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Archwilydd Cyffredinol Cymru  
Auditor General for Wales

# NHS Waiting Times: Summary Analysis of Patient Surveys



WALES AUDIT OFFICE  
SWYDDFA ARCHWILIO CYMRU





I have prepared and published this report in accordance with the Government of Wales Act 1998 and 2006.

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# Introduction

- 1 This report sets out the findings of surveys carried out as part of our review of waiting times for elective care in Wales. The key messages from the surveys are incorporated into our main report. However, we also want to provide more detailed insight into patients' views and experiences for those with an interest. This report follows the structure of the surveys, which was designed to mirror the process of being on a waiting list from first referral through to treatment and discharge.
- 2 We conducted two surveys to understand patients' experience of waiting for NHS treatment. We sent a postal survey to a random sample of 900 patients who had undergone one of three procedures as an elective patient during October and November 2013. The procedures were cataract surgery, surgery to remove the gall bladder (both high-volume procedures with a high number of elective admissions), and catheterisation of the heart (a high-volume diagnostic procedure). We also conducted a shorter online survey targeted at patients who had undergone a planned operation in the last three years.
- 3 Four-hundred people responded to the postal survey (a response rate of 44 per cent), and we had a higher number of responses from people who had a cataract operation and from people who were residents of Aneurin Bevan Health Board, Abertawe Bro Morgannwg University Health Board and Betsi Cadwaladr University Health Board areas at the time. The findings of this survey have been analysed to see whether there are any relationships between responses depending on the procedure patients had, where they live, the level of involvement they had in decisions about their treatment, the level of information they received, whether they experienced cancellations and the length of time they waited. In most cases, the numbers are too small to be statistically valid and further work would need to be done to understand the relationships between different groups of patients. Where findings are statistically significant, confidence levels are given.
- 4 There were 95 valid responses to the online survey<sup>1</sup>. More people living in Cardiff and Vale, Aneurin Bevan and Abertawe Bro Morgannwg Health Board areas and people aged 35 and over responded to the survey. People who responded to the online survey had undergone a range of operations.

<sup>1</sup> One hundred and four people responded in total but nine people had their operation more than three years ago and have been excluded from the analysis for this reason. Responses have not been recorded as percentages due to the low numbers.

Part 1

Referral to see a specialist



## Who made the decision to refer you to hospital?

1.1 The majority of heart (73 per cent) and gall bladder (67 per cent) patients were referred to hospital to see a specialist by a GP. Cataract patients were most likely to have been referred by someone else (60 per cent), usually an optician or eye specialist.

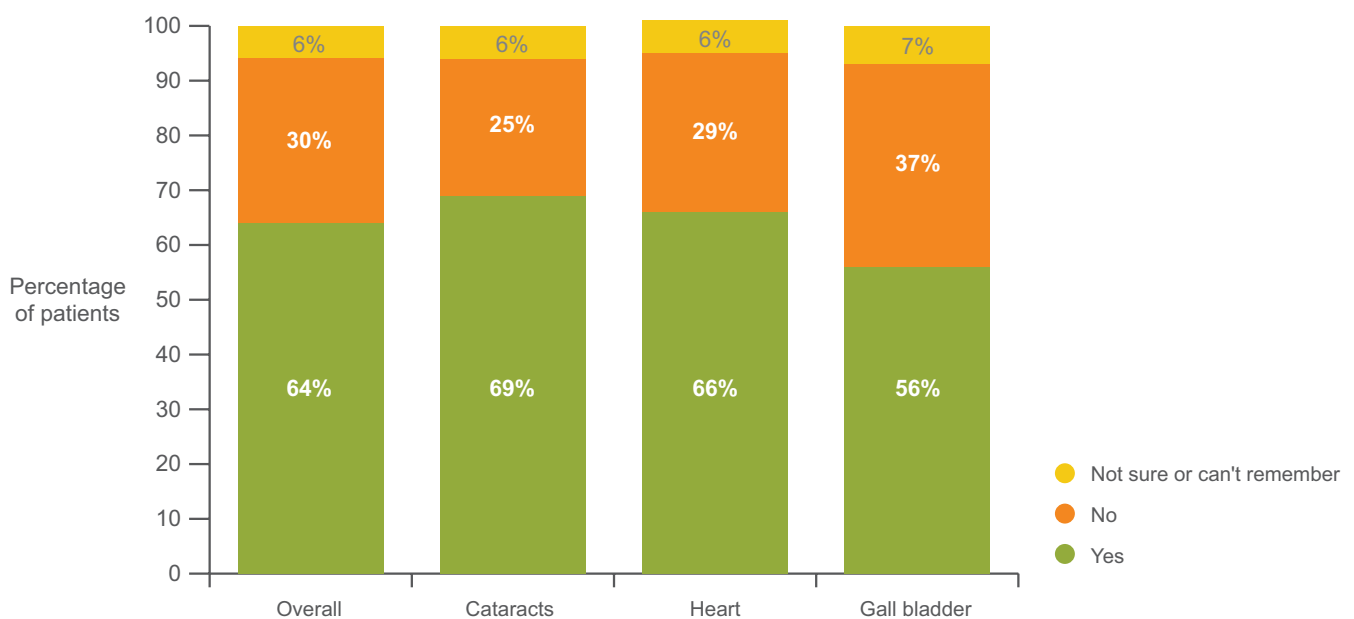
## Were you involved in the decision to refer you to see a specialist in hospital?

1.2 Most patients from the postal survey said that they were involved in the initial decision to refer them for treatment (70 per cent said they were definitely involved and 18 per cent were involved to some extent).

## Did anyone explain how long you could expect to wait to see a specialist?

1.3 The majority (64 per cent) of patients in our postal survey said that they were given information about how long they could expect to wait to see a specialist when they were referred for treatment. Around a third of patients told us that no one gave them this information. Gall bladder patients were the least likely of the three sample groups to say they received information on waiting times (Figure 1).

Figure 1 – Did anyone explain how long you could expect to wait to see a specialist at the point of referral?





## Were you given information about how your waiting time to see a specialist could be affected if you could not attend appointments?

- 1.4 We asked patients whether they were given information about how their waiting time would be affected if they:
- a told the hospital they could not attend appointments;
  - b failed to attend appointments without telling the hospital; and
  - c were not available for an appointment for more than a two-week period.

Many patients in our postal survey reported that they did not receive information about the implications of missed or cancelled appointments and holidays on their waiting time. Around a third said that no one explained what would happen to their waiting time if they cancelled or failed to attend appointments. A higher proportion (40 per cent) said that no one explained what would happen if they were not available for an appointment for more than a two-week period. One patient told us that they were placed at the bottom of the waiting list when they failed to attend an appointment.

I admit this was my own fault. Several months later I called the hospital to ask about my appointment and was told my name had been completely removed from the list.

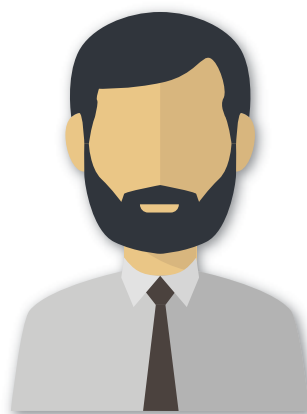
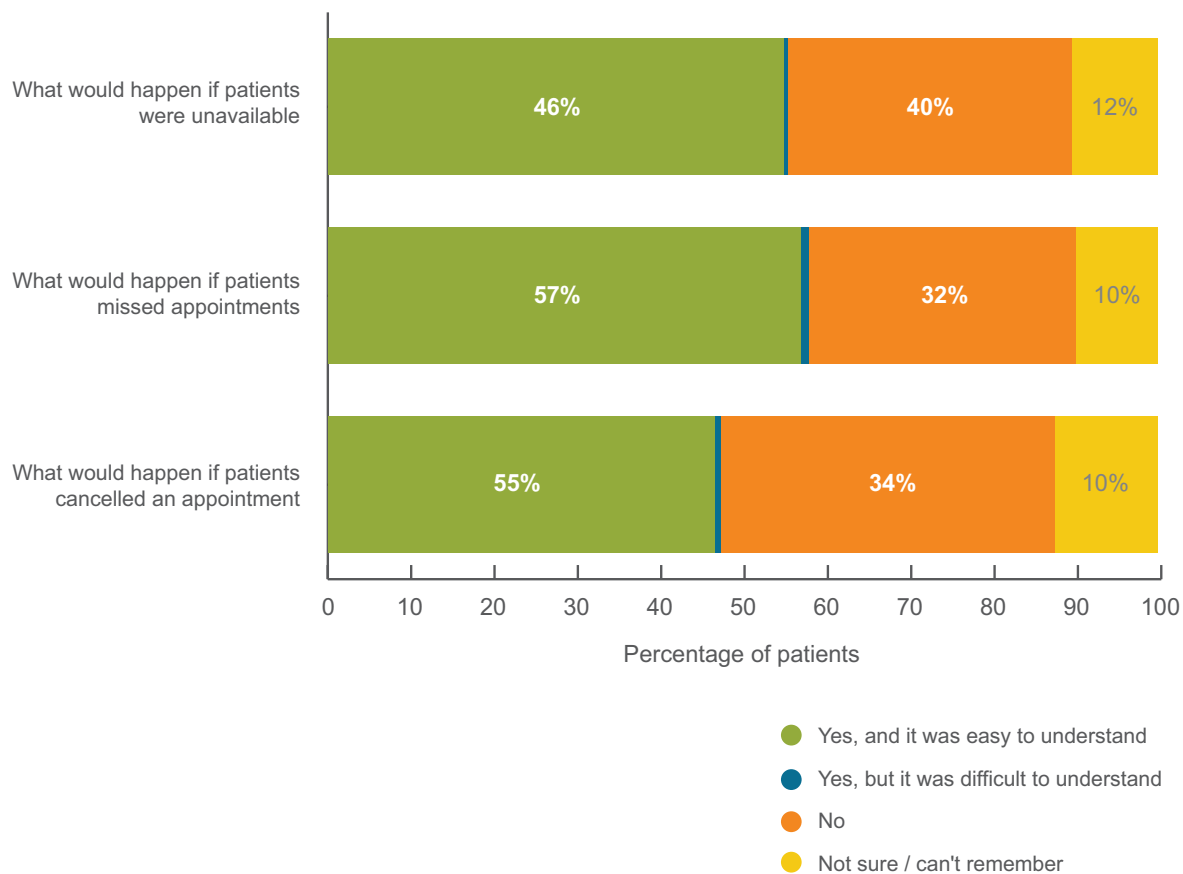


Figure 2 – Were you given information about how your waiting time could be affected?



**Whilst you were on the waiting list to see a specialist, did the hospital contact you at any point to find out whether you still needed an appointment?**

1.5 The majority (71 per cent) of patients in our postal survey said that the hospital did not contact them at any point to find out whether they needed an appointment. Patients waiting for cataract surgery were most likely to say they had been contacted by the hospital.

Part 2

Outpatient appointments



## On the whole, how convenient were the dates and times of your outpatient appointments?

- 2.1 Most patients in our postal survey found the dates and times of their outpatient appointments either very (55 per cent) or quite (41 per cent) convenient. One person commented on their 'excellent' experience of being a virtual patient<sup>2</sup>:

If this service, out of house GP, surgical assessment unit and day surgery unit were not available I feel I would have waited much longer for surgery.

Another patient praised the staff for their flexibility:

The secretary was really helpful whenever I rang with a query or to discuss new operation date. Very understanding about my job as a teacher needing to be sorted first.



## Were any of your outpatient appointments changed to a later date by the hospital?

- 2.2 The majority (79 per cent) of patients in our postal survey found that none of their outpatient appointments were changed to a later date by the hospital. Only three per cent of patients said that their outpatient appointments were changed to a later date more than once.

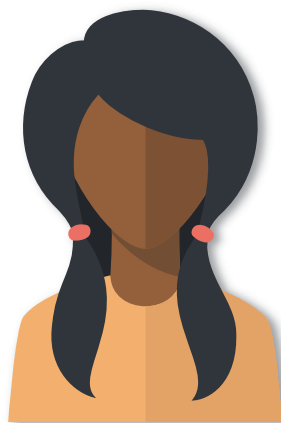
<sup>2</sup> This patient did not tell us what being a virtual patient means. Our *Compendium of Good and Promising Practice* includes examples of virtual models including virtual outpatient clinics where patients are assessed remotely using photographs or the results of diagnostic tests and can then be booked into the relevant outpatient clinic.

## Did you fail to attend any of your appointments without telling the hospital?

2.3 Only a very small number of patients in our postal survey said that they cancelled or failed to attend an outpatient appointment (less than four per cent).

One patient remarked:

I would always attend appointments made for me. I would not think of not telling the hospital if I could not attend due to an emergency. It is unthinkable I could not keep an appointment.



## Were you involved as much as you wanted to be in decisions about your treatment?

- 2.4 We asked patients in our postal survey whether they were involved as much as they wanted to be in decisions about their treatment after they had been referred to a specialist. Most people felt that they were either definitely involved (69 per cent) or involved to some extent in decisions about their treatment (20 per cent).
- 2.5 People who responded to the online survey were less likely than postal survey respondents to say that they were involved in decisions about their treatment. Around a third of the online respondents said that they were not involved in decisions about their treatment, but would have liked more involvement. Some people told us that doctors did not take the time to discuss treatment with them:

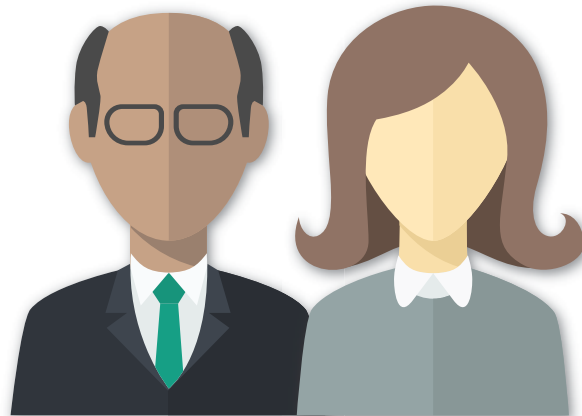
Risks and benefits explained by my wife, not by consultant – or maybe they were and I couldn't hear – being deaf due to the delay in surgery and all...

No discussion whatsoever.

Doctors didn't take the time to explain the process to me properly. Appointments felt rushed. However nurses were a lot better and the receptionists were brilliant.

Other online survey respondents complained about having to chase hospitals for progress on their referral:

I had to ring to get any progress on the referral and appointments, no one ever contacted me to progress my care or explain the process and waiting times involved.



## Patient comments about outpatient appointments

2.6 Some patients made comments about the inconvenience of travelling to appointments or treatment, particularly if this was in another county:

Because I had to go outside my county to have my eyes done sooner, this meant I had to have someone to drive me to Aberystwyth and pay for two people to stay overnight as I had to report back to the clinic the following morning. Also two journeys to Cardigan for follow-up appointments so this cost me quite a lot of money.

The most inconvenient part was that I had to stay overnight in a hotel near Morriston and take my wife with me to drive me back home (which many people cannot do) and the consultant involved works five minutes walking distance from where I live. I don't suppose that I can claim the money for travel and hotel stay!

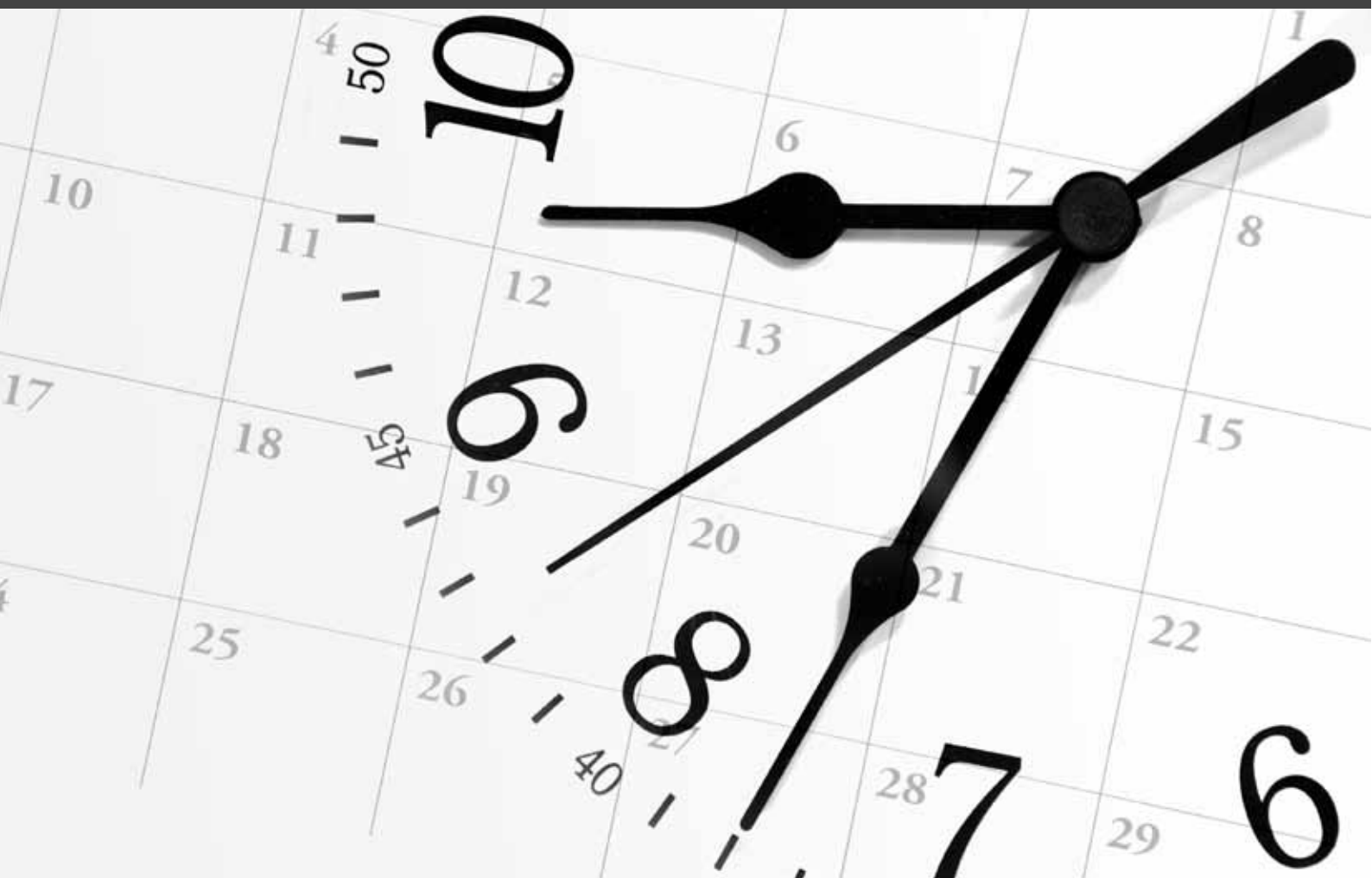
Other patients were happy to travel for treatment if it meant that they were treated sooner:

Brilliant pre-op service at day hospital – incredibly flexible. Also attended new hospital well away from home to get shorter time and this was a truly excellent experience.



# Part 3

## Waiting for treatment



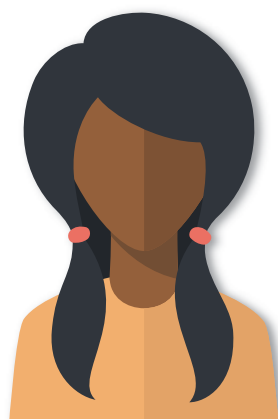


## Did anyone explain how long you could expect to wait for your operation?

- 3.1 The majority (74 per cent) of patients in our postal survey told us that they were given information about how long they would wait for treatment once the decision to operate had been made. However, 21 per cent of patients did not have a clear idea of how long they would wait for their operation at this point.
- 3.2 Several patients said that they found it difficult to get information about how long they could expect to wait.

One person said:

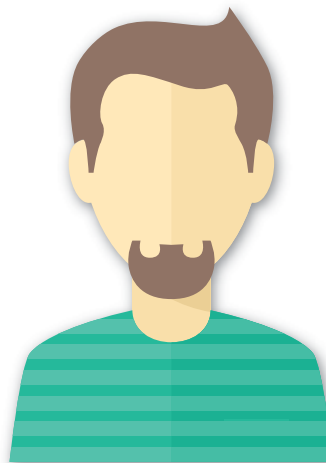
I was not always aware of when my surgery date was – I phoned the surgeon's receptionist and they said I was not yet on the list and that they would call back. They did not call back. I phoned again a week later and the receptionist was surprised that I had not received a letter to tell me my surgery was scheduled for three days' time.



Another person expressed frustration at having to 'constantly chase' appointments and an admission date. Some patients told us that they found it difficult to plan their lives around waiting for treatment because they did not know how long they were likely to wait.

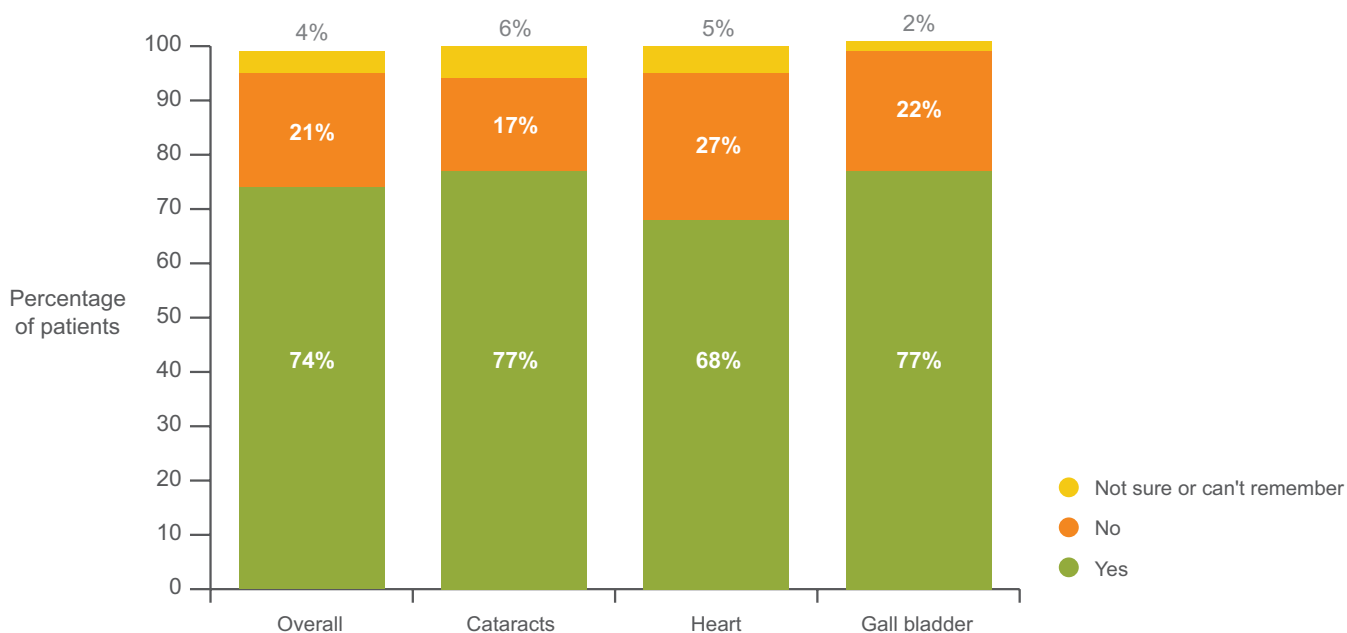
One person said:

During the waiting period no indication was given as to whether we were moving up a list or whether the original time stated was likely to be longer or shorter. As a result a lot of decisions regarding family and personal life were put on hold.



3.3 Patients waiting for the catheterisation of the heart procedure were least likely to receive information on how long they would wait after the decision to operate had been made.

Figure 3 – Did anyone explain how long you could expect to wait for your operation after the decision to operate had been made?



3.4 Some of the respondents to the online survey made comments about the lack of information patients receive on waiting times:

I thought communication about when my operation would be was poor and the timescales indicated of when I could expect to receive the medical intervention were inaccurate and misleading. I was also frustrated that the intervention was eventually scheduled, after waiting 14 months, on my Birthday.

You are never given any idea of the length of the waiting list. GPs don't know and are often surprised and horrified at the amount of time patients are left waiting in pain. It's simply not good enough.

Several people who responded to the online survey told us that they felt that information on waiting times is being manipulated:

I was unable to get a definite date for the operation, always told 'in the queue', 'by October' etc. Until I made a formal complaint when I discovered: A) Consultant I was allocated to was a cancer specialist and it appears I (and others) were waiting for him to have a free session. B) Appointments staff had been trying to be "helpful" but the result was I believed I was being lied to. C: The claim that I was central to the issue was totally the reverse as to change surgeons would have meant going to the back of another surgeons list. To summarise the wait was at the limit of the target waiting time, made worse by dishonesty and manipulation of information.

Eight months for a pre-op, then I was cancelled because of hypertension, put back on the list after a month and told I now have to wait ANOTHER 52 weeks to be seen again, I feel this is manipulating the RTT figures.



## Was your operation changed to a later date by the hospital?

- 3.5 The majority of patients in our postal survey (84 per cent) said that their operation was not changed to a later date by the hospital. However, 16 per cent of patients experienced a cancelled operation, and a small number of people had their operation date changed four times or more. Gall bladder patients were most likely to experience a cancelled operation (25 per cent compared to 16 per cent overall).

## If your operation was changed to a later date by the hospital, what reason did they give?

- 3.6 Patients in our postal survey were most likely to say that their operation was changed to a later date by the hospital because there were not enough beds (21 per cent). Eleven per cent of patients were not given a reason for the cancellation and 10 per cent of patients were unfit for surgery.

Part 4

Admission to hospital



## Did your operation take place the first time you were admitted to hospital?

- 4.1 Most patients in our postal survey had their operation the first time they were admitted to hospital (90 per cent). Ten per cent of patients were sent home the first time they were admitted to hospital. This was twice as likely to happen to gall bladder patients.

## If the hospital sent you home the first time you were admitted to hospital – what reason did they give?

- 4.2 Patients who were sent home without treatment the first time they were admitted to hospital were most likely to say that this was due to a lack of beds (21 per cent) or that they were unfit for the operation (21 per cent).
- 4.3 Some of the patients who experienced cancellations described a frustrating experience:

It was difficult being deferred so often due to lack of beds, as arrangements at home had to be cancelled and rearranged each time.

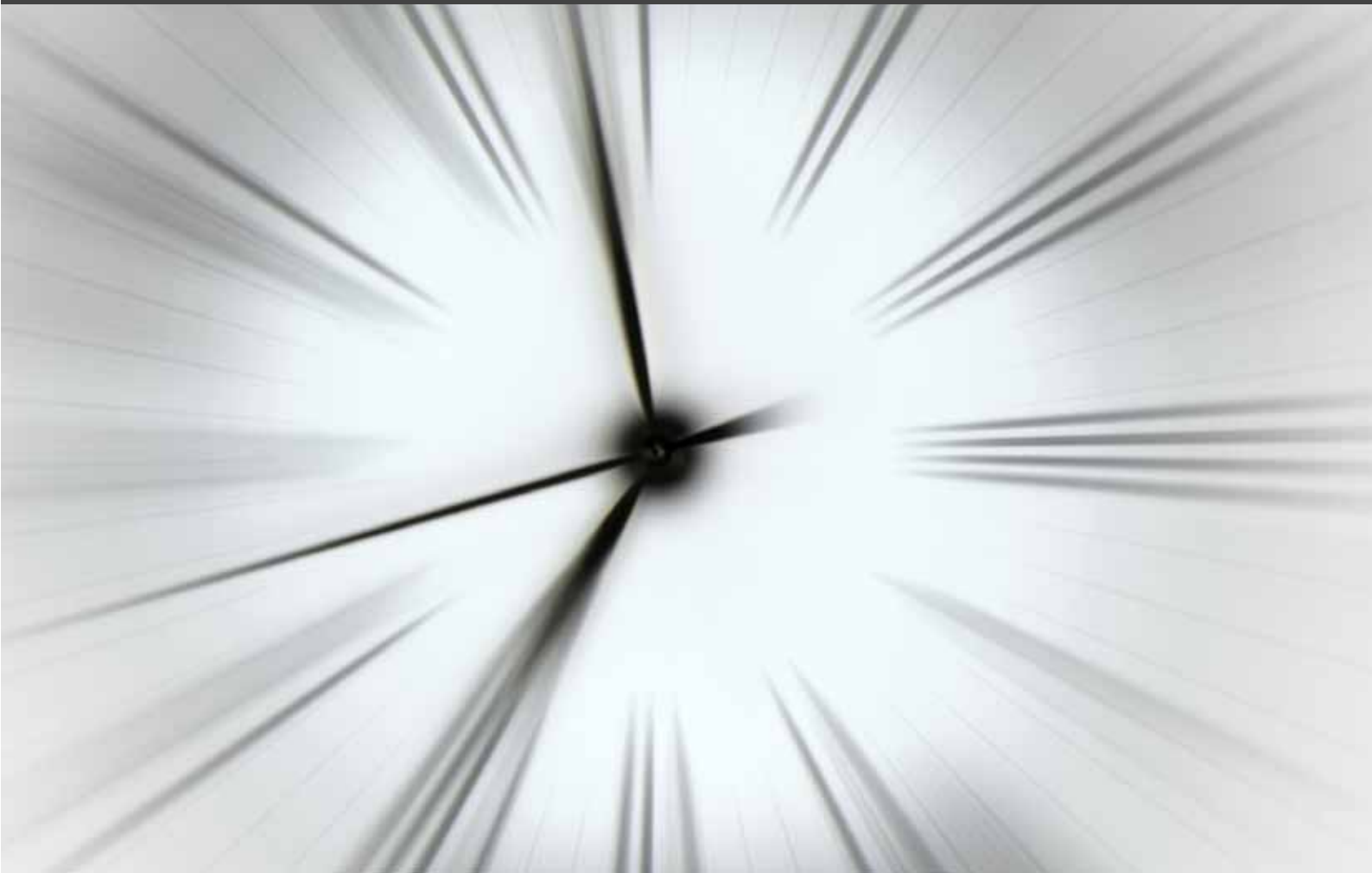
My operation was cancelled on seven occasions between February 2011 and November 2013, because of the lack of beds and the lack of communication between the departments (surgical and anaesthetics).

On the second occasion I was given a date to have my operation. I was admitted, there was a bed, I was gowned up and ready to go to theatre and was told by the nurse on duty my operation was cancelled as there was an emergency and the consultant wouldn't have time. I was sent home with no future date and when I telephoned the waiting list clerk, they couldn't offer me a new date. I then complained to the local health board and consequently was given another date and then had my operation on that date!



Part 5

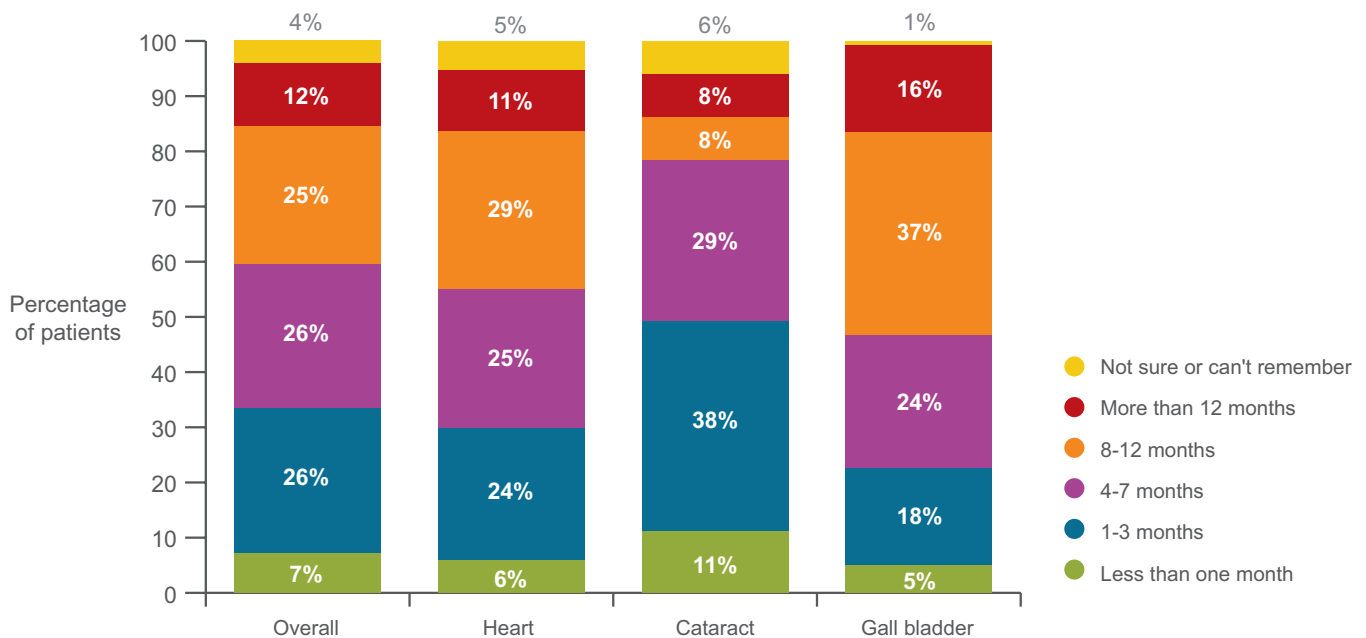
Overall waiting time



## From the time you were first told you were being referred to the hospital, how long did you wait for your operation?

5.1 Over half of the patients who responded to the postal survey said that they waited less than eight months from referral to treatment but a third waited longer for their operation. Gall bladder patients were most likely to experience longer waits with 16 per cent waiting more than 12 months for their operation<sup>3</sup>.

Figure 4 – How long did you wait for treatment?



5.2 People who responded to the online survey were more likely to say that they waited longer for their operation with over half waiting for eight months or more (55 people).

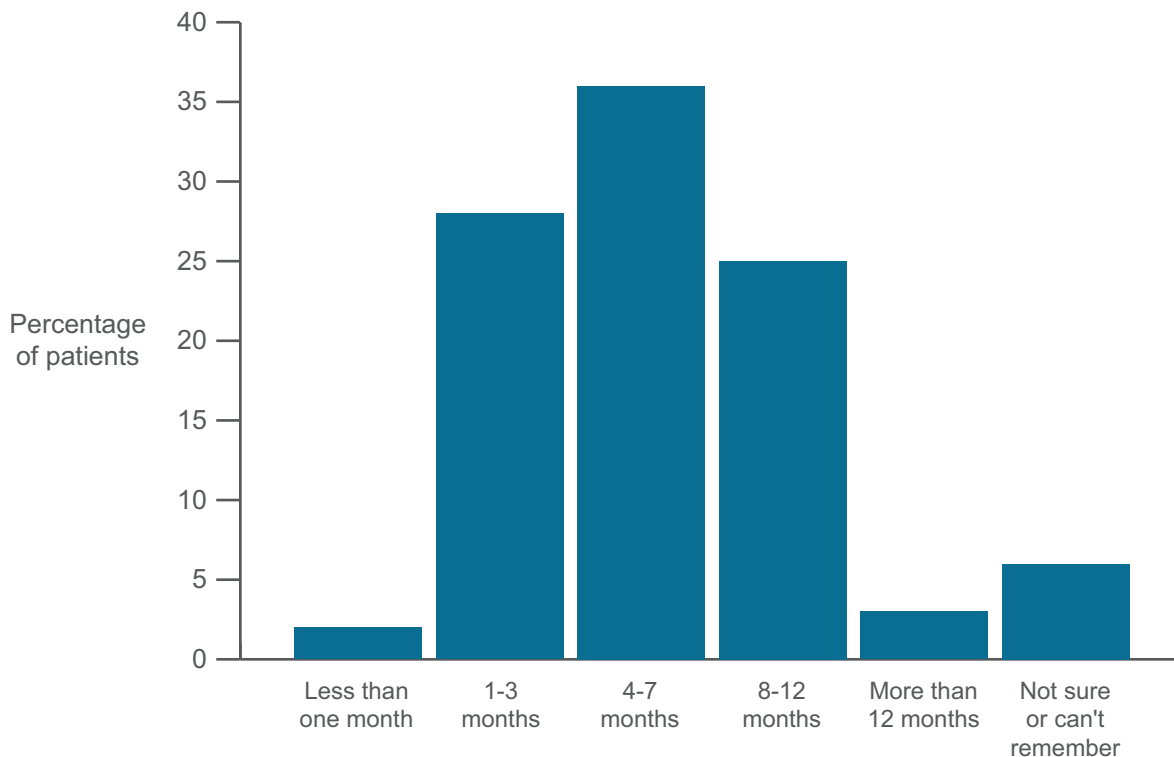
<sup>3</sup> Results are statistically significant (99 per cent confidence level).



## How do you feel about the length of time you were on the waiting list before your operation?

- 5.3 We asked patients how they felt about the length of time they were on the waiting list before their operation. Twenty-three per cent of those who replied to our postal survey said that they had their operation quickly and just over half said that they had to wait, but this was not a problem. Twenty-four per cent of patients said that they had to wait too long for their operation.
- 5.4 People who responded to the online survey were more likely to say that they had to wait too long for their operation than respondents to the postal survey with two-thirds of online respondents expressing this view. Only 10 of the online survey respondents said that waiting was not a problem.
- 5.5 The majority of patients who said that waiting for treatment was not a problem had waited for more than four months for their operation (Figure 5).

Figure 5 – How long did you wait for treatment? By patients who did not mind waiting



5.6 Patients who told us that waiting for treatment was not a problem gave a number of comments about their waiting time. Some people appreciated being kept informed of expected waiting times because they were aware of the number of other people waiting for treatment:

I feel that the length of time was expected in view of the high number of patients waiting for care.

Naturally I would have liked to have had the treatment quickly but I understand that that was not possible due to pressures on the specialist and that there were patients who needed the treatment more quickly than me.

My optician told me that I would wait a maximum of eight months for my first appointment which was fairly accurate. Therefore I was forewarned about the length of delay and so I was prepared.



One person said that they were happy to wait because they were not in extreme pain.

A number of patients made positive comments about their experience of NHS care from referral to treatment:

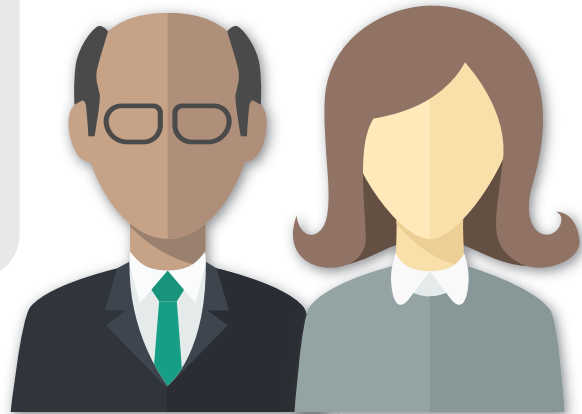
Thank you for first class service and treatment.

Everyone involved with my operation was extremely pleasant and looked after me very well indeed. All the staff and doctors were very good and caring.

This was my first experience in some time of the NHS and I was surprised to see how few staff dealt with so many patients. I cannot fault the treatment I received under the circumstances.

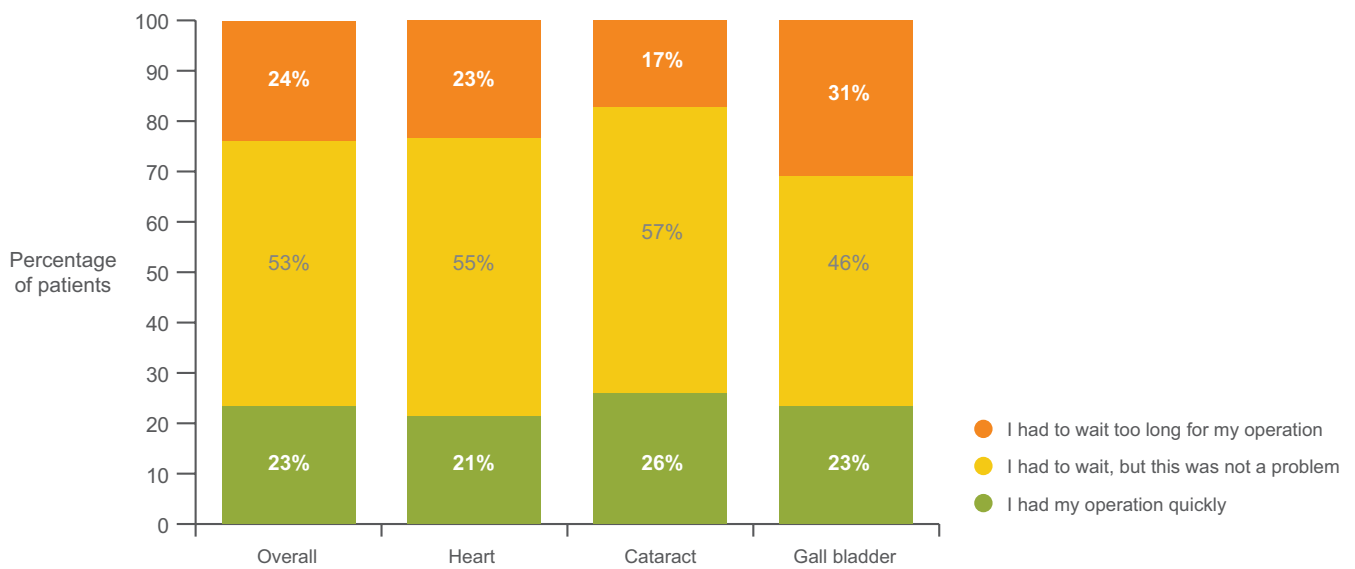
I'm over the moon with the results and no complaints whatsoever.

My gall bladder was removed because it contained "multiple polyps" when I was told this by the consultant I was terrified as my mother died of gall bladder cancer. He was very kind and understanding and agreed to remove it. Having said I could go at short notice I was called for pre-op checks two weeks later and the operation was two weeks after that. Wonderful!



5.7 Gall bladder patients were most likely to say that they had to wait too long for their operation (31 per cent compared to 24 per cent overall). Many of the gall bladder patients who said that they waited too long for treatment told us that they were in pain during this time.

Figure 6 – How do you feel about the length of time you were on the waiting list before your operation?



5.8 People who said that they had to wait too long for treatment made a number of comments about their waiting time. Fourteen people said that they were in pain whilst they waited for their operation and several visited A&E units during this time. Almost all of the patients who said they were in pain whilst they were on the waiting list were waiting for a gall bladder operation:

Two visits [to A&E] in almost three weeks because of the pain. On the third visit, I was admitted to a ward for a week to get pain under control. Did not see specialist till day six.

[I waited too long] considering I was on an urgent list, and was seen in Accident and Emergency on numerous occasions due to the pain.

The first time I was admitted to hospital I went as an emergency, I was in agony, doctor took stones twice from me. I was given medication and could not control my bowels. I lost two and a half stone in weight and felt awful, so I asked to go home to recover. I waited for my operation another nine months in agony, when at last I had gall bladder removal and was home in three days.



Six patients told us that they were removed from the waiting list due to administrative errors or notes being 'mislaidd'.

One person said:

I was very unhappy with them, that someone took me off the emergency waiting list. There was no reason given to my wife, I had to go through all the processes again which took another year. Before I had the operation I suffered very badly with my health while waiting.



Several patients said that they had to wait too long for a second cataract operation and some made more general comments about the length of their wait:

To wait over 56 weeks for a cardiac investigation procedure (angiogram) is unacceptable in a modern day health service. Thirty minutes over the border in England the waiting time is far less (post code lottery). After originally being referred for a cardiac problem in September 2012, I am still waiting to have it resolved on the waiting list for angioplasty procedure. Waiting 84 weeks and counting!!!!

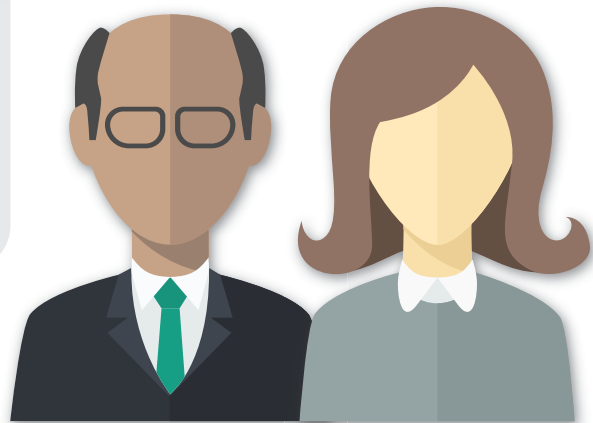
I waited over a year for my operation, which was far too long.



- 5.9 Patients who felt that they had to wait too long for their operation also made comments about the inconvenience of travelling for treatment, incorrect information about the length of time patients could expect to wait, and lack of communication between hospital departments:

I was told by the specialist the waiting list for the operation was approximately six months but after having my operation cancelled three times I waited over 18 months.

To wait 11 months and be told that you have to go to another hospital and they did not know I am 75 years old and my husband is 83 years old. My local hospital is three miles away and the hospital I was sent to is 20 miles away. To be taken out of the area very very bad for the elderly.



5.10 Patients who said that they had to wait too long for treatment in our online survey made a number of comments about their experience. Most patients focused on poor health and the impact that this had on their quality of life:

My prolapse got worse, which led to my bladder prolapsing as well.

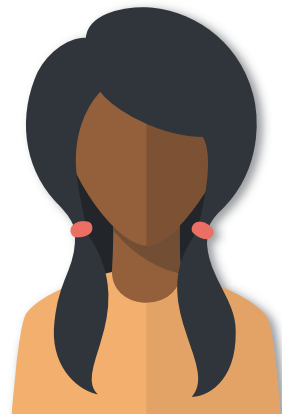
Due to waiting lists, the operation went from simple to complex. It was cancelled twice – once the day before, once whilst we were travelling to the hospital.

Even though I was told I was on the URGENT list I still had to wait 8 months before I finally had my operation. The length of time it took caused extreme anxiety and stress and further long term posture and long term problems with pain in shoulder, elbow and fingers.



One person said that the experience caused so much distress that they decided not to have the treatment at all:

In the end we came off the waiting list for dental surgery because it caused too much distress for a disabled person. It was arranged 4 times before being cancelled and one time we were actually waiting in the hospital and were sent home.





Several patients pointed out that waiting times are too long for people experiencing pain:

Ten months and still waiting. It is far too long when you are in extreme pain on a daily basis; especially when your mobility, activities of daily living and social activities are badly affected.

Other patients described the negative impact waiting for surgery had on their work and social life:

My quality of life is non-existent, I cannot move anywhere and the pain is horrendous plus, I have been off work now for over 28 weeks and it's looking more likely that I shall be sacked from my place of work.

The time that I spent waiting for a diagnosis was completely unacceptable and I lost pay because of that.

This is not acceptable because I have been waiting so long and I am still waiting and because of this I have lost my job.



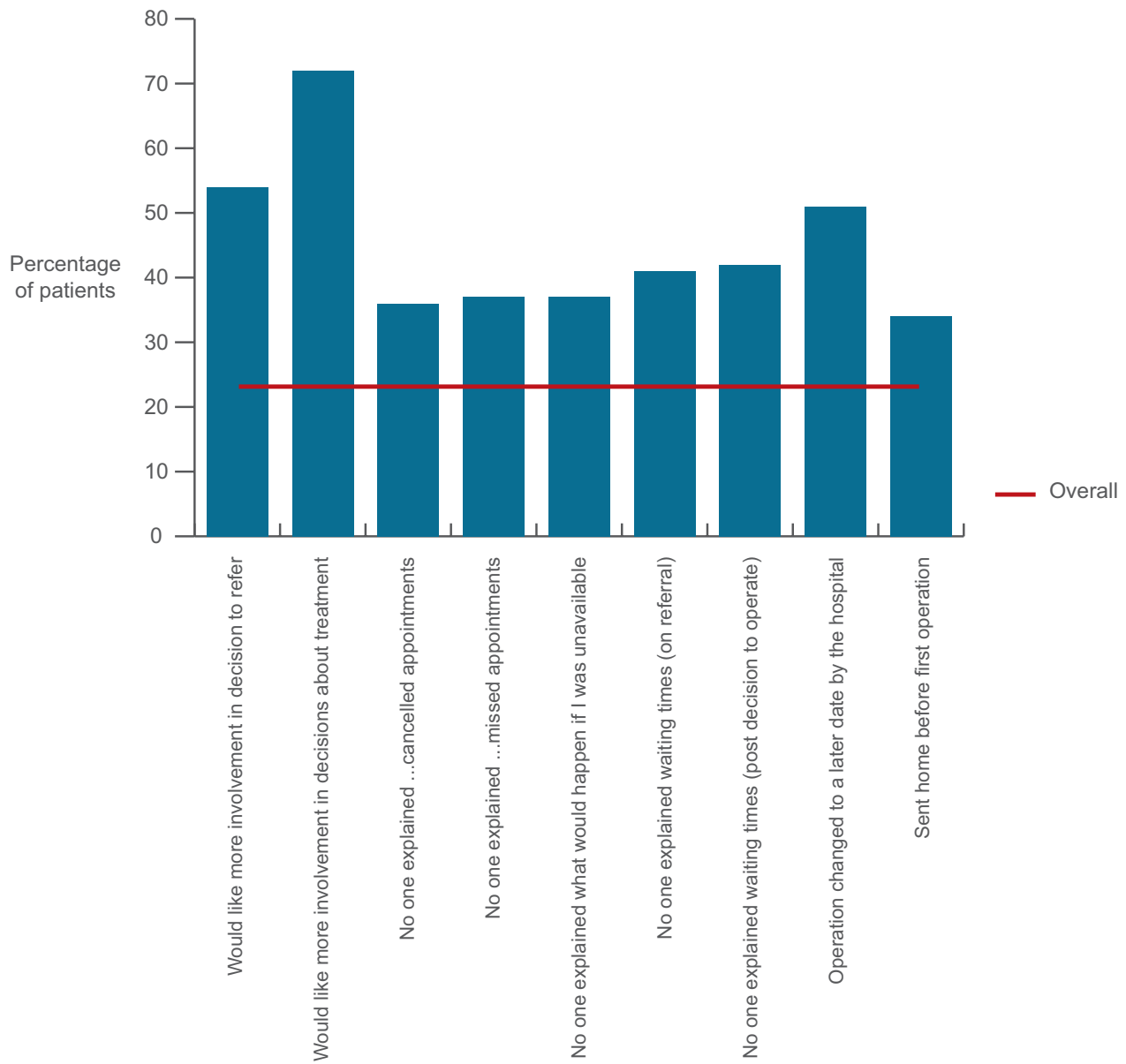
## Factors influencing patient views about the length of time they waited for treatment?

- 5.11 We looked at all of the factors that increased the likelihood of patients saying that they waited too long for treatment. Patients were more likely to have a negative view of their waiting time if they said:
- a they were not involved in decisions about their referral and treatment;
  - b they were not given information about their responsibilities as a patient;
  - c they were not given information about expected waiting times<sup>4</sup>;
  - d their operation was changed to a later date by the hospital; and
  - e they were sent home without treatment the first time they were admitted to hospital.

We analysed patients' responses to the question 'how do you feel about the length of time you were on the waiting list before your operation?' depending on how they felt about their involvement in decisions about their treatment, the level of information they received about their treatment and whether they experienced a cancellation. **Figure 7** compares the percentage of people from our postal survey who said that they waited too long for treatment by each of these factors with the percentage of all patients who felt this way.

<sup>4</sup> The difference in patient views on the length of their wait depending on whether they were given information on expected waiting times at the point of referral is statistically significant (99 per cent confidence level) but further research would need to be done to understand the differences between the views of patients depending on whether they were given information on waiting times after the decision had been made to operate.

Figure 7 – The factors that make patients more likely to say that they waited too long for treatment

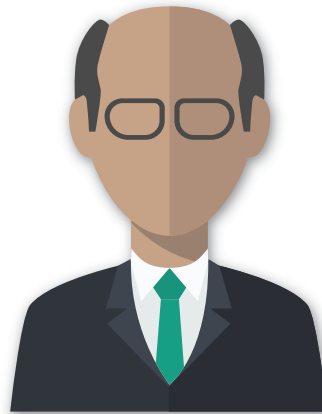


## Comments from patients who chose to pay for private treatment

5.12 We heard from 10 people who told us that they chose to pay for private treatment as a result of long NHS waiting times.

One cataract patient told us:

I could not afford to wait one to two years as I could have lost my driving license so I decided to go private.



Another patient said:

Because of the long wait for cataract operations I decided to go privately – my sight was so bad I was really afraid to drive.

A patient who paid to have the catheterisation of the heart procedure privately told us:

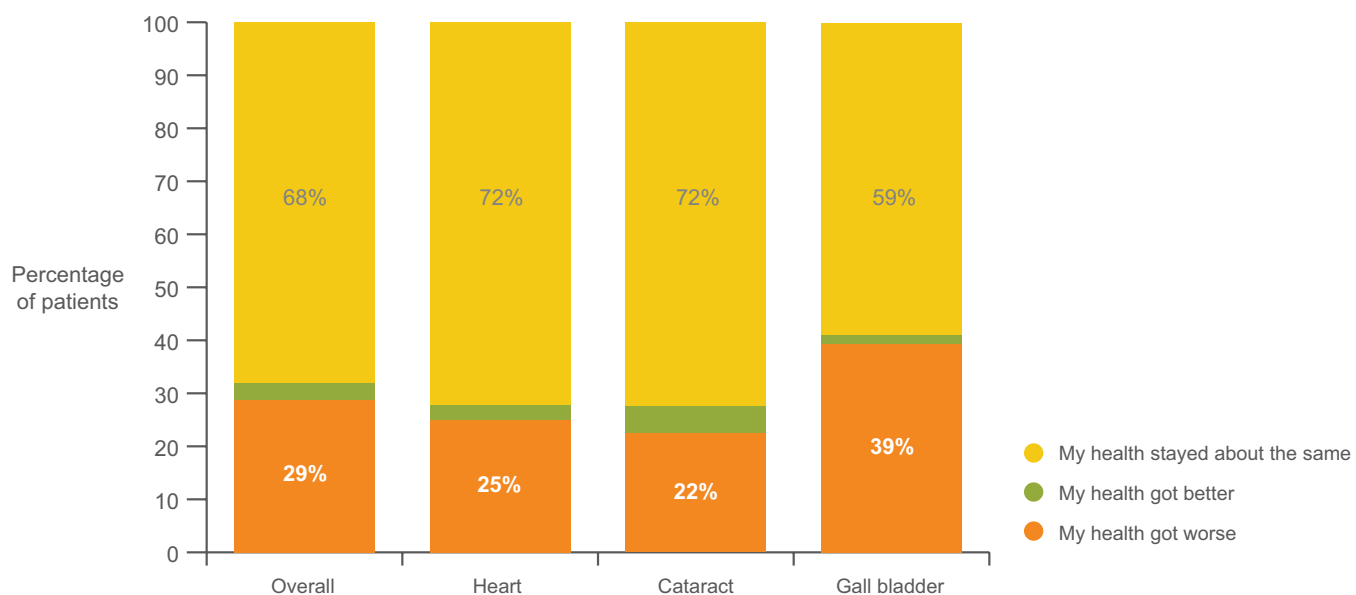
If I hadn't paid I would have been waiting over three months just to see a consultant and probably another three or four months for the angiogram. The stress and worry of waiting to see a consultant is not good for anyone but for individuals with long term heart problems it's not good.



## Did your health get worse, get better or stay about the same while you were waiting to be admitted?

5.13 The majority of patients (68 per cent) from our postal survey said that their health stayed the same whilst they waited for treatment. Twenty-nine per cent of patients said that their health got worse and gall bladder patients were the most likely to describe a deterioration in their health.

Figure 8 – Did your health get worse, get better or stay about the same while you were waiting to be admitted?



5.14 Gall bladder patients frequently described being in constant pain during their waiting time which had significant impact on their quality of life. Many patients made visits to A&E and to their GP as a result of the pain they experienced:

I was being sick with nearly every meal, the pain was chronic at times and I lost quite a lot of weight before operation.

As time went on I suffered more and more painful attacks.

I was admitted to hospital on a few occasions because I was having severe pain. I was given antibiotics and sent home usually within 24 hours.

To be in constant pain affects your quality of life and my pain peaked to unbearable levels which stopped me working on a few occasions and also made me visit Accident and Emergency at night for pain relief and also visits to GP to try to speed up my referral.

I was in pain more days while waiting for my operation. I was eating very little due to the pain and needing to take prescription pain killers very often. My work and whole life was affected.

Not only did the pain get worse with each episode, I missed a lot of work, which not only put financial strain on me, but also emotional strain.

My partner had to take me to Accident and Emergency twice because of the pain I was in. They sent me home at two o'clock in the morning one of the times.



5.15 Patients waiting for a catheterisation of the heart procedure who said that their health got worse described breathing difficulties, anxiety, restricted mobility and pain:

Breathing difficulties, tired, worried.  
Waiting times in Wales are not acceptable.

Breathlessness got worse  
stopping me from working.

I became more breathless  
and immobile.

The fear of not knowing what was wrong with me made  
me feel very anxious. I used my angina spray more  
often, I think the waiting contributed to the condition.

My condition gradually deteriorated. I gradually  
became more breathless and had greater  
chest discomfort/pain. My mobility decreased  
and hobbies such as gardening were no  
longer able to be enjoyed by me. I even had to  
pay someone to mow my lawn!

Developed anxiety waiting for a diagnosis.  
Explained this to specialist but it was one of  
those things.



5.16 Cataract patients who said that their health got worse whilst they waited for their operation told us that they experienced anxiety, mobility and balance problems and deteriorating vision. Several patients had falls and some had to give up reading, driving and hobbies as a result of poor vision:

Because I was continually worrying about whether the other operation would be done and having had one eye done and needing the second to be done caused me to lose my balance and fall on a number of occasions and lose my confidence. This meant I had one clear lens in my glasses while the other one was a prescription lens. Fourteen months for a second operation really is too long to expect a person to wait.

During the delay my eyes became much worse leaving me distressed.

Reading became difficult.

My eyesight deteriorated which resulted in me having several falls.

My mobility deteriorated even further while waiting for the operation and I was no longer able to get out of my wheelchair unless by hoist. This had not been taken into account even though staff knew this at my outpatient appointment. You would think hospitals would have hoists etc. for this purpose to help disabled patients.

My eyes got worse and I couldn't drive anymore which was very inconvenient as I am elderly and I live alone.

I couldn't see where I was going and had a few falls and was bumping into things. I became afraid to go out and everyday tasks became a nightmare. I hope other patients in future will not have to wait too long.





5.17 People who responded to the online survey were more likely to say that their health got worse whilst they waited for treatment with over half describing deterioration. Online respondents who said that their health got worse whilst waiting for their operation made comments about how this affected their lives including:

My son suffers from mild cerebral palsy and during this wait, his walking was dramatically affected. He struggled to participate in school and was in pain from the affected leg.

I was not able to be more than a minute away from a toilet and therefore practically unable to function normally at work or in my personal life.

My hearing capacity went down by over 80% as no follow up appointments at ENT.

A year from initial GP referral, I am still undergoing a series of diagnostic tests with the aim of cardiac surgery, with a wait between each diagnostic test is extending the referral to treatment time. After 32 years of an unblemished work record with only 15 days sickness during that time, I have lost my job because I am no longer able to sustain the necessary hours due to severe fatigue. For the want of early intervention, I have become disabled by my condition and reliant on benefit. I doubt I will survive the wait for a heart operation.

I am now housebound and dependent on my family for care and shopping. When originally referred for surgery, I was still able to drive and live independently. I feel badly let down by the NHS in Wales.

The long wait for my surgery has meant that I now face a much more serious operation and will be left with a permanent ileostomy. Whilst waiting I have had a number of admissions to hospital to treat problems directly relating to the condition that I am waiting for surgery for.



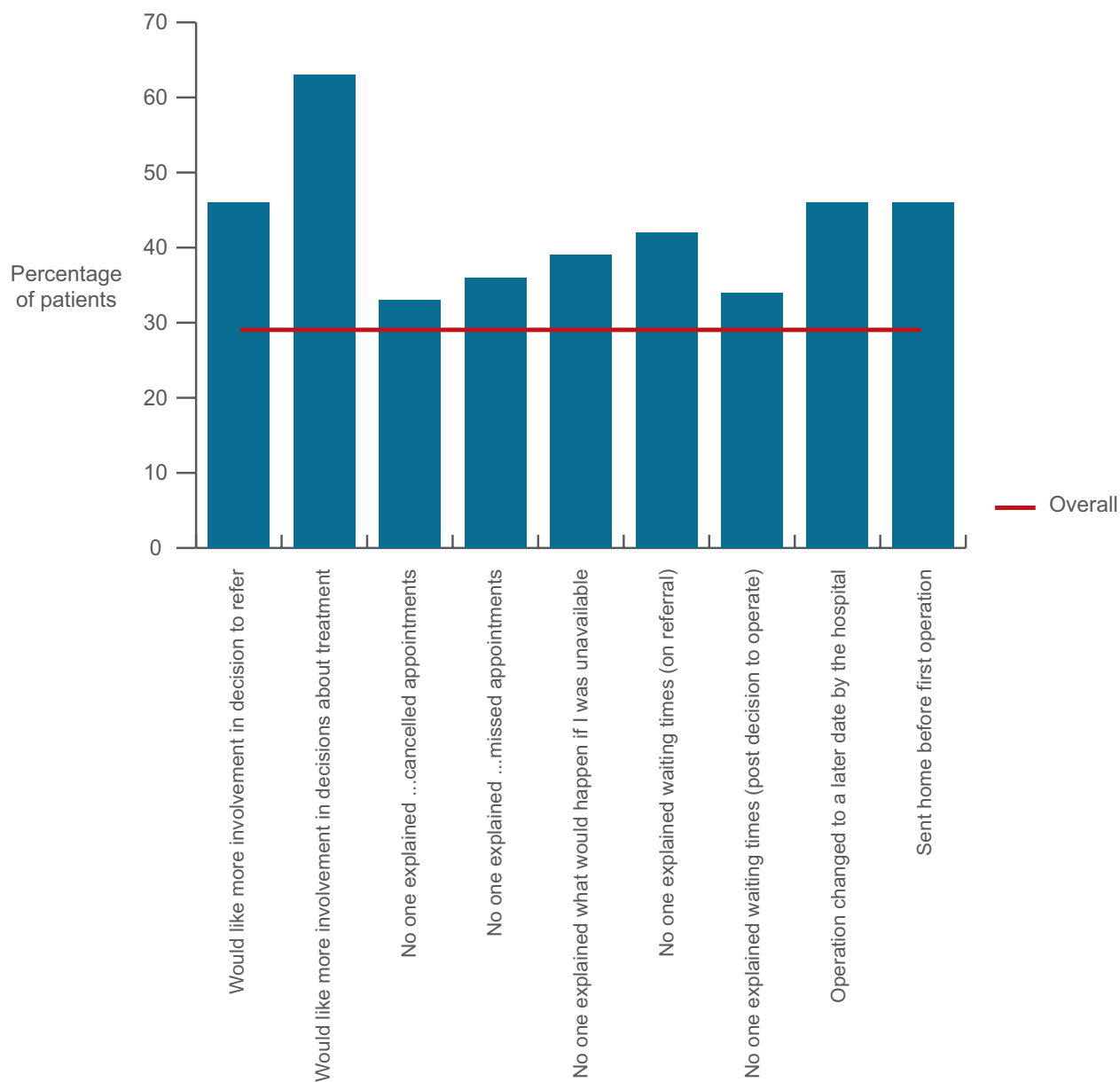
## Factors influencing patient views about their health whilst they waited for treatment

5.18 Patients were more likely to say that their health deteriorated whilst they were waiting for treatment if:

- a they were not involved in decisions about their referral and treatment;
- b they were not given information about their responsibilities as a patient;
- c they were not given information about expected waiting times;
- d their operation was changed to a later date by the hospital; and
- e they were sent home without treatment the first time they were admitted to hospital.

Figure 9 compares the percentage of patients who said that their health got worse whilst they were on the waiting list by all of the factors that affected their experience of waiting for treatment.

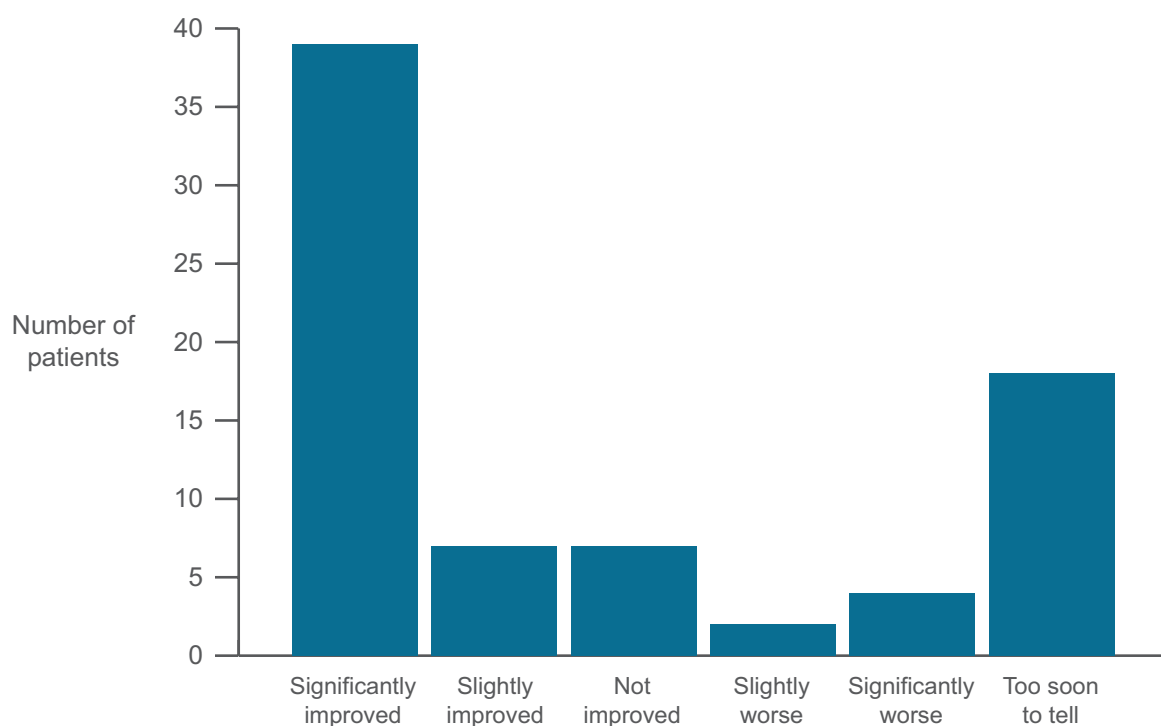
Figure 9 – The factors that made patients more likely to say that their health got worse whilst they were on the waiting list



## How much impact has your operation had on your quality of life?

5.19 We asked people completing the online survey how much impact their operation had on their quality of life. Half of the respondents said that the operation significantly improved their quality of life. Thirteen people told us that their quality of life had not been improved by their operation.

Figure 10 – Please indicate how much impact your operation has had on your quality of life



5.20 Online respondents who said that their quality of life significantly improved as a result of their operation made comments about the impact of their treatment:

The operation has given me a big wake up call, a second chance and made me value every day. I have more energy, am less tired and feel great. The NHS looked after me very well.

I can't begin to describe how much my quality of life has improved since surgery – best thing I ever did.

I can see the TV now and am able to drive again allowing me to go shopping and to children's school events.

Able to fully do my job again.



## Thinking about when you left hospital, did you feel you were discharged at the right time?

5.21 The majority of patients felt that they were discharged from hospital at the right time (90 per cent) but almost a quarter of gall bladder patients felt that they were discharged too early. Gall bladder patients made a number of comments about being discharged from hospital. Several people experienced complications following surgery and were readmitted to hospital at a later date

I had a bladder problem (catheter removed too soon??) but was still discharged – which resulted in me being re-admitted.

I was readmitted 24 hours after discharge due to complications. I was finally discharged after six days.

I had a bleed from the site of my operation, but the staff were keen that I leave before the department closed. I was still bleeding and was left with a haematoma which took quite a long time to improve.

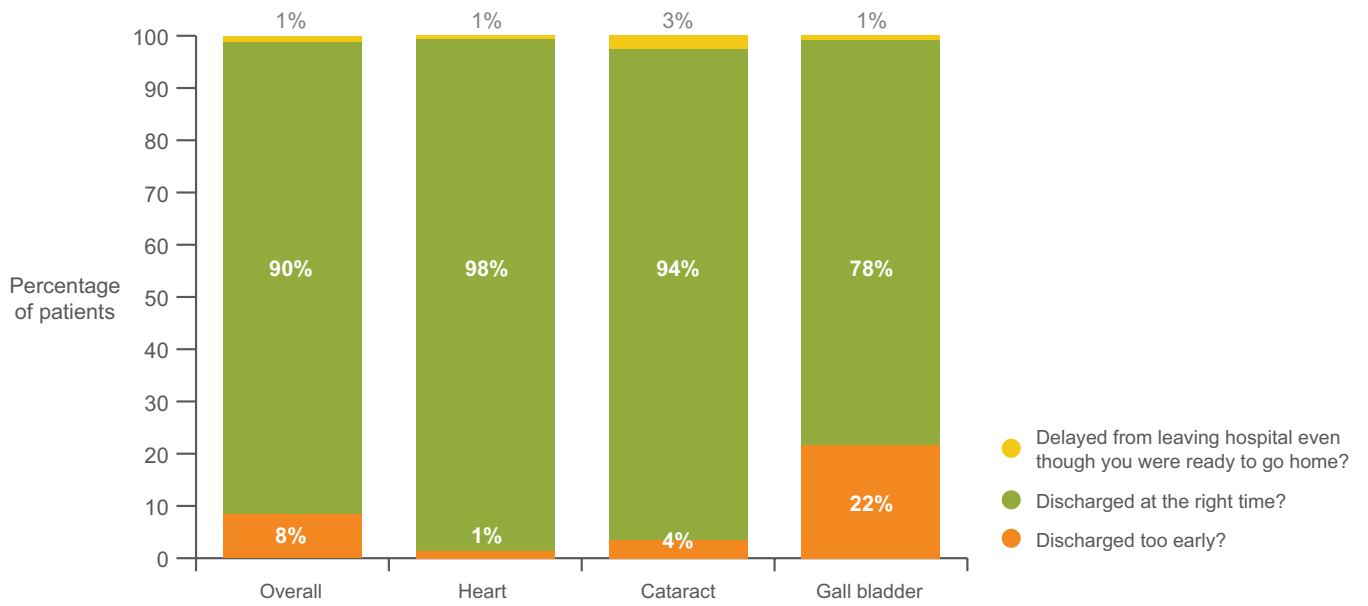
I still had clips in after the operation and the district nurse had to come every day to change them. I told them I was living on my own but they still sent me home. Then I had a bleed and had to call the lifeline system. An ambulance came and I was in hospital for six days. I told them I was scared and would end up in a pool of blood but they sent me home anyway. I feel like I needed more information about what would happen after the surgery. They asked if I had any questions but I didn't think of it at the time.

Other patients felt they did not have enough time to recover after surgery before being sent home:

I had not long come out of recovery before being told that most were being sent home as ward was shutting for weekend due to lack of staff. Felt very painful and groggy. Family expecting to visit told to pick me up and they were very unhappy. No follow-up with consultant – wounds had problems healing – with continuing symptoms.



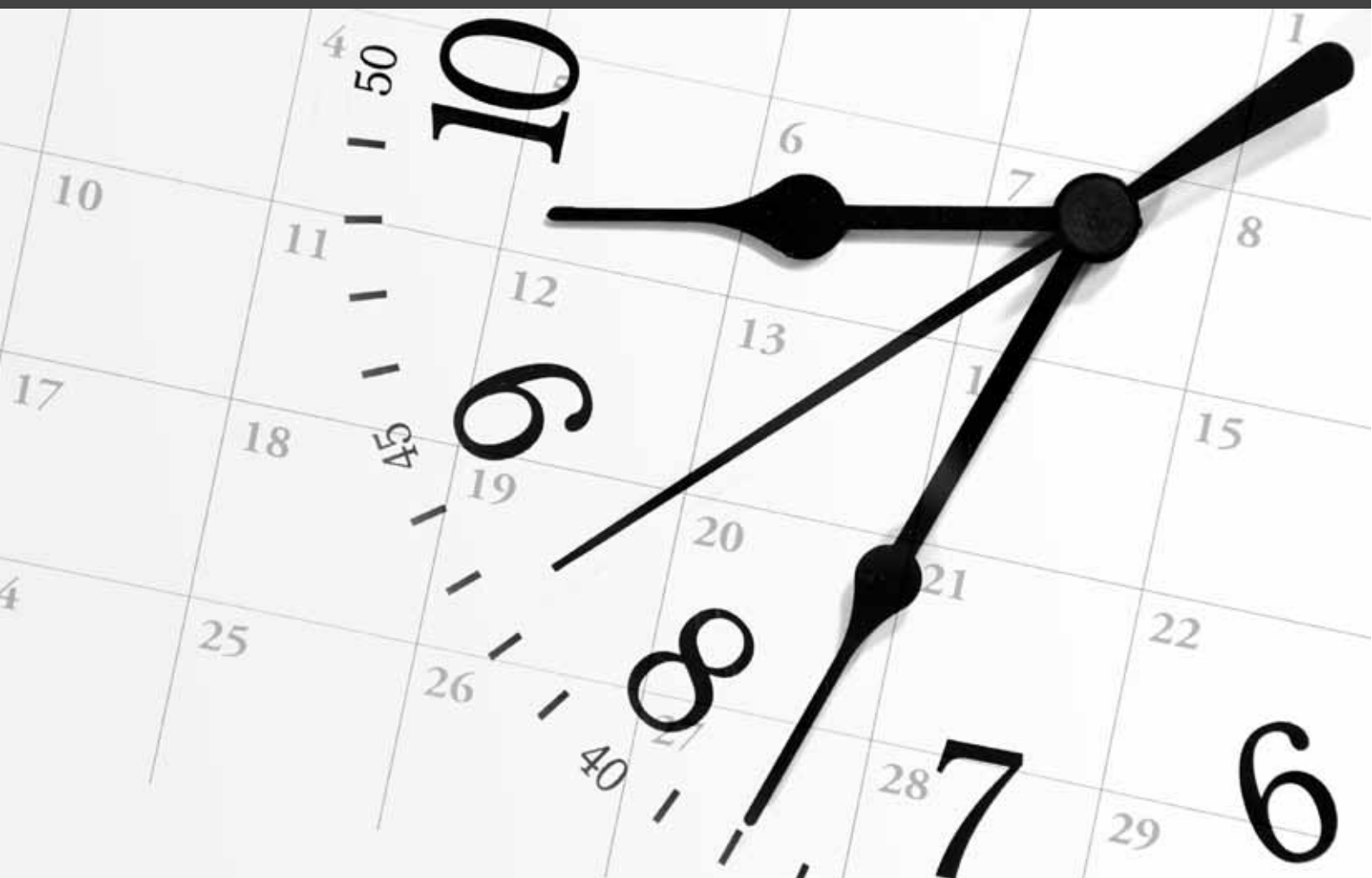
Figure 11 – Patients' views on their discharge from hospital



# Appendices

Appendix 1 - Postal survey: summary of quantitative results

Appendix 2 - Online survey: summary of quantitative results





# Appendix 1 - Postal survey: summary of quantitative results

## First, some questions about when you were referred to hospital to see a specialist...

Q1 Who made the decision to refer you to hospital?

- 1.5% Not sure or can't remember
- 54.8% GP
- 8.9% A private doctor or specialist
- 34.7% Someone else

Q2 Were you involved in the decision to refer you to see a specialist in hospital?

- 70.4% Yes, definitely
- 17.9% Yes, to some extent
- 3.3% No, but I would have liked to have been more involved
- 5.9% No, but I did not want to be involved
- 2.6% Not sure or can't remember

Q3 Did anyone explain how long you could expect to wait to see a specialist?

- 64.0% Yes
- 29.8% No
- 6.2% Not sure or can't remember

Q4 Were you given information about how your waiting time to see a specialist could be affected if you told the hospital you could not attend appointments?

- 54.7% Yes, and it was easy to understand
- 0.5% Yes, but it was difficult to understand
- 34.4% No one explained what would happen
- 10.4% Not sure or can't remember

Q5 Were you given information about how your waiting time to see a specialist could be affected if you failed to attend appointments without telling the hospital?

- 56.7% Yes, and it was easy to understand
- 1.0% Yes, but it was difficult to understand
- 32.4% No one explained what would happen
- 9.9% Not sure or can't remember

Q6 Were you given information about how your waiting time to see a specialist could be affected if you were not available for an appointment for more than a two-week period (for example if you were on holiday for three weeks)?

- 46.4% Yes, and it was easy to understand
- 0.8% Yes, but it was difficult to understand
- 40.4% No one explained what would happen
- 12.4% Not sure or can't remember

Q7 Whilst you were on the waiting list to see a specialist, did the hospital contact you at any point to find out whether you still needed an appointment?

- 24.3% Yes
- 70.8% No
- 4.9% Not sure or can't remember

**These questions are about your appointments at the hospital before your operation (these are sometimes called outpatients appointments)...**

Q8 On the whole, how convenient were the dates and times of your outpatient appointments?

- 54.7% Very convenient
- 41.1% Quite convenient
- 1.8% Not very convenient
- 1.3% Not convenient at all
- 1.0% Not sure or can't remember

Q9 Were any of your outpatient appointments changed to a later date by the hospital?

- 79.2% No
- 15.7% Yes, once
- 3.3% Yes, 2 or 3 times
- 0.0% Yes, 4 times or more
- 1.8% Not sure or can't remember

Q10 Did you contact the hospital to cancel any of your outpatient appointments?

- 3.3% Yes
- 95.9% No
- 0.8% Not sure or can't remember

Q11 Did you fail to attend any of your appointments without telling the hospital?

- 1.5% Yes
- 98.2% No
- 0.3% Not sure or can't remember

Q12 Were you involved as much as you wanted to be in decisions about your treatment?

- 69.1% Yes, definitely
- 19.7% Yes, to some extent
- 6.3% No, but I would like to have been more involved
- 3.0% No, but I did not want to be involved
- 1.8% Not sure or can't remember

**These questions are about the period between a specialist telling you that you would need an operation and you actually being admitted to hospital...**

Q13 Did anyone explain how long you could expect to wait for your operation?

74.2% Yes

21.4% No

4.3% Not sure or can't remember

Q14 Was your operation changed to a later date by the hospital?

83.5% No

12.7% Yes, once

2.6% Yes, 2 or 3 times

1.0% Yes, 4 times or more

0.3% Not sure or can't remember

Q15 If your operation was changed to a later date by the hospital, what reason did they give?

21.0% There weren't enough beds

9.7% Doctors said I was not fit for surgery

11.3% I was not given a reason

6.5% Not sure or can't remember

51.6% Another reason

**These questions are about what happened when you were admitted to hospital for your operation...**

Q16 Did your operation take place the first time you were admitted to hospital?

90.1% Yes

9.9% No, I was sent home by the hospital

Q17 If the hospital sent you home the first time you were admitted to hospital – what reason did they give?

- 21.1% There weren't enough beds
- 21.1% Doctors said I was not fit for the operation
- 10.5% I was not given a reason
- 5.3% Not sure or can't remember
- 42.1% Another reason

**Think about the overall time you waited for your operation...**

Q18 From the time you were first told you were being referred to the hospital, how long did you wait for your operation?

- 7.2% Less than one month
- 26.2% 1-3 months
- 26.2% 4-7 months
- 24.9% 8-12 months
- 11.5% More than 12 months
- 4.1% Not sure or can't remember

Q19 How do you feel about the length of time you were on the waiting list before your operation?

- 23.3% I had my operation quickly
- 52.8% I had to wait, but this was not a problem
- 23.8% I had to wait too long for my operation

Q20 If you have any comments about the length of time you waited for your operation please write them here

Q21 Did your health get worse, get better or stay about the same while you were waiting to be admitted?

28.8% My health got worse

3.1% My health got better

68.1% My health stayed about the same

Q22 If you said that your health got either better or worse, please tell us more about this.

Q23 Thinking about when you left hospital, did you feel that you were...

8.4% Discharged too early?

90.3% Discharged at the right time?

1.3% Delayed from leaving hospital even though you were ready to go home?

Q24 Please use this space for anything else you would like to tell us about your experience of waiting for your operation

## Finally...

Q25 Which local authority area do you live in?

2.0%	Blaenau Gwent
5.8%	Bridgend
6.6%	Caerphilly
5.3%	Cardiff
6.6%	Carmarthenshire
3.3%	Ceredigion
3.5%	Conwy
5.1%	Denbighshire
1.3%	Flintshire
2.3%	Gwynedd
3.5%	Isle of Anglesey
2.8%	Merthyr Tydfil
2.0%	Monmouthshire
4.8%	Neath Port Talbot
7.1%	Newport
2.8%	Pembrokeshire
5.6%	Powys
9.8%	Rhondda Cynon Taf
8.6%	Swansea
2.8%	Torfaen
4.5%	Vale of Glamorgan
3.0%	Wrexham
1.0%	Other (please tell us in the box below)

## Appendix 2 - Online survey: summary of quantitative results<sup>5</sup>

**We'll start with some questions about you...**

Q1 Which local authority area do you live in?

2	Blaenau Gwent
2	Bridgend
6	Caerphilly
20	Cardiff
1	Carmarthenshire
7	Ceredigion
6	Conwy
0	Denbighshire
2	Flintshire
3	Gwynedd
1	Isle of Anglesey
1	Merthyr Tydfil
3	Monmouthshire
4	Neath Port Talbot
5	Newport
1	Pembrokeshire
2	Powys
6	Rhondda Cynon Taf
13	Swansea
3	Torfaen
3	Vale of Glamorgan
3	Wrexham
1	Other

<sup>5</sup> Results are given as counts due to low numbers.



Q2 When did you have your operation?

Q3 Please describe the type of operation you had - you don't need to know the medical term - you can just write 'foot operation' to help us understand the type of treatment you had.

Q4 How old are you?

2	Under 16
4	16-24
7	25-34
18	35-44
19	45-54
24	55-64
14	65-74
6	75 or over

**Now some questions about waiting for your operation...**

Q5 From the time you were first told you were being referred to the hospital, how long did you wait for your operation?

9	Less than one month
10	1-3 months
18	4-7 months
23	8-12 months
32	More than 12 months
2	Not sure or can't remember

Q6 How do you feel about the length of time you were on the waiting list before your operation?

21 I had my operation quickly

10 I had to wait, but this was not a problem

60 I had to wait too long for my operation

If you have any comments about the length of time you waited for your operation please write them here

Q7 Did your health get worse, get better or stay about the same while you were waiting to be admitted?

48 My health got worse

7 My health got better

37 My health stayed about the same

If you have any comments about what happened to your health whilst you waited to be admitted please write them here

Q8 Please indicate how much impact your operation has had on your quality of life?

39 The operation has significantly improved my quality of life

7 The operation has slightly improved my quality of life

7 The operation has not improved my quality of life

2 The operation has made my quality of life slightly worse

4 The operation has made my quality of life significantly worse

18 It's too soon to tell what impact the operation will have on my quality of life

If you have any comments about the impact your operation had on your quality of life please write them here

Q9 Overall, were you involved as much as you wanted to be in decisions about your treatment?

34 Yes, definitely

19 Yes, to some extent

27 No, but I would have liked to have been more involved

2 No, but I did not want to be involved

2 Not sure or can't remember

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