

Patient Engagement Report

28 Day

Faster Diagnosis Standard

Title	Patient Engagement Report for 28 Day FDS Project
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Purpose	Evaluate patients experience of the current cancer pathway
Date	17/10/17
Version	V5

Appreciation

Our thanks are extended to our partners in the Cancer Services User Group (CSUG) who have offered their time to contribute to this report in many ways. Their continued effort has ensured that the questionnaire and interviews were a success. I also want to thank Cancer Research UK Facilitators for their continued support to the programme.

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Executive Summary

The 28 day Faster Diagnostic Standard (FDS) pilot project seeks to explore how best to deliver a new cancer waiting time standard. This standard proposes that once an urgent referral for suspected cancer is received from a GP or dentist the patient is provided an outcome of diagnostic tests within 28 days. Ipswich Hospital has been selected as one of five hospitals across the country to pilot this standard evaluating two specialities, Gynae Oncology and Colorectal LGI.

To ensure patients are at the centre of any improvement initiative, a consultation with patients who had previous experience of cancer pathways took place. This patient engagement was divided into two phases:

Phase one: Patient questionnaires and one to one interviews

The aim of this phase of the patient engagement was to gather feedback from patients to support the work being undertaken by colleagues across the trust and our partners in the CCG towards improving the patient pathway and experience.

Methodology

A questionnaire was circulated to patients who have had an experience of a cancer pathway irrespective of the tumour site. This approach allowed us to gather a wide range of feedback.

The questionnaire was developed with input from members of the FDS engagement team and the NHS England national insight team. The questionnaire had 4 sections:

- Your experience with your GP
- Your first hospital appointment
- Diagnostic testing
- Getting your results

The questionnaire was available on online or by hard copies distributed to:

- Woolverstone day unit
- Radiotherapy day unit
- Cancer patients in the post
- Gynae support group.

Patients from both Gynae and Colorectal pathways were interviewed. Six interviews have been conducted for colorectal patients and these were carried out by Ipswich Hospital staff, Volunteers and Cancer Research UK Facilitators.

A representative from the Cancer Service User Group attended a Gynae support group meeting. Patients were engaged in an interactive open exchange to gather information on their experience of the pathway.

Recommendations will be made after Phase two of this consultation process.

Themes to take forward to Phase two are:

- Patients concerns and recommendations regarding the 28 day pathway
- How patients are informed about their diagnosis/cancer exclusion
- Information throughout the patient pathway
- Role of GP before and after diagnosis.
- Communication

- Patient awareness
- Continuity of Care

Phase Two: Further consultations

70 of the patients who completed questionnaires said they would be happy to speak to a member of staff, while 24 patients would be interested in being involved in a forum or focus group to discuss their experience further.

The patient engagement forum was held on 23rd September at Ipswich Hospital. There were 26 patients invited to the forum of which 13 indicated an interest to attend the forum and 6 attended on the day. 2 patients attended the forum with a carer; their input gave an insight into their experience. The CCG Cancer Lead, the Ipswich Hospital Trust Cancer Clinical Lead and Nursing Director were available to provide clinical input. We also had support in facilitating the forum from Ipswich Hospital staff, Ipswich Cancer Services User Group Volunteers and Cancer Research UK Facilitators

Following the completion of the forum these are the recommendations:

- Include a training course on communication for - clinicians, nurse specialists and booking clerks on patient pathway
- Consider the inclusion of a more diverse group of patients not captured in the course of patient engagement exercises carried out. A wider more diverse group of patients need to be engaged to ensure their views are fed in to the 28 Day FDS pilot
- Arrange the integration of all cancer pathways including those activated by the cancer screening programmes and other hospital routes. Ensure that the patient information is clearly visible on the GP and hospital patient record.
- Patients should always be told that somebody was welcome to accompany them to appointments and that this is encouraged
- Patient information leaflet should be produced in more than one language

PHASE ONE: PATIENT QUESTIONNAIRE AND INTERVIEWS

1. RESULT OF QUANTITATIVE ANALYSIS

We received 107 completed questionnaires, with the majority completed by patients in the Woolverstone day unit and the radiotherapy day unit of the hospital.

1.1 Demographics

Age:

The majority of the participants were of the age range 50 – over 75, with 77 participants falling into this category.

Response	Count	Percentage
Not answered	19	18%
Under 18	0	0.0%
19-35	3	3%
36-50	8	7.5%
51-65	23	21%
66-74	31	29%
Over 75	23	21.5%

Gender

The table below provides a breakdown of participants' gender

Response	Count	Percentage
Male	49	45.79%
Female	51	47.66%
Rather not say	7	6.54%

Sexual orientation:

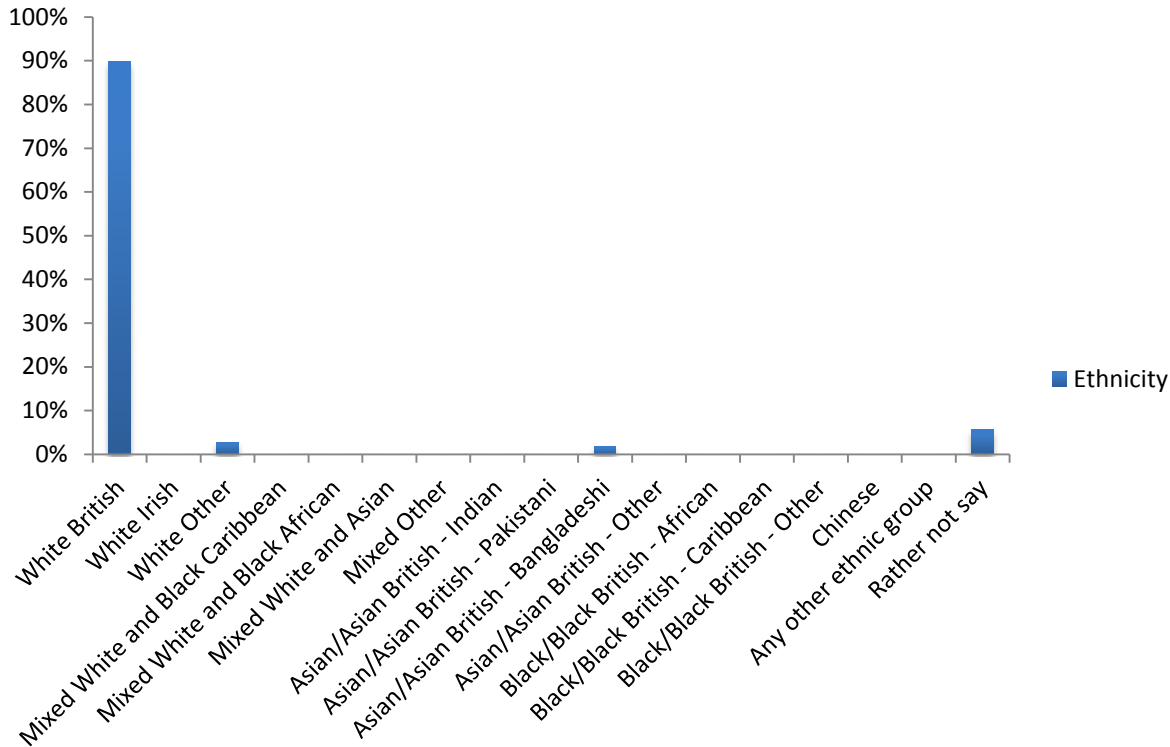
The table below provides a breakdown of participants' sexuality

Response	Count
Heterosexual / Straight	90
Gay man	2
Gay woman	0
Lesbian	1
Bisexual	2
Other	0
Rather not say	12

Ethnicity:

90% of the patients who participated were white British. It is important to note that Ipswich and its environs has a population of 90.5% white British

Ethnicity



1.2 Survey Questions

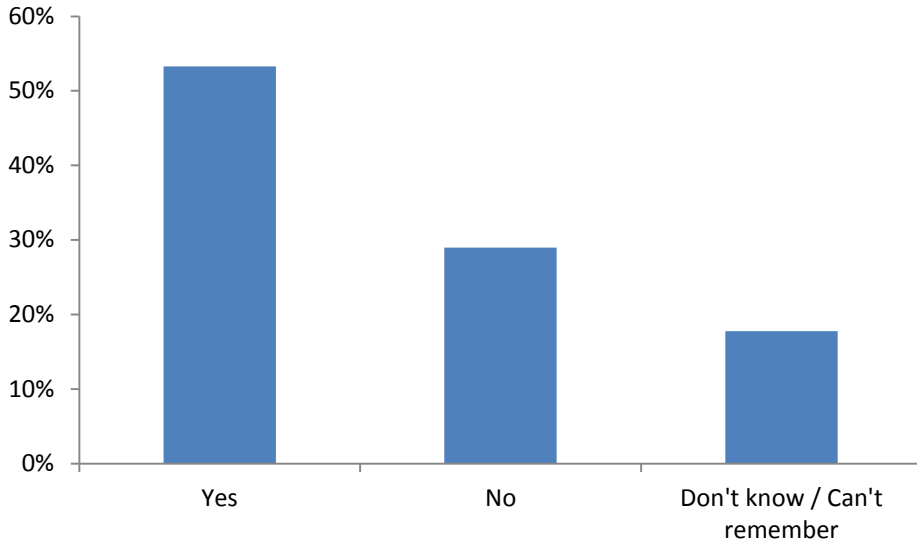
The survey was categorised into the following four sections

- Your experience with your GP
- Your first Hospital appointment
- Diagnostic testing
- Getting your results.

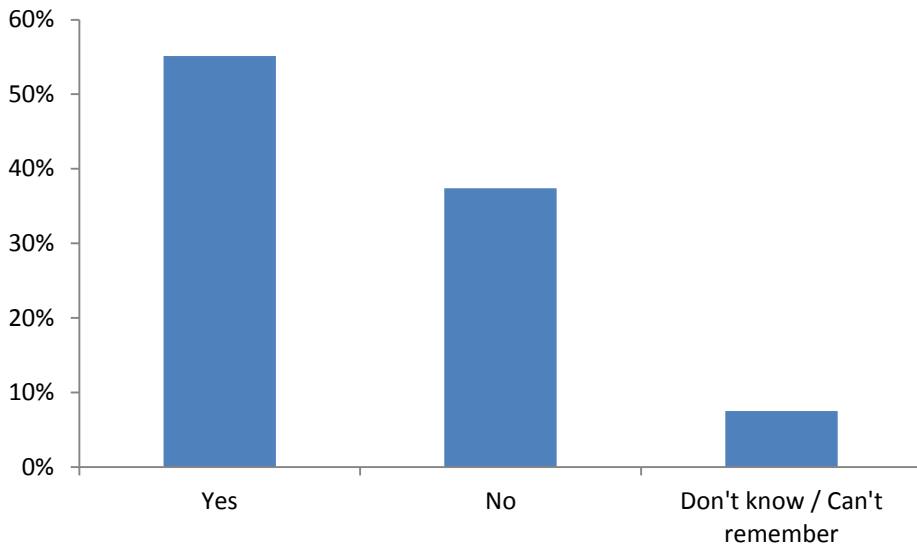
Section 1: Your experience with your GP

Four questions were asked in this section, the results are as follows:

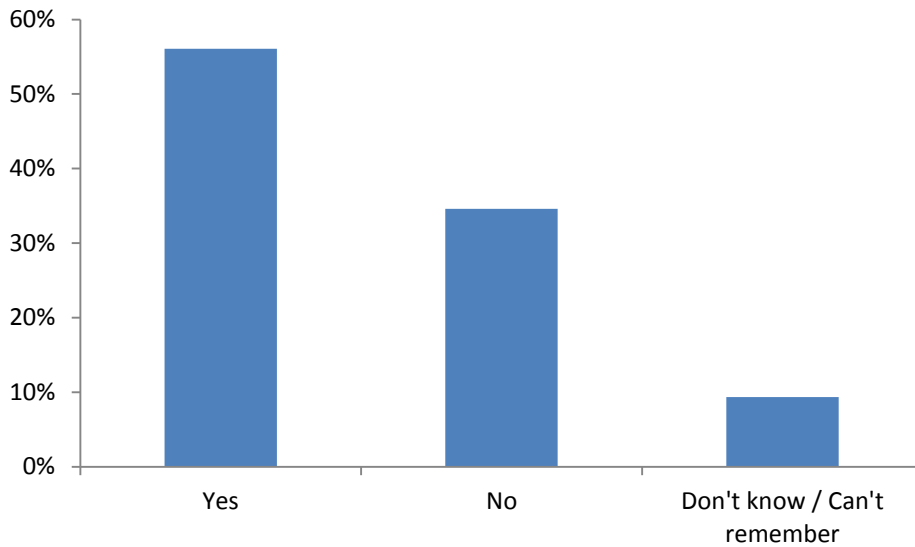
1. Did your GP explain that you would be given a hospital appointment within two weeks?



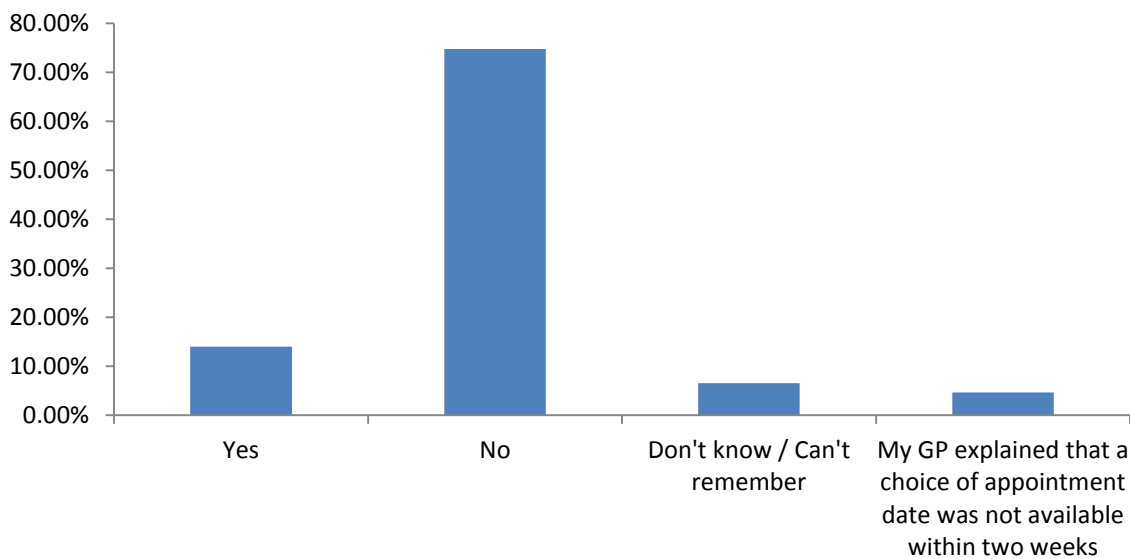
2. Did your GP explain that your referral related to the investigation of cancer?



3. Do you feel your GP gave you all of the information you needed before your first hospital appointment?



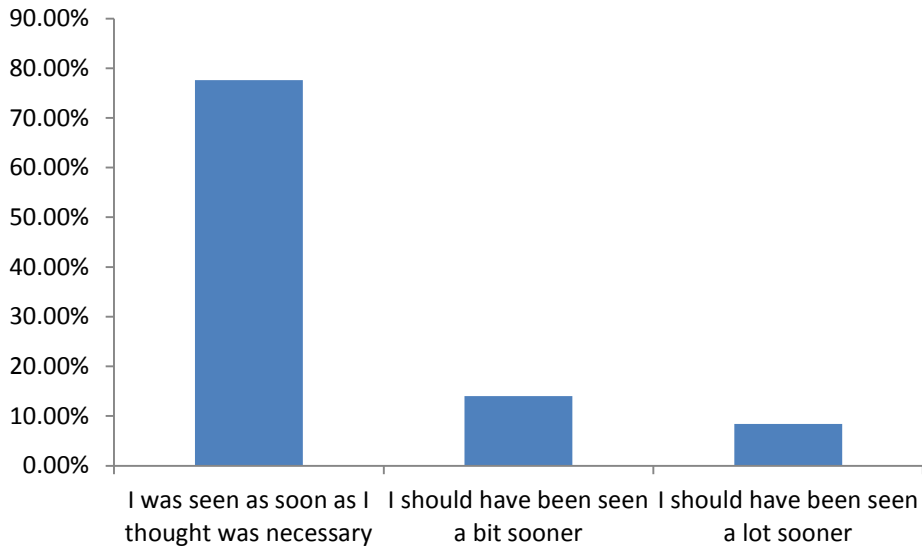
4. Did your GP offer you a choice of hospital appointment dates?



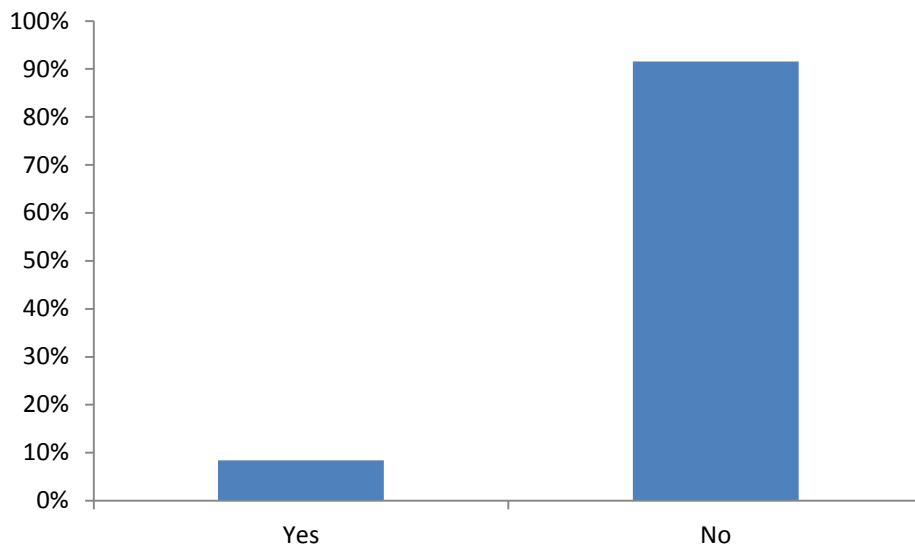
Over 53% of the participants in the survey said their GP explained that they needed to be available for a hospital appointment within two weeks. The hospital receives referrals from patients who go on to rearrange their appointments. It therefore means time is lost before the patient starts the pathway and seen by a consultant. This usually has an impact on the overall time it would take to process the patient through the pathway.

Section 2: Your first Hospital appointment

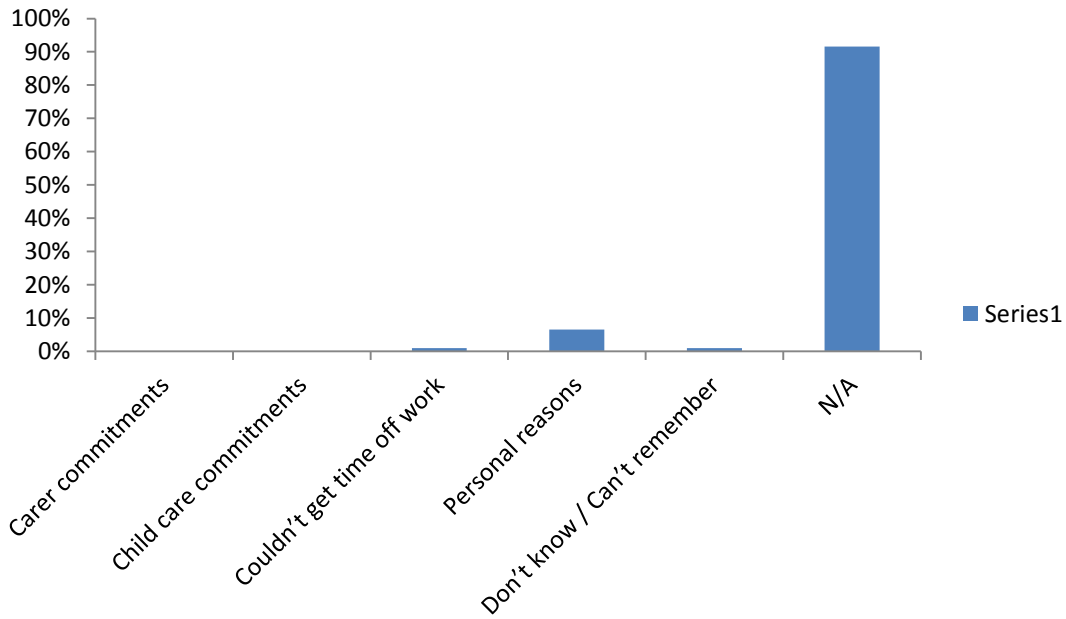
5. How do you feel about the length of time you had to wait before your first appointment?



6. Did you rearrange your first hospital appointment?

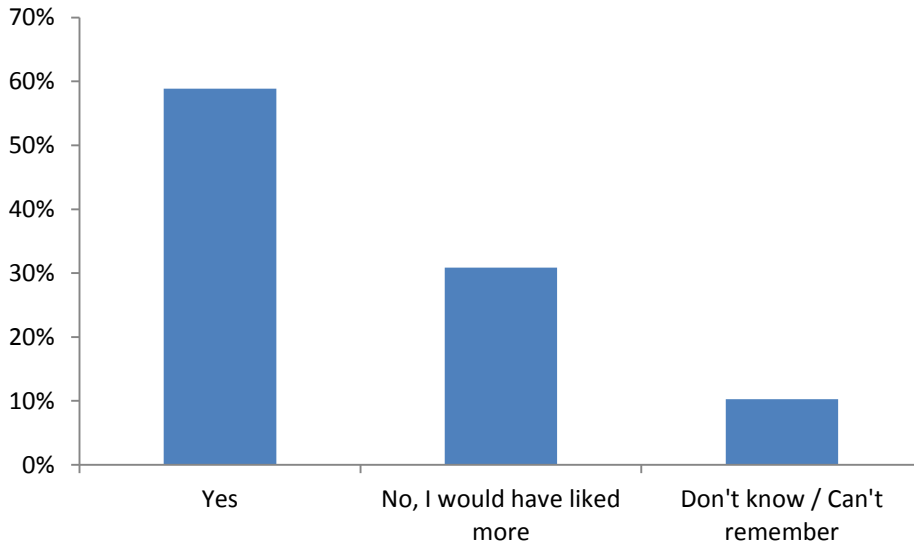


7. What was the reason for rearranging your first hospital appointment?

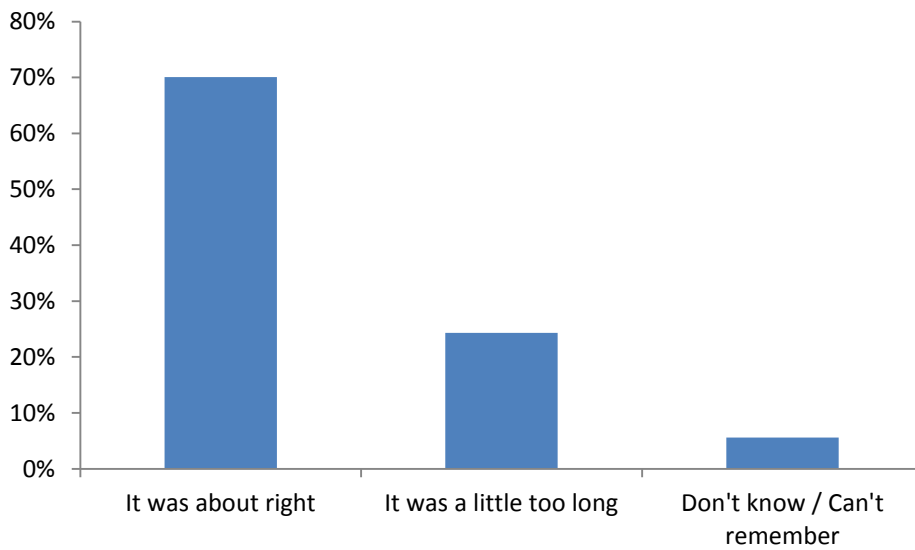


Section 3: Diagnostic testing

8. Before undergoing investigations did you have all the information you needed about your test?

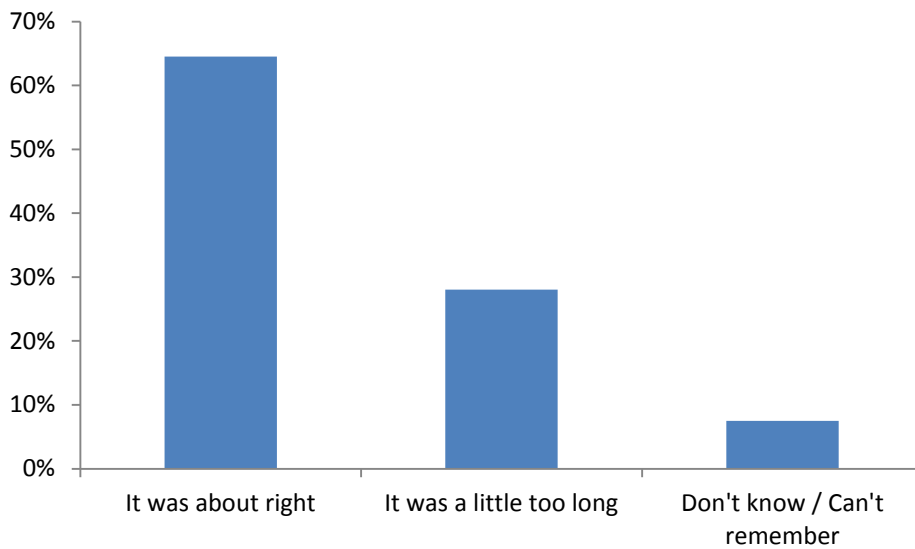


9. How do you feel about the length of time you had to wait before your diagnostic tests were carried out?

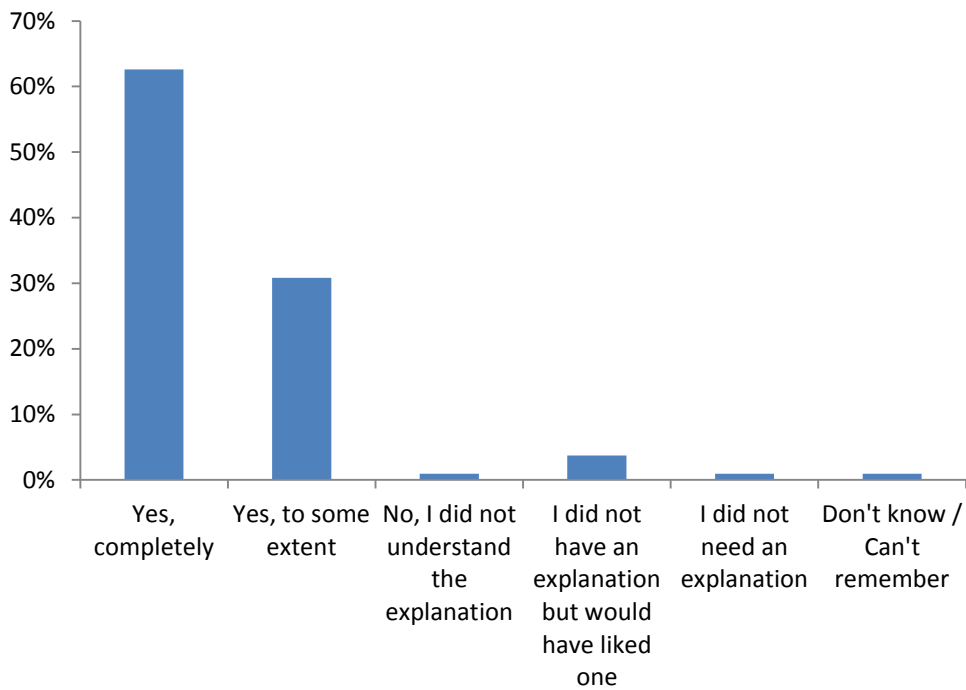


Section 4: Getting your results

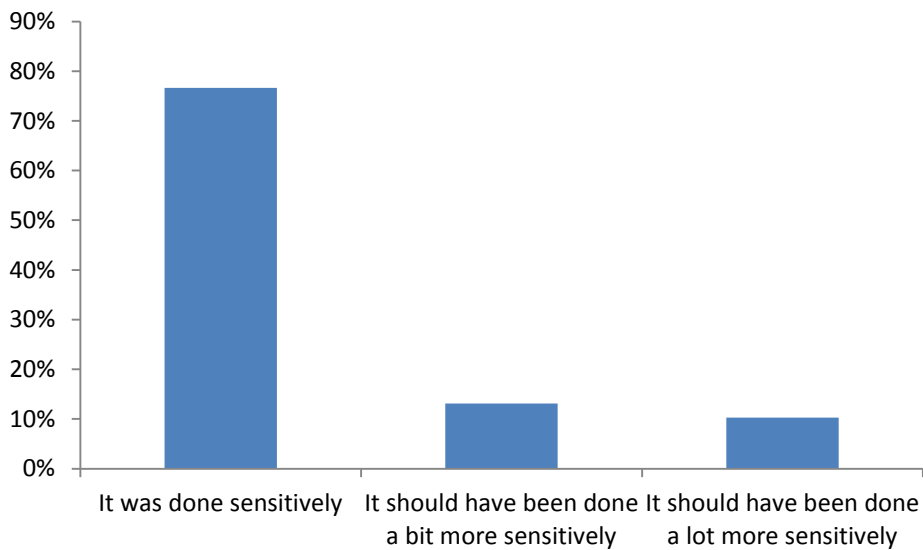
10. How do you feel about the length of time it took to receive your results?



11. Were the results of the test explained to you in a way you could understand?



12. How do you feel about the way you were given the results?



How patients are informed about their diagnosis/cancer exclusion

Getting an unexpected cancer diagnosis over the phone and then not having any support or contact from anyone for two weeks was not a nice experience to go through. I felt totally alone. I had to arrange my own scan and consultant's appointment two weeks later and I didn't really know what I was doing.

I had to wait an incredibly long time before results were given to me - and they were posted! I had to wait about 6 weeks over the Christmas period although I had been told it would be 10 days. This was about three years ago. It was the most stressful period of my life.

Poor discharge planning Told of terminal illness with no relative present to support me Felt very upset and alone I am now terminally ill.

My results appointment was brought forward by one week because of a cancellation. I was not told and thought it was bad news so I had an anxious week.

Administrative services, I actually received a letter telling me I had an appointment with Oncology, days before the consultant told me I had cancer!

When they told me I had cancer I feel it should have been more private than on my ward bed and with a friend/family member with me.

I was told I had rectal cancer. Locum was helpful but then I left his room and I was all alone in the corridor in complete shock

On the actual day that I was given the news, I was kept waiting for nearly an hour. The nurse said the "consultant wanted to see you himself" I was stressed by this

I was alone when I got the news I had cancer. I was sent out into the waiting room and was so shocked I went and sat in the chapel no one told me that the Macmillan support centre was 250 yards away

Information throughout the patient pathway

The Hospital needs to explain the type of cancer to their patients better.

Not enough information about implications of radiotherapy beforehand I should have been offered alternatives

A little bit more explanation about having a Pet scan

Suitable waiting rooms/environment

It would be better not to wait so long as everyone in the waiting room is anxious and you pick up on each other's nerves and some people become irritated.

Ambience of mammography waiting room! I spent a long time there and it was very gloomy and overcrowded.

Role of GP before and after diagnosis

A GP should have never ignored my symptoms!!

Much better GP care/after care and support. Awful experience trying to get blood tests/prescriptions. Awful, Awful, Awful!

Better GP - to hospital referral

Awareness that my symptoms could be indicating cancer should have been recognised earlier.

Felt I was passed off by my GP although I made several visits with my symptoms

That my GP took the problem more seriously as despite several attempts I was told there was no problem when I was finally referred I was then told I had cancer.

2. RESULT OF QUALITATIVE ANALYSIS

2.1 Interviews

Two sets of interviews took place; six colorectal patients were interviewed at the hospital and six Gynae patients were interviewed at a local support group.

All Patients had the 28 day Faster Diagnosis Standard explained to them. The questions asked mirrored those in the questionnaire. Patients who were interviewed by Cancer Research UK Facilitators (CRUK) had the role of a Facilitator explained to them and were asked if they gave their consent to go ahead with the discussion. The interviews provided an opportunity to explore questions from the questionnaire further. It provided us with a set of themes that we intend using to shape further discussions in the second phase of the patient engagement.

2.2 What people were saying?

Below is a summary of the themes generated from the feedback:

- Communication
- Appointment and Waiting Times
- Technology
- Equipment
- Supporting Information and Guidance
- Patient awareness
- Continuity of Care

Communication

From feedback gathered, communication was divided into two categories:

- Communication with GP
- Communication with the Hospital

- **Communication with GP:**

The outcome was mixed, as some patients interviewed mentioned that although their GPs were supportive they did not communicate the reasons for their referral. The Gynae support group were cautious for early use of the word “cancer”, especially during their first appointment with their GP. One comment from a member of the group was that:

“It would just worry me more”

This needs further exploration in the second phase of engagements.

Bouncing backwards and forward to the GP was an issue for two people. One had had a chest X-ray and the cancer had been suspected then, she went on to say:

“But I had to go back to the GP to arrange a CA 125 test. No explanation was given of what that was for but suddenly an appointment the same day at the hospital.”

- **Communication with the Hospital**

Feedback received was mixed, one colorectal patient describing the communication provided to him as:

During tests *“Very caring and kind staff who kept him informed throughout”*

Consultant appointment *“He went into great detail and was very informative”*

Receiving results His wife was with him for the results and felt involved and supported.

The comments from the Gynae support group were less complimentary.

“There is no privacy in the older areas of the hospital”

“The waiting rooms are stressful - surrounded by people who may be tearful and by notices like ‘Just been diagnosed? – here’s a cancer support group’”

In regards to the duration it took the hospital to communicate to patients following their first appointment there was noticeable inconsistency in the duration patients were told they would receive either the outcome of their results or follow up appointments.

A Colorectal patient was told:

“Biopsy results would be sent in 3 – 4 weeks maximum.” The reality was that a letter with results was received at 8 weeks”.

Appointment and waiting times

From the feedback gathered it was determined that patients would like the option available to book a GP appointment a few weeks ahead. Most found that the availability for appointments only in the current week is difficult especially if they have work and other commitments. Examples are:

“Everyone at work then wants to know what’s happening.”

“You can’t walk in and see a GP – I had to see a male Practice Nurse”

Cancelled appointments and difficulty in getting through on the phone were issues raised by one patient however the same patient commented on the excellent support and information provided by her nurse specialist in relation to tests

Another patient said that:

“She felt she attended unnecessary appointments to be told what was going to happen next then had to wait for that appointment.”

This patient also said *“she then had to wait for a CT scan appointment, when she phoned the colorectal department they told her she should phone the CT team to chase it up.”*

While another Colorectal patient had a different experience. She said:

“Following my first appointment at Ipswich Hospital, and with an examination and blood results available, a scan was to be arranged. This appointment was received within 24 hours.”

Technology

Patients found that the inability to book a routine GP appointment online was very inconvenient. With the advent of the digital age, this was seen as a setback. One of the patients interviewed felt GPs had improved very recently but there was some degree of concern about the lack of flexibility in booking an appointment at their GP

Equipment

When asked what their experience of scans was, patients responded that they were being informed of what the procedure would entail and were provided information prior to a test being carried out.

Supporting Information and Guidance

Most patients interviewed indicated that they had some form of information provided to them when they came into contact with the hospital. This was either in the form of the next steps or information about the tests being undertaken.

Patient awareness

Most patients interviewed initially delayed visiting a GP. One patient did not feel the need to visit the GP as their symptoms weren't anywhere relating to cancer. One interviewee thought it was a stomach bug that wouldn't go.

Another patient said:

“I didn't want to have to make a big thing and say I'm worried it might be cancer but to be able to run it past someone more informally first. In the end I did that – with my rheumatism nurse - but then she suspected it might be my medication and changed that for a trial period leading to more delay.”

Continuity of Care

A patient interviewed said that the experience with the GP was unhelpful.

“GP unhelpful and wanted to send me back to A&E – I felt like no-one wanted to take responsibility for my care.”

A comment made by a patient was that they

Rang the 'pink card' again and one nurse took up his fight with GP and insisted the GP deal with it – GP then accommodating but this was a poor experience.” There was a lack of ownership for reviewing the patient's care

Another patient had been told many times that her consultant had changed. There was no consistency of care. One patient had their consultant changed after surgery and didn't feel the same level of connection.

3. NEXT STEPS PHASE TWO: FURTHER CONSULTATIONS

70 of the patients who completed questionnaires said they would be happy to speak to a member of staff, while 24 patients would be interested in being involved in a forum or focus group to discuss their experience further.

The patient engagement forum was held on 23rd September at Ipswich Hospital. There were 26 patients invited to the forum of which 13 indicated an interest to attend the forum, however 6 attended on the day. 2 patients attended the forum with a carer; their input gave an insight of their experience. The CCG cancer lead, the Ipswich Hospital Trust Cancer Clinical Lead and Nursing Director were available to provide clinical input. We also had support in facilitating the forum from Ipswich Hospital staff, Volunteers and Cancer Research UK Facilitators

Included in each theme below are patient quotes from interviews and the survey carried out earlier in the project. These quotes provided a steer in the development of themes which were taken forward to the patient forum.

Theme 1: Role of GP before diagnosis/cancer exclusion

Patients quote

"Awareness that my symptoms could be indicating cancer should have been recognised"

- Patients do want to be told about referral for a possible cancer diagnosis in a sensitive manner
- Patients do want to see the same GP if possible with the system flagging patient history and treatment status

Theme 2: Information throughout a patient's cancer journey

Patient quote

"The hospital needs to explain the type of cancer to their patients better"

- Patients do not want to know about cancer waiting times but they do want to know about time frames
- Patients would like a clear plan for follow up
- A Clinical Nurse Specialist or other professional should always be present when a diagnosis is delivered and should be available to answer questions and offer support afterwards – where this is not possible follow up processes should be in place

Theme 3: How patients are informed about their diagnosis/cancer exclusion-including suitability of waiting rooms and time waiting.

Patient quote

"I had to wait an incredibly long time before results were given to me –and (when) they were given to me - they were posted! I had to wait 6 weeks over the Christmas period although I had been told it would be 10 days. It was the most stressful period of my Life"

- Patients want to be reassured that things are being done to secure the best possible outcome

- Patients should always be told that somebody is welcome to accompany them to appointments and that this is encouraged – Director of Nursing was interested in this being included in all patient appointment letters, not just for cancer referrals
- Clinicians should ask patients if they have any questions at the end of an appointment
- Information is very important and patients want it in a timely fashion, not all at once. This could be followed up with written information, possibly frequently asked question sheets and signposting to reliable websites. Any written information should be easy to read and available in multiple languages

Theme 4: Your concerns and recommendations regarding the 28 Day Faster Diagnosis standard including issues such as time waiting for appointments and results

Patient quote

“Waiting for results after 3 wks I phoned the hospital, eventually got a call back asking me to return the next day (26 days after the biopsy)”

- Patients suggested that the 28 day FDS should be communicated clearly from the beginning of the pathway
- Patients would prefer a highly visible flag on patients GP records to highlight to the GP, who may not have seen the patient before that they are being treated for cancer or have been treated in the past.
- Patients want a clear follow up plan with possible timeframes where possible

4. RECOMMENDATIONS

Following the completion of the forum these are the recommendations considered to explore

- Include a training course on communication for - clinicians, nurse specialists and booking clerks on patient pathway
- Consider the inclusion of a more diverse group of patients not captured in the course of patient engagement exercises carried out. A wider more diverse group of patients need to be engaged to ensure their views are fed in to the 28 Day FDS pilot
- Arrange the integration of all cancer pathways including those activated by the cancer screening programmes and other hospital routes. Ensure that the patient information is clearly visible on the GP and hospital patient record.
- Patients should always be told that somebody was welcome to accompany them to appointments and that this is encouraged
- Patient information leaflet should be produced in more than one language

APPENDIX

28 Day Standard Patient Questionnaire

GP

1. Did your GP explain that you would be given a hospital appointment within 2 weeks?
 Yes
 No
 Don't know/can't remember

2. Did your GP explain that your referral related to the investigation of cancer?
 Yes
 No
 Don't know/can't remember

3. Do you feel your GP gave you all of the information you needed before your first Hospital appointment?
 Yes
 No
 Don't know/can't remember

4. Did your GP offer you a choice of hospital appointment dates?
 Yes
 No
 My GP explained that a choice of appointment date was not available within 2 weeks?
 Don't know/can't remember

First hospital appointment

5. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?
 I was seen as soon as I thought was necessary
 I should have been seen a bit sooner
 I should have been seen a lot sooner

6. Did you re-arrange your first Hospital appointment?
 Yes (continue to question 7)
 No (go to question 9)

7. What was the reason for re-arranging your first Hospital appointment
 Carer commitments
 Child care commitments
 Couldn't get time off work

- Personal reasons
- Don't know/can't remember

8. How do you feel about the process of rearranging a Hospital appointment?

- It was very easy
- It was quite easy
- It was neither easy nor difficult
- It was quite difficult
- It was very difficult
- Don't know/can't remember

Diagnostic Testing

9. Before, did you have all the information you needed about your test?

- Yes
- No, I would have liked more information
- Don't know/can't remember

10. How do you feel about the length of time you had to wait before your diagnostic test(s) were carried out?

- It was about right
- It was a little too long
- It was too long
- Don't know/can't remember

Getting Your Results

11. How do you feel about the length of time it took to receive your results?

- It was about right
- It was a little too long
- It was too long
- Don't know/can't remember

12. Were the results of the test explained in a way you could understand?

- Yes, completely
- Yes, to some extent
- No, I did not understand the explanation
- I did not have an explanation but would have liked one
- I did not need an explanation
- Don't know/can't remember

13. How do you feel about the way you were given your results?

- It was done sensitively
- It should have been done a bit more sensitively
- It should have been done a lot more sensitively

14. Was there anything particularly good about your experience?

15. Is there anything that could have been improved about your experience?

16. Would you be happy to be contacted to discuss your experience with a member of hospital staff? Yes

No If Yes, Please fill in your details below:

Name: _____

Contact number: _____

Email Address: _____