

 **North London Cancer Network  
Patient Survey 2008**

**EXECUTIVE SUMMARY**

PICKER INSTITUTE EUROPE

MAY 2009

# Picker Institute Europe

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count. There are three key strands to our work:

- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

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## Executive summary

North London Cancer Network commissioned the Picker Institute to carry out a survey of cancer patients to gain feedback on the quality of service provided. The survey was conducted in October 2008 - January 2009, using a postal questionnaire. A total of 1,390 patients returned a questionnaire. The response rate from 'eligible' patients was 51%.

### **PART A. FINDING OUT WHAT WAS WRONG WITH YOU**

Eight out of ten patients had seen their GP about their condition before attending hospital.

54% of patients reported that they were seen by a specialist within two weeks of being referred by their GP, 25% were seen 2 weeks-one month later and 21% more than a month later. Three out of ten patients (31%) thought they should have been seen sooner. Twenty-three percent of patients felt that their condition worsened while waiting to see a specialist.

Eight out of ten patients thought that the GP care was excellent/good, 10% rated it as fair and 11% as poor.

Around a third of all respondents (35%) could remember being offered a choice of hospital for their first hospital appointment.

One in two patients (53%) indicated that they would have found it of benefit to have had access to advice and support from a nurse with specialist experience in their disease when they were first referred to hospital. A fifth of all patients (19%) indicated that they didn't know/not sure whether or not they would have found such a service of benefit.

51% of patients reported that they knew the name of their key worker. 62% thought it was the CNS and 25% identified the hospital doctor.

97% of patients reported that they were first told what was wrong with them in person and thought that the face to face delivery of the diagnosis was the right approach. Most patients (89%) reported that a hospital doctor was present to deliver the diagnosis or in support. A CNS was present for 32% of all patients.

Three out of four patients (74%) understood the explanation of what was wrong with them and felt that the explanation was delivered in a sensitive manner.

Nine out of ten patients (92%) indicated that they wanted to ask questions about their condition and that they had received answers that they could understand.

Six out of ten patients (61%) reported that they had received an understandable explanation of the different treatment options for their condition. 20% of patients had an

explanation, but this was only understood to some extent and 14% of patients said that no explanation was given to them.

Eighty percent of patients indicated that during the diagnosis, they had felt involved (as much as they wanted to be) in discussions about their treatment. Only 26% of patients reported that they had received a record of the discussion that occurred at the diagnosis.

Two out of three patients (66%) recalled being given printed information about their condition/treatment. 73% felt that the information was easy to understand. However, one in four reported that they only understood the information to only “some extent” or not at all. Nine out of ten patients indicated that it covered all the areas they felt it needed and that they had received about the right amount of information.

## **PART B. OUTPATIENT TREATMENT & APPOINTMENTS**

Three out of four outpatients (76%) felt that they had been given sufficient time to discuss their health problems with the doctors or nurses. However, a quarter of outpatients reported that in their experience this was only true to some extent.

The majority of patients (83%) had complete confidence and trust in doctors and nurses and felt that they had been treated with respect and dignity.

91% of patients felt that the frequency of their outpatient appointments was about right.

Eight out of ten of patients (82%) indicated that they had received an understandable explanation about the possible treatments.

74% of patients had discussed and fully understood the explanations about the side effects of the treatment. 15% of patients understood some of the explanation, 7% said that there was no discussion and 3% reported that they did not need to have this explanation.

Most patients (83%) felt that the doctors and nurses listened to what they had to say during the outpatient appointment.

96% of patients wanted to ask the doctor/nurses questions. All those who wanted to ask questions felt that they had the opportunity to do so.

95% of patients felt that the doctors who treated them knew enough about their condition or treatment. Nine out of ten patients (91%) said that in their experience the nurses and other healthcare staff knew enough about their condition and treatment.

94% of those who wished to involve family/friends reported that they had the opportunity to do so.

Around half (53%) of all outpatients received copies of letters sent from their hospital doctor to their GP. 31% of patients had not received any letters, and would have liked to have them.

Sixty-four percent of outpatients recalled being given printed information about their condition/treatment. 81% felt the information was easy to understand and 92% thought it covered all the necessary issues.

## **PART C. YOUR MOST RECENT OVERNIGHT STAY IN HOSPITAL**

56% of inpatients recalled being given the name of their Clinical Nurse Specialist.

Most inpatients (89%) who knew their CNS had wanted to ask questions. 85% of patients received understandable answers.

84% of patients reported that they had complete confidence and trust in their CNS. 77% of patients had complete confidence and trust in all the doctors who treated them. A fifth of patients (21%) reported that they only had confidence and trust in some doctors.

Almost all patients (94%) had questions that they wanted to ask their hospital doctor. 77% of patients received understandable answers.

91% of patients indicated that they were always treated with respect and dignity by their doctors.

The response from patients on the subject of staffing levels was similar for doctors and nurses, with around seven out of ten patients reporting that in their experience there were always enough nurses on duty.

79% of patients felt that the nursing staff always treated them with respect and dignity.

72% of patients received an explanation of their condition which they were completely able to understand. A discussion about the operation was held with 96% of patients.

Almost all patients (97%) wished to discuss the possible side effects of the operation/treatment. A discussion was held with most patients (87%).

Two out of ten patients (22%) felt that staff gave conflicting information about their treatment/condition.

78% of patients felt involved as much as they wanted to be in discussion about their care and treatment. 14% of patients reported that they felt involved, but only to some extent and 8% said that they were not involved.

For those who wanted to involve family members or close friends, 88% said were able to do so, while 12% said they were unable to do so.

Most patients (93%) received an explanation from a member of staff about how the operation/treatment had gone. Seventy-three percent of patients said that they completely understand the explanation.

78% of patients felt that the amount of information they received about the outcome of their treatment was about right. Approximately a fifth of patients (22%) indicated that they would have liked more information.

Before leaving hospital, around half the patients (47%) who had stayed overnight were treated by an occupational therapist, physiotherapist, speech and language therapist or a dietitian.

38% of inpatients remembered being given printed information about their condition or treatment. Eight-three percent of these patients reported that they found the information to be easy to understand. Almost all inpatients (94%) thought that it covered the necessary issues.

Three out of four inpatients (76%) were in pain all or some of the time during their hospital stay. Of those in pain, 72% thought that the hospital staff always did everything they could to help control the pain.

Four out of ten patients reported having other symptoms all, or some of the time during their hospital stay. 61% of patients thought that the hospital staff always did everything they could to help the patient cope.

#### **PART D. LEAVING HOSPITAL**

Seven out of ten patients (72%) felt that staff spent the right amount of time to explain what would happen after they left hospital. 16% of patients reported that not enough time was spent explaining the next steps and 12% of patients indicated that they did not have any explanation.

Six out of ten inpatients (59%) remembered being given printed information about what they should or should not do after leaving hospital. Nine out of ten patients thought that this information was easy to understand and that it covered all the necessary issues.

Two out of three patients (66%) felt that the staff had taken full account of their home situation before sending them home. 34% of patients thought that their home situation had been taken into account, but only to some extent/not at all.

53% of patients felt that it would have been useful to discuss what additional help they might need in order to resume activities such as household chores or returning to work. A discussion and help was provided for 56% of those who wanted it, with a further 13% of patients having the discussion about support took place, but the help did not materialise. 31% of patients did not get the opportunity to discuss their need for support regarding day to day activities.

Half of all inpatients (49%) said there was no discussion with hospital staff about the need for any nursing or support from other health service providers after leaving hospital.

Ninety-two percent of inpatients reported that they had been told who to contact if problems arise after discharge from hospital.

More than half of the inpatients (56%) said that they did not receive a written record of their consultation with the doctor about their condition or treatment.

Four out of five patients (79%) said that they required healthcare staff to look after them after leaving hospital. The main sources of assistance were the patient's own GP (48%),

CNS (32%) and Community/District nurses (28%). 90% of patients reported that this healthcare met their needs “very” or “fairly” well.

26% of patients did not know if they had 24 hour access to medical advice, support and treatment and 17% thought it was unavailable.

Six out of ten patients (59%) were in pain after leaving hospital. Of those in pain, 88% thought that they had been prescribed sufficient medication or help. After leaving hospital, most patients (84%) thought that they had received adequate treatment for any other symptoms of their condition.

Most patients (79%) said that after leaving hospital they felt involved in decisions about their continuing care, as much as they wanted to be. A fifth of patients would have welcomed more involvement.

## PART E. OVERALL

Eighty-six percent of patients felt that NHS staff worked closely together all or most of the time and 95% of patients felt that the overall quality of care and services offered to them was “excellent”, “very good” or “good”.

92% of patients considered the overall quality of information about their condition and treatment to be “excellent”, “very good” or “good” and 86% of patients indicated that they had received about the right amount of information about their condition and treatment.

The majority of patients (87%) indicated that they wanted emotional support during treatment. Three out of four patients (74%) who required support indicated that this was given all or most of the time.

Four out of ten patients (39%) said that they had needed help to cope with anxiety and/or depression. Around half these patients (47%) were asked by staff about their anxiety or depression.

Overall, 34% of all patients had received information about services offering psychological/emotional support. 16% of patients would have liked information about these services, but had not received any.

Thirty-six percent of all patients were given information on complementary therapies. Twenty-two percent of all patients had tried complementary therapies. Forty-five percent of patients who tried complementary therapies had found them to be “very useful” and a further forty-three percent had found the therapy to be “quite useful”.

Approximately half of all patients (47%) had been told about patient support groups for people with their condition. Support groups would definitely have been of interest to 13% of all patients, with a further 34% probably interested.

Twenty-three percent of patients were given information before they had left hospital about financial or other benefits to which they might be entitled. 32% of patients did not receive information and would have liked it, while the remaining forty-five percent of patients were not given information, but were not interested in receiving it.

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