

Involvement in decisions

Involvement in decisions is a key part of becoming a more patient centric health system – one of our strategic themes. The good news is that most patients report being as involved as they wanted to be in decisions about their care and treatment, but a significant minority, around one in five are telling us they would like more involvement. It's really great to see a significant two percentage point improvement in our overall performance on this measure since the last report in August 2014.

A large and growing proportion of outpatients (3 in 10) say that being involved in decisions about their health and care is one of the top three things that makes the most difference to their experience of care. It's great to read patients comments about how we are providing choice about treatment and that they are in charge of the decisions that are made about their care and treatment.

Something to bear in mind is that patients tell us it's important to be given time to consider their options, and to be given the right information to help them make these decisions. They appreciate it when staff take time to answer questions and when they feel listened to. They are asking us to not rush them into making a decision, and to ensure that all the relevant information they need, particularly test results, is available to inform the decision-making process.

Each month outpatients are asked to rate their overall care and treatment. "Very good" and "excellent" ratings are reasonably high across all directorates, but it's worth acknowledging Cancer and Blood and Adult Community and Long Term Conditions directorates who are meeting or exceeding our target of 90 percent of patients rating our care as very good or excellent – well done!

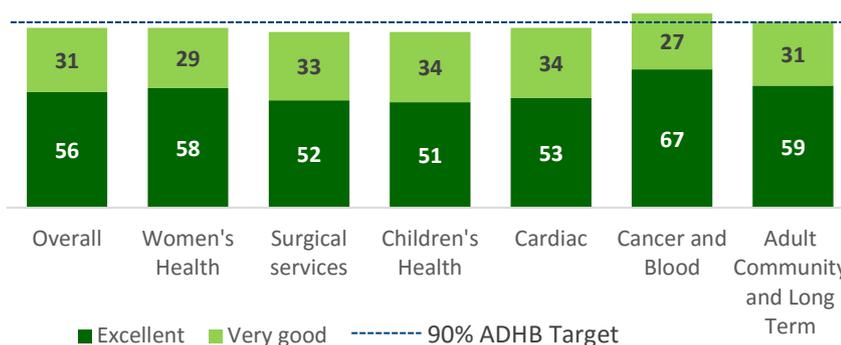
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VERY GOOD AND EXCELLENT RATINGS

Each month outpatients are asked to rate their overall care and treatment. "Very good" and "excellent" ratings are reasonably high across all directorates, with Cancer and Blood and Adult Community and Long Term Conditions directorates meeting or exceeding the ADHB target of 90 percent of patients rating our care as very good or excellent. The differences are significant ($p < 0.05$).

OUTPATIENT OVERALL EXPERIENCE OF CARE RATING, MAY 2015 TO APRIL 2016 (n=9838)



Adult community and long term conditions n=557; Cancer and Blood n=1066; Cardiac n=197; Children's Health n=659; Surgical n=2362; Women's Health n=724; Overall n=5562

TOP THREE

Our outpatients are asked to choose the three things that matter most.

1. Information (67%)

Getting good information is the aspect of our care most patients (67%) say makes a difference to the quality of their care and treatment.

"Hard copy information made available before, while in hospital and after care. This resulted in one feeling at ease within myself and being able to ask questions."

How are we doing on information?

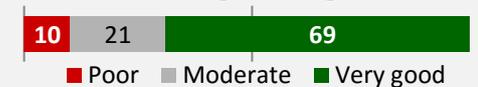


2. Organisation (53%)

For more than half of all our patients (53%), organisation, appointments and correspondence matter to the quality of their care and treatment.

"On visiting my GP after my hospital she had no information about my visit. In these days of emails it wouldn't take much to keep her informed how my visit went."

How are we doing with organisation?



3. Confidence (51%)

Half our patients (51%) rated having confidence in their care and treatment as one of the things that make the most difference.

"Felt like the specialist didn't really listen to me and what I was trying to explain but just assumed things from having read my file. It doesn't really instil trust and confidence in your care and treatment if you don't feel like the specialist is getting it."

How are we doing with confidence?



A focus on involvement in decisions

Three in 10 of our outpatients tell us that being involved in decisions about their health and care is one of the three things that makes the most difference to their care and treatment.



31 percent of our outpatients say that being involved in decisions about their health and care is one of the three things that makes the most difference to the quality of their care and treatment

HOW ARE WE DOING?

Outpatients who take part in the Outpatient Experience survey are asked if they were as involved as they wanted to be in decisions about their care and treatment.

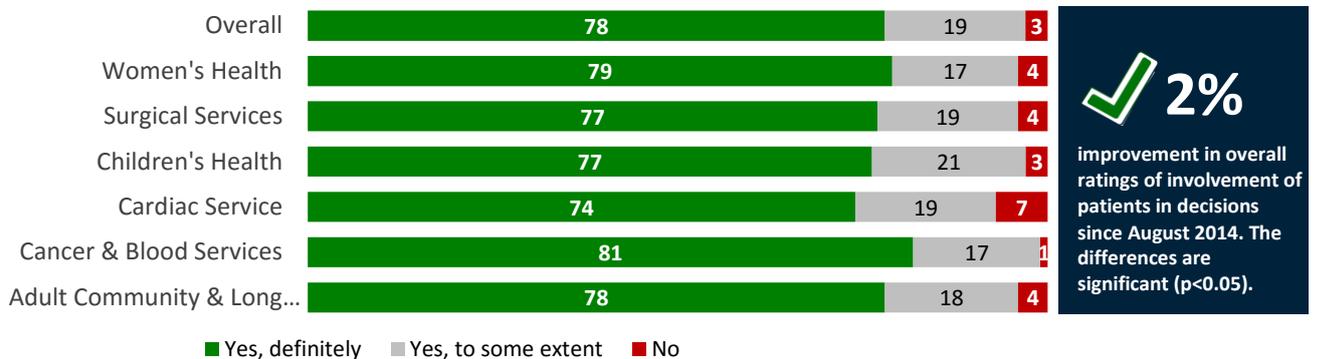
The following data are from the period May 1, 2015 to April 30, 2016. These data have been compared with data from the previous outpatient decisions report, in August 2014, in order to establish whether there have been any significant changes.

Involvement in decisions

The percentage of patients who say they were “definitely” as involved as they wanted to be in decisions about their care and treatment has increased by two percentage points when compared to the previous outpatient decisions report in August 2014. This difference is significant (p<0.05).

Although most directorates have experienced an increase of two percentage points in the percentage of those who say they were as involved in decisions as they wanted to be, these differences are not significant. The exception to this is Cardiac Services, where an additional six percent of patients tell us they were definitely not as involved as they wanted to be in decisions around their care and treatment (from 1% to 7%). The difference is significant (p<0.05).

Percentage of patients who say they were as involved as they wanted to be in decisions about their care and treatment



Adult community and long term conditions n=552; Cancer and Blood services n=1077; Cardiac service n=196; Children's health n=661; Surgical services n=2363; Women's Health n=722, Overall n=5571

Involvement in decisions rating: quarterly trend

Respondents who say being involved in decisions is important to them rated ADHB 8.4 out of 10 over the last 12 months.

Respondents who choose involvement in decisions as one of the three things most important to their care are asked to rate their experience out of 10.

Note that this differs to the question above, which is asked of *all* respondents.

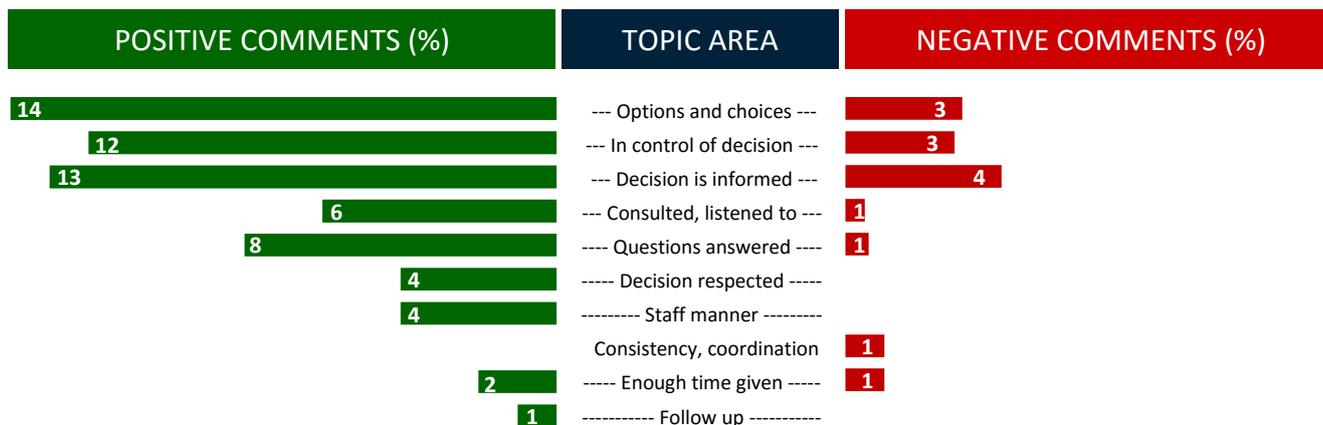
We can see from this data that the respondents who say being involved in decisions is important to them rated us, on average, 8.4 out of 10 over the 12 months to March 2016. Only Cancer and Blood is showing an upward trend to their rating (--), whilst the other directorates are either static (--) or slipping (--).

DIRECTORATE	APR JUN 2015	JUL SEP 2015	OCT DEC 2015	JAN MAR 2016	TREND
Overall	8.5	8.4	8.4	8.4	---
Women's Health	8.7	8.5	8.5	8.3	---
Surgical Services	8.5	8.3	8.2	8.3	---
Children's Health	8.4	8	7.9	8.4	---
Cancer and Blood Services	8.6	8.8	8.6	8.9	---

Cancer and Blood services n=382; Children's health n=168 Surgical services n=661; Women's Health n=194, Overall n=1627. Note that directorates with <100 respondents have been excluded from the data.

A closer look at patient comments

A total of 1455 outpatients commented on being involved in decisions. Most (83%) of the comments were positive, while 25 percent of the comments were negative (note that some patients made both positive and negative comments, which is why the total exceeds 100 percent).



PATIENT COMMENTS

GIVEN OPTIONS AND CHOICES (14%)

Our patients tell us that being given options and choices is important and gives them confidence in their care. There are several things that patients ask for when being presented with options and choices; that is to be given time to consider them, to have access to test results to put their decision in context and to be given thorough information on the pros and cons of each option.

Explanations of options were supported by evidence gathered from my own results. I felt very confident in their judgement because of their sound reasoning.

We were given the options for the condition and went through positives and negatives for both options and felt like we could choose the right decision and move forward with the right information.

I very much appreciate that options for my son's care are discussed thoroughly with me and I am given the reasons why each treatment option is being recommended. It helps me to feel confident that we are all working for the best of my son.

IN CONTROL OF DECISION (12%)

Patients want to be informed, included and involved and to feel they are in control of the decisions around their care.

Always involved in decision making. Never left me out, always considered my opinions and decisions.

Patients said they needed to feel heard, and to know that they are valued and their situation is well considered. They also want their treatment plan to be modified with their feedback.

It is important for me to be involved with the specialist about what care and treatment I receive as this empowers me and makes me feel I have some say in the matter, and that my feelings are considered. That I make decisions with the specialist involved, that I am treated as a human being and not a number.

OPTIONS AND CHOICES LACKING (3%)

Some patients said they were not given options for treatment, or were rushed to make a decision. Patients wanted more information about their options such as choosing less powerful medications.

No discussion, it felt like a pre-determined outcome, and no alternatives were offered or discussed

The doctor gave a fairly direct indication of the type of surgery he considered appropriate for me, however did not really cover any of the alternatives.

Some patients wanted clinical staff to engage with them seriously about alternative therapies such as acupuncture, complementary treatments and diet.

The only small criticism I have is in regard to complimentary therapies. I realise that conventional doctors do not need to have knowledge of any other therapies but I feel it would be helpful for them to be a little more open minded and interested in what their clients are doing to support themselves.

NOT IN CONTROL OF DECISION (3%)

A small number of patients said that they didn't feel in control if they were not fully informed, or felt they were not included in decisions or spoken down to.

I believe I had no choice about my treatment.

I felt as if the doctor just decided how it should be.

I keep getting told my 'case' will go to a panel and they'll decide what's best for my unborn baby but I'm not often asked what I'd like or what's best for me.

I didn't want to have treatment, but the doctors pressured me into having treatment.

PATIENT COMMENTS (cont...)

INFORMED DECISION MADE (13%)

Being given good information about their treatment was very important to patients. They also commented on the way they were given information and how they were treated by staff.

I am always spoken too as an individual and with the information to make my own decisions about my care. I am given respect and listened to with dignity.

Being given information about what to do between appointments was also very helpful.

I was given phone numbers to call if I needed to for extra support while at home before my next appointment with the clinic.

Giving honest assessments of treatment options was valued by patients.

My team are wonderful at providing me with the knowledge and advice to make decisions about my health in terms of my options and care. They consistently discuss the treatment options available and are incredibly honest about how well they believe each treatment will work for my condition. I find this honesty very helpful and have never felt like they have made the decision about what course of treatment I get. It is a joint decision.

QUESTIONS ASKED AND ANSWERED (8%)

Patients particularly appreciated it when staff took time to answer questions properly and answered honestly.

Having the doctor listen to my questions and answer them thoroughly without making me feel bad for asking is great.

My surgeon assisted me with my questions and decisions for care and treatment very considerately and respectfully with as much information as I needed.

FELT LISTENED TO (6%)

Patients value being listened to, especially when they have ongoing health needs and they are very informed about their conditions. For many, this meant their treatment plans were adjusted to better meet their needs.

The previous months were discussed and I felt I was listened to. I felt the doctor took into consideration my emotional wellbeing, family situation, and was very empathetic. At all stages of my examination I felt I was told what was being looked for and reassured.

OTHER

- Staff delivered information empathetically and involved patients in decision-making in a way that made them feel cared for and gave them confidence (4%)
- Patients feel the decision they made is respected and acknowledged (4%)
- Patients given time to make decisions (2%)

NOT PROPERLY INFORMED (4%)

Some patients said that they needed more information about their care. They told us that when this doesn't happen they feel excluded from the decision-making process and that their ability to make good decisions is compromised.

I am left with feeling a decision to do surgery or not is up to me - but I don't feel that I have enough information at this time to make an informed decision. I'm no clearer after this latest appointment about the best course of action.

Some said they had to wait too long for results, and occasionally these delays effected the information available at appointments.

Had to call in 3 times and be spoken to in a demeaning way when checking for results which should have been communicated.

Other patients said they needed more information on discharge, including information on medication and side effects.

If there is any outstanding test result this should be communicated efficiently... I had to call in 3 times and be spoken to in a demeaning way when checking for results which should have been communicated.

QUESTIONS NOT ANSWERED (1%)

Very few patients said that they did not feel they could ask questions, or that hospital staff were rushed and did not give them the results or information they needed, however when this happened it left them feeling discounted and ignored.

My question on ongoing pain was ignored.

NOT CONSULTED OR LISTENED TO (1%)

The most common concern from patients who responded they didn't feel listened to was from those with long-term and complex health issues. They felt that staff needed to listen more to hear their knowledge to avoid delays, ineffective treatments, serious allergies and discomfort.

I know my body I have had a lot of health issues and I am in tune with changes ... the changes I pointed out were disregarded completely and are now more prominent and concerning.

OTHER

- Conflicting information given (patient sometimes told one thing by one staff member and then given different information by another) or information not consistent across teams (1%)