought yeah, well everyone has been who I've dealt with so far. (p18)

*And you would do the same thing again?*

Yeah, oh yeah, definitely.(p18)

*Even though it's cancer that you're talking about?*

Yeah, yeah. (p18)

Well I was pleased that we were able to call.(p21)

Really, we felt the sooner the better. (wife of p21)

Yes, that's right.(p21) *in speed too and choice*

*Is there anything that we told you that you would rather not have known?*

No, no, it was absolutely straightforward, the manner and everything was good and it was, you know, this is something sort of one's given the impression this is something to – that we together would deal with. And what more could you ask? Because it was nobody's fault. If it had been somebody had ripped him to bits or something, you know, that's a different matter. (wife p21)

*Is there anything – anything else around that call or anything else that you want to – to tell me about?*

Don't think so, no, it was straightforward.(wife p21)

*It was, straightforward. Okay, is there anything that you think we could do differently?*

I think the service we've had is superb. And I think we both...(wife p21)

Yeah. I couldn't think of any way which it could have been improved.(p21)

there's a lady who was very kind at that frank interview who gave me her card, I've got it in there, I've forgotten what her name – there's sort of three of you who are very connected and – and she stressed it and this was good too, that any time, if you're worried, call. I think that's a very good idea, because if somebody erm was really worried and they needed to talk this is a lifeline. And I think that is a very good aspect. But we didn't want – need to because it all worked sort of on the timetable we were given. Er short length of time for the biopsies to be examined and the tests – er the results given. And then the phone call.(wife p21)

*so the preparation in place before the biopsy helped?*

Yes. Helped tremendously. That was a very good thing from our – the way – the sort of people we are, and being able to ask questions, perhaps it was a daft question about me and what's the difference between an MRI and a bone scan? But he didn't treat me as daft and explained what was going to happen and, you know, then we went up for the bone scan. And that I think we might have been very worried if the erm results of the bone scan had been very different. Because you're then moving, aren't you, sort of a subset, out of prostate into goodness knows what. (wife p21) *moving forwards and in satisfaction and in preparation*

*how helpful are the letters?*

Oh yes, they're – they're important because if when you're talking about phone calls and if it goes between the two of us, and what (*husband*) remembers or doesn't remember, and then if you've got confirmation here you know exactly where you are. Oh yes, I think that's important. Not only for records, for what you're doing, but for peace of mind or for us, for example if one of the children, one of the boys came and said all right, you seem in a right muddle, let me read that letter for you, you know. I think that's important.( Wife p21)

I think we've had very good service from our own GP and from everything we've met at the hospital (wife p21)

Yeah, and she was very nice. And she said well I'm sorry Mr (*name*), you're, you know, whatever and she said of the four samples taken she said that shows prostate cancer. And that was it really. (p22)

I wasn't at all surprised, if the PSA – if the PSA test had been 1 or 2 and then that would have probably well not alarmed me more, it's no good getting alarmed, but of course so consequently I was satisfied with that, he was straightforward with it, and away (p23)

they said ring up at that specific time from half past one to three o'clock. So I rang up immediately, I think it was at quarter to two, er so I knew what were we were doing and erm and of course I got the information which she had available to give to me, and then erm – so I had that and I think 24 or 48 hours later I got a letter confirming what she'd said. Which I thought was all right. I couldn't see nothing wrong with that. I mean they said ring up, I rang up and she was there, erm and erm, you know, so that was 100% as far as I could see. I couldn't see you do any more. That was either a case of doing that or wait until, well I don't know, wait until – I don't know how else you would have known. And then of course they then erm arranged, she said straightway, fair enough, so you know what's happening, now I'm now going to arrange a bone scan which she did (p23) *and in choice and in disposition-accepting*

*what did you think about being told that you could telephone for the results if you wanted to?*

I thought it was ideal.(p23)

*Did you?*

Definitely. Yeah.(p23)

*In what way?*

Because I like to keep aware of what's going on. Erm and I like to – I like to know exactly what's going on and the best treat- obviously I put myself in your hands. And – and as I say I just feel – I like to know what's going on rather than just wandering up there and I don't know what's going to happen. And the possibly this, that and the other. So I, my point, I thought it was a good idea. (p23)

I – I – mainly because I think that the pressures which doctors, nurses, what have you, consultants, that's better to do it like this rather than me going to waste someone's time for quarter of an hour waffling on and – and you know, I could – I could hear what she said then she sent it by mail and, you know, just going over it, what she told me, and I thought rather than going up there and erm wasting time, if that was it, perhaps this hospital, just wander up here, no problem at all, but that's so much hassle up there, so I – I personally think it's a good idea(p23) *and in disposition and choice*

Oh yeah, yeah. Erm I – I can't criticise at all because you've done everything by the book. Erm, everything, all the appointments have been erm – erm booked in very quickly all the time. Erm I can't – I can't think how I could have been any better off because I mean

everything booked – worked out right. Erm...and so the whole thing has worked – is working well from that point of view. So I can't – I can't say to you oh you should do this, that and the other because if – if everyone had the same attention as what I've had I can't see how anyone can criticise it. And I can't at all, you know. And erm right from the start, right up to this point in time. (p23)

I thought well perhaps I'm sort of fairly lucky that that is only the one side and not spread, you know, or not got in both sides. So yeah, I was sort of quite...well, I wouldn't say chuffed, but relieved when I got that information over the phone. Erm, I mean really it doesn't matter whether I get it over the phone or in letter but it's a bit more personal if somebody actually speaks to you on the phone than sort of suddenly getting a letter come through the post. I mean for an appointment that's totally different, but when somebody actually sort of explains it to you, yeah, I found that was sort of better for that. (p2) *also in choice and relief*

ten on the left hand side were clear. Seven out of the ten on the right showed signs of cancer. I thought that was very well sort of explained erm instead of just saying we've taken 20 and seven of them are showing cancer. Erm, so no, I thought that was very well explained. Erm, I thought the phone call I had to say, the one phone call that I made, erm, the bone scan was clear. That was put very nicely that nothing to worry about, the bone scan, the words were is crystal clear. (p2)

So yeah, I've been very well informed, considering how busy you are. (p2)

*Is there anything you've found out since that you wish you were told earlier on?*

Erm, not really because when you sent me that booklet I mean a lot of it is explained in there if you take the time, it might take you a sort of couple of times to read it for it to sink in but no, that is, I think that's sort of quite well explained in there. And because there's the sort of the [22.03] possibly I haven't filled it in correctly but erm where it says PSA level then date of bone scan and I've just written the date in and the date that I knew it was clear. So yeah, you can keep a record. Erm, the only thing I weren't erm sure about was localised or locally advanced and I worked out that was probably localised.(p2)

*Is there anything that...the sort of...the treating team of doctors and nurses could do differently do you think?*

[sighs] Don't think so. I seem to have been very, very...very good, very caring (p2)

I mean I don't know who phoned me, whether that was you or, or somebody else. But whoever phoned erm done it in a nice way, that was done very slowly and gradually. Er, obviously the first step was to say that it had come back and it was cancer. But then it weren't rushed into, you know, this, that and the other. There was a pause for me to, to get that to sink in. erm, so that was nice. Er, so I, I thought yeah, that's cancer, that's just what I thought. And obviously all the time you're hoping for good bits to come after that, you know, the positive bits to come after that. Erm, and there was some obviously.(p6)

she also explained that I was er, as I said this was all done nice and slowly, gradually, not sort of rushed into. Er so I had time to take in each piece of information. Erm and er then she went onto to say that erm I was relatively young erm, which we joked about, but er yeah, so you know she, she gave me obviously the, the bad news, and then enlightened me on the various other aspects of what I had and I felt that was done, you know, really well because there's no way you can make it sound like good news, but I always find that erm...I mean we went to the doctors, my GP, just the other day and erm although he's a good GP he, he just ran on through things and I came away not knowing really what he'd said. But I must admit that conversation that day, considering that was where it was and in the circumstances it was I came away remembering every word that was said, I could relay it to my wife almost word for word which is unusual because I'm not that good at gathering information. Erm, and that become more apparent later when, when we were able to talk, because I couldn't tell her straightaway. I just told her that that was cancer and whatever, erm but that wasn't until that evening which was about five or six hours later that I could relay the whole conversation and I could actually relay the whole conversation, you know, which was, you know, quite good really. (p6)

. I thought, no, I just, just want to know if it is a cancer how bad is it, what sort of treatment will I have. And they were all answered without me actually asking. So yeah, that was, that was fine. Erm...you know when I think back I'm sure that there was nothing else I wanted to ask at the time. I didn't come off, because I often come off the phone and think oh, I should have...but I can honestly say that I can't ever feeling that at all when I came off the phone. You know.(p6)

then I made another call after that as well on the same number, so I obviously weren't, you know, worried about making a call, phoned up again and each time I think I had to leave a message but I was happy with that, that was fine. Erm, because we then moved onto another place where I couldn't get any reception on my phone, so I thought well I can't get a letter at home, and I can't get a phone call. So I, I made another call and erm I think, I explained the situation and I says I can't get any calls from where I am but during the day when I'm out and



about, you know, I can. So I was told to phone them, you know, because I didn't want to bother anyone but they said erm, no, phone us each day basically. And that's what I done, I used to phone each day to see whether I had an appointment come through. (p6) *could argue that he actually sounds very anxious but he was very calm and relaxed throughout the interview*

...I felt quite happy to phone them erm, they, they didn't make me feel as if I was being a burden, ever. You know, I mean I, as I say, I phoned I don't know how many times, two or three times anyway, and erm each time I was, I think each time I had a, erm an answerphone. Yeah, and I think one day they didn't get in touch with me until the next morning. But that was fine. And erm as I say not once did they make me feel that, you know, I was being a burden. I would have phoned anytime I wanted, er and that's unusual for me because I'm not normally like that, I do tend to put of phoning people. Erm but I...again this is going to sound a silly thing to say but I felt as if they were quite friendly.(p6)

so I found that quite easy to do, quite easy to phone and if I'd a question, I didn't have a question about my cancer, but if I did I wouldn't have hesitated to phone up and ask. (p6)

Yeah, so I found it, you know, more than easy to, to get in touch and talk to somebody.(p6)

I can't pretend that I weren't disappointed. I said to my wife, I said oh I've got an answerphone. Erm...but I can't say there's anything else that I was er, you know, at all er...I'm trying to think here what I felt at the time. But...no, I don't think there's anything I would say could have been done better. Certainly no, certainly not the message I was given. Certainly not the information I was given couldn't have been better. Not only in its content but the way that was delivered to me. Because I felt that whoever I was talking to was er reading my erm...er reactions even on the phone. They were gauging my reaction, that's how I took it. I mean I deal with the public on the phone all the time and er...and sometimes you can even though you can't see people, body language, etc., you can gauge how they're taking things. I mean my work is not, you know, nothing like yours obviously, but at the same time I can tell whether, you know, people can take a joke, whether they can see the funny side of things, whether they're very serious, whether they're very straight to the point, and that's how I felt on the phone. I felt that, because I laughed when, when I was told that I was young, you know, I sort of laughed and, and er there was a reaction to that, you know, so I felt whoever was talking to me was talking to me on my level. You know. And that's what I found the other day when I went, just to give you a contrast, when I went to the doctor he was talking to me as if I was a medical student and he was talking purely medical terms and I came away and I didn't know anything that he'd said at all. And er he had his head down, he didn't look at me, and he just said this, this, this and I asked him a question and he sort of like...he was quite impatient

as if to say well I've now told you that. And I thought oh, I ain't going to ask nothing else and I came away. Now I didn't feel like that all, I felt that I could have chatted to the nurse for half an hour, I felt as if I could have chatted. Not just asked questions but chatted to her like, you know, like I'm talking to you. Erm, yeah, so that was fine. That was, I was really impressed with that and I actually told my wife. I actually said to my wife, they're really good on the phone, the way they give you the news, that's done in small bits, erm, you know, and they seem to gauge your reactions before they go on to the next bit. That's how I felt. ( P6)

the other good thing about it is they tell you the day to phone, you're not just told to ring in about a week's time, I was given a date and the timeframe. Er and that was excellent that was. Erm...the other good thing about was as I said the way they delivered the information, it was very personal and very erm human like. Erm, the bad thing about it was er, if you can call it bad, was not getting somebody when I expected to and having the answerphone. Erm.....that's it really. I think the only question I asked at the time, thinking back, I, I said I didn't ask any questions, I did say how long would it be before had the biopsy and er she told me it would be within a three week timescale. (p6)

I think I was surprised that I, I was able to phone up for the results because I, I have tests on various things, obviously through the years, erm, and normally they say you have to make an appointment to see your doctor. And often I don't get results of things as well, you know, minor things obviously. But like blood tests I, I have two blood tests every year and I never get any results, no one ever phone me up to say you're all right, so it's obviously up to me to phone them up and I never bother to be honest with you. But erm, yeah, so it's nice to, for someone to say if you want to know, phone this number. That was great. Didn't even have to...(p6)

*Even though it's potentially cancer?*

Yeah, especially because it's potentially cancer. Yeah. And if that had been a blood test for, you know, an in growing toenail I wouldn't have bothered, but because that was such an important thing that was lovely to, not just be, be told that er oh, you know, get, make, I mean as I say the consultant said make an appointment to see your doctor because they probably wouldn't get in touch with you. I thought yeah, that's typical [laughs].(p6) *and in choice*

as I said that was nice because they didn't say phone up in about a week's time, and then you've got to find what number, what department you want. They said phone up this number, the nurses' names are that, that and that. Er, that was great, that was absolutely fantastic I thought. That side of things were really good. Er, especially for me because I always want to

know good or bad, I always want to know. Like if, as I said if it had been two days time I'd have phoned up in two days time. And erm if that had been a week's time but I could have come and got them face to face with somebody I probably would. Not for any particular reason, just that I would have felt I wouldn't have forgotten anything. And as it happened I don't think I did forget anything. But I mean you can tell from me I go on and on and on. And if I'm with somebody I, you know, that'll come out. You know, something I'm anxious about, don't even know I'm anxious about, will come out. Erm, so I'd always rather meet somebody er face to face. Yeah, I definitely would have come up otherwise. But that was certainly the, you know, the next best thing. (P6)

*Okay.*

Easily. And ideal because I was away. I couldn't have come up anyway. (p6)

Well I think primarily on the, the day that I got the results from (*nurse's name*), and there's not a problem with that I hasten to add, that was, she was fine, absolutely no problem at all, erm and it sort of sunk in (p9)

Erm, the first phone call was, no, that wasn't a problem because it was, it was pretty factual, yes it is unfortunately, 10/10 on the biopsies are the issue. Right. Erm...so what's that going to entail? Almost certainly hormone and radiotherapy, so (*nurse's name*) was really very upfront which I appreciate because I'm not one, I'm not the sort of person that has it, don't want it coming in dribs, I'd rather know what the score is. Erm, so that, that was fine.(p9)

But I started asking more questions. And then I thought of other things which is when I rang and you, you kindly contacted me so...erm, so I don't have a problem with the first phone call at all, erm, I asked for the information and I got it and I got it in a sympathetic way. Erm, but it was factual erm and I wouldn't want it any differently at all. In terms of the information I've subsequently got it's been great because I've been able to ask the sort of questions I wanted to know. And I think when (*nurse's name*) rang me about the results of the scans the only thing I heard really was your bone scan's clear and I thought thank Christ for that. [laughs] Erm...and it was only after the event I suddenly thought well that's a bit silly because I should have asked her about the MRI scan in a bit more detail. Because she was saying it wasn't, you weren't sure at the time but you were a bit suspicious as to what was going on there but it wasn't totally indicative. Erm, but really and truthfully Wendy I mean I really have not a problem with anything in terms of the information you've given me. That's genuine as well, I'm not just saying that, I really don't have a problem at all. You've answered the questions I've asked, you've...I've asked three of you about surgery and all three of you have been consistent in that. Erm...which is fine now because I know the score on that one and why.

Erm, but yeah, the biggest problem I think is, is in a way the lack of information about, to be able to ask people like yourself the right questions at the right time.(p9)

Erm, and that eight was bloody dodgy, erm, or big. Thankfully it wasn't a nine or a ten but it was on the high side of being a difficult situation to deal with, so I knew what that was going to, to be about. erm...10/10 biopsies are pretty evident when it's totally cancerous inside there in fact. Erm, so there was nothing that I got from (*nurse's name*) that I didn't understand really.(p9) *recall, reflection*

*Yeah, it is. Okay. Is there anything else that you'd like to tell me, good or bad, about your experience?*

[laughs] Erm, certainly nothing bad. Erm because I think, as I say in terms of people definitely nothing bad, erm, at all. In fact I have had no cause to sort of take umbrage or dislike or anything with anybody. Everybody has been, that I've had erm opportunity to talk to, have been really helpful. And that's a genuine comment, I'm not just saying this for your research. Erm...so the good side is clearly you as a group of people if you like. Erm, as a group of nurses and, and the doctors. And erm the consultant that I saw, Mr(*urologist*) in the end, erm, he was great as well, erm, because again unfortunately I'm the sort of person that tends to sort of make a bit of a joke and have a bit of a laugh about things, even though I know I shouldn't do it. But even with the consultant, we had a bit of a laugh. Erm and it just takes the tension out of it. Everybody seemed to be quite sort of free and easy with it. So I, I think the people are great. Erm, the hospital is a hospital isn't it? You can't complain about that, the only thing I'd have major complaint about is the car parking down there which is an absolute pain. Erm but, you know all that as well. But other than that, it, it's really, it's been okay actually, Wendy, really. (p9)

Erm, I can't remember when it was but I know, I think it was you phoned me the following day to see how I was. [sighs] (p20)

*Are you okay?*

Yeah. Erm, I said to you I was very pleased you had phoned because erm...I was a bit more...(p20)

You felt more able didn't you?(wife p20)

...I was a bit more able to talk then. And we talked about it and obviously erm various questions were sort of brought up in our minds so, I was able to talk to you a bit more sort of broadly about what the situation was and what goes on now. erm...what treatments were available erm and you said that you'd probably erm be arranging erm for the MRI scan, the

bone scan, erm and then erm I don't know whether this all took place in that actual phone call but I know I was erm, I was very pleased to get it. [5.56 – patient becoming very upset] (p20)

so that was, I was very pleased up to now with the, the treatment and how I've been sort of looked after. I think you are the same aren't you?(p20)

Yeah.(wife p20)

Erm and so, and as I say in between this I got the phone call from you asking me whether I'd be happy to join in your research erm and have a meeting which erm I think it was a, a letter I got first of all and again we discussed it and I said well, you know, anything that can help me but also can help cancer victims or patients, whatever you like to say, in general in the future. Anything like that can help. I was quite happy to be able to phone up rather than – and find out...(P20)

*Were you?*

...rather than sort of wait for letters or anything like this to call. (p20)

Well at the time I did in as far as I was asked do you have any questions? And I suppose thing is that it knocked me back so I really couldn't think of any questions to ask. I'd been told what I wanted to know basically. Erm, because that's all I expected when I phoned up, I was going to be given the results of the biopsy and I suppose the thing is the way I was looking at it was that erm yes, I'm going to be told that I've – the biopsy is erm a negative or a positive result. I've either got cancer or I haven't because that's basically what was going to come out of it. but at the back of my mind I was still quite reasonably confident that I didn't have cancer, basically. (p20)

*Okay.*

I still hadn't resigned myself to the fact that I could have it. Erm so that's probably why it was a bit of a shock. But I wasn't – I was pleased that I phoned and got the answer there and then. I wasn't sort of, you know, sort of looking at it negatively oh, I wish I'd never phoned. Because what would I have gained? I'd have only just delayed it and then if I delayed it until perhaps waiting until the results go through to the doctors and that, I'd have probably started thinking well what's going to happen? Shall I ring the doctor and he's not there so I can't talk to anyone. And then I might get sort of someone else look at the file, computer, and say oh yes, we've got the results through and get it from someone that is not used to dealing with it quite so much. I don't know. So I was – I was relieved to be able to have got the answer but erm it was a bit of a shock. And that's why I didn't real- I hadn't prepared myself for any questions, what do I do now sort of thing? (P20)

but I was quite – I was very pleased erm, erm and I'm feeling a bit better with it now, to get the phone call the following day..(P20)

but I was very pleased to get that phone call because I thought it was very nice, erm thoughtful, erm and I was able to perhaps erm ask a few questions then because I as in a better state of mind. Erm, it was out of the blue, I didn't expect it, but we'd been talking about, you know, the results and everything there and, with my daughter.(p20) *following feedback from p9*

so that was very nice to get that second phone call and when I could actually then talk to someone and that is something that I would say was a plus, a very big plus.(p20)

*Okay, if (nurse) hadn't have called you the next day would you have called her or us?*

No I don't think so. No. That's why I say I was quite pleased because you'd, you'd done what you'd...what you'd said you'd do, you know, you'd ring me. No, sorry, I rang you didn't I?(p20)

*Yeah.*

I'd done and I was able to get through not the first time but you'd actually taken the message and you'd rung me back, so you'd done what you sort of said you'd do and you'd given me the results. So I didn't expect, that was – it was out of the blue, erm and I don't think I would have...(p20)

Well to be honest we're not used to that level of careful thought from the medical profession, the doctors and everything that we go to see at the surgery, they never ask or very rarely do you see the same doctor so they don't know your medical history, any more than...I mean years ago they used to know your medical history, you'd see the same doctor all the time. Erm...(wife p20)

It was your family doctor.(p20)

But, but now you, you might, you might see, well I have done, three or four different doctors, erm over whatever your, is wrong with you. And they just look on the computer oh yes, yes, yes, they don't ask – concerned with how you're feeling. I mean they're just concerned with whatever's wrong with you but not how you're feeling about it. So as I say we're not used to that erm pastoral care I supposed you'd call it. (wife p20)

So on the second day I got the phone call er from (*nurse*) just er just to sort of see how I was basically so it was very nice to receive that phone call and I was then able to sort of talk to her in a more positive way in sort of asking one or two questions, there weren't many questions, but one or two questions that our family together had sort of talked about it the previous evening. And certainly since then I would have no hesitation in phoning your department and trying to speak to one of the nurses there if I had a problem that I wanted to speak to someone about. Or wanted to know something about, I wouldn't have any hesitation in phoning you, in fact I think you know I'd phone you rather than phoning the GP or anyone else.(p20)

what I received over the phone was quite good you know I was quite pleased about things. And they explained everything to me. And that were alright, you know.(p1)

*OK. In what way did you think it was good?*

P1: Well the way it was presented. I mean, err, you know quite well, err, quite understanding about things which is you know, I mean not surprising, well they're used to it , every day and err in general I was quite pleased how it was done you know.(p1)

P1: I can phone back you know if I wanted to, if I got any queries or things...no, I felt... I read the literature about things it says who to get in touch with anytime you know.....so well that's fair enough

*is there anything you think they could do better?*

P1: they can be better?

Interviewer: *well, is there anything we can do as a team?*

P1 : well like I said before I was quite satisfied in a way, you know, it was, well the way I was answered over the phone you know well she couldn't have been any better

*did it help to get the letter to get the letter a few days later clarifying that call or did that make things worse?*

As I said that, that clarified and then I could start reading the books and knowing what some of the bits that were mentioned. And...after I'd had the MRI I felt better because they, well, no one can guarantee it but they told me it's nowhere else.( P8)

And I was right glad I did phone up, yeah. I can't argue with that, that's by far...because that was going to be the soonest I knew. And that's what, unfortunately that is what you want to do. Well, me personally, I'm only speaking as me personally. (p8)

I must admit er...I've got to say the way I was treated with the biopsy and er being told afterwards I thought was excellent. I, I couldn't wish for better, if you know what I mean, the way the consultant possibly hoped, apart from the cancer.(p8) *?feeling vulnerable*

*Right.*

But the way I was treated I thought was, was very good.(p8)

*Okay. But about that call, you felt that the actual telephone call that you made for your results, erm, I mean you said that I wasn't there when you made that call and...*

That's right, yeah. (p8)

*How did that feel? Did, did you get somebody else or did you get an answerphone? (Double question)*

No, no, I spoke to someone and er you were on a call. Not call, you were doing rounds or something like that.(p8)

*Right.*

And er so I did phone back later. No, you phoned me actually. (p8)

*Did I?*

Yes.(p8)

*Okay. So how did that feel, you rang up to get your results, that could be cancer...*

I'd like to know.(p8)

*...and you got somebody else.*

Yeah.(p8)

*Mmm.*

But I'm glad I weren't told then because that was a lot better coming from yourself. Don't ask me why. But it was, you know.(p8)

I, I think if someone else had have said it, because I'd got to phone this (*name*)...and I think if someone else had have told me that would have been second rate. Kick you right down again. Am I saying that right? So I'm glad I spoke to you. I didn't want someone saying oh, I've just looked at your notes and you have got cancer. You know, but...the way you told it to me I, I must admit was...(p8)

*But...*

*...I've got to thank you very much. (p8) caution- may be suddenly feeling very vulnerable as he had been so honest with his responses and not all good*



Yes, yes, I was given a – I was given a choice. But we felt that it was best to talk to somebody about it rather than to have it anonymously over the phone. But the time factor is important.(p24)

otherwise as I say it's just sort of rolled over gently and – and maybe we're just lucky that we've – in that sense that we've hit a patch where the hospital, the administration etc. is able to – to process me in that way. Which we are grateful for.(p24)

the best decision we made was to have the biopsy results from the consultant and not over the phone because we were – he then explained...(Wife of p24)

Yes.(p24)

...this is not life threatening.(wife) (? *false reassurance*)

*And you were both there?*

Yes, yes.(wife)

Yes, we were both there. (p24)*Service satisfaction face to face*

Even before then we were told we could ring which was why we rang to decide how we wanted the results. And whoever we – you spoke to on the phone was no – so helpful and the phone call back by the end of the day telling us that we would be seeing the consultant the – on the Friday was so reassuring. If there had been any wait then yes. (wife p24) *positive experience*

*is there anything that we could do differently as nurses or doctors do you think?*

No I don't – I don't think so, not from my point of view, it would be nice to think that everybody will get the same level of treatment sort of rolling on one week, one week, one week, so that you – you're making a progression rather than saying well I've got a dental appointment in six months, you know. I've got a prostate cancer in er - interview in six weeks. No, you know, I'd like to think that everybody would be lucky enough to have a – a programme like that. I do realise that with financial constraints the way they are things might not be as – as clear cut as that. but I - we have found it helpful to have support all the way along the line, right from the day when the doctor said you've got to have a blood test, your blood is fine, but your PSA result is high which is an indicator of prostate cancer, well no, and indicator of a none life threatening, right from the start none life threatening cancer erm and – and I'll – I'll make an arrangement for you to see a specialist, you know, and that's the way it was. So...(p24)

But you know then we went in and – and er Dr...(P24)

I don't know his name, I can't remember his name.(wife)

The doctor was – was very - very reassuring. He had a good bed – bedside manner and he explained things er to me and to (wife) and erm we both asked questions and – and that was fine. Yes. Yes.(p24)

*How comfortable did you feel about asking questions?*

Well I was – I was at home with them. I – you – he was a person I could get on with, yeah.(p25)

*you said earlier erm when, before we started, that in your opinion erm you can't beat face to face, that's what you said?*

No you can't. Because you – you can erm read the person's face and erm you can query something. (p25)

*Yes, and you can't do that over the...?*

No, no. (p25)

*Over the phone.*

I – I'm not very good on the phone whatever happens because I'm hard of hearing.(p25)

*is there anything that erm you think that as nurses and doctors we could do differently around biopsies and giving results?*

[sighs] I can't – I can't see where – where you can do anything. I – you see when I attended the hospital erm my appointment, I always got there on time and erm they always attended to me on time. So I mean what can I say? (P25)

generally I've been extremely happy with my experience. (p5) *septicaemia post biopsy, told cancer diagnosis in dayroom on ward without warning!!!*

### ***Not so good experiences/ negative experiences/ lessons learnt***

So to be quite honest, that was the, shall we say the most upsetting part of it for me. Erm, after that for me it was not mechanical but erm, you know, you can see it's a well-trodden path. It's the biggest, er, the biggest problem I think men face these days.(p10) *not so good*

*how did it feel when you, you, telephoned and I wasn't there?*

Erm, it, it's didn't cause a problem because one of your colleagues stepped in.(p10) *quite matter of fact about this but not good*

*What do you think we could do differently with the service?*

Erm...it went, it went fairly slick erm and I think, I think if anything I would er, I know it's the most common form of cancer but it, you do feel you're on a bit of a treadmill. (p10)

Yeah, you do feel you're on a bit of a treadmill, I think. I don't know. It's the first time I've engaged, had to engage with the National Health Service for any, anything other than a physical ailment.(p10)

*Okay. In what way?*

Erm, I phoned up once because obviously, erm, I wanted to find out erm what the sequence of events were. Erm, I left a message, I didn't get an answer but the next day it's happened that the, one of these appointments popped through the letterbox. You know, so...I think twice I've left messages on the answerphone and not had a response.

*Right.*

However the system is...just trundled down its way, so I thought it was a touch impersonal there.(p10) *negative experience of service*

Perhaps, I didn't understand the process, we were just erm sort of leapfrogging into the dark each time erm because obviously I don't think you have this sort of ailment repetitively, it's a one off, so erm...erm, I personally would have liked to have known that the sequence of events that this happens, then this, this, this.(p10)

*This is what's happening next, in this timescale, and...right, okay.*

And it might even be useful to, to know the timescales for the treatment options as well.(p10)

*Okay.*

I know it might vary by individual but, er...but for me that would have been helpful.(p10)

*Is there anything we could do differently?*

I don't think...this might be a bit unfair to...this is not a criticism I hope, when I had to come up er I think it was on the 24<sup>th</sup> or something and they were running late, about an hour and a quarter late that afternoon. And I can't think of the, the doctor I saw, er he, he had he had to confirm whether I needed a biopsy or not. And they were running late and, forgive me for saying, but the, the foreign gentleman, I couldn't really understand what he was trying to say to me. But he had to do an examination from the back passage, I went through into the, the next

room, and he, and he, he didn't actually do it properly, I know because I've had one or two done. And that was, and he was trying to answer the phone at the same, same time, because (*wife*) was there, weren't you? And I found that was a bit, a bit too quick and he was saying even before, he said yes, you'll need a biopsy and, and that was it. that was...that probably weren't his fault Wendy, in as much because he was running, running so late, and other departments were calling him up, could he call round a bit later on to wherever he had to go to, and, and like I say the poor chap was really getting in a little bit of a, in a little bit of a muddle really because he was trying to do his best for me and he was getting calls from other departments to go and...But that was just that one afternoon. But apart from that one, I, I've no complaints at all. But it's...and so I had the biopsy done and that was it. It's just that one incident. Yeah, if, if they run late then you don't expect, I suppose you don't expect to be treated quite so gently as you would do if you'd been on time sort, kind of thing. I might be wrong to say that, I don't know. Or do you expect to be treated exactly right? You do, you...yeah, well all right Wendy yeah, I take...then he should have done.(p4) *previous bad experience at an OPA- did this affect his decision to call and his satisfaction with the call?*

I thought when I came up erm I saw was it Mr (*name*) or something like that, I found him a bit abrupt, and you, you're in a bit of a state and he said right, these are your choices and erm you think well, how do I know what is the right choice? Yes, I should have read more, I would have had more idea perhaps. Erm...and I, I could have been anybody, I wasn't an individual to him. I was just somebody [wiping or clapping hands] with prostate cancer, you know, here's another one sort of thing. whereas from there erm I was a bit sort of, I don't know, not miffed but slightly unhappy about it and erm afterwards, because my wife was with me, erm (*nurse's name*) was there, and she took us to a side room and sat and chatted to us for ages. And that sort of put my mind back at rest whereas erm your Mr (*name*) didn't put my mind at rest at all and last Thursday I saw Mr (*Urologist*) who apparently will be doing my operation and he was exactly the opposite, you know he, he had time, he treated you as an individual, he talked you through everything, and he even showed me the MRI scan and that was horrible, I don't like looking inside my body. So, you know, Mr (*urologist*) was reassuring, er full of information, and he sounded so competent as well. That, you know, it's putting your mind at rest all the time when you get that sort of treatment, whereas Mr (*name*) didn't do anything to help me from that point of view. (*Nurses name*) did afterwards. (p14) *good and bad experiences*

*so is it the information that helps you feel reassured, or the way it's delivered?*

[sighs] Probably yes, yes. And you do need to be treated as an individual as well, not as just nobody. (p14)

*That's how it felt?*

It did I'm afraid. Yeah.(p14)

Well, it was the way we were told. Which was diabolical. We saw this doctor who went up, because he'd had a swollen testicle and erm that's what we went up for, our doctor had already reassured us that it was only fluid and he's had all these scans and you name it, he'd had it all done. And er this man walked in and as soon as he walked in I thought um, I usually weigh people up pretty well, and his whole attitude was one of I'm in charge, you just wait and listen. Do you know what I mean? And I went to ask him something and he said be quiet, I'm talking about you later. And he went and examined (*husband*). So I said well? He said that's cancer. But don't go home and worry about it, he went. I said excuse me, what sort of idiot are you to say my husband's got cancer and then tell us not to worry? You don't even know whether it's cancer or not yet, do you? No, but it probably is. But then I said you shouldn't say that word until you're absolutely positive, until all those biopsies are done and what have you, then you should not say that word. They say well we're not sure, we're going to do a few more tests to, to see if we can find out what it is, there are ways and means. And I thought that was diabolical and I've never got over it. (wife p13) *bad experience at clinic*

. And he was lovely and I told him our experience. He said well that's not acceptable. I said you're telling me. I said I worked in that caring business for many years and you just don't do it, you don't say it. And erm I said I never want to see that man again. And then when they rang up again for us to go up there I said I'll see anybody, I've never seen the consultant yet, or that other doctor who spoke to us on the phone. We never saw either of those, we saw this lady. But if any time we have to see this other consultant I should flatly refuse. Because he was so arrogant. So arrogant, oh that's cancer, he went. But don't go home worrying about it. I thought oh god...I've lost three of my friends with cancer and that's the last thing you want to hear. Especially with your husband. In that way. Why didn't he just say well, you know, there's an obstruction, we'll do some more tests just to find out what it is, don't worry about it until we find out properly what it is and where it is and what have you. And then you wouldn't even have entered your mind, you know, it could have been anything, it could have been stones, it could have been anything. I don't know. It's just the way he come out with it. And he wasn't even sure whether it was that. Why mention the word cancer if you don't know? You know what I mean?

That was, that was rather upsetting.(p13)

That was upsetting. We both come out of there in tears. (wife p13)

Yeah, it was rather upsetting (p13).

It was the way we were told. (wife p13)

And of course I – I thought, well, you know and you know how you do and you put up with it and then I rang my doctor and she – the district nurse came round and of course I had to have a catheter in for a week and they came and took it out within a week, erm and that felt a lot better but then of course the problem arose again and subsequently I got an appointment on the 24<sup>th</sup> of December and I saw a – a doctor, well I assume he was, I don't know what his nationality was, but he wasn't English, and I tried to explain to him what the problem was and he said well I don't want to know about that. He said you're here for erm – you're in the urology clinic and erm that's it, you know, so he cut me off short and there was another gentleman with him, a tall gentleman, I think he was a nurse, I think. And erm – and he said – he said well you shouldn't have this catheter in, you know, because I still had this catheter in in December. And I had it in for eight weeks. Erm but anyway to cut a – so with that I then – he then said well, you know, he then checked my prostate and that was on the 24<sup>th</sup> December. And of course I didn't hear anything else and then they – before I went out...(p22)

But he did tell you that it was hard on one side, on December the 24<sup>th</sup>.(wife p22)

No, before then (*wife's name*)(p22)

Oh before then? Oh.(wife p22)

Yeah, so he didn't say anything. And then – I then – then they had a word, they talked between themselves, and they said erm I'll, well, you know, they said well we'll give you a prescription for some tablets to relax the bladder muscle or I understood him to say the bladder muscle but subsequently I found it was the prostate, whatever that – you know, I know what it is, and so I went down into the pharmacy with this prescription and I've been on these tablets ever since. So – and I have one a day, and erm...(p22)

You have known that the prostate has been hard on one side for, well, that must be nearly a year. (*wife p22*) *sounding very angry*

And your PSA, - is it PSA – has been high. And it's only just, in November, when he had all this, when it came to light that you've got cancer so you've – he's been having this for just about a year and nothing's been done about it, has it? (*wife p22 angry*)

The events leading up to – to this and of course they had made me an appointment in July, which erm we went on holiday, which I had to cancel, er for a week but then they made another appointment for later on and then they cancelled it three if not four times and of course I eventually saw Mr (*consultant*) in I think October time wasn't it? End of October. (p22)

*You had three or four cancelled appointments?*

Yes, yes we did.(wife p22)

*When he finally got seen by the consultant and referred for a biopsy he had nothing but praise for the consultant BUT ironically he was cancelled due to lack of clinics for leave.*

The face to face erm – face to face consultation that as – I go back to last year, December, when I saw that other man he was absolutely horrible to me and I thought well do I really want this, you know? Which I didn't. But I mean I don't know who he was. You know, I mean he wasn't English, that's all I can tell you. but erm – but I think he was under pressure, you know, because they had a lot to get through and things like that but...there we are. And I ended up having a cystoscopy I think, that's what he put down for me to have and apparently I did go subsequently back and erm I think it was after Christmas wasn't it I had this cystoscopy, and I still had this catheter in and he sort of roared at me about that. so I thought – well, I said it's not my problem, I said I'm – I'm – I'm not a doctor. You're guided by what they do for you aren't they? And if the Dr ( *GP Name*) had said take the catheter out the district nurse would have come and took it out. But obviously she didn't. Uh. (p22)

you know, then that would have, you know, if – if – because what I'm saying we have – I have been a bit in the dark with it. But when, as I say I referred back to Mr (*consultant*), he said that erm the – your team, his – well whether it's your team or the oncology nurse, would be in touch with me. You know, so I mean – but we haven't heard anything, not yet. (p22)

*Okay. What way have you felt in the dark?*

Well erm...when I say felt in the dark erm I just felt that it's quite a lot to take in and I think the time factor again, because I know we had an appointment on Tuesday erm this week at half past nine, well that meant that we had to get up early, which I mean we're up but (*wife's name*) is up but – and to drive up to Norwich, which we did, we left at quarter to eight, and of course we got there about ten past nine I think, which was fair enough, but we didn't see Mr (*consultant*) until half past ten, you had to wait, you know, because obviously he – he's obviously with the time span, I think he's got a lot to do, do you understand my meaning? I think – erm well, that's it. You know, I feel he – if I'd asked the questions I feel he would have answered them, but you're not always familiar with what you need to ask. (p22) *sense of worthlessness also in service improvement, i.e. consultant needs to communicate with us!!!!*

I mean he was all right. He was all right, you know. But I mean when someone is sort of saying I don't want to hear about that you don't know where to look do you? I looked at him, he looked at me, and do you understand what I mean? And then you think crumbs, if I wasn't seeing him

he wouldn't have a job would he? Do you understand what I'm trying to say? (p22) *a lot of damage done at that first appointment*

*can you tell me about how you received your biopsy results?*

I phoned yourself.(p8)

*You phoned?*

Yes, but you weren't there, you weren't available and er...then I did get you later on because you were very busy. But, er, er...so you did come back to me later on and I was told I did have cancer of the prostate. You then told me erm...the various things I had wrong, I know I had something one side and some the other. And the biopsy. And er...you told me PSAs and things like that, and you told me the things but quite honestly it didn't mean nothing to me.(p8) *lessons learnt*

*when you made that call, did it, did you feel you had too much information?*

No, no.(p8)

*Or did you feel you didn't have enough?*

I, I felt I didn't have quite enough.(p8)

So I thought well let me have this MRI. And I was waiting to hear whether or not I was going to have an MRI and er it didn't arrive and the next thing that arrived was my letter to ask me if I'd come here.(p8)

*Right.*

So I thought to myself well, then that seemed to me as if that was more important coming here than me having cancer.(p8) *delay with MRI pre our radiology training and pre protocol approved, relied on Drs to request scans (now been resolved with CNS training and protocol approved).*

And the bad...and, and why I'm saying this is because I, I think if you'd have said to me at the time you've got prostate cancer, but that is now er...you can now have...medical treatment to cure it. and I think even if it weren't going to I think them words would have made me feel a lot better at that time. Because that would have done away with the word terminal. (p8)

Which it might still be but what I'm saying is, and he convinced me that, that they've advanced so far in the treatment of prostate cancer that...I should be possibly to have it cured. So that made me...if I'd heard that when I heard, had the telephone call about my PSA and all this here, the, the medical terms didn't mean too much to me. I knew the word cancer.(p8)



But I didn't know much about all the other stuff. And I wish that you'd have told me that I was, that was treatable.(p8)

### ***SERVICE IMPROVEMENT***

Yeah, straightaway the reassurance should come in, you know, erm...to make people aware that that's, that's not the deadliest of things that could happen to them, you know, if it's caught on time.(P11)

*, is there at else that we could do differently?*

Well, the thing that struck me when I read the pamphlet er about after the biopsy options was er I did notice the one paragraph in it was prepare yourself for bad news, er and I thought to myself well that sounds, you know, all a bit daunting to read that in. it might be a good idea to, to get that bit out of it because I think most people are already that erm they're either going to get good or bad news with the phone call but I don't think you need to really emphasise that. (P11)

Like I remember reading that and thinking oh, prepare yourself for bad news. So you're really winding the mind up to...do you see what I mean?(P11)

maybe a few more tests to be done, you know, something along that lines rather than just saying yeah, that's looking as if you have got cancer, you know. erm, a more softer approach to it because that's, it is a bit of a shock to your, to your mind, especially if you've been fairly well all your life, you know, to hear that word, cancer...(P11)

Only a bit I picked up in the er...[coughing] the er...in the area, you know, the waiting room area, the big clinic area where they're all pushing and shoving, coming and going, sitting down. That, there was a table with bits of paper on it, ambled across to that, looked, noticed it, made sure no one was looking, I'll have that, have a quick shifty and mmm...that's...oh...right, that's...right...I'll have one of those sheets and folded it up and put it in my pocket. I'll look at that later. That's all, that's the only information I had (p15) *service improvement, leaflets+++!*

That's the only thought, maybe, maybe one thing that could be added that if you do get a negative result, because I had a negative, you know, that er this time, or that the point is made that this isn't forever, you know (p15)

*Had you met (nurse) before?*

No.(p22)

*Okay, Do you think that would have made any difference if you had or...?*

I think perhaps it would have been.(p22)

*In what way?*

Well, you know, I'm quite a people person actually erm, you know, I like to be erm friendly, you know, and affable with people, I don't like bad feeling because if you have bad feeling with people you're not at your best are you? (p22)

*So you think it would have helped if you'd had met her before and...*

Oh yes, I think it would have done, yes. Yeah, I think it would have done, yes. You know, because then you feel erm a bit more special perhaps, if you like. If someone takes an interest in you, you think well they're nice. (p22)

*is there anything that we could do differently as – as nurses and doctors when we're giving results or...?*

No, the only thing I think would be if you could meet the lady who was sort of in your care, if you like, I think that would be nice. (p22)

Erm, the bad news that, you know, I, I couldn't speak for how people must feel but I should imagine it must be pretty devastating to someone to get that. But if, I think if in the future people could be told if it is bad news that in a positive way. That's not, you know, that's not all bad. That's, that's what I think would help a lot of people in the future if they did get the bad news to say look, yes you have got some cancer there, but that's, you know, not too far advanced, we can sort it out with maybe radio...you know, I'm sure they can tell how far it's advanced. (P11)

*at the end of it ,it says erm please be aware we may be explaining bad news to you.*

Yes.(p15)

*How, how did you find that? That sentence?*

Very straightforward, very obvious common sense, well of course it would have to wouldn't they? Once you make contact on the phone they can't say oh god, damn it, oh, why...it's awful, oh god, can't slam the phone down. You've made contact, now you've got to see it through. You're, you know, you're on the hook as much as I am.(p15)

*Is, is there anything you, you think that we could do differently for men having their biopsies and their results?*

I think just to give them both options, both choices. Some people no doubt would prefer to erm come to discuss it face to face. Er I think if you can just give the two choices I'm not sure what more you could do. (p16)

*Okay, in an equal timeframe would you say or...?*

I think it would be, yeah, if the timeframe could be brought forward rather than thinking you have to wait, erm, I think I would have still gone with the telephone call but erm my main decision probably was because I wanted to know rather than wait. Well I would have still been probably happy to go the telephone call in my environment. (p16) *also in horses courses*

And that letter say that anyhow, don't it, give you the number to phone and they said you must be aware that that could be bad news.(p18)

*Yeah. What do you think about that sentence, I've had sort of varied feedback about that.*

Well I think it's a good idea because some people would phone in thinking by phone it's got to be good and if that's bad then it's going to hit them harder won't it?(p18)

*That's right, yeah.*

So I think that's good, no, you've got to tell...you've got to tell people that could be like that. It's...when you ring that's what you, you know, you expect whatever they have found to be told don't you? It's no good ringing up and then sort of going crazy because they tell you the bad news. If you don't want to do that you don't bother ringing, you wait until you see your GP or something don't you? But then that's another week or so I expect, I don't know how long it takes for those tests to go through to your GP. (p18)

At the time the waiting is the thing that er is er frustrating and annoying and worrying thing. (p16)

*Mmm. was it, was it okay to have erm...you said you had a morning slot to phone, would you have preferred an exact appointment to phone?*

No. No. That would have been worse, well, for me personally it would have been worse. To think that I had to aim for that particular time erm, to be able to pick my time suited me... (p16)

*To suit you?*

...when I sort of felt more suitable. It's a bit of a build up to it. So to say you have to be ringing at that precise time would be more of a build-up, more anxious, I think.(p16)

*And what, what if we called you at a precise time?*

No, I would prefer to ring, pick my time. .(p16)

*Okay.*

No, I think I'd be on edge all of the while waiting for that to happen, as it was I was at work and able to do some work until I felt comfortable to make that call. Trying to, trying to keep it from your mind, instead of it dominating your mind, if I could work or do something reasonably normal, erm, it helped me remove that worry from my mind as regards the result. And it just enabled me to, when I thought I was ready, to pick up the call and go for it then. .(p16) *also in service feedback*

*If, if we'd have said to you erm, okay, your, after you had your biopsy, you can come up and see us in a week's time, at this time, or you can call us in a week's time, no difference in the time, what would you have done do you think?*

I'd have probably still called. .(p18)

*Would you?*

Yeah. .(p18)

*Why?*

Just I can't see anything difference in calling and speaking to someone on the phone as there is to going in and seeing them. You know. It's probably less pressure actually. .(p18)

*What?*

Less pressure on the phone. Well to me, but yeah. .(p18)

*In what way?*

Well if you've got to go and sit there and they're behind and you're sitting there waiting and you just get...whereas on the phone you pick it up, phone, and you're straight through and you get your result. But you might have to go and sit there 10 or 15 minutes before you get in and then you're worried about, you know, what you're going to be told when you get there. But no, I thought the phone was quite good, that suited me anyhow. I mean some people it might not I suppose. But phone is good enough for me. Yeah. .(p18) *also in disposition and choice*

*And that time span of those two hours or three hours that you're given would, would...was that okay or would you have preferred to have a specific time to call?*

No, I think they've got to do a certain time because some people are probably on the phone longer than others. So you can't actually say five to ten if someone's on at ten to ten and they might still be on there at ten o'clock, if you know what I mean because some people do stay on the phone a lot longer don't they?(p18)

*Uh uh.*

So no, I think you get the timescale, you phone and you get through. (p18)

I think if I could have rung up for this I'd have rung up after the result of the bone scan and then – and then of course I got the appointment with him, then at least I should have had some idea what to talk to him about. but I shall go there now and he'll – and that – and well maybe it will be a shock in the sense that maybe I shall may be a bit confused and may not be able to answer – ask him the things which I should do because of the shock and then I shall come home and think well I ought to have asked him that.(p23)

If they'd have said to me phone up like they did with your side of the business, you know, phone up at half past one to three o'clock on Friday the so and so, if they'd have done that, said half past one today or something, I would have done so. But there was nothing, you just – just the bone scan and I assume that that's just another – and you're working in the – you're – that is another department obviously isn't it, even though the information is fed into your – yeah – but if they'd have said to me er – erm if they'd have said to me yes, right, we'll do the bone scan and of course they said on the erm on the paper – on the letter I got the result will be in x number of days, but if they'd have said to me you can phone up and find out the result erm I would have phoned up. (p23)

*So would you have – if – if the erm bone scan results came through to us would you have appreciated a call to let you know what the result was so that you're prepared?*

Yeah, yeah, I would have done.(p23)

Well that's the only thing, you see, I thought about it, I thought other than that everything has gone well, everything – everyone has done everything well, even with the biopsy nurse, she give me the injection, I had a good talk to her, erm talk this, that and the other then – and then of course when I laid on the thing there when – talking to that nurse, I had a good quarter of an hour and then – and you know...(p23)

But as I say there was no problem. Er she just er I think asked the date of birth to – to – just ensure that I am who I am. And she give it and erm and when – and then afterwards all over, there wasn't – there wasn't really much I could say, she said there's – there's possibly there's

three, there's cancer in two of the biopsies, and erm – and then we went – and then I want to book you in for a bone scan which I'll do immediately. And erm so there wasn't much more I could ask, there was nothing more really I could ask her.(p23)

*whether you'd met the nurse that gave you your results, what difference do you think it would make, if any, if you had met her and you knew the person you were talking to on the phone?*

Oh...well, probably....it might be reassuring if every time you went up there you see the same person, definitely.(p23)

*Right.*

But – but I'm realistic that I know that ain't possible. (p23)

The only thing is what I spoke to you about reference the – when – after coming away from the biopsy and the nurse ushered me away and was talking about one thing and another, giving me instructions to ring up in erm the specific time when – from half past one to three o'clock, if I could have sat down there for, you know, in an office or up the corner, and just sat down momentarily I might well have said – said right, er so and so, so and so, perhaps I thought about asking her but we was walking out and then I thought to myself well we want to get way from here now, you've done your job, but if – that's the only thing I find, well it ain't a fault...(p23) *service improvement*

Yeah, that's the only thing you could have done differently. But saying that you see she may well have had to – she may well have to get that in, get ready for the next bloke to come in, I don't know. But that's the only – that ain't a criticism, that's just a suggestion. (p23)

with what's gone on. Erm I can't – I can't think of anything to improve what you've already done for me. Erm and as I say all the – the nurses and everyone who's erm had any dealings with me over this – over this has been very reassuring and – and er we laugh and joke and erm you know I – I couldn't – I can't – I can't fault anything what's happened at all. And I just erm, you know, I've – I've thought about this interview before you got here to think but I can't – I can't – I ain't got a list because there's nothing I can find wrong. And you've done everything er which er as I say that all the doctors and nurses right from (*place*)right up to the top they've been 100% so there's nothing more and as I say the only thing I said to you about is if I'd had five minutes to sit down when you come out.(p23)

you were going to ring me on, or someone was going to, no, I had, no, I was told to ring you...(p3)

*Right.*

...on Friday 3<sup>rd</sup> September, whenever it was in September.(p3)

*Right, okay.*

Which I did. And er you were busy because you weren't actually where, at the end of the phone. And the secretary said you were out on the floor or whatever, I said okay, erm, I'll ring back and she said yeah, okay, lovely. So it was (*wife's*) day off as well so we went out, came back and I rang again and you still weren't there you were still busy. Erm it was then she said actually, we can't find your...or we haven't got your erm...your notes yet. And I said oh okay, she said but I'll have a word with you and erm we'll get it together and we'll ring you back. I said okay and then you rang me at four o'clock. (p3)

*Right, I remember, yes. It was erm...the results had taken a little bit longer to be reported I think. (had to chase results as weren't showing on the screen)*

*(Bad experience- not how it's supposed to work- Friday 3<sup>rd</sup> was double booked to do clinic and telephone results on own!)*

Just that little bit of waiting. And you've got to wait...you had your biopsy and that and you've got to wait but at least I knew when I got off the table she said ring Wendy on the 3<sup>rd</sup> of whatever it was. I don't know whether it was the 3<sup>rd</sup> or later. But, you know, then I thought oh okay, that's Friday week. (p3)

Yeah.

Or it might have been, might have had it on the Wednesday so Friday week and that's fine. Can't do anything about it. So, fine. But it's when you pick up the phone and you get Wendy's not there. What? (p3) *lessons learnt*

*And how did that feel when you got an answerphone?*

Erm...yeah, I was a bit disappointed in that. Yeah. That is one thing I was disappointed in because erm you know although I wasn't anxious er in feeling, you know, stressed, anxious, er I was curious to know, I wanted to know because erm basically I erm I lead, you know, quite a busy life and this may sound really trivial but I want to, even like now I'm obviously going to find out what sort of treatment I'm going to have, but I want to know so that I can plan around it, even in advance, do you know what I mean? I'm that sort of person that erm I want to sort of...it doesn't matter whether it's good or bad news as long as I know what's happening.(p6)  
*also in disposition*

...I mean I was disappointed that that was an answerphone only because I knew that I had to wait a little bit longer. Er I wasn't disappointed because I thought oh, they're, they're, you know, they're not running the show properly because obviously when you phone up the hospital, when I phone up the hospital, erm, you know, you assume that everybody is working 100%. So you don't expect just to be fitted in but at the same time you're a little bit disappointed because you thought oh, I thought I was going to know. Yeah. So that was a little bit of a disappointment but not much really.(p6) *also in wait and disposition*

*What do you think we could do differently when we're giving out, giving results or diagnosis?*

I, I've thought about this knowing that I was going to come up here. Erm, because what I tried to do was I tried to think of things because I knew that that was going to be a couple of weeks and I think I forget things. But really the only thing I thought of was that erm, what you mentioned before, was the, you know, answerphone situation. But yeah, I don't know whether that would be better or worse or, or indifferent. But that was the only disappointment I had of the whole experience.( P6)

And I think that's because I didn't expect, that's the other thing, that said on there phone between such and such an hour, now you know obviously I didn't think too much about it, so I just thought well if I phone in that time if I get somebody, you know, if I get through there'll be somebody answer me, I think that's what I thought in my head because they were the times I was told. And when I phoned and I got an answerphone I think that's probably what, why I was a bit disappointed because I expected to get somebody. Maybe if it hadn't said that, er maybe if that said that we would get back to you between these hours, or whatever, yeah, I think that's probably why I was disappointed. Yeah. (p6)

And that could have been very useful. Now equally I could have rung one of you. Erm, which I didn't, I chose not to do that because I thought it would...because your mind is a bit of a mix. And there's all sorts of things I wanted to ask and hadn't really thought them through properly. And to be quite frank didn't know enough about the problem erm to know, to ask the right sort of questions. Erm, once I'd got over that subsequent day I was pretty well okay.(p9)

Essentially it's been since, because it was really that was not a lot of point, I knew what was involved in the biopsy and I sort of had a broad vision of what prostate issues were about. And erm I hadn't gone into it in any great depth prior to finding out if there was a problem really. Erm, so once I actually had got it, er well I knew what the score was, I started actually getting into a bit more detail, then of course a lot of information can be horrendous actually. You start reading and you think Jesus! [laughs] This is the end of the line coming, you know, very quickly. I mean you've got to sort of...there are so many websites out there with dis-information almost erm, giving you the horror stories, that you tend...and your mind because of the way



things are, your mind tends to home in on the bits that are the worst rather than on the more positive issues.(P9) *in preparation & death*

*Is there anything...that you think we could do differently?*

Only, only in the sense as I said very early on in this, erm was, was perhaps the follow up phone call, the following day. (p9)

*Mmm.*

Erm now again I appreciate you've got so many people, and er so many things to do, and it, but it might just have been the sort of the friendly voice at the other end of the phone, how are you? I'm sort of all right-ish sort of idea but...er...Is there anything else you need to know or can I help at all? (p9)

*when you said it would have been, it would have been a help to get a call the next day, if you had been seen, I know it's difficult to say because it's all in hindsight and that's not how it happened, but do you think that had you come up and sat down with either one of us or one of the doctors and been told, do you, do you think you would have been able to ask questions more freely? Or...*

Probably because I, I tend to react better when I'm with people and I can actually see them and talk to them and look at people's faces, gauge reactions the same way that you're doing with me Erm, it's the personal bit. Erm, the phone can be very impersonal. Er, so yes, on hindsight, and it's a difficult one but in terms of your research I think it's quite important that my experience would be really erm, having gone through the whole lot, I would probably have preferred to have come up and seen somebody and talked to them. I might not have been able to ask the questions any better than I would have done over the phone initially, but there would have been then somebody that I knew and a point of contact. Who I could then have actually put a name to a face when I picked up the phone. Erm, I mean you all sound very nice which, I don't mean that in a condescending way, erm, and you are, and you're very good, all of you, in the way you come across but it's much better for me to know who you are. Er, it's as simple as that really. So I think yes. See I mean I actually appreciated when I had, prior to the biopsy was when I saw Dr (name) I mean he was great, he was, he was up front, he wasn't, he wasn't pushy, he wasn't erm...he was very factual and he got my wife in as well and said look, this is what he thought the score would be. But you know, it's never sure until it's sure. But not to worry because there's all this and that and the other things we can do. And I thought that was very good. I was very impressed with him actually. Because he did it in a very factual, non-threatening sort of way. Erm, and my guess is that if I'd have seen either you or one of your

colleagues or whoever, that it would have been still as much of a shock but maybe not as...I wouldn't have maybe have got the reaction that I did the following day, I don't know, it's difficult to say really Wendy.(p9)

*Service improvement*

*. I was speaking to another gentleman and he erm or somebody fed back to me it would be helpful to have those good websites on our information when people come up for their biopsy.*

It would, I think it would actually be helpful to have them erm, yeah.(p26)

*Because people search for information at different times it seems, some after they've had their PSA tests and others after they've had their biopsy and it's as you say it's those American sites that people are coming back to me and saying they're a bit, you know, erm not – often not very helpful.*

Well – well I didn't find them helpful I must admit. I dare say there are good ones there, it's just that there are so many bad ones there that, you know, you can't really kind of see the wood for the trees almost.(p26)

*So if we could pick out, pick out the good ones?*

But certainly – certainly the prostate cancer charity one was a good one. I think that's run by Macmillan isn't it? (p26)

*Erm the Prostate Cancer Charity one isn't, no, that's one on its own. Erm but there is a Macmillan cancer Backup one which is also very good.*

Well that's the other one in fact I was put on to afterwards by erm somebody here, actually I can't recall who it was, but I found that one to be – I mean in terms of the quality of information it's nearly the same actually, I mean I found them both to be very good indeed. But yeah, I think it would have been useful and I been pointed at those at an earlier stage I must say. Maybe it was my own GP should have done it actually but if I – come to think of it I mean it's when I went back to him when the results of the biopsy were first available erm I was talking to him about the options and so on erm it was then that he pointed me towards the Cancer Backup, it was he who did it actually, I've just remembered. It wasn't actually – it wasn't here. (p26)

I'd – I felt okay. I mean I felt – I felt I'd been given as much information as I needed at that stage. Erm and I knew from having talked to the erm – the nurse that erm I was going to be in there a week or ten days to see the urologist. Erm and that I would get further information at that stage. And I think probably looking back on it, now you've asked me how I felt immediately after the call, I felt okay then. But I think looking back on it I probably now would ask more questions about the other non-Gleason score stuff.(p26)

saying is you should make the information available to people as soon as it's available to you.(p26)

*Whichever way?*

Yeah. (p26)

Erm I mean if – if – and I don't think it's ever going to be the case but erm – well no, I could see a situation where you could actually say to somebody the information will be available at, you know half past eight on Tuesday morning. Come up and see us at 9 o'clock. If you could do that that would be a better way of doing it but if that wasn't possible then over the phone is to me acceptable. But as I said I'm speaking with respect to somebody who was actually caught at quite an early stage. If it wasn't that I probably wouldn't be saying this to you now.(p26)

*Is there anything else that you think we could do differently?*

Well I think you should make the information available on more than one day, for more than one day and make all the information, have all the information available for more than one day so that if there are lots of supplementary questions and so on they can be answered erm...because in my case I could ring up on the Wednesday and you know as I said some of the information wasn't available. Erm in the event it didn't cause me that much stress or concern, but it might have actually and I think it – I can't quite see why stuff has to be put away if the person doesn't ring on the day in question. That strikes me as odd actually I must say.(p26)

I think it was all done erm pretty efficiently. I mean I've – I don't have any...there's nothing at all in fact I mean that erm strikes me as in need of improvement. I think the timescales were pretty okay, erm might have been maybe a week or two faster, but Christmas intervened and I suppose that inevitably does affect things erm because I'd said at the beginning that I knew I didn't want active surveillance, again it's just not suitable for someone like me actually because I just – I know I'd worry usually about it.(p26)

Because that's the first time I'd had anything to do with it and as I said as soon as the word cancer used...that was what done it. if you'd have been able to phone and you'd have said to me, you know, we're now very, very advanced on prostate cancer and we can cure it, er I think them words would have been superb.(p8) *lessons learnt*

I, I didn't...I suppose I, I...I, because with you telling me that was nothing to do with you. So you, you didn't affect me if you know what I mean. (p8)

That was something, that was something that you'd got to do and you've done it and then as I say I was pleased in the way in which it was done. That was just...that's the personal feeling you can't get of, because whoever had told me that would have been, I suppose, just the same. (p8)

*Right. Do you think it would have been easier face to face for you?*

I'd have felt a lot more comfortable I think. (p8)

I, I, think me personally I, I like if you were now to tell me because see people say any questions? Well, you don't have qu...same when I went to see Dr(*urologist*), he said to me any questions? And I, I, I can't ask questions because that's the future. (p8)

So he said go away and talk to your wife and think about it and then ring back and tell his secretary. Well that was last Monday I went to see, see him and er by the Tuesday I decided I was going to have the operation. I thought to myself well that's there, er, if I have the radiotherapy it's possible it'll come back. And if it aint there that can't do me much harm. That's the way my mind...so I, I accepted to have the operation. So I phoned the secretary and told her I was going to have the operation last Tuesday. And she said to me well I'll, I'll tell him and he'll most probably phone you up. Well I've heard nothing. (p8)

, I, read the letter to say, you know, it may be bad news, well I appreciated all that and er the bad news weren't your fault, so that's why I accepted it easy myself because that, that's, it weren't your fault at all. And er just thank you for telling me. (p8) *backtracking, still under our care, sounding more relaxed though on tape*

My dad, as I say died at 86 from pneumonia. You know, he didn't die from any cancers or anything like that. My brother's got it and he's two and a half years older than me and he's, like everything else, he just has to go once a year for a check-up, you know, they said everything's right but we've got to keep an eye on it, you know. But I didn't know at the time. Anyway, that's another story. Anyway, basically erm waited for Thursday, yeah. Half past one, I rang, I got the answerphone. You can imagine...you know when you build yourself up, that probably last half, probably half hour, to an hour, was really horrible. And I got the answerphone. And I just thought oh no, you know, like I don't want an answerphone. I want to talk to somebody, you know? so I left a message and sat there and sat there, it wasn't that long, I can't remember, ten minutes, I can't remember, I can't remember the exact time, but you know, it's just like you know...it was hours, if you can understand that. Anyway, so I got the result and it was clear. Fine, you know, everything just, you know, as you say, everything comes back to normal, your life comes back to normal. Anyway, I went home on the Friday and on my doorstep was a letter dated the Friday before to say that your autopsy, or your biopsy, was clear. That had been sitting on my doorstep for three days. Now you tell me, I'd gone through that whole week of

worrying have I got it? Haven't I got it? And there's a letter sitting on my doormat. (p12)  
*lessons learnt*

I called from her house, yeah. Yeah. If I'd have known there was a possibility, there's nothing in the letter about possibly a letter going to your home before that time. you know, I'd done that, I got family all round there, they could all have gone round there to look see if there was a letter sitting on the doormat. (p12)

So you can imagine how I felt on the Friday when I went home and saw this letter sitting there stating that everything is okay, fine, there's no, no traces, you know, so that whole probably from I assume Monday or Tuesday, all that pain, all the worry, etc. would have gone. (p12)

Well that's right, it could be, it could be something you could put on the form, erm, where will you be for the next week, you know, it could be abroad or something. They could go on holiday or something, I don't know exactly. But you could say somewhere where will you be for the next week in case we need to get hold of you, you know. I can't remember if I put a mobile number on there or what, I can't remember. (p12)

*what you think we as a team can do differently for people having their results?*

[sighs] It's difficult, it's difficult to say because I don't know the ins and outs of how those results come to you.(p12)

*Just from your, just your perspective.*

Yeah, you know, it's like anything. As you emphasise in your letter everybody is going to be different, everybody is going to look at the situation and handle it differently. You know, some people are strong, don't worry about it and when it happens and then they'll go down that road. You know, some people worry, unfortunately I'm a worrier, you know. It plays on my mind. I try to put it to the back of my mind but it's always coming back forward and I'm thinking about it. so from the point of view of what, from what you're saying, the only thing I can think of is what I said, you know, if you've got this situation where you can ring people, you know, there should be somewhere in the book or somewhere saying where will you be up to that Thursday. That's what I'm trying to say, you know, so that way if you can give people good news, yeah, without...what's the word, you know, penalising the people with the bad news, you know. Can that be done? I know it's, it's labour intensive because you're making phone calls, you know. But that would be nice if it could be done.(p12)

*some of the experts say is that erm if you're giving bad news and you're not giving it face to face you obviously lose all the non-verbal communication. Erm, how did that feel, I know your results were okay, how did that feel on the, yeah, on the telephone, just...?*

I suppose, I suppose if you'd have got bad news that you'd have felt that it was cold.(p12)

*Right.*

You know. It was cold because you got bad news and it's on the telephone. It's not face to face, you know. Er, but how would you get round that? How could you say to somebody we need you to come and see us? Because once you say you've got to come and see us you know there's a problem. So it's not taking that problem away, by saying that, you...that is a very difficult, to me it's very difficult, you know, because...bad news is bad news, whether it's on the phone or face to face. It's still going to make you think god, what's going to happen now, you know. What is the time factor from say somebody ringing you on the Thursday for you making an appointment to see them again face to face, after that?(p12)

*is there anything else that you want to tell me?*

No. That was the major issue, was the letter because it was, it was sitting on my doormat, it's sitting there looking at me saying you're all right, you're all right, you know. And when I got it Friday I just kind of went I don't believe this. How long has this been sitting on my doormat? I'd gone, as my partner wanted, she wanted to kind of protect me, she wanted me to be in people's company, not on my own, in my own house. You know? That would be worse, being on my own, that would have just blown my mind completely. You just need somebody to talk to you and change the subject and, you know...(p12)

*Is there anything that you think that we can do differently as nurses and doctors?*

Erm, I would preface my comment by saying that er I've had nothing but erm kindness and care from the doctors in my surgery and those I met at the hospital. Erm, the one thing that er could be done is to shorten the timescale of....Waiting for the results.(p19)

when the doctor said only go on that site then that's what I did, I just went on the Macmillan site and found that that was reassuring, so if I go on the internet I go onto two sites, I go onto either the Macmillan or I go onto this prostate cancer site. I never go onto any other site because...(p24)

*Would that have been helpful to know that when you came up to clinic?*

Erm, the Macmillan? Yes. (Patient 24)

Possibly. (wife)

Yes, yes, it would have been helpful if they'd said look, all the information is out there if you want to find out but just go to this site, because this is what the doctor said, she said it would be like three men in a boat, you know, that er that you'll look at this and you'll discover almost that the most – the most terrible things and you don't need to know that, just – you just need to know the basic facts and the support that is available. You know, like today, you talking to the both of us is helping us to – to come to terms with this.(p24)

But they were a bit reluctant to say that definitely, but you know, that's the impression that I got. Anyway I had a...think...I went and saw Mr (*urologist*) about the results and he said the clock is ticking for you now and you'll get some appointments for erm bone scan and MRI just to see if there's any spread. You know. And basically that was it really. I, you know, I asked what I thought were the relevant questions because you never ask all the questions at the time, you can't always think of them can you? (P5) *didn't know what to ask, service improvement?*

when I went and saw the...erm, the consultant over the road here, Colney, he was very brisk explaining things. I walked out of there and I cried. I, he'd thrown so much at me, information, and I said to the nurse, (*name*) her name was, I said I've just had overload. I said I can't cope with it. [laughs] I think it, I think that's the first time it really hit me, when he was talking about my treatment and what was going to happen to me. And I think it suddenly dawned on me, you know, this is a bit of a deal, you know. This is not your bog standard cold or you know what I mean, it's...(p5) *face to face feedback but after diagnosis*

## Glossary

**Benign:** no cancer cells

**Bone scan:** Scan to look for spread of cancer to the bone

**BPH:** benign prostatic hypertrophy, non-cancerous enlargement of the prostate

**Clinical diagnosis of prostate cancer** based on high level of PSA AND abnormal DRE

**CNS:** Clinical Nurse Specialist,; within this thesis this abbreviation refers to the uro oncology Nurse specialists who's main role is to provide support and information to patients and their families who have a suspected or confirmed urological cancer. This includes prostate, bladder, kidney and ureters, penile, testicular.

**CRUK** Cancer Research UK

**Curative treatment: treatment** with the intention of curing/ getting rid of the cancer, with prostate cancer this refers to surgery to remove the prostate or radiotherapy usually with hormone deprivation treatment

**DRE:** Digital Rectal Examination, this is an examination via the rectum to feel the prostate. A normal prostate should feel smooth and soft or firm. An obviously cancerous prostate will feel hard and nodular. The DRE alone is not usually diagnostic for prostate cancer.

**Gleason score:** refers to how prostate cells look under the microscope. The cells are given a grade which gives an idea how the cancer may develop. The pattern ranges from 1 to 5 and the 2 most common patterns are added together to give an overall score or grade. It is most common to see grades 6-10. The higher the grade the more likely the cancer will grow quickly and spread.

**HCP:** Health Care Professional, in this thesis this term encompasses all doctors and nurses in primary and secondary care.

**Histology:** refers to cells and how the structures within a cell appear.

**Lymphoma;** cancer of the lymphatic system

**Malignant:** cancer

**MRI:** Magnetic Resonance Imaging, a scan to assess the extent of the disease within the prostate and to look for spread of the cancer outside the prostate

**OPD:** Outpatient Department



**Palliative treatment:** treatment that will not cure the cancer but will control it for a period of time, with prostate cancer this is usually hormone deprivation treatment

**PSA:** Prostate specific antigen. This is a protein that is released by prostate cells when they divide. Therefore every man who has a prostate will also have a PSA level if tested. The PSA can be raised for a number of reasons including normal enlargement of the prostate which is a natural process of aging, a urine infection or infection or inflammation of the prostate, vigorous exercise before a test or ejaculation. Prostate cancer can also make a PSA value higher than normal but this is not always the case. A PSA test alone will not diagnose prostate cancer unless above 100ng/ml.

**TRUS/P:** Trans rectal ultrasound scan and prostate biopsy; performed usually under local anaesthetic as an outpatient. The procedure takes about 10 minutes and the aim is to look for evidence of prostate cancer (to obtain histology).

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