



RAISING THE BAR ON THE NATIONAL PATIENT EXPERIENCE SURVEY

REPORT FINDINGS AND
RECOMMENDATIONS

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REPORT BY

#ogilvychange

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PREPARED FOR



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EXECUTIVE SUMMARY

CHAPTER 1

Every quarter, the Health Quality and Safety Commission (the Commission) collects data for the National Patient Experience Survey, in order to understand the patient experience and evaluate the quality of inpatient care in New Zealand's public hospitals.

Since the survey was launched in August 2014, two questions have consistently received the lowest scores. They are:

- Did a member of staff tell you about medication side effects to watch for when you went home?
- Do you feel you received enough information from the hospital on how to manage your condition after your discharge?

In November 2016, the Commission tasked #ogilvychange with:

- 1) understanding why patients give relatively negative responses to these questions, and
- 2) designing a series of cost-effective interventions which District Health Boards (DHBs) could roll out, to improve patient ratings on the two questions

By helping patients to understand the side effects of their medication, and how to manage their condition at home, this project should ultimately:

- improve patient outcomes
- reduce re-admission rates
- reduce healthcare costs associated with re-admission

To meet the project objectives, our research team completed a secondary analysis of data from the National Patient Experience Survey, and we conducted primary research at four District Health Boards (DHBs) around New Zealand.

Using insights gleaned from the research phase, we then developed a number of recommended interventions. These interventions are all based on robust behavioural science frameworks, and they have all been reviewed by #ogilvychange cultural advisors, Tātou.

Our recommended interventions are listed below.

QUICK WINS

These quick wins are changes that could be made relatively quickly, without a significant increase in resource. They are 'nudge' interventions – small changes that are likely to have a significant impact on behaviour.

1) Focus on 'down side' medicines

At present, information about medication side effects is shared in an ad-hoc manner. Most information is shared verbally, and patients struggle to remember what they are told. We recommend the following changes:

- Develop a uniform list of medicines with common or serious side effects.
- Formally 'flag' patients, if they are prescribed these medicines on the ward or at discharge.
- Prompt nursing staff to hand out short, simple information sheets about these medicines.
- Prompt a pharmacist to verbally provide follow-up education - highlighting the key side effects, providing balanced risk information, and actively encouraging patients to ask questions.

2) Create an optimised discharge summary for patients

In its current format, the discharge summary is of little value for patients. The language used is complex, much of the content is irrelevant for patients, and the sections that are relevant are often 'buried' in the document. We recommend the following changes:

- Split the discharge summary letter into two – and include the patient-relevant section first.
- In the discharge summary for patients:
 - Simplify and standardise the content – for instance, including do's and don'ts lists, and providing warning signs for patients to look out for.
 - Make use of best-practice communication devices – particularly visual devices.
 - Make it easier for patients to get answers to questions that may arise, once at home.

We also recommend that staff members take the time to read through the discharge summary for patients. This is particularly important for Māori, who value face-to-face contact or ‘kanohi ki te kanohi’.

3) Use the Discharge Lounge as an education safety net

The Discharge Lounge is the final ‘stop’ in the hospital journey, for many patients. This is a logical place to provide educational resources and advice about how to manage after hospital, as patients are feeling relatively well and they are about to head home. We recommend the following changes:

- Introduce a ‘Home safe’ checklist, to identify any knowledge gaps that patients have about their condition, medicines or ongoing care plan. The checklist will prompt staff members to ‘fill these gaps’ before the patient is discharged. By making it easier for patients to say what they still need to know, we can normalise question asking, and help to protect patients from potential shame or ‘whakamā’.
- Make it easier for patients to access multi-sensory education resources, whilst in the Discharge Lounge. This will benefit all patients, because learning styles differ between individuals - but it should be particularly beneficial for Māori patients, who have a bent towards visual and kinaesthetic or hands-on learning.

BIG WINS

These big wins are changes which require more resource investment, but which should help to drive significant improvements in patient care, and significant improvements in responses to the National Patient Experience Survey. They are not ‘nudges’, but they are still informed by behavioural science.

1) Provide follow-up phone calls

Research conducted at Nelson-Marlborough DHB indicates that re-admission rates are reduced when patients receive a proactive follow-up call from hospital staff, about their care. Open-ended feedback from the National Patient Experience Survey also suggests that patients really value receiving a follow-up call. As such, we recommend that the Commission:

- Run a pilot test in a number of wards or DHBs, to more formally evaluate the benefits of providing patients with a proactive follow-up phone call, after discharge.
- If considered cost-effective, roll out this initiative nationwide.

2) Increase pharmacy resource

Pharmacists have specialist knowledge about medicines, so they are best-placed to provide patients with education and related support services. But at present, pharmacy appears to be under-resourced.

We recommend the following changes:

- Increase the number of full-time pharmacists, in public hospitals.

With more pharmacists on board, it should be possible to:

- Formally include pharmacists in the multi-disciplinary team (MDT), and ensure that higher-risk patients receive the input they need, prior to discharge.
- Provide the medicine reconciliation service to more patients.
- Prepare medication cards for more patients.
- Have relevant sections of the discharge summary written or reviewed by pharmacists.
- Improve handover processes between the hospital and community pharmacies.

3) Continue to roll out technology-based solutions

A number of technological solutions are already being rolled out, to improve information sharing around medication and condition management. This includes electronic medicines management, shared online workstations between hospitals and community pharmacies / GPs, and greater use of apps for patients. These are positive changes, and so our final recommendation is:

- Continue to roll out technological solutions

From here, we suggest that the Commission review the results and recommended interventions outlined in this report. #ogilvychange and the Commission can then collaborate further, to pilot test the most promising interventions at DHBs around the country.

PROJECT BACKGROUND

CHAPTER 2

THE NATIONAL PATIENT EXPERIENCE SURVEY

In August 2014, the Health Quality and Safety Commission (the Commission) launched an adult inpatient survey, to understand the patient experience and evaluate the quality of inpatient care in New Zealand's public hospitals.

The National Patient Experience Survey (NPES) covers 4 domains, including (1) communication, (2) partnership, (3) coordination and (4) physical and emotional needs. Every quarter, the survey is sent to a sample of recent adult inpatients, with results collected and collated by the Commission.

Since the survey began, two questions have consistently received the lowest scores. These questions are:

- Did a member of staff tell you about medication side effects to watch for when you went home? (Hereafter referred to as the Medication Side Effects question)
- Do you feel you received enough information from the hospital on how to manage your condition after your discharge? (Hereafter referred to as the Condition Management question).

PROJECT OBJECTIVES

The objectives of this project are:

- To understand why patients are giving relatively negative responses to the Medication Side Effects and Condition Management questions in the NPES.
- To design a series of cost-effective interventions which DHBs can roll out, to improve patient ratings on these two questions.

By helping patients to understand the side effects of their medication, and how to manage their condition at home, this project should ultimately:

- improve patient outcomes
- reduce re-admission rates
- reduce healthcare costs associated with re-admission

PROJECT PHASES

In order to achieve the project objectives, our team completed a 2-phase project.

PHASE 1 | RESEARCH

Guiding research questions

Throughout the research phase, we sought to answer the following questions:

- 1) Why do patients feel that staff members are not sufficiently informing them about medication side effects to watch out for, after discharge?
- 2) Why do patients feel they did not receive enough information from the hospital about how to manage their condition, after discharge?
- 3) Which factors influence how patients answer these questions? (The factors may have a positive or negative effect on responses.)
- 4) Do high-performing DHBs have any best practices which could be scaled up and applied in other DHBs?
- 5) Do low-performing DHBs have any sub-standard practices which need to be addressed?

PHASE 1A | SECONDARY DATA ANALYSIS

In December 2016 and January 2017, our team conducted a secondary analysis of the NPES data. We wanted to find out:

- If responses to the key questions differed according to key demographic variables, including patient age, gender and ethnicity.
- If there were common themes in the qualitative responses - for instance, key communication weaknesses to be addressed, or best practices which could be scaled up.

PHASE 1B | PRIMARY RESEARCH

In February and March 2017, our team conducted mixed-methods research at four DHBs - Northland, Waikato, Bay of Plenty (BOP), and Nelson-Marlborough.

These DHB sites were selected for the following reasons:

- **Performance in the National Patient Experience Survey.** We aimed to recruit DHBs with varying levels of performance on the Medication Side Effects and Condition Management questions of the NPES. Northland and BOP had relatively poor performance, Waikato had middling performance, and Nelson-Marlborough had above-average performance.
- **Geography.** We aimed for a good geographical spread across the North and South Island, with weighting towards the more densely populated upper-North Island.
- **Ethnicity.** We aimed to include DHBs with a relatively high proportion of Māori. Waikato, BOP and Northland all have above-average representation from Māori - constituting 21%, 23% and 30% of the local population, against a national average of 15% (Ministry of Health, 2015).
- **DHB interest.** Selected DHBs were approached and asked if they would like to participate. There was no obligation to be involved.

We attended each DHB for two days, during which we:

- Reviewed key documents and processes related to information sharing and discharge preparation.
- Observed discharge discussions with patients, and conducted follow-up interviews.
- Conducted background interviews with staff members.
- Conducted a focus group with staff members involved in discharge planning.

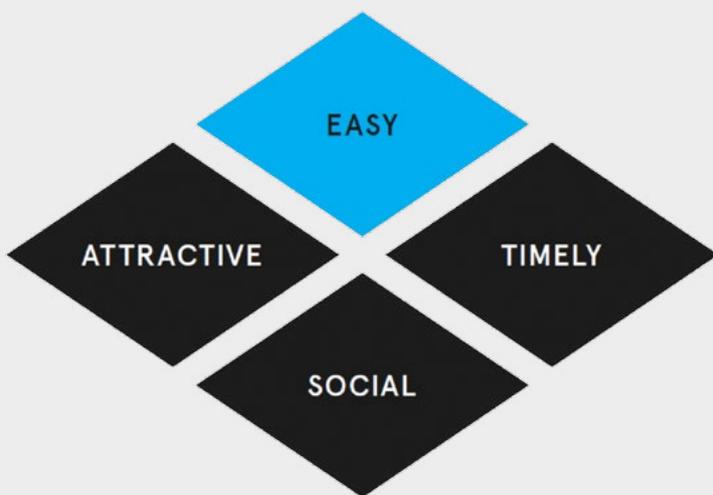
More details about our research approach can be found in the following chapters.

PHASE 2 | INTERVENTION DESIGN

Using our research insights as a starting point, we then designed a series of interventions which aim to:

- Address or minimise the factors that negatively affect patient responses to the Medication Side Effects and Condition Management questions.
- Enhance the factors that positively affect patient responses to the Medication Side Effects and Condition Management questions.

These interventions were designed using best-practice behaviour change frameworks, such as MINDSPACE and EAST, in collaboration with #ogilvychange’s cultural advisors from Tātou.



Behaviour-change frameworks

MINDSPACE and EAST are tools for tapping into the automatic and emotional parts of the brain, which are responsible for most decision-making and behaviour. The frameworks were developed by the UK Cabinet Office Behavioural Insights Team, and they are used by public sector bodies in the UK, US, Singapore, Australia, Central America and beyond, to encourage people to make better choices - around health, retirement saving, education and training, personal safety, climate change mitigation and more.

Each framework is an acronym, highlighting key ways that ‘change agents’ can help to make behaviour-change interventions more successful. For instance, the EAST framework states that if you want to change people’s behaviour, you need to make the desired change Easy, Attractive, Social, and give a Timely prompt.

In Chapter 7 - Recommended interventions, we outline how our recommended changes align with the MINDSPACE and EAST frameworks, and with other key principles from behavioural science.

RESULTS & NEXT STEPS

This report contains a summary of our key research findings, and our recommended interventions.

From here, we suggest that the Commission first review these recommendations, and then, in collaboration with #ogilvychange, determine which interventions to pilot test at selected DHB sites.

REFERENCES

Ministry of Health. (2015, October 8). Population projections. Retrieved from <http://www.health.govt.nz/our-work/populations/Māori-health/tatau-kahukura-Māori-health-statistics/tatauranga-taupori-demographics/population-projections>

RESEARCH METHODS

CHAPTER 3 | SECONDARY ANALYSIS OF PATIENT EXPERIENCE DATA

SECONDARY ANALYSIS OF PATIENT EXPERIENCE DATA

In this chapter, we outline the methods we used to collect and analyse existing data from the NPES.

OUR AIM

In analysing the NPES data, we sought answers to the following research questions.

- 1) Why do patients feel that staff members are not sufficiently informing them about medication side effects to watch out for, after discharge?
- 2) Why do patients feel they did not receive enough information from the hospital about how to manage their condition, after discharge?
- 3) Which factors influence how patients answer these questions?
 - > In particular – do responses vary according to a patient's age, gender, or ethnicity?

DATA COLLECTION

The Commission provided our team with existing NPES data, for the period from Q3-2014 to Q3-2016. This data set included 14,976 patient responses.

DATA ANALYSIS

Developing descriptive statistics

We began by compiling descriptive statistics for the data set. We identified the demographic breakdown of our sample, in terms of gender, age and ethnicity.

Conducting quantitative analysis

To determine whether patient responses differed by age, gender or ethnicity, we first prepared frequency count tables, and then ran Chi-square tests, to see how survey responses varied by demographic and to determine if any of the relationships were statistically significant.

Conducting qualitative analysis

The Medication Side Effects question is #4 in the NPES, grouped with other communication questions (#1 - #5). The Condition Management question is #10, and it is grouped with another coordination question (#9 - #10). Alongside these questions, respondents see an overarching prompt, asking them “Can you give us some examples why you rated it that way? It is these examples that help us understand your point of view.”

To analyse the qualitative data, we first collated all open-ended comments related to communication (n=9963 comments) and coordination (n=6918 comments). Next, we conducted a brief review of the comments, to identify the keywords that appeared in the most relevant comments (see text box).

KEYWORDS

Medication Side Effects

- Side effects
- Discharge
- Medication
- Medicine
- Meds
- Drugs
- GP
- Pharmacist / pharmacy
- Home

Condition Management

- Manage
- Condition
- Discharge
- Home
- Post

RESEARCH METHODS

CHAPTER 3 | SECONDARY ANALYSIS OF PATIENT EXPERIENCE DATA

From there, we ran a keyword search of responses, to rapidly isolate only the most relevant comments. In this way, we were able to reduce the total number of comments as follows:

- from 9963 to 1468 comments related to medication side effects
- from 6918 to 1252 comments related to condition management

Next, we read through all of the qualitative comments, identifying the dominant themes, and colour-coding according to whether the comments were positive (green), negative (red), or unrelated (grey). As a general rule, we tended to be more inclusive rather than exclusive with our coding.

The final stage of our analysis was to identify the key factors that negatively or positively affected patient responses to the survey questions. In other words – what is working now, that could be scaled up? And what isn't working, that could be improved on? These findings are summarised in Chapter 5 – Results of secondary analysis.

Ethical considerations

The key ethical considerations for this research component are (a) patient confidentiality and (b) data security.

In terms of **confidentiality** - the NPES data does not capture patient's names – only their age, gender and ethnicity. To further protect the identity of respondents, all identifying demographic features have been removed from direct NPES quotes cited in this report.

In terms of **data security** – all files related to the project are stored at #ogilvychange, on a secure encrypted server.



RESEARCH METHODS

CHAPTER 4 | PRIMARY RESEARCH AT DHBS

PRIMARY RESEARCH AT DHBS

In this chapter, we outline the methods used to collect and analyse primary data from four DHBs: Northland, Waikato, Bay of Plenty and Nelson-Marlborough. We visited one hospital per DHB:

- Northland – Whangarei hospital
- Waikato – Waikato hospital
- Bay of Plenty – Tauranga hospital
- Nelson-Marlborough – Nelson hospital

OUR AIM

In visiting the 4 DHBs, we sought answers to the following research questions:

- 1) Why do patients feel that staff members are not sufficiently informing them about medication side effects to watch out for, after discharge?
- 2) Why do patients feel they did not receive enough information from the hospital about how to manage their condition, after discharge?
- 3) Which factors influence how patients answer these questions?
- 4) Do high-performing DHBs have any best practices which could be scaled up and applied in other DHBs?
- 5) Do low-performing DHBs have any sub-standard practices which need to be addressed?

RESEARCH COMPONENTS AND RATIONALE

Our research team attended each DHB for a 2-day period, in order to complete the following primary research:

- a) **Review of key documents and processes**
- b) **Observation of discharge discussions + follow-up patient interviews**
- c) **Interviews with staff members**
- d) **Focus groups with staff members**

The rationale for each component of the research is outlined below.

- a) **We reviewed key documents and processes** related to information sharing and discharge preparation. The rationale here is that you need to know the status quo, before you can seek to optimise any processes or communications.
- b) **We observed discharge discussions with patients, and conducted follow-up interviews.** The rationale for the observation is that we wanted to get a better understanding of what really happens during discharge discussions – what information is shared, how is it shared, whether there is room for improvement, etc. The rationale for the follow-up interviews was that we could ‘dig deeper’ with patients, to see how much they really understood about the side effects of their medication, and how to manage their condition. We could also ask about their broader hospital experience, to determine when they received information, who shared the information, how it was shared, and so forth. By understanding the formal processes, what staff say happens, and what patients experience, we could identify those areas of disconnect – for instance, where staff members are sharing information, but the information is not properly received or understood by patients.
- c) **We conducted interviews with staff members.** While this was not part of the original research proposal, we began to incorporate staff interviews during the first DHB visit. We did this for a number of reasons:
 - We wished to supplement the observations and patient interviews, as we were only able to speak to 5 patients rather than 10, at the first DHB. We had limited success because (a) there were practical challenges in getting to the right place at the right time, with discharge discussions occurring throughout staff shifts, not necessarily at a pre-agreed time, and (b) there was no Discharge Lounge at the first DHB we visited, which made it more difficult to access patients who were in the process of being discharged from hospital.

- During the initial site visit, we learnt that information about medication side effects and condition management may be shared throughout the patient’s stay, not predominantly during the discharge discussion. Given this, staff members were well placed to tell us what information they usually share, when, and how.
- Staff members often had helpful suggestions about how processes and communications could be improved. In contrast, patients were less forthcoming with this sort of feedback.

d) We aimed to conduct one focus group at each DHB.

Focus groups are a cost-effective way of gathering the views of staff members, while highlighting both common approaches and inconsistencies in information sharing. The focus groups also gave staff members a chance to brainstorm possible interventions that we could trial, in order to improve communication about medication side effects and condition management. We could begin to see what kind of interventions would and wouldn’t be acceptable to DHB staff.

DATA COLLECTION METHODS

a) Review of key documents and processes

Prior to and during site visits, our team asked DHB staff members to supply any relevant documents related to discharge processes, or information sharing with patients. Across the four DHBs, we collected the following.

- Related to Medication
 - > Medication cards
 - > Drug information sheets / brochures
- Related to Condition Management
 - > General patient information sheets (e.g. breathing exercises)

- Related to discharge more broadly
 - > Admission-to-discharge planning policies
 - > Discharge summary letter
 - > Discharge planning forms/checklists – e.g. the ‘Ticket home’ initiative in BOP DHB, and the ‘Transfer from hospital to residential aged care’ envelope
- Results of prior research conducted at the DHB
 - > For instance - the impact of pharmacists in the transit lounge, at BOP and Northland DHB.

b) Observation of discharge discussions + follow-up patient interviews

At each DHB site visit, we sought to observe 10 discharge discussions between staff members and patients, and then conduct follow-up interviews with patients. At all site visits, we also actively sought to recruit a high proportion of Māori respondents.

To set up these observations and interviews, we liaised with key DHB staff members prior to our site visit, and identified the wards that we would focus on. We also prepared an information sheet for staff members, so that we could inform them ahead of time about the goals of the research, and what we hoped to achieve whilst on the wards.

During the observations, we were listening out for any information about medication side effects and condition management. We also took note of key events – for instance, if patients asked clarifying questions about how to manage their condition.

During the semi-structured interviews, our aim was to find out:

- whether patients felt well informed about medication side effects to watch out for, and how to manage their condition, at home
- what they remember being told, when, how, by whom
- any suggested changes, to improve information sharing.

Initially, we had planned to start the interview by asking the Medication Side Effects question from the NPES – i.e. “Did a member of staff tell you about medication side effects to watch for when you went home?”.

However, this question felt out-of-place when put to patients directly after a discharge discussion – because if patients had been told about side effects, the question felt redundant, and if they had not been told, it appeared that the researcher had not been listening.

As such, we revised our question schedule, and started with a more open-ended question. An indicative question schedule is shown below.

Question schedule: patient interviews

Note – this is an approximate question schedule only, as the interviews were semi-structured, and we adjusted our questions based on the answers given by patients.

Medication side effects

- Do you know what medication you are on? (If yes, please explain)
- What have you been told about these medicines?
- (If side effects not mentioned) Were you told about the side effects to look out for?
- How did you find out this information? Who told you? When?
- Was the information shared verbally, in writing, or both?
- If I were to ask ‘Did a member of staff tell you about medication side effects to watch for when you went home?’, would you say ‘Yes, completely’, ‘Yes, to some extent’ or ‘No’?
- What could we do differently, to improve how we share information with you? To make it easier for you to take information in?
- In general, do you feel confident that you’ll be able to safely take your medication when you get home?

Condition management

- Have you been told how to manage your condition at home?
- What have you been told? How did you find this out? Who told you? When?
- Was the information shared verbally, in writing, or both?
- If asked ‘Do you feel you received enough information about how to manage your condition after discharge?’, would you say ‘Yes, definitely’, ‘Yes, to some extent’, or ‘No’?
- What could we do differently, to improve how we share information about condition management? To make it easier for you to take information in?
- In general, do you feel confident that you’ll be able to manage your condition well, when you get home?
- Any other comments?



c) Interviews with staff members

During site visits, we conducted semi-structured interviews with staff members. The questions we asked varied according to the staff member's role, and the amount of time available. But the general, overarching questions are outlined in the question schedule below.

Question schedule: staff interviews

- What is the standard process that you go through, with discharge planning?
- What type of information do you share?
- How do you decide what information to prioritise?
- Do you have any tips or tricks that you use, to try to help patients absorb information?
- Do you have any suggestions about how we could:
 - > make it easier for patients to understand the information we share?
 - > share information about medication side effects, in a more effective way?
 - > share information about condition management at home, in a more effective way?

d) Focus groups with staff members

We sought to run one focus group at each of the four participating DHBs. However, at one site it was too difficult to get staff members to attend the group at a coordinated time, so in place of a focus group, we conducted more interviews with staff.

At the three DHBs where focus groups were conducted:

- participants were recruited by a key contact at the DHB
- we aimed to enlist 4-8 DHB team members involved in discharge planning / discharge discussions
- the focus groups ran for 1 hour

Attendees were asked a series of open-ended questions, to determine (a) what is being done at the moment, to help patients to understand the side effects of their medication, and how to manage their condition after discharge, and (b) what could be improved on, in each of these areas.

The question schedule is outlined below.

Question schedule: Focus groups 1 & 2

[Preamble] In the National Patient Experience Survey, patients are giving relatively negative responses to a couple of questions related to the sharing of information. We're not here to point fingers or accuse, but rather to try and understand the contributing factors and how to improve the experience.

The discharge summary seems to be a key way that we share information with patients, before they go home.

- How useful do you think the discharge summary is for patients, at the moment?
- How do you think we could communicate the key information in the discharge letter, in a more patient-friendly way? What would you like to see happen?
 - > (prompts)
 - > what content should be included? Excluded?
 - > how could the information be shared? Is a letter best?
 - > what tools could we use, to aid patient's understanding?
- Besides the discharge summary, are there other times / ways that you share information with patients, about their medication?
- How do you decide what to tell patients about their medicines? How do you prioritise information?
- How could this information sharing process could be improved?
- Thinking now about helping patients to manage their condition once they get home – how do you normally tell patients about this?
- How do you decide what to tell patients? How do you prioritise information?
- How could the information sharing process could be improved?

Question schedule: Focus group 3

Note: We adjusted the question schedule for our third and final discussion – to focus more on sense-checking our proposed interventions.

[Preamble]

In the quarterly National Patient Experience Survey, we've found that when patients go home, many don't understand the side effects of their medication, or how to manage their condition at home.

To try to understand these issues, we've been conducting research at 4 DHBs, and [this site] is our 4th and final. Today, I'd like for us to brainstorm some solutions, and sense-check some of the solutions we've already developed.

Brainstorming solutions

- We understand the discharge letter has some issues regarding the transference of key information. What would you like to see happen to help convey information in a more patient-friendly way?
 - > what content should be included? Excluded?
 - > how could the information be shared? Is a letter best?
 - > what tools could we use, to aid patient's understanding?
- What tips or tricks do you use, to try to help patients take information in?

Sense-checking solutions**Empowering patients**

One angle we're exploring is empowering patients to ask good questions, and basically fill in their own 'understanding checklist' at discharge.

- What is your gut feel about this? How come?
- What are the pros and cons of empowering patients to ask questions / to take more responsibility for understanding their care?

- Are there any patient groups that are more likely to be deferential to providers and have a 'doc knows best' viewpoint?
- How does this 'empower the patient' angle fit with a Māori /Pasifika perspective?

Relying more on community pharmacists

Another point that has been raised is that people can't absorb much information in hospital, as they are in pain, stressed, under the influence of medication, etc.

So – we could spread information sharing over time, and get community pharmacists to share more of the load, in terms of educating patients about medicines.

- What is your gut feel about this? How come? Pros and cons? Issues? Opportunities?
- How close are the ties between the hospital and the community pharmacists, at the moment? E.g. do you ever 'refer' patients to talk to community pharmacists?
 - > If yes – how does this happen? Is it process-driven or ad-hoc?
 - > If no – are there reasons why isn't this happening at the moment?
- As a hospital team, what do you think we can do to encourage community pharmacists to take more of a patient education role?

Sending people to credible sources

Another idea is that hospital staff become 'curators of information' – directing people to find out more in their own time, online.

- What is your gut feel about this? How come?
- Do you ever direct patients to online resources? Or print content off for people? If so what sources do you use? What is out there?

General catch-all question

- Any other ideas about what we could do, to help patients understand the side effects of their medication, and how to manage their condition, once at home?

DATA ANALYSIS METHODS

a) Review of key documents and processes

We audited the key processes and documents that we collected – to identify:

- standard processes and procedures
- sub-optimal practices which could be improved
- best practices which could be scaled up, and other opportunities for improvement

b) Background interviews with staff members

c) Observation of discharge discussions & follow-up interviews with patients

d) Focus groups with staff members involved in discharge planning

The #ogilvychange team first transcribed the focus groups in full, along with the key points from patient and staff interviews. Next, we grouped the responses in terms of how they related to these key questions:

- What information is being shared with patients?
- How is information being shared with patients?
- Who usually shares information with patients?
- What is working well? What could be improved?

We then used these key themes and insights as a springboard, to develop interventions that would:

- Equip staff members to more effectively share information.
- Equip patients to more effectively absorb information.

ETHICAL CONSIDERATIONS

As researchers in the public health space, we take our ethical responsibilities seriously. In this project, we have taken the following steps to protect the interests of participating patients and staff members.

Protection of vulnerable patients

Patients were excluded from this project if they were younger than 18 years of age, or if they had recently received treatment from mental health services.

Informed consent

All patients and staff members were told the purpose of this research, and given the option to participate. If people chose to participate, they signed an informed consent form, which was then uploaded to a password-protected server, and the originals destroyed.

Anonymity

In terms of our primary research – no patients or staff members were referred to by name in the transcript, progress reports, or in this final report. For the most part, respondents have been referred to in general terms, for instance ‘staff member, Northland’ or ‘patient, Waikato DHB’. In a small number of instances, we have included a staff member’s role or a patient’s demographics, if those details gave relevant context to a quote.

Confidentiality

Audio files were retained in-house, and only listened to by two members of the #ogilvychange team. No audio files will ever be distributed or made publicly available.

Data security

All files related to this project are stored at #ogilvychange on a secure encrypted server.

Equity

We have retained an equity lens throughout this project, aiming to ensure that our recommended interventions either (a) lift health outcomes for all, or (b) have a disproportionately positive impact on those groups with poorer health outcomes. We are keen to avoid solutions that primarily benefit those at the ‘top of the bell curve’, which would essentially exacerbate health inequalities.

Cultural responsiveness

It is one of the government’s priority objectives to improve the health status of Māori.

Our project took this priority into account, in the following ways:

- **Proactively seeking Māori respondents.** We conducted primary research at four DHBs, three of which have an above-average percentage of Māori by total population. In all sites, we also proactively sought out the views of Māori patients and staff members.
- **Culturally appropriate solutions.** Our cultural advisors from Tātou reviewed all intervention ideas, to ensure that these would resonate with Māori patients and their whānau.



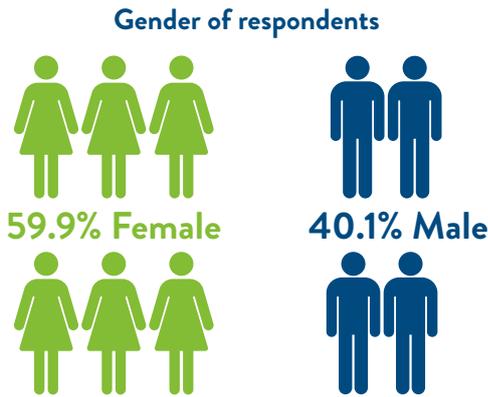
RESULTS OF SECONDARY ANALYSIS

CHAPTER 5

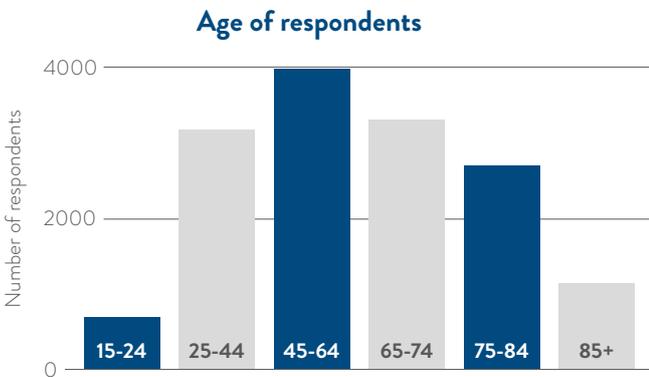
DESCRIPTIVE STATISTICS

The NPES data set included 14,976 responses.

Of these respondents, 59.9% were female and 40.1% were male.



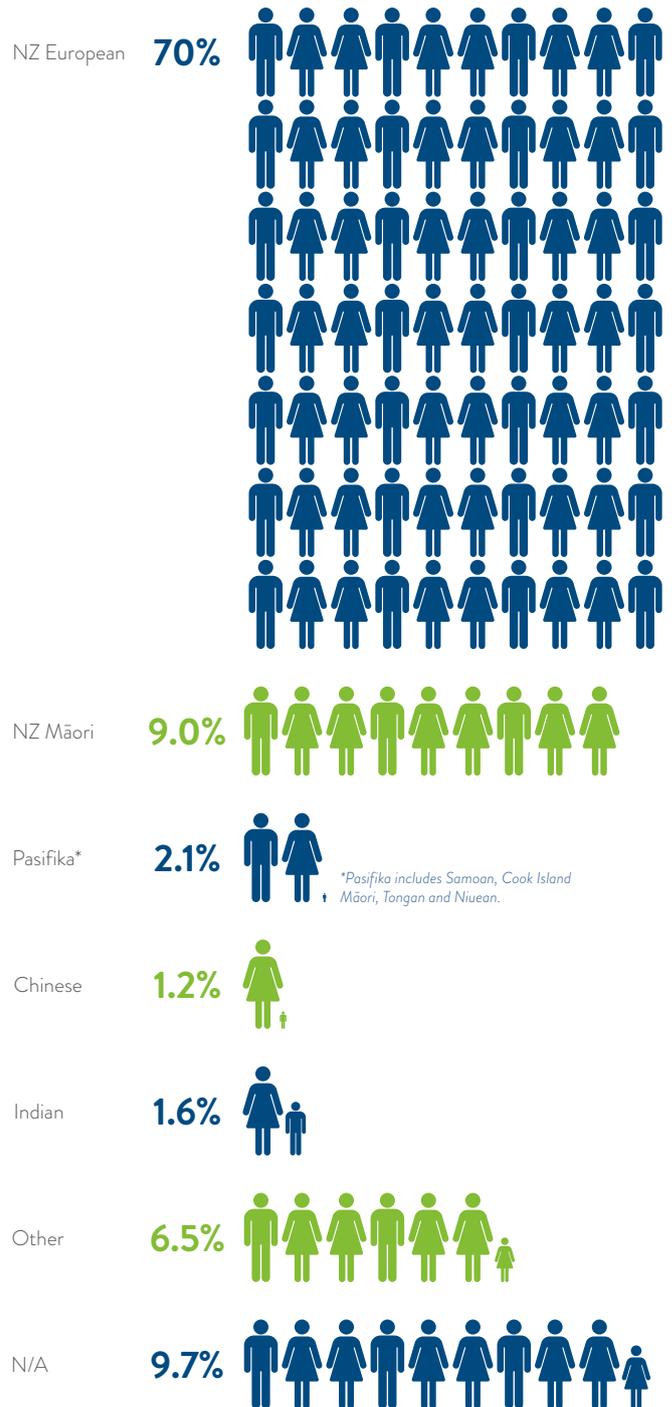
Respondents typically fell in the 45-64 years age bracket.



Over three-quarters of respondents identified as a singular ethnicity, with the vast majority of these people identifying as New Zealand European.

When drilling down and coding the 801 respondents who identified as multiple ethnicities, the proportion of people identifying as NZ Māori increased significantly, from 5.1% to 9% of the population. Nevertheless, 'NZ European' remained the most common ethnicity.

Ethnicity of respondents



HOW DO RESPONSES DIFFER BY GENDER, AGE AND ETHNICITY?

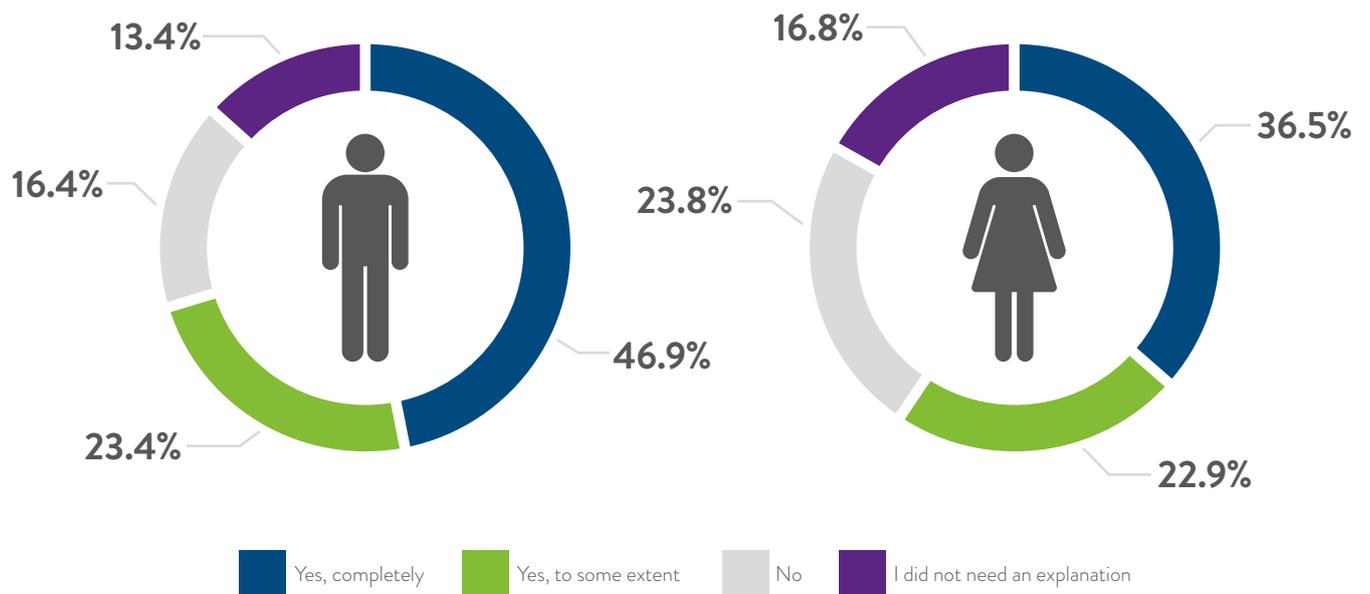
Responses by gender

Medication Side Effects question

Our analyses of the Medication Side Effects question showed that females generally gave more negative responses than males, and this relationship was statistically significant (Chi square statistic = 194.49, $p < 0.01$).

Medication Side Effects question - responses by gender

“Did a member of staff tell you about medication side effects to watch for when you went home?”

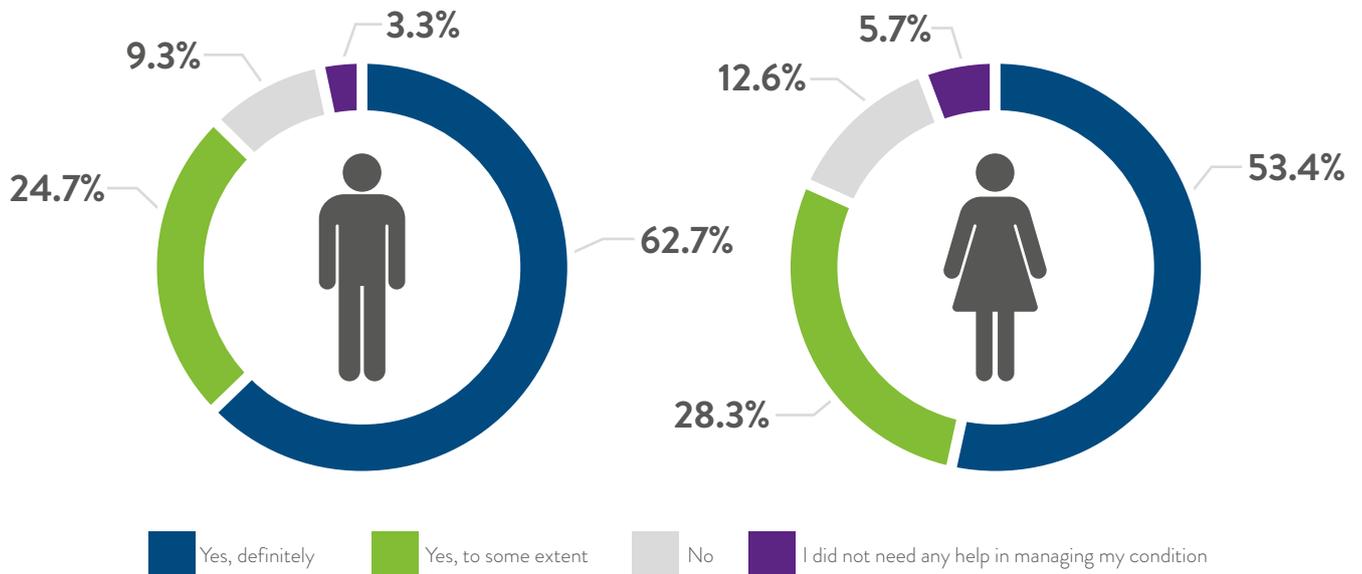


Condition Management question

Responses to the Condition Management question were also significantly associated with gender (Chi square 146.5, $p < 0.01$). On the whole, male respondents were more satisfied with the information they received – as when asked “Do you feel you received enough information from the hospital on how to manage your condition after your discharge?”, 62.7% of males answered ‘Yes, definitely’ compared to 53.4% of females, and only 9.3% of males answered ‘No’, in comparison to 12.6% of females.

Condition Management question - responses by gender

“Do you feel you received enough information from the hospital on how to manage your condition after your discharge?”



Responses by age

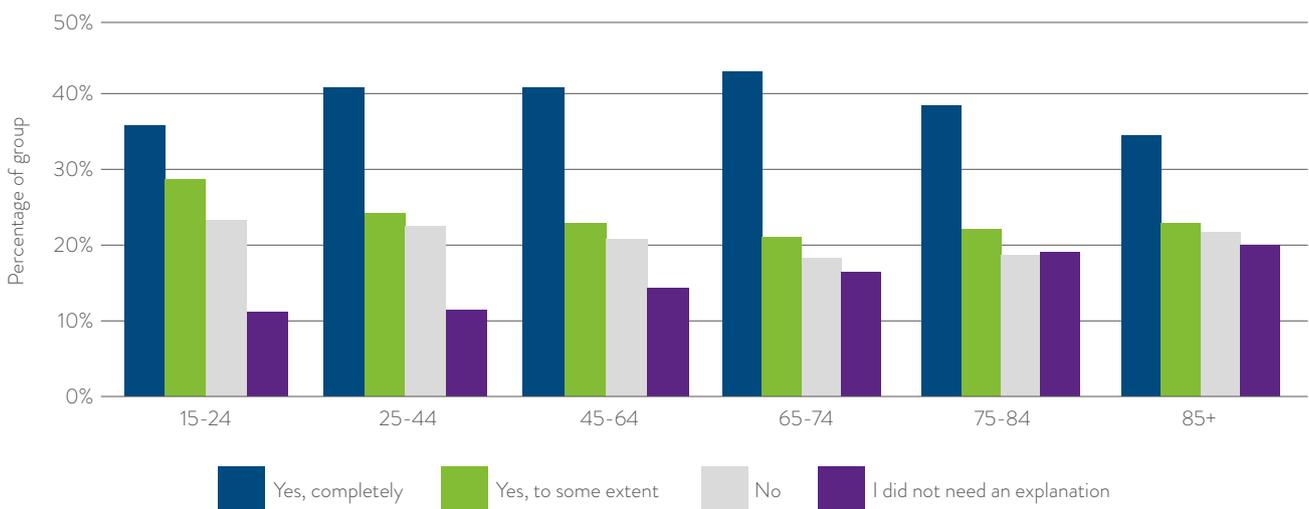
Medication Side Effects question

Responses to the Medication Side Effects question were related to the age group of respondents (Chi square statistic = 140.0, $p < 0.01$).

In particular, patients in older age groups were more likely to select the response option “I did not need an explanation”. Presumably this is because older patients have received treatment for chronic conditions for some time, and therefore, there is less need for clinicians to once again explain the potential side effects of medicines.

Medication Side Effects question - responses by age group

“Did a member of staff tell you about medication side effects to watch out for when you went home?”



Another interesting observation is that people in the youngest age bracket, of 15-24 years, were most likely to answer ‘No’ in response to the question “Did a member of staff tell you about medication side effects to watch out for when you went home?”. We may have observed this result because (a) younger patients are genuinely not receiving information, and/or (b) younger patients have higher expectations as to the level of information they will receive. However, we should avoid reading too much into this result, as there are a relatively small number of respondents in the 15-24 age group, which increases the risk of skewed results

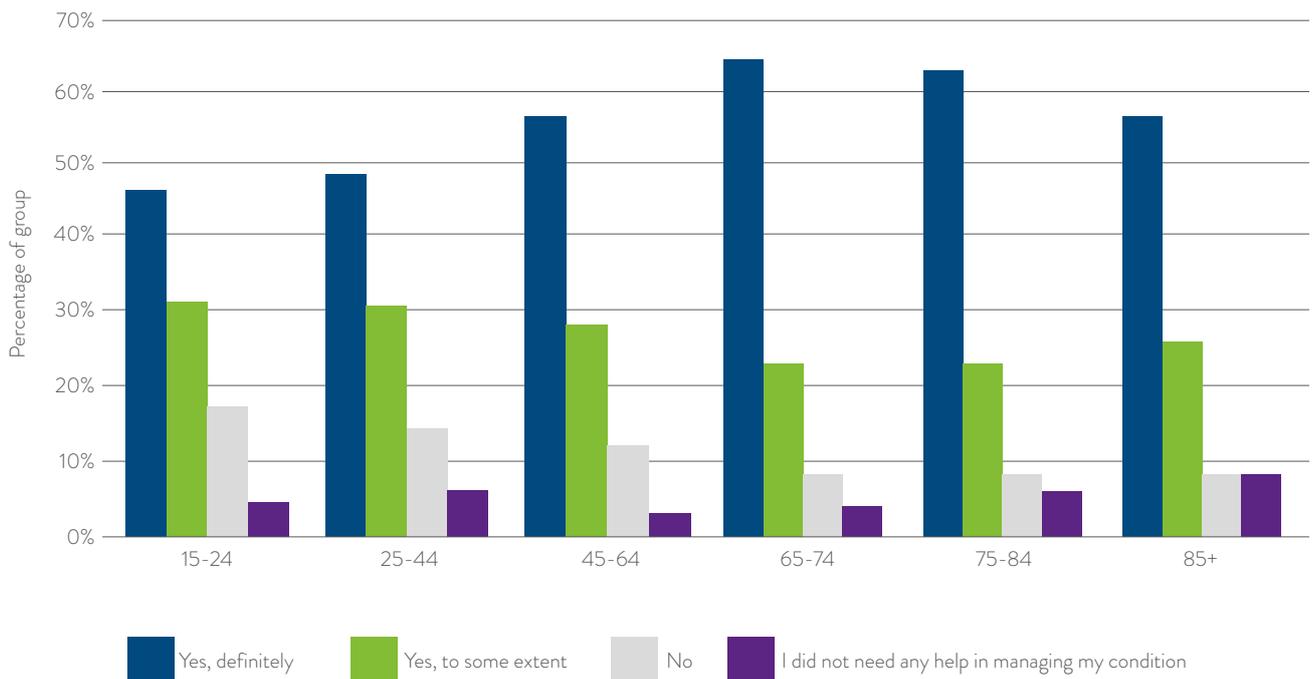
Condition Management question

We also found a relationship between responses to the Condition Management question, and the age of respondents (Chi square 357.1, $p < 0.01$).

People in the 15-24 year age bracket most often answered 'No', they did not receive enough information. And in general, the older the respondent, the more likely they were to say that they 'definitely' received enough information about how to manage their condition after discharge. People in the 85+ year age bracket were also more likely to say that they did not need any help managing their condition – again, we can hypothesise that this is because patients of this age are dealing with chronic conditions which they have managed for many years.

Condition Management question - responses by age

“Do you feel you received enough information from the hospital on how to manage your condition after your discharge?”



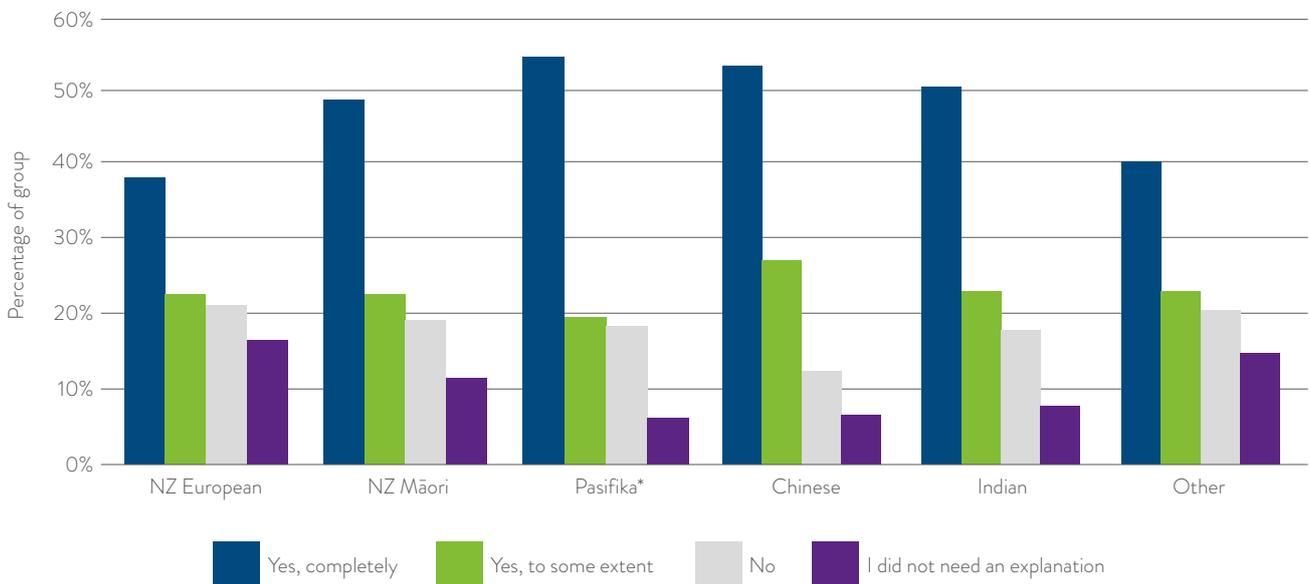
Responses by ethnicity

Medication Side Effects question

We found a relationship between responses to the Medication Side Effects question and the ethnicity of respondents (Chi square 160.2, $p < 0.01$).

Medication Side Effects question - responses by ethnicity

“Did a member of staff tell you about medication side effects to watch out for when you went home?”



*Pasifika includes Samoan, Cook Island Māori, Tongan and Niuean.

Digging into the Chi square data, we find that the significant between-group difference is primarily driven by the proportion of people answering ‘Yes, completely’ and ‘I did not need an explanation’, in different ethnic groups. More specifically we found that more NZ European patients than expected said “I did not need an explanation”, whereas fewer NZ Māori and Pasifika patients than expected said they didn’t need an explanation. The other key trend was that more NZ Māori and Pasifika people than expected answered ‘Yes, completely’, indicating that they had been told about medication side effects, whereas fewer NZ European people than expected answered ‘Yes, completely’.

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	Did a member of staff tell you about medication side effects to watch for when you went home?			
	Yes, completely	Yes, to some extent	No	I did not need an explanation
NZ European	3843 (4045.1) [10.1]	2287 (2281.8) [0.0]	2124 (2073.5) [1.2]	1639 (1492.6) [14.4]
NZ Māori	645 (533.6) [23.3]	296 (301.0) [0.1]	254 (273.5) [1.4]	110 (196.9) [38.3]
Pasifika	174 (128.8) [15.9]	63 (72.7) [1.3]	58 (66.0) [1.0]	20 (47.5) [15.9]
Chinese	97 (74.0) [7.1]	49 (41.7) [1.3]	23 (37.9) [5.9]	12 (27.3) [8.6]
Indian	117 (94.0) [5.6]	53 (53.0) [0.0]	42 (48.2) [0.8]	18 (34.7) [8.0]
Other	368 (368.4) [0.0]	210 (207.8) [0.0]	187 (188.8) [0.0]	136 (135.9) [0.0]

Top line of cell = observed value

(Round brackets) = expected value

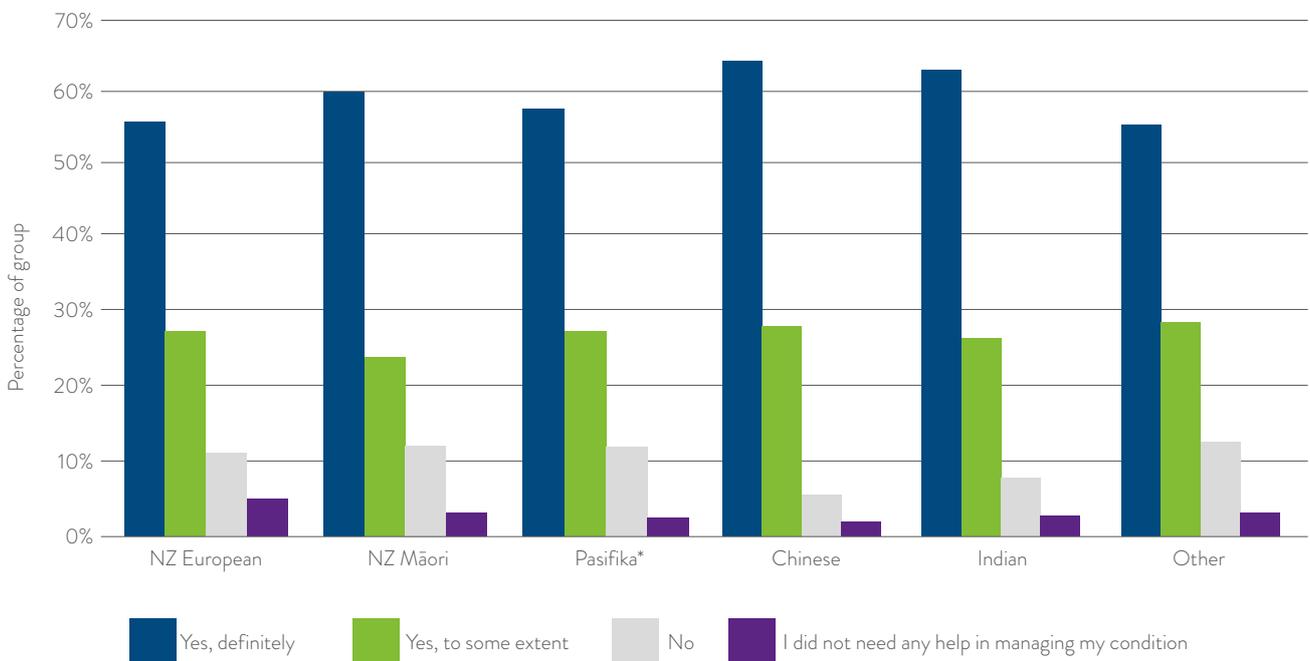
[Square brackets] = chi square statistic for cell

Condition Management question

Responses to the Condition Management question were also related to the ethnicity of respondents (Chi square 45.0, $p < 0.01$), although the Chi square statistic was smaller for this finding than for other questions, indicating a weaker relationship between the variables.

Condition Management question - responses by ethnicity

“Do you feel you received enough information from the hospital on how to manage your condition after your discharge?”



*Pasifika includes Samoan, Cook Island Māori, Tongan and Niuean.

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Looking at the Chi square table, the only strong theme in the data was that, again, more NZ Europeans than expected said 'I did not need any help in managing my condition', whereas in all other ethnic groups, fewer patients than expected said they did not need help.

Do you feel you received enough information from the hospital on how to manage your condition after your discharge?				
	Yes, definitely	Yes, to some extent	No	I did not need any help in managing my condition
NZ European	6085 (6156.2) [0.8]	2995 (2971.7) [0.2]	1266 (1266.1) [0.0]	554 (506.1) [4.5]
NZ Māori	843 (794.1) [3.0]	342 (383.3) [4.5]	175 (163.3) [0.8]	46 (65.3) [5.7]
Pasifika	193 (188.6) [0.1]	92 (91.1) [0.0]	40 (38.8) [0.0]	9 (15.5) [2.7]
Chinese	124 (109.0) [2.1]	54 (52.6) [0.0]	11 (22.4) [5.8]	4 (9.0) [2.7]
Indian	155 (138.9) [1.9]	65 (67.1) [0.1]	20 (28.6) [2.6]	6 (11.4) [2.6]
Other	555 (568.2) [0.3]	292 (274.3) [1.1]	124 (116.8) [0.4]	35 (46.7) [2.9]

Top line of cell = observed value

(Round brackets) = expected value

[Square brackets] = chi square statistic for cell

IMPLICATIONS OF THE RESULTS

According to our analysis:

- Females feel less informed than males.
- Younger patients feel less informed than older patients.
- Compared to other ethnic groups, NZ European patients are more likely to say they don't need an explanation of medication side effects, or how to manage their condition.
- More NZ Māori and Pasifika patients than expected said they received a complete explanation of medication side effects.



What explains these results, and what are the implications?

Gender differences

We hypothesise that the difference in responses is driven by men's reluctance to say that they do not have enough information. As Addis and Mahalik (2003) put it, "A large body of empirical research supports the popular belief that men are reluctant to seek help from health professionals" (p.5). And in our own in-hospital research, we found on a number of occasions that male patients would indicate they were happy with the level of information provided, while female family members would notice gaps in the information given, and ask follow-up questions.

If our hypothesis is correct, then our proposed interventions will need to actively prompt reluctant demographic groups – like men – to ask more questions and ensure they have the information they need.

Age differences

Younger patients feel less informed than older patients, and we expect that this reflects two factors. Firstly, staff members do tend to share more information with older, more medically complex patients, rather than with younger patients who are more likely to come in for acute treatments. Secondly, younger patients may have higher expectations about the level of information they will receive from hospital staff, because as a general trend, younger people are less likely to defer to authority figures (like doctors), and more likely to want to participate in their own care.

If these hypotheses are correct, then there is potentially an easy win here. If we are able to provide younger, less complex patients with slightly more information, it may be possible to improve patient understanding, and lift survey scores amongst younger cohorts, without a significant time cost for hospital staff.

Ethnic differences

In terms of differences between ethnicities, the strongest theme we found was that New Zealand Europeans were more likely than expected to say that they ‘didn’t need an explanation’ about their medication side effects or condition management. This suggests that these patients have received the information they need, in previous encounters with health professionals.

Another interesting theme was that Māori and Pasifika people were more likely than expected to answer ‘Yes, completely’, when asked if they had been told about the side effects of their medication. This could suggest that these demographic groups are better informed – perhaps because they are flagged as a priority population by hospital staff members. However, even if this is the case, we will work to ensure that our interventions promote information-sharing with, and information-retention by, Māori and Pasifika patients. We will take this stance for two reasons.

Firstly, the ability to take in health-related information is impacted by a patient’s health literacy – and health literacy levels are lower in communities “with more limited education, lower socio-economic status, and those whose primary language is not local” (Statistics New Zealand, circa. 2010) – issues that disproportionately affect Māori and Pasifika people.

Secondly, Māori and Pacific cultures tend to be more deferential towards authority, which may lead patients to say they are ‘completely’ happy with the information they’ve received, even if they haven’t received all the key information. As Sachdev explains in *The New Zealand Māori and the Contemporary Health System*:

“A number of authors have commented on the Māori’s deference to the authority of the health professional, especially the doctor (Durie 1984; Mackay 1985) . . . A doctor is therefore approached only warily, and few demands are made on him or her. This attitude may also extend to nurses, physiotherapists, and the like (Rostenburg 1981)” (p.121).

Given these factors, we maintained an equity lens when developing our interventions – aiming to suggest measures that will positively impact on all patients, but particularly Māori and Pasifika peoples.

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QUALITATIVE SURVEY DATA – COMMON THEMES

WHICH FACTORS INFLUENCE HOW PATIENTS ANSWER THE MEDICATION SIDE EFFECTS QUESTION?

Overview

We have identified 5 common factors which influence how patients answer the question, “Did a member of staff tell you about medication side effects to watch for when you went home?”. This includes:

- 1) the quality of the explanation
 - 2) the patient’s ability to absorb information
 - 3) issues with prescribed medication
 - 4) whether patients experience side effects, and whether prescriptions are pre-emptively given to manage side effects
 - 5) the quality of follow-up care, after discharge
- We will now discuss each of these themes in more depth.

Factor #1 – Quality of explanation

“My post-operative medication for example: not only was it explained to me what they were, I was also given names of what they were commonly referred to, their side effects and how I should take them. As a patient, I don’t think you can ask for more.”

When asked ‘Did a member of staff tell you about medication side effects to watch for when you went home?’, one key factor which influenced the patient response was the quality of the explanation given. Explanation quality varied along a spectrum, as shown on the diagram below

MEDICATION SIDE EFFECTS

Quality of explanation: the spectrum

- Insufficient explanation
 - > No explanation
 - > Rushed explanation
 - > Unclear explanation
 - > Some explanation
- Inconsistent explanation
- Thorough explanation

Insufficient explanation

No explanation

In many cases, patients simply didn't receive an explanation as to the side effects of the medication they were prescribed.

- "I haven't got any information about medication side effects."
- "I had vein surgery, I was given Tramadol, but no side effects were explained to me."

When faced with a lack of information, some patients actively asked about side effects – but found staff were unable to give an adequate explanation.

- "I did want to know what all the medications were that I was prescribed when I left the hospital, but the nurse did not know."
- "She [the nurse] couldn't advise my discharge process nor could she explain my meds."

In other cases, patients conducted independent research to find out about medication side effects.

- "No discussion around side effects for other medication, which I found information on the internet after suffering side effects. Discovered that the medication I was given could preclude me from driving which I think was quite an important point."
- "I asked for pain relief for episiotomy and was given tramadol - no explanation of side effects and I later found out this would affect my baby."

It's useful to note that patients were unhappy with the lack of explanation, regardless of whether the medication was prescribed at discharge, or in hospital with side effects 'kicking in' after discharge.

- "I was not given any advice that the medication given to me while in hospital would cause constipation and went home in a lot of pain from this."
- "First time in for an operation and wasn't informed by nurse when leaving that I may vomit after the GA [general anaesthetic] when home."

This suggests that patients would benefit from being told about side effects before medicines are administered in hospital or prescribed at discharge, so they are not surprised if/when they experience these side effects.

Rushed explanation

Some patients felt that the explanation of medication side effects was very rushed.

- "Medication to take at home explained too quickly."
- "I felt the discharge was really rush[ed] as they just wanted you to the transfer lounge and the medication should of been explained to me better."
- "I was told by a rude doctor that there may be side effects but did not elaborate. The doctor in charge appeared to be in a bit of a hurry and didn't really explain anything."

Unclear explanation

At times, patients found the explanation of medication side effects unclear. A number noted that 'medical jargon' was a barrier to their understanding – a topic which we will return to.

- "I also found the language to be a barrier sometimes and felt embarrassed having to say "pardon" so many times."
- "Would help if they talked in patients' terms."

A small number of patients also found it difficult to understand the accents of medical staff.

Some explanation – but not comprehensive

It was fairly common for patients to receive some information about medication side effects, but to note that the information was not comprehensive. For instance:

- "Some medication side effects were told to us but not all, I ended up constipated."
- "It would have helpful to have had a better explanation of discharge medication side effects."

Inconsistent explanation

Patients found it confusing when staff members passed on conflicting medicines. While general miscommunication between staff members is outside the scope of this project, it is important that patients have a clear understanding of the medication they are taking, and the potential side effects.

Thorough explanation

Patients were more likely to give a positive qualitative response when they received a thorough explanation of their medication/s, and the side effects to watch out for. 'Thorough' in this context means patients would like an explanation of:

- what medicines have been given, and why
- when to take the medication – including when the last dose was administered, whilst in hospital
- how to take them (e.g. with or without food, or other medications)
- how long to take the medication for
- what the potential side effects are, and how to manage these
- what activities they can and cannot do safely, whilst on the medication (e.g. driving)
- who to contact if they have any concerns

“My illness, the drugs I was taking and the side effects were fully explained to me and I was questioned as to whether I fully understood what the medical staff were telling me. This was also backed up with written information that I could read in my own time.”

Factor #2 – Ability to absorb information

“I believe that the communication was good, but at times one is either far too tired or affected by drugs to take much notice. Must be [communicated at] better times or explained to relatives.”

Patients are more likely to give positive qualitative responses when they are able to 'take in' the information that they are receiving from the clinical team. A number of factors influence this, including:

- a) the type of language used
- b) the patients' physical and mental state
- c) how information is shared (verbal vs written)
- d) whether a patient's family are involved
- e) whether a patient can ask questions
- f) language barriers

We will now discuss each factor.

a) Type of language used

Patients find it harder to absorb information when clinical staff use medical terms and abbreviations, as these quotes indicate.

- “I did not understand big words, medical terms etc. especially on my discharge sheet, and would have liked someone to go over it with me to explain the facts.”
- “A bit of the information RE: the medication was unclear due to the use of abbreviations on the discharge form.”

Patients prefer it when clinical staff use simple, everyday language in their explanations. For instance, patients praised the following:

- “Everything was explained in a way that a normal person could understand.”
- “The staff member I asked always answered me in a way I could understand (not all medical jargon which you need a degree to understand!)”
- “Doctor spoke straightforwardly with his explanations pitched exactly to my level of understanding.”

b) Patients’ physical and mental state

In-patients may be under the influence of strong medicines, in pain, feeling anxious about their health, or any combination of the above. In these states, it is difficult for people to absorb information, as the following quotes show:

- “I wasn’t always in a position where I could understand everything as clearly as I would have liked, due to my illness and associated medications.”
- “I found it hard to understand what was going on, so many different doctors and [they] talk to me while I was unable to focus because of medicine and struggling to breathe.”

Patients found it easier to absorb information when the clinical team allowed them to recover, before sharing key updates. For instance:

- “The doctor chatted to me the next day after surgery so I wasn’t still foggy from the anaesthesia.”

If patients are affected by medication, illness and stress, it’s particularly important that staff members keep their language and explanations simple:

- “I always knew what was going on and what medication I was being given. They also understood I was pretty hazy from the drugs so kept it simple.”

c) How information is shared – verbal vs written

Patients noted that it was hard for them to remember all the information they were told during verbal discussions – and as such, written materials were valuable.

- “I came home taking numerous pills and felt that for a person of my age that it would be better if it were written down.”
- “Medication was given, with explanations, and a sheet print out explaining any side effects which may present.”
- “Nursing staff gave clear info on my discharge and also gave me an information sheet which was helpful, as after surgery it is easy to forget things you have been told.”

In terms of best practice, patients were particularly complimentary when the written information was compiled in one place, and presented in a simple way.

- “I thought it was good to put the discharge information into one document so that I could refer to it over the next few days and not try to remember it (which proved unreliable at that time!). Also good in just one concise document, not multiple.”
- “When taking many different meds, it would be helpful to have more detailed information in one document about times and dosage.”
- “I don’t remember being told what side effects there would be but the pharmacist gave me a card with all my medications and what each tablet was for. It is so helpful, I keep it in my purse and show it to whoever needs to know my medication. A fabulous help.”

Patients with complex drug regimens also commented on the need for a clear schedule of when to take what.

- “Once home and still in major pain with 8 different drugs that I had no idea of when and how to take them.”
- “We were given a prescription with a long list of drugs. It would have been extremely helpful if this was accompanied by a leaflet outlining the purpose of each drug and a medication schedule – e.g. Severe pain - take oxynorm/ oxycodone/tramadol (slow/ fast release?) 4/6 hourly with /without paracetamol and ibuprofen. Moderate pain - give examples likewise. Also which drugs can or cannot be taken in combination.”
- “The clinical pharmacist was excellent - very thorough and detailed. She covered side effects of medicines as well as designed an ‘easy to follow’ schedule when to take which medications.”

d) Involvement of patient’s family

Because it can be so difficult for patients to recall all the information they are told, it is beneficial if family members are involved in key discussions.

- “I usually had my daughter with me to help remember “what was said” when I got home (just to make sure I heard completely).”
- “I was given a choice . . . to have my family with me when explanations about procedures, medications, operation, etc. It was spoken in a way that we all understood, and [this meant there were] less questions from myself and whānau.”

e) Ability of patient to ask questions

Patients find it easier to absorb information when they are given the chance to ask clarifying questions. However, under the influence of stress and medication, patients may forget to ask questions, or they may feel that staff members are too busy to answer their queries:

- “Discussions seemed to be under urgency due to the work load of the staff, so explanations were short, and I did not want to take up time which was obviously already in short supply.”
- “My impression was that the Drs were always in a mad hurry so there was no time to ask questions.”

Ideally, patients would feel comfortable asking questions, as the following respondents were:

- “Any questions I did ask of any staff member were treated as valid and in no way was I ever made to feel stupid or a nuisance or wasting their time for having asked.”
- “The more information I have, the easier it is to cope with things, all staff were happy to answer any of my questions regarding treatment and medications.”

Patients mentioned a number of situations in which they felt more comfortable asking questions. First off, patients appreciated it when staff members sat down to share information, as this “is a very positive gesture of indicating ‘I have time to spend with you’”. Secondly, some staff members would proactively ask patients if they understood what was said, and if they had any questions. One female patient also chose to write down the questions that she had, prior to discharge, so that she could run through these with the clinical team.

f) Language barriers

Some patients treated in New Zealand hospitals are not fluent in English. When there is a language barrier, patients are unlikely to fully understand the medication that they are taking, and the potential side effects. Ideally, translators will be provided in this situation.

Factor #3 – Issues with prescribed medication

A large number of patients gave negative qualitative responses to the Medication Side Effects question when there were issues with the drugs they were administered or prescribed. Many of the patient comments highlight systemic issues that we cannot tackle within the scope of this project. However, we have included the common issues here, as we have aimed to address as many of these as possible, with our suggested interventions.

Common issues include:

- a) patients prescribed medicines which they have a known reaction to
- b) patients prescribed medicines which interact
- c) patients prescribed medicines which they cannot administer

We will briefly explore each of these themes.

a) Patient prescribed medicines which they have a known reaction to

Patients were not pleased when they were repeatedly prescribed medicines which they had a known reaction to. Many of the issues arose because clinical staff did not read patient charts, or listen to patient feedback, as the following quotes demonstrate:

- “When one of the doctors prescribed some medication he gave me one of the ones I was allergic to, it was on my chart but he didn’t look, I was lucky I recognised the named before the nurse gave it to me otherwise ...”
- “TWICE I was brought medication that I could not take and it had been recorded on my file, then came home with prescription for 220 of the tablets!”
- “The discharging doctor gave me a prescription for medication that I am allergic to and admitted she hadn’t checked my file!”

b) Patient prescribed medicines which interact

A second key issue is that patients often have difficulties combining their newly prescribed medicines with their current medication. In some instances, patients are given drugs which are not safe to take in combination:

- “While in hospital I was given tramadol and on discharge I was given a script for it. It wasn’t till my pharmacist pointed out that there could be some possible side effects when this was combined with another medication I was taking. In hindsight I believe this was the reason I was feeling so unwell during my stay in hospital.”
- “I had one incident where I’d repeatedly told the nurses and doctors I couldn’t take tramadol as it clashes with my antidepressant, but when it came time for my medications and post-surgical prescription, tramadol was listed.”
- “I was given several different medications. . . There was no discussion or reassurance about how they would/ could interact with my usual meds.”

As with all of these matters, some patients had a very positive experience:

- “Any new medication given to me was always explained to me “why” . . . and that the new medication is also compatible to that medication.”

c) Patient prescribed medicines which they cannot administer

The third common theme was that patients found it frustrating when they were given medicines which they could not administer. For instance, one patient could only swallow liquid medication but they were brought pills both during their hospital stay and at discharge. Another patient left hospital without their medication, as IV drugs were prescribed but the IV line had already been taken out.

Factor #4 – The experience & treatment of side effects

Not surprisingly, it was very common for patients to give negative qualitative feedback when they experienced unexpected side effects from their medication. This was distressing on two levels – firstly, because the side effects themselves were troubling, and secondly, because the patients were worried about whether their experiences were normal. Here’s a sample of quotes, all with a similar theme:

- “I was given tranexamic acid and had chest pains when I came home every time I took it (the medication). I called emergency services and they told me to see my GP who told me it was a side effect of the medication, if I had known previously, I could have saved myself a lot of time, worry and money.”
- “I was prescribed over 100 tramadol tablets with absolutely no warning of possible side effects. I had a terrible time on them and ceased using them after the adverse affects became obvious. It was terrifying for me, I felt like I was back in my darkest days of illness. I wish the possible side effects of tramadol had been explained.”
- “I did have a severe reaction to one of the medicines I was on and this was a frightening experience, as being through surgery and then starting chemotherapy, I imagined it was my body not coping.”
- “Would of liked side effects mentioned about medication taken in hospital before I took it, rather than when I started feeling strange, as I freaked out quite a bit only to be told that it can be normal.”

Patients were more likely to respond positively if they were both forewarned about side effects, and given prescriptions to counteract the most likely side effects (e.g. laxatives to counteract opioid-induced constipation).

Factor #5 – Quality of follow-up care, after discharge

The final common theme influencing patient responses to the Medication Side Effects question was the quality of follow up, after discharge. Patients particularly valued:

- a) having a key contact
- b) having their care proactively followed up

a) The importance of a key contact

No matter how much information patients are told whilst in hospital, it is common for questions and issues to arise once they return home.

- “Now I am home I realise there are things that the doc hasn’t told me that I wasn’t aware to ask.”
- “There was some information I was not given at the time and did not know to ask for until after I was discharged, at which time it was too late to talk to anyone as there was no follow-up.”

Some patients noted, directly or indirectly, that it would be very helpful to have a contact phone number to call if they had questions.

- “No information what to do when you got home, who you could phone for helpful information.”
- “A note paper of what to expect when you were recovering at home and when to seek help if certain conditions arose would be a great help.”
- “Because of the serious incident I had post operation . . . I felt I should have been told personally while still in hospital that if I felt unwell to call the ambulance immediately.”

In many instances, GPs and pharmacists play this role of key community contact, by answering patient questions and ‘catching’ issues with prescribed medication:

- “I did not get told of any side effects of the antibiotics I was prescribed, the chemist actually gave me the run down on them as they were so strong and he was concerned.”
- “My GP told me medication side effects after I came home.”

b) The value of proactive follow-up

Patients gave particularly glowing feedback when the hospital went ‘above and beyond’ by proactively phoning to check on their follow up. It is clear how pleased patients are, in the following comments:

- “After care, at home, from [Medwise], was needed and really appreciated. She rang four times over several days until I felt confident with the meds and my condition.”
- “When I got home, I had the anaesthetist ring to see if I had any problems with the nerve block he gave me prior to the operation. I felt that was awesome of him.”

WHICH FACTORS INFLUENCE HOW PATIENTS ANSWER THE CONDITION MANAGEMENT QUESTION?

Overview

Responses to the Condition Management were fairly similar to the Medication Side Effects question. We identified 4 key factors which influenced responses, including:

- 1) the quality of the explanation given
- 2) the patient's ability to absorb information
- 3) if patient's had unclear or unmet expectations about their condition and recovery
- 4) the quality of follow-up care

Factor #1– Quality of explanation

As with the Medication Side Effects question, patients received a variable amount of information about how to manage their condition at home, and this could be mapped along a spectrum.

CONDITION MANAGEMENT

Quality of explanation: the spectrum

- Insufficient information sharing
- Inconsistent information sharing
- Delayed information sharing
- Thorough information sharing

Insufficient information sharing

In terms of the dominant themes, many patients felt they did not receive enough information about:

- what they could and could not do – e.g. in terms of driving, exercise, diet, work, and other activities of daily living
- wound management / changing dressings
- pain management
- when to seek further medical care – i.e. the signs to look out for
- expectations in terms of recovery time

Inconsistent information sharing

A number of patients also noted that the information they received about condition management was inconsistent. While this may reflect the patient’s evolving care plan, it could also reflect a lack of communication between staff members:

- “Every single midwife on each shift contradicted the previous midwives “care plan” & being in the hospital for 5 days that became very very frustrating!”
- “I would be going home the day after surgery, 2 days after surgery, 4 days after surgery? I went home 4 days after surgery. I could put weight on leg hours after surgery - not for 2 weeks - not for 4 weeks?”
- “Appeared to be no communication between the different agencies such as physio and OT and nursing staff.”

Delayed information sharing

One new theme to arise was the issue of delayed information – particularly amongst patients who did not receive a discharge summary letter. There were various reasons for this – some patients chose to leave hospital without their papers, some were discharged on the weekend and told the papers would be sent in the mail, and some didn’t receive their papers for unknown reasons.

Thorough information sharing

As always, some patients were very happy with the information they received:

- “Everything was explained to me in full detail.”
- “Am very clear on discharge what I need to do regarding medications, follow up and treatment.”
- “I came home with all the information to manage my condition which is why I am doing so well, now friends are surprised I healed so quickly, and am so mobile.”

From reviewing patient feedback, we can ascertain that a thorough explanation of condition management would cover:

- Follow-up care:
 - > Equipment provided, and how to use it
 - > Further tests / referrals to community-based care
 - > Instructions for any self-care (e.g. wound management, physio exercises)
- Do’s & don’ts in terms of diet, exercise, driving, lifting etc.
- Medicines to take, how to take them safely
- Expected recovery time
- Warning signs/symptoms to look out for – i.e. when to escalate your treatment and contact someone for help
- Who to contact if issues arise

“Everything was explained in terms that I could understand and I felt that I could ask questions and be given an honest answer. When changes were made to my medication I was told why.”

Factor #2 – Ability to absorb information

As with the Medication Side Effects question, a patient's ability to absorb information is affected by (a) the type of language used, (b) the patient's physical and mental state, (c) how information is shared (verbal vs written), (d) whether a patient's family are involved, (e) whether the patient can ask questions and (f) language barriers.

However, responses to this question differed in two key ways – firstly, written and visual information sharing appeared to be even more important, and secondly, patients appreciated receiving practical demonstrations. We'll now discuss these two new themes.

The value of written information – and visuals

When it came to condition management, some patients received information from numerous specialties, and this led to a feeling of "information overload":

- "On the morning of my discharge I became rather overwhelmed at all the information (physio, dietitian, social worker, doctor) being fired at me. Very difficult to take it all in."

In these instances, short-form written content was highly valued:

- "Too much information at once is very confusing but dr gave us written information to take with us that was really helpful."

Even if patients were only seen by one specialty, written information was valuable as it could be taken home and reviewed when patients had partially recovered.

In terms of best practice, a number of patients mentioned the value of 'do's and don'ts' lists:

- "I was given a very informative booklet (ERAS) at my pre-admission apt [appointment] so I was able to read about all the do's and don'ts after a hip replacement."
- "I was given a discharge letter that outlined the conditions of my recovery at home. A list of do's and don'ts. Quite clear I thought."
- "Several times it was made very clear as to do's and don'ts relating to my care on discharge."

After the value of written information was highlighted, our team went back into the data set to see if patients also had a preference for visual information. By conducting a keyword search on **visual**, **picture**, and **draw**, we were able to identify a number of quotes indicating that patients valued visual information. For instance:

- "The medical terminology was explained by all medical staff in easy terms and if I still didn't understand they would even draw picture/diagrams."
- "It was a new condition and the doctor went to the trouble of drawing a diagram to explain it."

As a side note, the practice of providing visual diagrams appeared to be more common in the surgical wards:

- "I was given a good explanation and even sketched a picture of what it will be taken off or removed during the operation."
- "Everything was explained well. The surgeon especially took the time to draw a diagram to show what he would be doing."

The value of demonstrations

Another best-practice theme to arise was the value of demonstration to help patients manage their condition once at home:

- "The thrombosis lady explained how to inject myself at home very well, as did the nurse who gave me a trial run."
- "The staff always spoke to me in a polite fashion, and were very helpful showing me how to use stoma bags."

Factor #3 – Unclear or unmet expectations about condition & recovery

According to the dataset, patients felt less informed about how to manage at home when they had unclear or unmet expectations about their condition and recovery.

Some patients did not know what to expect:

- “During the week following discharge I realised I did not know much about what to expect during recovery. I was not told how long the bleeding might continue, so was a bit anxious as to whether my case was within the normal range.”

Other patients found their condition did not progress as they expected:

- “Had a pacemaker inserted and didn’t feel as well as expected after discharge, I spent a lot of time thinking is this normal... Should I go to ED..... I don’t want to waste anyone’s time.”

A relatively large number of patients also experienced more pain than they expected, or felt able to cope with:

- “The care from surgeons was very good, just I was not fit to go home in that much pain that I could not control.”
- “I needed an extra day in hospital because I did not have adequate support at home and my pain was not well managed.”

On a related note, many patients felt that they were prescribed insufficient pain medication, at discharge:

- “The pain relief regime recommended after discharge was not totally effective.”
- “Was discharged with no pain medication. Just told to keep taking paracetamol. I had a c-section.”
- “I was discharged from hospital with [paracetamol] for pain which was not strong enough. I had to contact my doctor for tramadol.”
- “The painkillers prescribed on discharge were not strong enough.”
- “I needed to know how to manage pain better if the regime of medication proved insufficient. This happened the 2 days after I left hospital where I was in considerable pain and yet I had taken my tablets as instructed. That day I was just beside myself with pain. Had there been a pistol in the house I think I’d have been tempted to use it.”

Given these comments, an important part of information sharing is helping patients to know what to expect once they get home. In particular, patients need to know whether their experiences are part of a normal recovery, or a ‘red flag’ indicating that they should seek medical attention.

Factor #4 – Quality of follow-up care

The final factor that influenced patient responses to the Condition Management question was the quality of follow-up care. Breaking this down further, the key variables that affected patient responses were:

- a) whether equipment and follow-up care was arranged, and delivered
- b) whether patients had a contact point, if required
- c) whether hospital staff made proactive follow-up phone call/s

a) Equipment and follow-up care arranged, and delivered

When it comes to the provision of equipment, like walkers, shower stools and crutches, it seemed that most patients received the gear that they needed, prior to discharge. Here are just a handful of comments:

- “Before being discharged a physiotherapist looked at what kind of tools I would need such as a walking frame etc., and it all was delivered even before I came home.”
- “Provided equipment to enable me to live at home. E.g. commode, indoor frame walker with basket and tray.”
- “I went home with a crutch, toilet seat, shower stool & a wonderful handle to hold when getting in & out of bed.”

In contrast, a relatively large number of patients were unhappy that they had not been referred for community-based follow-up, or that the follow-up care had never eventuated:

- “I was told a cardiac nurse would be visiting me at home, which hasn’t happened over a month later.”
- “I wasn’t really told anything about my condition and was referred to an OT [occupational therapist] but have never heard from them.”
- “If help is offered it would generally be expected for someone to arrive or a phone call to confirm what is happening.”
- “The aftercare has been slack and very upsetting, we shouldn’t have to chase everyone. Please fix this. This is not good for the elderly.”

b) Patients have contact point, if required

As noted earlier, patients often have questions or issues that arise, once they get home. Given this, patients valued having the contact details of people who could help:

- “I had a confusing condition, a bit more reassurance and possible contacts would have saved stress.”
- “I went home knowing who I could contact for more urgent matters. Never had that before.”
- “I had amazing care, even given a cellphone no. I could call when I got home if I needed the doctors which I found reassuring.”

c) Hospital staff proactively make follow-up phone call/s

As with the Medication Side Effects question, patients were particularly happy when they received follow-up phone calls from the hospital, about their progress:

- “Physio staff were concerned what would happen when I went home. Even had a telephone call to home checking that all was well and what to do if I needed a physio.”
- “Since being home, the hospital ward staff have each week phoned me as a follow up to my condition and how I’m doing and feeling.”

“A nurse took great care in showing me how to administer my take home medication, also giving me written instructions and highlighting the phone number [for follow up].”

IMPLICATIONS OF THE RESULTS

After analysing the qualitative responses from the National Patient Experience Survey, we have compiled the following best-practice checklist, to help patients better understand the side effects of their medication, and how to manage their condition, once at home.

We took these best practice factors into account, when designing our recommended interventions.

A BEST PRACTICE CHECKLIST

Explaining medication side effects & condition management:

- Explanation is thorough
 - Patient is given clear expectations as to medication side effects & condition management
 - Language is simple
-
- Information is compiled in one place
 - Verbal explanations are supplemented with simple written materials
 - Visual diagrams / pictures are included, if relevant
 - Practical demonstrations are given, when possible
-
- Insofar as possible, patient is not influenced by medication / illness / stress at the time
 - Patient's family members are included (if patient consents to this)
 - A translator is provided if patient is not fluent in English
-
- Strategies are used to help patients feel comfortable asking questions
-
- A follow-up contact phone number is given
 - Proactive follow-up is provided, insofar as possible



RESULTS OF PRIMARY RESEARCH AT DHBS

CHAPTER 6

PARTICIPANTS

We recruited the following participants, at the 4 DHBs we visited.

Patients

- 48 patients
- 50 / 50 gender split
- Ethnic split:
 - > 73% NZ European
 - > 21% NZ Māori
 - > 4% Pasifika
 - > 2% Other

Staff members

- 51 staff members:
 - > 21 nursing staff
 - > 12 pharmacy staff
 - > 7 physiotherapists / occupational therapists
 - > 6 house officers
 - > 3 staff members from governance / quality improvement
 - > 2 anaesthetists

Our researcher also sat in on a ward round, a bed traffic planning meeting, and a multi-disciplinary team meeting.

Nelson-Marlborough

Respondent	Observation + interview	Interview	Focus group
PATIENTS			
1	Patient in Surgical Ward Male, NZ European, approx. 75 years	X	
2	Patient in Surgical Ward Female, NZ European, approx. 70 years	X	
3	Patient in AT&R Male, NZ European, approx. 75 years		X
4	Patient in AT&R Male, NZ European, approx. 70 years		X
5	Patient in AT&R Female, NZ European, approx. 90 years Questions answered by her daughter (approx. 70 years)		X

Nelson-Marlborough *continued*

	Respondent	Observation + interview	Interview	Focus group
STAFF MEMBERS				
6	Pharmacist	X		
7	Pharmacist			X
8	Pharmacy Team Leader			X
9	Charge Nurse		X	X
10	Charge Nurse			X
11	Ward Nurse		X	
12	Ward Nurse		X	
13	House Officer	X	X	X
14	Allied Health Leader			X
15	Physiotherapist			X
16	Occupational Therapist			X
17	Clinical Governance			X

Plus supplementary telephone interview with:

- MyMedicines Coordinator, Clinical Pharmacology Department, Christchurch Hospital

Bay of Plenty

	Respondent	Observation + interview	Interview	Focus group
PATIENTS				
1	Patient in Transit Lounge Female, NZ Māori, approx. 60 years	X		
2	Patient in Transit Lounge Female, NZ European, approx. 70 years	X		
3	Patient in Transit Lounge Female, NZ European, approx. 50 years	X	X	
4	Patient in Transit Lounge Female, NZ European, approx. 55 years		X	
5	Patient in Transit Lounge Male, NZ Māori, approx. 20 years		X	
6	Patient in Transit Lounge Male, NZ European, approx. 50 years		X	
7	Patient in Transit Lounge Female, NZ European, approx. 90 years		X	
8	Patient in Transit Lounge Male, NZ European, 98 years		X	
9	Patient in Transit Lounge Male, NZ European, approx. 50 years		X	
10	Patient in Transit Lounge Male, Rarotongan, approx. 65 years		X	
11	Patient in Transit Lounge Female, NZ European, approx. 20 years		X	
12	Patient in Transit Lounge Male, NZ European, approx. 20 years		X	
13	Patient in Transit Lounge Male, NZ European, approx. 70 years		X	
14	Patient in Transit Lounge Male, NZ European, approx. 60 years		X	
15	Patient in Transit Lounge Female, NZ European, approx. 40 years		X	

Bay of Plenty *continued*

	Respondent	Observation + interview	Interview	Focus group
STAFF MEMBERS				
16	Pharmacist			X
17	Pharmacist			X
18	Nurse Manager			X
19	Charge Nurse		X	
20	Charge Nurse		X	
21	Nurse in Transit Lounge		X	
22	Nurse in Transit Lounge		X	
23	House Officer		X	
24	House Officer			X
25	Quality & Patient Safety			X

Northland

	Respondent	Observation	Observation + interview	Interview
PATIENTS				
1	Patient in Discharge Lounge Female, NZ Māori, approx. 65 years	X		
2	Patient in Discharge Lounge Male, NZ European, approx. 70 years		X	
3	Patient in Discharge Lounge Male, NZ Māori, approx. 40 years		X	
4	Patient in Ward then Discharge Lounge Female, NZ European, approx. 60 years		X	
5	Patient in Discharge Lounge Female, NZ European, approx. 30 years		X	
6	Patient in Discharge Lounge Male, NZ Māori, approx. 40 years		X (pharmacist discussion)	
7	Patient in Discharge Lounge Male, NZ European, approx. 65 years	X (Doctor and pharmacist)		
8	Patient in Discharge Lounge Male, Pasifika, 21 years			X
9	Patient in Discharge Lounge Female, NZ European, approx. 50 years			X
10	Patient in Discharge Lounge Female, African, approx. 50 years			X
11	Patient in Discharge Lounge Male, NZ Māori, approx. 55 years			X
12	Patient in Discharge Lounge Female, NZ European, approx. 50 years			X

Northland *continued*

Respondent		Observation	Observation + interview	Interview
STAFF MEMBERS				
13	Clinical Lead in Pharmacy			X
14	Pharmacist			X
15	Pharmacist			X
16	Clinical Nurse Educator			X
17	Nurse Specialist – Pain Team			X
18	Nurse in Discharge Lounge			X
19	Nurse - Short stay surgical			X
20	Nurse - Short stay surgical			X
21	Anaesthesia specialist			X
22	Patient Experience Specialist			X

Waikato

	Respondent	Observation + interview	Interview	Focus group
PATIENTS				
1	Patient in Surgical Ward <i>Female, NZ European, approx. 75 years</i>		X	
2	Patient in Surgical Ward <i>Male, NZ European, approx. 50 years</i>		X	
3	Patient in Transit Lounge <i>Female, NZ European, approx. 65 years</i>		X	
4	Patient in Transit Lounge <i>Female, NZ European, approx. 70 years</i>		X	
5	Patient in Transit Lounge <i>Female, NZ European, approx. 85 years</i>		X	
6	Patient in Transit Lounge <i>Male, NZ European, approx. 70 years</i>		X	
7	Patient in Transit Lounge <i>Male, NZ European, approx. 70 years</i>		X	
8	Patient in Transit Lounge <i>Female, NZ European, approx. 80 years</i>		X	
9	Patient in Transit Lounge <i>Male, NZ Māori, approx. 70 years</i>		X	
10	Patient in Transit Lounge <i>Female, NZ European, approx. 90 years</i>		X	
11	Patient in Transit Lounge <i>Female, NZ European, 99 years</i>		X	
12	Patient in Transit Lounge <i>Male, NZ Māori, approx. 45 years</i>		X	
13	Patient in Transit Lounge <i>Female, NZ Māori, approx. 55 years</i>		X	
14	Patient in Transit Lounge <i>Male, NZ European, approx. 65 years</i>		X	
15	Patient in Transit Lounge <i>Male, NZ European, approx. 75 years</i>		X	
16	Patient in Transit Lounge <i>Female, NZ Māori, approx. 60 years</i>		X	

RESULTS OF PRIMARY RESEARCH AT DHBS
CHAPTER 6

Waikato *continued*

	Respondent	Observation + interview	Interview	Focus group
STAFF MEMBERS				
17	Team Leader, Pharmacy			X
18	Pharmacist			X
19	Pharmacist		X	
20	Pharmacist		X	
21	Charge Nurse Manager		X	
22	Clinical Nurse Specialist - Oncology			X
23	Registered Nurse		X	
24	Registered Nurse		X	
25	Registered Nurse		X	
26	Registered Nurse		X	
27	Registered Nurse		X	
28	Consultant Anaesthetist			X
29	House Officer		X	
30	House Officer		X	
31	House Officer			X
32	Physiotherapist		X	
33	Physiotherapist		X	
34	Physiotherapist		X	
35	Occupational Therapist		X	

INTRODUCTION

During our primary research at 4 DHBs, we sought to find out:

- What information is usually shared about medication side effects, and condition management?
- Who usually shares the information?
- How is information shared?
- What is working well, and what could be improved?

The answers to these questions are outlined below. But before we get into these new themes, we'd like to mention the areas of overlap between the NPES data, which we've discussed, and the primary research that we conducted.

“What do you do to make it easy for people to remember what you tell them?”

“So – a variety of means. Talking with someone, always gaining feedback as to whether they understood, or whether they need a different form of media. With a lot of our stuff it's exercises, or giving information, so giving written directions or instructions, or using images quite a bit as well. . . And then, you follow-up with someone . . . to get that reinforcement in the community”

(staff member, Waikato).

6.1 | THEMES OBSERVED IN PRIMARY RESEARCH THAT ECHOED THE NATIONAL PATIENT EXPERIENCE SURVEY DATA

Varied quality of explanations

As you would expect, some patients were very pleased with the explanations given to them by staff members, whilst others felt that the explanations were rushed or incomplete. There was also variability between staff members – a small number of patients mentioned that the nurses were thorough and took the time to explain things clearly, whilst the doctors gave rushed explanations:

- “From the nurses point of view, very well, from the surgeons or doctors, not so. All very rushed . . . I would have liked to have asked a few questions, but they didn't stop moving” (patient, BOP).

Patients have limited ability to absorb information

A number of patients noted that they struggled to take in the information that was shared with them, because of their health, tiredness, or a general feeling of being overwhelmed. These were common issues, regardless of the patient's age:

- “I felt like they told me a lot, but I was normally falling asleep at the time” (young Māori male patient, Northland).
- “I'll probably start remembering [the side effects] once I get back, and see the meds . . . but just everything's been a whirlwind in the last 24 hours” (middle-aged male patient, Waikato).
- “Well my doctor probably did [tell me the side effects of my medications], but I just can't remember . . . I'm not at my best right now” (elderly female patient, BOP).

A very large proportion of staff members also noted that patients struggle to retain what they are told, because of the stressful context that they are in. For instance:

- “If you’ve got people in acute crisis – they’ll want information, but they’re not best placed to take it on” (staff member, Nelson).
- “Especially after surgery, when they’ve had anaesthetics and pain relief – a lot of things don’t get taken on board, straight away” (staff member, BOP).
- “People who are in crisis – and coming into hospital is a crisis, for most people – they don’t actually have the capability to take in that information, at the time” (staff member, Waikato).
- “I suspect, a lot of people might have been told, quite adequately, in hospital. But you forget, halfway down the road, or you’re more worried about who’s going to pick me up, or what state the house is in. There’s a lot going on in their mind – remembering specifics about some new medicines falls off” (staff member, Northland).

We observed patients ‘forgetting’ information first-hand, when we sat in on a discharge discussion with a patient in Nelson. The patient was told the side effects of tramadol, and given a laxative and an anti-nausea pill, in case they started to experience constipation or nausea. But minutes later, the patient did not think they had been told any side effects - and the information was only retained by the patient’s wife.

Easier to absorb when information is simple & not just verbal

Not surprisingly, patients found it easier to absorb information when it was shared in a simple way. That includes:

- **Information highlights**, rather than ‘all the details’
 - > “Sometimes you go to the pharmacy and they give you a fold-up paper, which would take about an hour to read it all thoroughly. . . it doesn’t have to be massive. Probably the less complicated it is, the better” (patient, Waikato).
 - > “Three pieces of information and you’ve lost them” (staff member, Nelson).
- **Simple terms used**
- **Information compiled in one place**

A large number of both patients and staff members also pointed out that **written information** is valuable – because it’s so difficult for patients to take everything in, whilst in hospital. To quote just one patient:

- “A little booklet would have been handy – something to refer to. What you get told in hospital, you can be a bit foggy at the time. Your brain can be a bit, you know, you’re recovering from the anaesthetic and painkillers and that sort of thing. So probably something to take home afterwards . . . what you can and can’t do” (patient, BOP).

In fact, the Tauranga Transit Lounge sought feedback from patients, about how they could improve the patient experience. The following sentiment was echoed in every DHB we visited:

- “What we took from that feedback, is a lot of people have said they get a lot of information while they are in hospital, verbal, but when they get home, it’s actually really hard to remember everything. And pamphlets, for them, worked really well” (staff member, BOP).

Finally, echoing the NPES data, we found that patients preferred **visual information and demonstrations**. This is a topic that we will discuss in more depth, in section 6.9A.

Easier to absorb when family members are included

Patients felt they could absorb more information when their family members were included in discussions:

- “You often need someone else to hear, because you often only remember a certain amount” (patient, BOP).
- “Information-wise, I think there needs to be a carer or somebody else who has that information as well” (patient, Waikato).

Whānau inclusion is particularly important for Māori, who view health as a collective concern. For instance, when we asked a Māori couple how we could improve the information-sharing process, the patient’s wife noted, “Tell the partner. If the partner is with them, and they communicate with the partner, it will be alright” (Waikato).

Staff members – including those who work closely with Māori – are already well aware of the value of including family. For instance, in a Tauranga Medical Ward that predominantly serves Māori patients, staff members aim to include whānau in key meetings, particularly around discharge destinations and the level of support that people need. In other wards and locations, staff members aim to include a support person in key conversations – because two pairs of ears is better than one, and because often a family member will help to manage a patient’s condition or their medication.

In section 6.6C, we will explore how family members could be brought into key discussions, to a greater extent.

We’ll now move on to the new themes that we identified during the primary research.

6.2A | WHAT INFORMATION IS USUALLY SHARED ABOUT MEDICATION SIDE EFFECTS?

Before we can begin to recommend changes to the information-sharing process, we need to determine what is being shared at the moment.

Standard process

Side effects - only a priority for certain medicines

When new medicines are administered on the ward, or at discharge, patients are typically told (a) what they are taking and (b) what the medication is for / why it has been prescribed. In many instances, sharing information about side effects is not a priority.

- Researcher: “In terms of the priority of what gets shared – side effects is one of the goals of our project, that people understand side effects. Where does that fall, in the hierarchy of information?”

Staff member: “It falls really low” (Northland).

Having said that, patients are more likely to be told about the side effects of their medication, if they are starting on a treatment that is considered high-risk, with **common** or **serious** side effects. There is no formalised process for identifying these high-risk drugs, and “different pharmacists probably have different ones that they flag” (staff member, Northland). But the following drugs were mentioned, during the course of our research.

- Anti-coagulants (warfarin, dabigatran, etc.)
- Anti-arrhythmics
- Cardiac medicines more generally
- Treatments for COPD, heart failure
- Treatments for renal conditions
- Anti-epileptics
- Anti-rheumatics
- Chemotherapy
- Steroids
- Opiates (to some extent)

Staff members also mentioned particular ‘categories’ of side effect – and they had different motivations for discussing these.

- **Common side effects** - e.g. a beta blocker will make you feel tired. Staff mention these side effects to help set patient expectations, and to encourage patients to remain compliant with their regime.
- **Side effects that indicate a change in dosage is required** – e.g. bleeding gums whilst on anti-coagulants.
- **Side effects that seem minor but which indicate something serious** – e.g. pain under the ribs, which is a sign of liver toxicity.

Across the board, staff members noted that they would not share all of the side effects of the medicines they prescribe.

- “I don’t think that we would go through every single side effect that there is” (pharmacist, Northland).
- “Yeah – probably just one or two, probably not the whole list” (House Officer, Waikato).
- “With side effects – [we] tend to pick out the main ones that you want someone to watch out for” (pharmacist, Waikato).

This has interesting implications for the wording of the Medication Side Effects question – see blue section below, for further discussion on this point.

Side effects - more of a priority for certain patient populations

Staff members also noted that sharing information about side effects is more of a priority with certain patient groups. This includes:

- Older patients
- Māori & Pasifika patients
- Patients with heart failure or COPD
- Patients on medical ward (over surgical)
- Patients with complex conditions, on a large number of medicines
- People whose medication has changed a lot
- Anyone on blister packs
- Anyone flagged as high-risk by nurses/doctors

DO WE NEED TO CHANGE THE MEDICATION SIDE EFFECTS QUESTION?

At present, the wording of the Medication Side Effects question is “Did a member of staff tell you about medication side effects to watch for when you went home?”

- Yes, completely
- Yes, to some extent
- No

However, our research has shown that staff members only tend to share the common or serious side effects, for medicines that have been newly prescribed. This seems like a pragmatic balance to strike, given that staff members have limited time, and patients have a limited ability to absorb information.

As such, the Commission may like to consider rewording the question – so there is less of a focus on whether the information shared is ‘complete’, and more of a focus on whether **enough** information was provided.

For instance, the new wording could be:

- Did you start any new medication in hospital, or at discharge, which you continue to take at home?
 - > Yes
 - > No
- If yes – Do you feel you received enough information about the medication side effects to watch out for, once at home?
 - > Yes, I definitely received enough information
 - > I received some information, but I would have liked more
 - > No, I did not receive enough information

6.2B | WHAT'S WORKING?

Highlighting the key side effects

In our view, it is a good thing that staff members focus primarily on sharing the common and serious side effects of certain medicines.

If staff members shared all of the side effects of every medication, patients would rapidly become overloaded, and disinterested. These quotes are revealing:

- “I’d say I understand enough, I only want to know the key ones, I wouldn’t want too much information” (patient, BOP).
- Researcher: “What level of information would you like to be told, about side effects?”

Patient: “Well, it’s not relevant unless you have side effects is it? It’s a catch-22, yeah, because most people, nothing will happen to” (Nelson).

- “I would have liked some information on side effects as I had to ring my Doctor when my mornings were like living in a fog! Though, I must say that, after looking up clopidogrel, I saw about 100 side effects. Perhaps this is why no info given” (respondent in National Patient Experience Survey).

Patients are also likely to panic if they hear all of the risks of a medication, and this could negatively affect their compliance.

- “I generally try to go over the main – common or risky side effects. . . I don’t list everything, because then nobody would ever take what I give them” (staff member, BOP).
- “Yeah, it gets tricky, because you don’t want to put them off taking their medication” (staff member, Waikato).

Unfortunately, when staff members know that patients will panic when hearing about side effects, they may not share any information at all.

- “I totally think that that’s an issue. And it’s a lot of the reason why the nurses don’t feel confident giving that information” (pharmacist, Northland).

Given these issues, it’s vital that more staff members adopt the following best practice – giving balanced risk information.

Providing balanced risk information

If patients panic when hearing about the risks of medicines, that does not mean the information should be withheld – because then equally, patients will panic if they go home and Google the drug, or if they experience an unexpected side effect. This is where the behavioural science concept of **reference points** comes in handy.

One pharmacist reassured patients about their medicines, by using a ‘safe’ medicine as a reference point.

- “Because people read a whole bunch of side effects and freak themselves out, I’ll go, ‘the likelihood of you getting any of these side effects is low. But, they have to list them here as possibilities. And I just try and say, everything in the world can cause a side effect, even paracetamol – because people tend to see that as a safe medication” (pharmacist, Waikato).

Another pharmacist pointed out that *not* taking the medication was a greater risk than taking it, and potentially experiencing some side effects.

- “I would take the time to explain to patients, look this can happen but it’s highly unlikely. If you have any problems this is what we can do about it - but this is why it’s beneficial and if I was you, this is why I would take them” (pharmacist, Northland).

These are both examples of best practice, as staff members are able to inform patients, without frightening them and negatively affecting compliance.

6.2C | WHAT COULD BE IMPROVED?

Formally flag the high-risk new medicines

As noted earlier, we did not see any formalised processes for (a) classifying medicines as high-risk in terms of side effects, or (b) ‘flagging’ if a patient is due to start on a high-risk medication. The key exception we observed was for opiates – as safety around opiate prescribing has been a recent focus of the Commission. This isn’t to say that patients aren’t being told about high-risk medicines, but the processes are relatively ad-hoc and down to the professional judgement of staff members.

Given this set-up, there is a chance that patients starting on a high-risk medication will ‘fall through the cracks’, and leave hospital without knowing the side effects to look out for. There’s also a chance that staff members will become habituated to the risks of medication that they prescribe frequently. As one Waikato-based staff member explained, “with the things we prescribe all the time, you probably get a bit blasé about it”.

To avoid these issues, we recommend that:

- medicines are more formally classified according to how common and how risky the side effects are.
- patients are formally ‘flagged’ in the system if they are prescribed these medicines, and they are not ‘checked off’ until they have received education about the risks.

Remember to flag medication with ‘delayed’ side effects

Some medicines present risks to patients because they start the drugs on the ward, but they don’t experience side effects until they return home. For instance, in one short-term medical ward we visited, patients receive treatment with opiates whilst in hospital, and then stay an average of 2 days. When they go home, they may have the beginnings of constipation, which is defined as 3 days without a bowel movement, but they do not know what signs to look for. By day 5, the patient may be in serious trouble and need to be re-admitted.

Given this, any formalised classification of risk (as noted above), should factor in those medicines with delayed side effects.

Increased focus on patients with ‘simple’ medication plans

It should be relatively simple to educate younger, healthier patients about their medicines. Therefore, our recommended intervention will aim to make it easy for all patients to learn about medication side effects – regardless of age, treatment plan, etc.

6.3A | WHO USUALLY SHARES INFORMATION ABOUT MEDICATION SIDE EFFECTS?

Throughout the patient journey, a number of hospital staff may share information about medication side effects, including:

- Doctors on the ward, who make the decision to prescribe a drug
- Nurses on the ward, when they administer a drug
- A pharmacist on the ward – e.g. if they are called in by ward staff to explain a new higher-risk medication, or prepare medication cards
- A pharmacist in the discharge lounge
- A nurse in the discharge lounge

Information may also be shared outside the hospital – by community pharmacists and GPs.

6.3B | WHAT’S WORKING?

Greater involvement of hospital pharmacists

It makes sense for hospital pharmacists to play a greater role in information-sharing with patients – given their specialist knowledge about medication.

In one example of best practice, Northland DHB ran a 1-year pilot test in 2015, in which a pharmacist provided full-time discharge services. The results were impressive. After 6 months:

- 256 patients had received pharmacist input
- 173 medication errors had been identified and resolved
- fully 40% of the medical patients seen had 1 or more errors at discharge which required correcting, and 7% of patients had 3+ errors

As noted in the minutes of the Hospital Advisory Committee, the immediate benefits of the service included:

- “Improved accuracy of medicine information at discharge;
- reduction in errors;
- increased likelihood of funded, uninterrupted supply;
- improved communication with GP and community pharmacy;
- increased patient education regarding medication changes during admission;
- increased referral to other discharge services when appropriate;
- patient compliment after experiencing service provided” (Northland District Health Board, 2015, p.8)

In terms of the long-term benefits, a pharmacist service at discharge would:

- “improve equity by targeting a subset of patients with the greatest needs or highest risk of medication related harm
- provide value for money through cost reduction as a result of reduced medication related harm and re-hospitalisation
- improve the patient experience, health literacy and enable better patient engagement in self-care and management of chronic illness” (ibid).

In our on-the-ground research, we also found strong support for greater inclusion of pharmacists.

- In Northland where the pilot study took place, one nurse noted “having pharmacists on the ward has made a hell of a difference to what the patient outcome is, and it’s making the doctors think about what they’re doing.”
- In Nelson, we observed a patient receiving a medication card from a pharmacist, and the patient and their family were very positive about the input they had received.

On a related note, some staff members felt that House Officers should not be given the responsibility of sharing information about medication:

- “I think at the moment we rely on very junior staff to deliver a reasonably important job, which is the medicines. And it’s no wonder it’s not done all that well – partly because they are just not very experienced, partly because their jobs are just constant interruptions and time pressures” (staff member, Waikato).

This brings us to the suggested improvements.

6.3C | WHAT COULD BE IMPROVED?

More in-hospital pharmacists

In an ideal world, DHBs would hire more pharmacists, so that these specialists could be more involved with patient care.

With more pharmacists, the following changes could be made.

Pharmacist included in MDT – fewer patients ‘falling through the cracks’

At present, pharmacists are not considered part of the multi-disciplinary team (MDT), which includes physiotherapists, occupational therapists, dietitians, social workers and so forth.

- “Pharmacy’s a funny one – we’re not really deemed as essential before people leave or get signed out. I don’t know if you’ve seen but all other professions, there’s a whiteboard [that indicates if a patient needs to be seen by a specialist before they are ready for discharge] . . . and we’re not really on that list I guess, and we’re not resourced – the figures don’t stack up, the team’s not big enough to see everyone.” (pharmacist, Northland).

In some locations, pharmacists have introduced process changes to try to ensure that they can see key patients before discharge – but this process is not fool-proof:

- “We will put a sticker on the chart and we also put some notes on the electronic form we use, to say that they need to see us. At the moment that doesn’t always happen, we’re not always called at the discharge point, despite those flags being put up” (pharmacist, Northland).

If pharmacists were included in the MDT, it would help to avoid the issue of patients ‘falling through the cracks’ and not receiving the education they need, prior to discharge.

More patients receiving a medicine reconciliation

As we saw in the NPES data, respondents gave negative feedback when prescribed medicines which:

- cause a known reaction
- interact
- cannot be administered

In order to avoid these issues, the ideal scenario is that pharmacists conduct a medicine reconciliation at admission, and then again at discharge. (It’s worth noting that medicine reconciliation is already a focus of the Commission – however we have discussed the topic here, in order to be comprehensive.)

With the current level of pharmacy resource, it’s not possible for pharmacists to conduct ‘before and after’ medicine reconciliations. And if patients do not have a reconciliation completed, it puts more of the weight of decision making onto the House Officer’s shoulders, as this exchange between staff members demonstrates:

“Just to echo [attendee’s] point about the junior staff doing the medications a lot, quite a common situation is, someone will come into hospital, a lot of their drugs will be withheld, or the doses will be changed. The consultant will come around and say ‘the patient

can go home’. And then, the House Officer will sit down to do the discharge summary, and suddenly they’ll have to make five different decisions about medication. . .

“That haven’t been properly written down anywhere”
“. . . or discussed.”

“And so I think that’s where a lot of things happen, for us.”

(staff members, Waikato focus group)

More discharge summaries written / reviewed by a pharmacist

Even if it’s not possible for pharmacists to conduct a full medicine reconciliation for patients, it is useful if they are able to write or review discharge summaries, and note the medicines that have been **started, stopped** or **adjusted**. This is an example of best practice that we observed in the AT&R ward in Nelson. The hospital pharmacist writes a short cover letter to accompany the pharmacy script, outlining all the changes that have been made to the medicine regime, during the patient’s stay. With this information, community pharmacists are better equipped to check that the prescribed medicines are safe, when combined with the existing regime.

This also starts to align with best practice from overseas:

- “When I worked overseas – I’ve worked in Australia and the UK – it was standard practice for almost all of the prescriptions, all the discharges to go through the pharmacist. So that way, we don’t only check clinically that things were appropriate and spotted interactions, inappropriate doses and all that sort of thing, but we also got a chance to talk to the patients about the meds” (pharmacist, Northland).

More formalised handover to community pharmacy

On a similar note – with more hospital-based pharmacists, there is greater scope for a formal ‘handover’ of patients from the hospital to the community pharmacy.



6.4A | WHAT INFORMATION IS USUALLY SHARED ABOUT CONDITION MANAGEMENT?

Information about condition management is shared throughout the patient's journey from admission to discharge. The key moments in time are:

- During ward rounds, patients receive updates from consultants, nursing staff etc.
- If the MDT are referred in, patients will receive input from the relevant service, on the ward or just prior to discharge. The information may include:
 - > Exercises to improve their condition, from physiotherapists and occupational therapists
 - > Dietary advice
 - > Advice about how to use specific equipment (e.g. glucometers, negative pressure wound care systems)
 - > Equipment to help manage at home (e.g. shower stools, walkers)
 - > Referrals for support services, District Nursing, home help, social work services, etc.
- When running through the discharge summary, House Officers will convey information about:
 - > Activities of daily living – e.g. avoid heavy lifting for 6 weeks
 - > How to manage wounds, measure fluid leakage, etc.
 - > Troubleshooting or warning signs to look out for – e.g. if wound becomes red, hot or swollen, seek medical attention
 - > Referrals for other tests, outpatient appointments, etc.

6.4B | WHAT'S WORKING?

Generally, patients appear well informed

In our research, patients appeared to be relatively well informed about how to manage their condition at home, compared to how well informed they were about medication side effects. Many patients remembered the key warning signs that they needed to look out for, and knew they had referral appointments or District Nursing services arranged. Though, as expected, there was variability in terms of how well informed people felt.

6.4C | WHAT COULD BE IMPROVED?

More specific scenarios

Some patients found that they received vague information about how to manage, as this quote demonstrates:

- “I probably had to ask more questions in regard to what I could and couldn't do, in terms of heavy lifting . . . I sort of just know ‘6 weeks be careful’, but . . . is it ok to pick up a washing basket or shopping or – you know, what level can you pick up, without causing damage to your wound?” (patient, BOP).

Set expectations around pain management

We found that in a small number of cases, patients were leaving hospital in more pain than they felt able to deal with – a theme that had arisen in the NPES. This is likely to impact on answers to the Condition Management question, as people will feel unable to manage at home. For instance, one patient we talked to said:

- “I've had numerous bowel operations and I haven't had this pain before, and it's really quite painful, but they keep saying ‘it will go, it will go’ . . . the pain relief – it works for a short, very short time, and then the pain's back. And it's quite a hassle if you go, and have to come back” (patient, Waikato).

Another staff member said that patients and family members often say:

- “I’m still in pain, I’ve still got an issue, why am I being discharged?” (staff member, Waikato).

These issues relate to broader contextual changes in healthcare – as pressure on hospital beds has increased, patients are being discharged home sooner, potentially before they have recovered or feel ready. Addressing these issues is well outside the scope of this project. However, more could be done to help set patient expectations around pain management. For instance, we could help patients to self-assess their pain levels, and determine whether they are experiencing ‘normal’ or ‘unacceptably high’ levels of pain - in which case, they should seek further medical attention. Clarifying what is normal, and what is not, should help patients to feel more confident in managing at home, and in turn, reduce the number of negative responses to the Condition Management question.

Make it easier for patients to taper off pain management

On a related note, one best practice we observed is to give patients a detailed medication schedule, which helps them to manage their pain sufficiently, while safely tapering off pain medication over time. Again – providing these services to more patients would likely require an increase in pharmacy resource, or specialist pain services.

6.5A | WHO USUALLY SHARES INFORMATION ABOUT CONDITION MANAGEMENT?

As noted earlier, condition management information is generally shared by ward staff, and by members of the MDT.

6.5B | WHAT’S WORKING?

MDT referrals

There is a formalised process for referring patients to the MDT, and ensuring that each specialty ‘signs off’ a patient to indicate that they are ready for discharge. This appears to be working well.

6.5C | WHAT COULD BE IMPROVED?

There is scope to improve how staff share information during ward rounds – but we have addressed these issues in section 6.6a, on verbal information sharing. Beyond this, we believe that the right people are involved in sharing information about Condition Management.

HOW IS INFORMATION USUALLY SHARED, ABOUT MEDICATION SIDE EFFECTS & CONDITION MANAGEMENT?

In this section we will review how information is being shared, during the patient journey. We will address a number of topics, including:

- 6.6 Verbal information sharing
- 6.7 Medication cards / Yellow cards
- 6.8 Patient information sheets
- 6.9 Visual and audio-visual resources / demonstrations
- 6.10 The discharge summary
- 6.11 Prompts for patients & families
- 6.12 Information from community pharmacists & GPs
- 6.13 Follow up from ward staff

With each topic, we will provide a brief summary of how information is shared, followed by a review of what is working and what could be improved.

6.6A | VERBAL INFORMATION SHARING

In hospital, most information that is shared with patients is delivered verbally. One Nurse Educator from Whangarei estimated that “95% of the information you give to them is verbal”, and on the ward round that our researcher observed, the consultant shared all information verbally.

Patients may receive written information sheets about their medicines and the associated side effects, if they are starting on higher risk drugs like anti-coagulants. “But a lot of the more common stuff, I would say they probably just get verbal advice” (staff member, BOP).

Condition Management is slightly different, as it is more common to provide patients with paper handouts, in addition to verbal advice.

6.6B | WHAT'S WORKING?

Preferred by some patients – including those with literacy issues

Some patients prefer verbal explanations, as they find it difficult to absorb written information while affected by medication:

- “It’s actually ... better for me, after all these drugs, because they sort of [gestures confusion], for someone to verbalise it, rather than read it, because my eyes go a bit crossed” (patient, Nelson.)

Other patients we spoke to had literacy issues, and so they found it helpful if the staff talked things through with them:

- “I said to Helen [the doctor], “I’m a bit illiterate”. She didn’t know that – so by telling her, she was able to help me in a better way, you know” (patient, Northland).

Useful for connecting with Māori patients

According to cultural advisors from Tātou, many Māori have a preference for ‘kanohi ki te kanohi’, or face-to-face contact, which includes verbal explanations. In fact, “in the flesh is always best” is a common saying amongst Māori.

Staff can explain things in layman’s terms

In the interactions that we observed, staff members were skilled at explaining things to patients in layman’s terms.

Interactive – staff & patients can ask questions

In verbal interactions, staff members can ask patients questions to gauge how well they have understood a topic, and in turn, patients can ask questions to clarify issues that they are confused about. For instance, we observed a pharmacist explain warfarin to a patient – and then they asked “Which pills would you combine, to get a 7mg dose?”. When the patient answered correctly, the pharmacist had much more certainty that they could self-manage at home.

A little at a time

Because hospital staff know that patients experience ‘information overload’, they aim to share verbal information in little chunks, over time. “Just little bits at a time eh, rather than just going ‘bang!’” (staff member, Waikato).

6.6C | WHAT COULD BE IMPROVED?

Back up verbal information with written

As noted earlier, patients often find it difficult to absorb information when they are in poor health and in a stressful hospital environment. As such, it is useful if verbal information is supplemented with written information.

- “There’s definitely a need for information, and definitely written, but it does need to be from a patient friendly perspective, whether it’s a little booklet, or whatever the case may be” (staff member, Nelson).

Formalise the inclusion of family members

Because verbal information is shared at one point in time, family members may not be around to ‘catch’ it. This is a particular issue with ward rounds, which occur early in the morning, before hospital visiting hours. There is an opportunity here, to more formally include family members in discussions. For instance, during ward rounds, family members could be called so that they can hear what is being discussed. Or, patients could be prompted to record the information (on their phone, or on paper), so that they can relay it to family members at a later point.

Equip patients to ask questions – by giving them time & tools

During our research, we observed that patients and family members had questions about condition management – but at times, they thought of these questions after the staff member had briefed them, and then left the room. To improve this situation, we recommend that prompts are developed, to remind patients and family members to ask the right questions, at the right time. This is a topic that we will return to, in section 6.11.

Share information in a private setting

The hospital environment can be distracting, which can make it difficult for patients to absorb verbal information. Ideally, patients would be given verbal updates in a private setting, “that way we’re not distracted by what’s going on around us” (mother of young Pasifika patient, Waikato).

SAVE TIME BY ASKING QUESTIONS

Over time, patients generally become very familiar with their health conditions, medication and the associated side effects. As such, clinical staff can save time by asking questions to see how much a patient already understands, and tailoring the explanation accordingly.

6.7A | MEDICATION CARD / YELLOW CARD

Medication cards, or yellow cards, are a way of summarising:

- all the medicines that a patient is taking
- the reasons why they've been prescribed
- the recommended dosage and when to take the medication
- how to take the medication safely (e.g. with food)
- plus any other important notes

These cards are not provided to all patients. A hospital-based pharmacist is generally asked to prepare a medication card if a patient has a complex drug regimen, if they're starting many new medicines, or if they have cognitive limitations.

Community pharmacists may also prepare the cards, for their customers.

6.7B | WHAT'S WORKING?

The cards are popular with patients and family members

From our observations, patients and family members find the medication cards very useful - because they make it easy to follow the medication regime. For instance, this exchange occurred after a pharmacist ran through a medication card with a patient:

- Patient: "It's pretty simple isn't it?"
Wife: "Yeah I think that's awesome"
Daughter: "Everyone should be discharged with that" (Nelson)

Pharmacy team members also recognise the popularity of these cards:

- "A lot of patients really love those because we tell them exactly how many tablets to take, which drug and what time of day to take them and we also include in patient language what each medicine is for" (pharmacist, Northland).
- "If someone's on a whole lot of new medications, what we'll also do is create a medication chart. . . it can be a really good visual tool for people, that when they get home, they can check things off" (pharmacist, Waikato).

6.7C | WHAT COULD BE IMPROVED?

Routinely include key side effects

The medication cards that we saw did not routinely prompt pharmacists to mention key side effects. We recommend changing the design so that side effects are incorporated - and exploring whether content could be auto-populated, to save staff member time. For instance, if tramadol is entered into a medication card, auto-populated text could warn patients about constipation.

Include an image of each medication

The design of the medication card could be improved – in particular, it would be useful for patients to see what each drug looks like. This is common in other parts of the healthcare system – and it taps into the way that patients already talk and think about drugs:

- “They’ve started me on something, but I don’t know the names of some of them. But I can see that the colours are different” (patient, BOP).
- “That’s how a number of Māori whānau remember their meds. I take the yellow one in the morning, I take the white one in the afternoon” (staff member, Nelson).
- “Quite often I find patients don’t really understand what they’re talking about until they see the drugs” (staff member, Waikato).

In terms of the practicality of this - we believe that the TONIQ software used by community pharmacies has the functionality to display what a drug looks like.

Offer to more patients – by streamlining process

At the moment, providing patients with a medication card is resource-intensive and “a very manual process for each individual patient” (staff member, Waikato). As far as we could ascertain, the steps are:

- A pharmacist may, or may not, complete a medicine reconciliation at admission
- Doctors chart any medication changes
- The pharmacist goes back through the charts, and the medicine reconciliation if one is available, and then they manually fill in the medication card
- The House Officer completes the discharge summary
- 2 nurses check that the medication card matches the patient charts and the discharge summary

From what we observed, it took a pharmacist approximately 40 minutes to populate the card, and about 20 minutes to explain it to the patient.

If this process could be streamlined, then medication cards could be offered to more patients. This is out of the scope of our project – and it is already a focus of the Commission, who are aiming to scale up medicine reconciliation, and introduce electronic medicines management, which will enable healthcare professionals to rapidly determine what medicines a patient is taking, when and why changes were made, etc. We have noted the point here, to be thorough.

Offer a simplified version to all patients, as part of discharge summary

The medication card is valuable because it makes it easy for patients to understand when and how to take all of their medicine. If it’s not possible to provide the ‘gold standard’ card to all patients, because not all patients get a medicine reconciliation, we can still explore how to provide *better* information. For instance, there would be value in a technological solution that converts all new prescriptions into a simple table, comparable to a medication card. This table could be inserted into the discharge summary for patients, and use patient-friendly language – e.g. visually indicating that a drug should be taken twice a day, rather than ‘bid’. The table should also routinely include information on side effects to watch out for.

To give patients the context of how these newly prescribed medicines fit in with their old regime, the discharge summary for patients should also note if any drugs have been stopped, started, or changed.

6.8A | PATIENT INFORMATION SHEETS

The term ‘patient information sheets’ covers all printed information given to patients in hospital. For instance:

- Medication information sheets – e.g. from the NZ Formulary or Health Navigator
- Drug information brochures from pharmaceutical companies
- Health or condition-related information – e.g. from Diabetes New Zealand
- Sheets about condition management – e.g. breathing exercises for cardiac patients

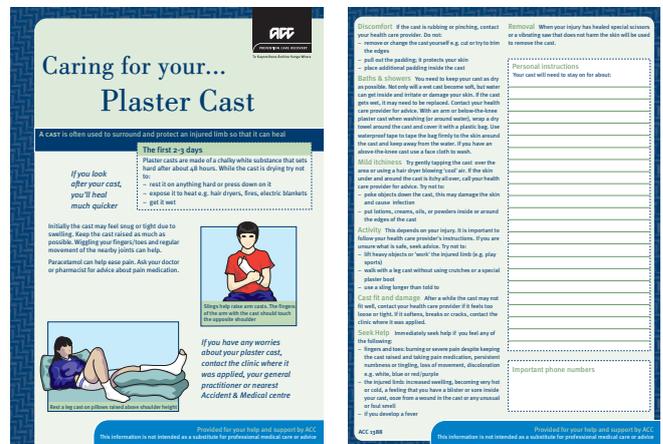
In our research, we observed a small number of patients who had received information sheets about condition management, including ‘Managing your plaster cast’ and ‘Managing a kidney infection’. On some wards, we also saw cabinets with printed resources used by members of the MDT.

In terms of medication, we sat in as one patient received in-depth counselling about warfarin, and he was provided with a take-home booklet at the end of the session. We did not see any other patients with drug information sheets, during our visits.

6.8B | WHAT’S WORKING?

Sheets generally use communications best principles

These information sheets are generally developed using communications best principles – with simple language, use of subheadings and small chunks of text, and pictures or diagrams. For instance, we saw a patient in Tauranga receive this sheet about managing his plaster cast:



Sheets help patients remember key information

Like all written resources, these sheets are useful for patients because they can refer back to them over time.

- “I think they have a lot of information to take on board when they leave . . . which is why it’s nice to give them something to take, and then they can read it at home, when they’re a bit quieter” (staff member, BOP).
- “They gave it [the information sheet about ‘Managing a kidney infection’] to me here, yesterday. They asked if I had been told much about it, and I said no, and they gave it to me. The Transit Lounge has been the best out of the 4 different areas I’ve been in” (patient, BOP).

6.8C | WHAT COULD BE IMPROVED?

Change default – give information sheets for all new take-home medicines

In some sites that we visited, such as Northland, there is an expectation that patients would be given an information sheet for any new take-home medication. However, as noted earlier, during 4 site visits we only saw one patient with a take-home resource about their medication. Staff seemed to be following two informal rules. If a patient is starting a higher-risk medication, they will receive printed content. But if they are starting a ‘regular’ drug, information is not provided unless the patient proactively asks:

- “It’s driven by the patients – I don’t think we give pamphlets otherwise” (staff member, Northland).
- “I don’t routinely do that though [give out information sheets], unless I’m asked about it. Maybe that’s an area that’s lacking, and maybe we should be more routine in doing that” (staff member, Nelson).

We recommend changing the default, so that whenever patients start on a new medication, staff members hand out a simple information sheet about the drug. Patients should also be actively prompted to ask questions – for instance, with a simple ‘Any questions?’ note on the bottom of the sheet. And staff members should take care to ensure the risk information is presented in a balanced way, as discussed earlier.

Develop central repository for information sheets – in wards & online

In wards - To make it easy for staff members to give out information sheets, wards could set up a filing cabinet or folder with stockpiles of the information sheets that will be given out most often. This is the approach taken in the Transit Lounge in Tauranga.

Online – At present, there is no comprehensive online repository of information sheets that staff members or patients can view. This is a significant issue.

Staff members may seek drug information from:

- The NZ Formulary
- TONIQ
- MIMS
- MedSafe

Information on condition management “is pulled from different sites, or it’s sheets that staff members have made up” (staff member, Waikato).

To equip staff members and patients to find the right information, easily, we recommend that the Commission and the Ministry of Health work on pooling written resources across DHBs, and establishing a centralised resource database. This has been done to some extent with the **Health Navigator website**, which includes useful information about medicines and condition management, but there is still room for improvement. There is also scope to increase people’s awareness of sites like Health Navigator, as very few people we spoke to had heard about it:

- “It would be cool if there was a national database which everyone contributes to, and you know the information is accurate, because it’s from the professionals. And the patient can go and search the database, instead of Googling. . . something more standardised. I’m not sure if there’s anything like that already” (staff member, Waikato).

Use the Discharge Lounge as an information ‘safety net’

The Transit or Discharge Lounge is often the last ‘touchpoint’ in a patient’s journey from admission to discharge. As such, it makes sense for the Discharge Lounge to be used as an information ‘safety net’ – i.e. a place where staff members can ensure that patients have the information sheets (or online resources) they need, to understand their medication and how to manage their condition at home.

We recommend that this process is formalised – for instance, patients could be provided with a checklist, which they ‘tick off’ if they have received enough education about their new medicines, and their condition management. This concept is discussed in more detail in section 6.11, and again in Chapter 7 - Recommended interventions.

6.9A | VISUAL AND AUDIO-VISUAL RESOURCES / DEMONSTRATIONS

When sharing information with patients, staff members may use a variety of visual and audio-visual resources, or give demonstrations. For instance, we saw or heard about the following tools being used, during our research visits:

- **Warfarin flipcharts.** The chart includes visuals and short-form text to explain key points to patients starting warfarin.
- **Diagrams.** These may be hand-drawn by staff members, or be incorporated into patient information sheets.
- **DVDs / online videos.** In the Tauranga Transit Lounge, patients starting warfarin or clexane are directed to view a short DVD. The physiotherapy service in Waikato directs people to online video clips about pain management.
- **Websites.** In the youth cancer service in the Waikato, iPads are available, and staff members can use these to show patients relevant website content.
- **Demonstrations.** Patients going home on clexane, or with a glucometer, will receive practical education about how to inject themselves once at home. The physiotherapy and occupational therapy services also use demonstrations to teach patients breathing exercises, stretches, etc.
- **App ‘prescribing’.** One Whangarei-based pharmacist we spoke to directs people to mobile apps, if they have trouble remembering when to take their medication.
- **Educational games.** This idea is in its infancy, but “There’s talk of using gaming – so going down the technological side of things, in terms of either, education about their condition or education about their medicines” (staff member, Waikato).

6.9B | WHAT’S WORKING?

Improves health literacy by appealing to people with different learning styles

If health literacy is the ability to understand and use health-related information, then it can only be a good thing if information is communicated in a way that appeals to people with different learning styles. Visual, audio-visual, and kinaesthetic or hands-on demonstrations are likely to help patients take in more – and the greatest learning gains are likely to be made amongst patients with the lowest health literacy. As one patient noted:

- “I see you fellas got quite a lot of those [TVs] – I see they’ve got a medical program on there, just show a few [educational videos] on there.”

If you turn on the TV in the Discharge Lounge “half the room would look at it . . . That’ll help, not me, because I know how to read – but the ones who can’t read. And I know there’s heaps come through here that won’t be able to read eh. So vision would be a good way . . . and hearing” (Māori male patient, Northland).

As cultural advisors from Tātou note, “visual devices and learning aids are incredibly important for Māori, who have a bent towards visual and kinaesthetic learning styles”. And in the words of Te Marino Lenihan, Strategic Advisor for Māori at the Ara Institute of Canterbury, “We are hands-on sort of people, accustomed to learning through doing” (Ara Institute of Canterbury, 2017).

A large number of staff members we spoke to saw the value in using these ‘multisensory’ teaching techniques:

- “Use as many senses as possible. You’re going written at the moment, so you need to think visual, you need to think auditory, you need to think maybe kinaesthetic, because people remember differently” (staff member, Nelson).
- “A lot of patients haven’t had a lot of medical dealings before, it’s very foreign for them. And the more media sources you have – the pamphlets, verbal, and maybe something to watch, you’re going to probably cater for everyone’s learning styles” (staff member, BOP).

- “Some people are aural learners, some people they like to see pictures, others want to read it, so we try and do everything, because you can’t always gauge what kind of learner a person is” (staff member, Waikato).

Likewise, there’s anecdotal evidence that patients enjoy receiving information through multi-sensory formats.

- “The feedback from patients that have had that education with the DVD, they’ve found it really helpful and easy” (staff member, BOP).
- With young cancer patients - “we’ll say ‘oh yeah we’re going to chemo and you’ll have port-a-cath’. Instead of me saying ‘oh yeah it’s this thing sitting under your skin, or [giving them] a paper brochure, I can go on the iPad and go ‘bang’, port-a-cath, and show them pictures and things like that. So that’s really helped, instead of me bleating, I can show them. It’s been a really powerful tool” (staff member, Waikato).

6.9C | WHAT COULD BE IMPROVED?

Develop more of these resources

The multi-sensory resources that have been developed are working well – but more are required. Ideally, most hospital-based education would be delivered via multi-sensory formats.

We recommend that DHBs develop an online library, in which staff members and patients can link through to educational videos, websites, perhaps games, etc.

Use the Discharge Lounge as a key site for multi-sensory education

Patients can spend a number of hours in the Discharge Lounge, before they receive their paperwork and are able to go home. Most patients we observed spent the time napping, talking to family members, reading magazines or watching the central television. There is an opportunity here, to provide patients with relevant information before they go home - and because this is a relatively low-stimuli environment, patients may be more willing to peruse different websites or online videos.

To facilitate this, DHBs could trial having hand-held computer devices attached to each Discharge Lounge chair. These devices could connect to a local intranet which displays useful websites, videos, etc.

- “There’s a lot of time waiting from when you are told you can go home, to when you get the discharge papers. And maybe that’s something we could give them to watch, while they’re waiting” (Transit Lounge Nurse, Tauranga).



6.10A | THE DISCHARGE SUMMARY

The discharge summary is the key written document that all patients get when leaving hospital – either in hand or via the post.

The summary typically outlines:

- Why the patient was admitted
- Family history & medical history
- Smokefree status
- Allergies / alerts / drug reactions
- The treatments the patient received whilst in hospital
- Any new medicines – along with dosages, when to take, and how long to take
- The discharge plan, including any follow-up appointments, referrals, tests, or support services that have been arranged
- Advice to patient – e.g. avoid heavy lifting for 6 weeks. This section is partly written by the Multi-Disciplinary Team of physios, OTs, dietitians, etc.

It's important to note that the discharge summary was primarily devised for medical professionals, to facilitate information sharing and the smooth handover of patient care, from the hospital, back to the community. The document was not primarily designed for patients.

- “So the discharge letter that's been given to the patient is actually just a by-product of the communication from us to the GPs and the external agencies. And by default, we're like ‘oh yeah, we'll give the patients one too’. But we need to create something for the patients” (staff member, Waikato).

6.10B | WHAT'S WORKING?

It can be useful for community professionals

To some extent, the discharge summary achieves its original function, of keeping GPs ‘in the loop’ about the care their patients have received.

The document is less valuable for community pharmacists – as they do not currently receive a copy, they often just receive a script in isolation. It can be useful for the pharmacists to see the discharge summary, or an accompanying cover letter, if either document outlines the medicines that have been started, stopped and changed, along with a rationale. This gives the pharmacist context for the script, so they can check if the prescribed medication regime is safe.

- “I think the written form has to be there, not only for the patient and their whānau or family, but also healthcare professionals and pharmacists in the community, who have absolutely no idea of what's happened in hospital” (staff member, Nelson).

There's plenty of scope for improvement

The discharge summary is a standard document that all patients receive – which means that any improvements made to the discharge summary will benefit a broad swathe of the in-patient population. In terms of a ‘bang for buck’ intervention, optimising the discharge summary letter is a great place to start.

6.10C | WHAT COULD BE IMPROVED?

There are a large number of issues to discuss, and as such, we will run through a full critique of the current discharge summary letter, and then outline our recommended improvements.

We have also prepared an optimised discharge summary for patients - see Chapter 7 for more details.

Content & layout issues

It's written in medical jargon & often irrelevant

Because the discharge summary letter was initially intended as a tool for health professionals, much of the content is written in short-form medical language, which confuses patients, and suggests they are not the intended audience. For instance, rather than saying a medication should be taken twice a day, or as required, the discharge summary says 'bid' and 'prn'.

- "Some people will write a discharge plan, in, kind of gobbledygook to the patient, like 'follow up in 1/52 blah blah blah'" (staff member, Nelson).
- "I think it's easy to look at if you are from a medical perspective . . . but for a normal patient . . . I think it is a bit tricky" (staff member, Northland).
- "I'd be really intrigued to see how many people going home are reading their discharge summary. As soon as they get to 'critical aortic stenosis', their eyes just glaze over and they think 'God, this isn't for me', I'm just going to put this down" (staff member, Nelson).

Beyond the language, many sections of the discharge summary are irrelevant to patients. This is concerning, because it means that patients are less likely to read the sections that *are* relevant to them.

- "The majority of what's actually contained in that document is quite irrelevant to the patient" (staff member, Nelson).
- "I think they kind of get confused and lost, one-third through it, and stop reading" (staff member, Waikato).

Even information about follow-up appointments can be confusing for patients, as the discharge summary asks them to return to particular outpatient clinics, like 'the fracture clinic', but then all way-finding signage in the hospital refers to the 'orthopaedic clinic'.

Having said all this – some specialties and some individuals do write their discharge summaries in a patient-centric way.

- "I'll got to the effort to write the discharge plan to the patient – so you need to do this, you will be followed up, we will send you an appointment, this is what you need to do" (staff member, Nelson).

Not all medicines are listed

As noted earlier, patients may go home confused about how to combine their new medicines with their 'baseline' treatments, because the discharge summary does not list all of their medicines.

- "Sometimes there'll be just one or two medicines [on the script], and pharmacies call us saying, 'is this to add, or is that subtracting', or things like that. And then patients might take those on top of what they were taking, and then they are over-medicated, and end up coming back in" (staff member, Waikato).

The content is not standardised

Although the discharge summary has standardised sub-headings, there are no prompts for staff members about what to include. This increases the risk that House Officers will forget to share key information, and that different patients will get differing levels of advice.

- "That's down to the House Officer who's discharging the patient, so the way that each discharge is written varies quite wildly, and varies wildly between specialties" (staff member, Nelson).

Sometimes practical information is not included

The discharge summary does not include some practical information that patients would like to receive – for instance, when they took their last dose of medication, which impacts on when they should take their next dose.

Contact details are not always provided

At the point of discharge, patients ‘don’t know what they don’t know’. As such, they may feel sufficiently informed about their medication and condition management, until they get home, and realise they have questions. Certainly in our research, we were surprised at how many patients said they were happy with the level of information they had received – in contrast to the views expressed in the NPES data.

At present, it is not standard practice to include a follow-up contact number in the discharge summary, if patients have any questions. Some ward staff may provide a phone number, and others will include general statements like, ‘If x happens, contact your GP or seek medical attention’.

Layout issue - Patient information is buried

In discharge summaries that we observed from Nelson, Waikato, and Auckland (via a family member), the ‘Advice to Patient’ section was buried far down in the document.

- “The most important part for you really is this bit at the bottom which has your discharge plan and then also our advice to you” (staff member, Nelson, emphasis added).

This is a concern because it means that patients may stop reading the summary, before they get to the part that is relevant to them.

In terms of best practice, the discharge summary in Northland is well laid out, with the ‘Advice to patient’ section on the front page of the document, right under ‘Diagnosis’.

Layout issue - Font is quite small

Two staff members we spoke to noted that the font on the discharge summary is small, and that older patients, in particular, may struggle to read this.

Improving the content & layout

Split the document for the 2 audiences

If the discharge summary is written for two audiences, then we recommend splitting the document in two – with one version for patients, and one version for healthcare professionals.

In terms of how this could be done, we received a number of suggestions:

- Krames software creates 2 versions of the discharge summary. The software is currently US-centric, but it can be locally customised.
- The back-end software could be developed so that the discharge summary is written in sections. When it comes time to print the document, the House Officer could select the patient-relevant sections from a drop-down list, and then only print these off.

As an interim step, the ‘Advice to patient’ section could be pulled to the front of the discharge summary, and placed in a call-out box, so that it visually stands out.

- “Making the plan stand out more, for the patient . . . Like when their next appointment is, and things that they need to do. . . So that needs to be highlighted, or even brought up to the front maybe” (staff member, Waikato).

Simplify content

If the content of the discharge summary for patients could be simplified, people would be able to understand and retain more of what they read.

The following list is a compilation of suggested improvements, generated by staff members, patients, and our research team:

Convert all medicines information into plain English

For instance, rather than saying a drug is to be taken 'PO, bid' the document should state 'take orally, twice a day'.

Present medicines information in a simple table

We recommend exploring whether all newly prescribed medication could be summarised in a simple table, like the medication card, using back-end software. This table should include the side effects to look out for. And if the discharge summary does not include all of a patient's medicines, because they did not receive a medicine reconciliation, then short notes above the table should state which medicines have been **started**, **stopped** or **changed**. The key changes should also be noted in the discharge summary for health professionals (see blue box, next page).

Use if-then scenarios

For instance - 'If you have heart failure and your weight has increased by 2kg, take [this drug] for 3 days. If your weight does not decrease, contact your GP'.

Use do's and don'ts lists

This list could be standardised in different wards, to save time. For instance, for condition management after surgery:

- DO keep your wound clean
- DO NOT drive a vehicle within x hours of taking tramadol

Use language 'signposts'

As the goal of this project is to improve responses to the National Patient Experience Survey, there is value in using 'language signposts', or headings in the discharge summary for patients which match the language used in the NPES. For instance – the summary should more explicitly mention medication side effects.

Use visual devices

We recommend increasing the use of colour, images, diagrams and flowcharts. For instance, a 'traffic light' visual could help patients identify if their symptoms are normal (green), or whether it's a good idea to seek medical help soon (orange) or immediately (red). Making greater use of visual devices is particularly beneficial for people with lower health literacy.

CHANGES TO THE DISCHARGE SUMMARY FOR HEALTH PROFESSIONALS

The scope of this project was to improve how information about medication side effects and condition management is shared, with patients.

One out-of-scope but important issue that kept arising, throughout the research, is that community pharmacies are not receiving enough information about what goes on in hospital, to check that prescribed medicines are safe when combined with a patient's baseline regime.

- “The key thing that community pharmacists tell us is ‘we didn’t know what’s going on, we haven’t got a clue’. You’ve got to take calls – is it stopped? Is it started? What’s the plan here?” (staff member, Nelson).
- “Quite often you’ll find that community pharmacy may get a prescription for medicine and think is this in addition to, or instead of, or what’s happened to all the other medicines that they have?” (pharmacist, Northland).

These issues could be avoided if:

- all patients received a **medicine reconciliation** at admission and discharge – which is a current focus of the Commission.
- if **electronic medication management** was more advanced – this is also a focus of the Commission.
- if hospitals and community pharmacies could **share an online workstation**, allowing them to track each other’s prescribing activities. We are aware of efforts to develop these workstations – for instance, in Whangarei, the Whānau Tahi programme will allow a patient’s record to be accessed by GPs, pharmacists and other providers. Likewise in the Waikato, shared workstations are being set up, to allow community pharmacies to see what has happened in hospital.

However, these solutions are not yet widespread. Therefore, at this point in time, we recommend that the **discharge summary for health professionals** include a list of **all medication changes**.

- What has been **stopped**
- What has been **changed** (e.g. a new dose of a current medication)
- What has been **started**
- Plus a **rationale** as to why these changes have been made

Many staff members endorse the idea of highlighting the changes, and the reasons these have been made:

- “If there’s a reason that we’ve stopped anything, that that’s reflected too. Because that is a massive communication let-down between community pharmacy and hospital” (staff member, Waikato).
- “More detail about the changes is useful. So if someone comes in on lots of medicines, and I know they’ve got heaps of them at home, I don’t always write them out again, because it takes me a very long time. But what I will write is, ‘I have made no intentional changes to this person’s medication’” (staff member, Waikato).
- “I know from a GP point of view, they like a reason for something being started or changed. So that, if there is a wrong list of medicines, they can see – or better predict – why something’s been started” (staff member, Waikato).

Standardise content

By standardising the content of discharge summaries, and the process of how these documents are written, we can (a) help to ensure that all patients get the information they need and (b) potentially save staff members' time. We recommend the following changes.

Prompt staff to include key content

Make greater use of sub-headings. For instance, the discharge summary could include sub-headings about (a) follow-up appointments, (b) warning signs to look out for, (c) your medication, etc. – reminding staff members to populate each section.

Add prompting questions in the back-end view. For instance, under a sub-heading about medication, the software could list key questions like:

- 'Have you STOPPED any of this patient's medicines?'
- 'Have you CHANGED THE DOSE of any of their medicines?'

Prompt staff to complete a checklist. House Officers could be prompted to complete a checklist, after they have written the discharge summary for patients, and before they've printed it out. Checklists are an excellent tool for quality control.

Include warning signs for condition management

A number of staff members mentioned that they give patients 'warning signs' to look out for at home, with 'troubleshooting' advice about what to do if those signs appear. These statements could easily be standardised – e.g. 'If your wound becomes red, hot, or swollen, do x'.

Use auto-populated text to save staff time

If sections of the discharge summary become more standardised, then some text could be auto-populated, to save staff time. For instance:

- For patients following digestive tract surgery: "Avoid heavy lifting for 6 weeks. By 'heavy' we mean anything that requires 2 hands to lift."
- For patients discharged home with tramadol: "This medication is an opiate, which may cause the side effect of constipation. To help you avoid constipation, we've also prescribed a laxative called laxsol."

Provide a contact number

As patients are likely to have questions when they get home, there is value in providing them with contact phone numbers. These could be 'triaged', for example:

- Phone an ambulance on 111, if you are experiencing [insert key symptoms]
- Phone Healthline on 0800 611 116, if you have an urgent query
- Phone your GP or local pharmacy, if you have a non-urgent query

Patients should also be supplied with contact numbers for services they have been referred to – such as District Nursing.

- "They'll say 'District Nurse is going to see you on the 10th day', and they're at home going [fingers drumming on table] when? Because I've got a life to live, I might have to go and pick up my kids or grandchildren or whatever, so a contact number for those referral services can actually help [patients] have control over their healthcare" (staff member, Waikato).

In terms of best practice, the phone number needs to direct people to a specific place, or they will get 'lost' in the system. This is illustrated by one staff member's tale:

- "I've had that experience myself, with my own health, where I've come in, and gone home, and they've said 'just ring up if you have any problems'. Well I had problems, but which department do I ring? ED? Was it Ward 9, or was it Day Stay? Because I've been through Day Stay, previously at ED, then Ward 9 and home" (staff member, Nelson).

Direct to websites / videos

We know from the NPES data, and from our on-the-ground research, that patients often go online to find out more about their condition and their medicines. Hospital staff could tap into this, and direct people to high-quality websites and online videos, via the discharge summary for patients. If the Summary is emailed out, then patients could simply click a hyperlink to get the information they need.

There are 3 clear benefits of this strategy. Firstly, patients can get in-depth answers to their queries. Secondly, clinicians could rest assured that the information conveyed is accurate. And thirdly, web-based content can be translated into other languages more readily than written hand-outs. It's also a sound behaviour-change principle to 'go with the flow' by tapping into and tweaking existing habits, rather than trying to introduce a wholesale change.

At the moment, we know that some staff members are directing their patients to websites, such as Diabetes NZ, online oncology resources, or Bay Navigator. A handful of staff members trained in the UK also direct their patients to NHS choices and Patient.co.uk, as they are not aware of comparable NZ-specific sites. But there is plenty of scope for improvement – and there's an appetite for online resources, from both staff members and patients:

- "I think being directed to [web]sites is really good too. . . it's good to know trusted sites" (patient, BOP).
- "It would be nice to have a website you can go to, that I can look it up myself, because I'm quite happy to do that" (patient, Waikato).
- "People go onto Google, and they don't know what's good information and what's poor information. They need to be sort of signposted, to a recognised website" (staff member, Nelson).

Any technology-based solution could potentially exacerbate healthcare inequalities between those with access to the internet and computers/devices/smartphones, and those without access. According to the World Internet Project data from 2015, 91% of New Zealanders are active users of the internet, and the demographic groups with the biggest proportion of people 'never using' the internet are:

- the elderly – 30% of those 70+ years are 'never users'
- Pasifika peoples - 15% classified as 'never users'
- people living in rural areas – 14% classified as 'never users' (Crothers et al, 2016)

For these populations, there is value in (a) recruiting younger, more urban family members to help share online content, and (b) providing as much online education as possible whilst the patient is in hospital – for instance, while they are waiting in the Discharge Lounge.

We also believe that the benefits of online education, particularly for those with lower health literacy, offset the potential risk of a growing 'digital divide'.

'Prescribe' apps

There is an opportunity for staff members to help people manage their own healthcare, by 'prescribing' useful apps in the discharge summary for patients. For instance, the following apps are attracting an increasing number of users, and could be 'prescribed' more often:

- **Patient Portal** - patientportals.co.nz
This portal allows patients to access their medical records, book appointments, and order repeat prescriptions.
- **Smarthealth in Waikato** - smarthealth.org.nz
This app, which is currently being pilot tested at Waikato DHB, connect patients to a range of health services. For instance, users can access credible resources; talk to a doctor out-of-hours via video, voice or text chat; schedule online health appointments, etc.
- **Manage my Health** - managemyhealth.co.nz
This app also gives patients access to their medical records, helps them connect with clinicians online, and enables GPs to share patient information with other health providers (e.g. emergency services).

More formally refer people to community pharmacists and GPs

As we've noted, the discharge summary is designed to facilitate handover between hospital- and community-based healthcare professionals. However, we feel it would be beneficial if patients received a more formal 'referral' to speak to a community pharmacist or GP.

For instance, if patients are finding their medicine regime confusing, the discharge summary could direct patients to ‘book’ a slot with their community pharmacist, in order to get more information, a medication card, etc.

- “In general, if they’ve got a regular pharmacy and they’ve got that relationship with them, that probably is the best place [for information sharing]. It probably is a lot better for them, because then they’re in a thinking pharmacy environment . . . [whereas here] there’s quite a lot going on, there’s a lot of information overload, and stuff gets missed” (pharmacist, Northland).

Likewise, if a patient would benefit from an education session with their GP, the discharge summary should ask them to book in a double appointment.

- “So say you give someone a script, and you’re like, please go and see your GP in a week, please make a double appointment, because that’s going to be an education session. You know, GPs can’t, in 15 minutes, be expected to follow up the patient after an admission, and explain 5 new medications” (staff member, Nelson).

We suspect that community-based professionals would be happy to receive these referrals and play a bigger education role – especially if they are able to book patients in at particular times, and thus balance this role with other daily demands.

- “I’ve often referred to community pharmacy directly, I’ve spoken to the pharmacists there and said ‘look this person’s a little bit overwhelmed or just needs a bit of extra information’ . . . if they know to give a bit of extra support they’re usually more than happy to” (pharmacist, Northland).

As a final note – pharmacists could only take on this more formalised education role if they see the discharge summary and it contains the contextual information we noted earlier – like which medicines a patient has started and stopped, and why.

- “Because they [community pharmacists] are often left out of the information loop aren’t they. So they’re just presented with prescriptions. So they would probably need more information from us, around plans etc., to be able to take on that role” (staff member, Waikato).

‘Nudge’ patients to book follow-up appointments

At present, patients are asked to make follow-up appointments – for instance, ‘book an appointment with your GP in the next 2 weeks’. But more could be done to encourage or ‘nudge’ patients to actually book and attend these appointments. Because, as one staff member notes:

- “A fair percentage of the patients won’t do that. And probably the very patient that you want to go and see their GP, to make sure everything’s sorted, is the one person that won’t go and do that. You know, they’ll be the person that can’t afford it, or just not organised enough, kids or sick or . . . something else will be important” (staff member, Waikato).

A few techniques – informed by behavioural science – could be used here.

Firstly, rather than asking that people see their GP ‘in the next 2 weeks’, the discharge summary for patients should specify a set date by which a patient should have seen their GP. This is behavioural science best practice, as it sets a mental trigger, by tying an action to a particular point in time. That way, even if patients haven’t made the appointment by ‘March 3rd’, for instance, when March 3rd comes, they are more likely to remember that they need to see the GP, and book this in.

A second option is for the discharge summary to have a check-box, or a blank line that patients fill in, once they’ve set the date of their follow-up appointment. This visually reminds people that they have something to ‘action’.

A final option is to change the default, and get patients (or staff members) to book in appointments, before patients leave the hospital. This was being trialled in some wards that we visited.

Delivery issues

There are a number of issues with the way the discharge summary is currently delivered to patients.

It's often given in a hurry

In the discharge discussions that we observed, House Officers ran through the discharge summary very quickly – generally spending a few minutes with each patient. And at times, patients may not receive any verbal explanation – the document is just handed over.

- “Having more time to sit down and explain all the changes would be beneficial, I think, for everyone, but sometimes if you're rushed, you do end up just writing the letter and not talking with them” (House Officer, Waikato).
- “Often they don't. Often the doctors don't [go through discharge papers with patients]. They'll just pop them in their paperwork and walk away. We encourage them to, because often the patients have got a question that they want to ask” (staff member, Waikato).

Delivery method is risky

Discharge summaries are handed over loosely to patients, along with pharmacy scripts and any other essential paperwork. It would be relatively easy for a patient to lose track of these documents.

At weekends – patients may not receive a discharge summary

Some DHBs we visited are particularly short-staffed at the weekend, which means that many patients leave hospital without a discharge summary.

- “Over 25% of the week is the weekend, and the staff is really limited, so people often won't even get a discharge summary. They'll just say you can go home, and so there's no discharge process, because there's simply not the staff there to have those conversations.”

These patients are meant to receive their discharge summary in the post; however, comments from the NPES indicate that the documents are often delayed, or not received at all.

Improving delivery

Aim to read through the patient-relevant section

We recommend that House Officers read through the relevant section of the discharge summary, with patients. While this requires a time investment, the increase in 'reading time' should be partially offset by the time saved writing the discharge summary, given that some sections can be auto-populated.

Provide an envelope & checklist for patients

Patients could be provided with a large envelope to store all of their important documents. This could have a checklist on the outside, so patients can mark off:

- that they have received the right paperwork
- that they understand their condition and their medicines

We'll discuss this idea further, in section 6.11.

Send out electronically, when possible

Pieces of paper can get lost – which is why we recommend that hospitals also email people a copy of the discharge summary for patients, or share the document via apps like Smarthealth and the Patient Portal.

At weekends – increase resource & provide patient-relevant section

The discharge summary is crucial for helping patients to understand their condition and their medication. As such, we recommend that hospitals evaluate the costs and benefits of increasing weekend staffing levels, so that patients can, as a minimum, receive the patient-relevant section of the discharge summary. See Chapter 7 for a mock-up of an optimised discharge summary for patients.



6.11A | PROMPTS FOR PATIENTS / FAMILIES

Staff members in some wards that we visited had launched initiatives to encourage patients to ask questions, and take greater responsibility for their health. These initiatives or ‘prompts’ affect how much information is shared with patients, and therefore, how well patients understand the side effects of their medication, and how to manage their condition, once at home.

The initiatives we heard about include:

- In the Bay of Plenty, the **‘Ticket Home’** initiative is now being trialled on the three medical wards, including the Kaupapa Ward where Māori patients receive clinical and culturally appropriate care. Patients in these wards are given a booklet with blank sections, so they can fill in details about (a) who their care team is, (b) why they have been admitted, (c) what needs to be organised before they can go home, and (d) their expected date of discharge. Patients are also actively encouraged to ask questions about aspects of their care.
- Also in the Bay of Plenty, a member of the Quality Improvement team previously trialled an intervention - encouraging patients and family members to write down questions, make a note of medication changes, and so forth. However, the initiative did not gain traction as a large number of other projects were being rolled out at the same time.
- In the Waikato, members of the Cardiac Ward offer patients a pen and paper, to encourage them to write down questions.
 - > “I’ll say to them, here’s a piece of paper and a pen, while you’re sitting there pondering about why you’re in here, just write some questions down. Because . . . when you come face-to-face with that consultant tomorrow, your mind just goes blank. . . I encourage their families to do it as well” (Cardiac nurse, Waikato).
- In other wards, staff members sometimes ask patients to buy a notebook and jot down questions.

6.11B | WHAT’S WORKING?

In theory - empowers patients and families to take responsibility

These interventions are designed to empower patients and family members – to make them more active participants in their own care. Ideally, the prompts should help people feel more confident asking questions if they don’t fully understand a topic, or challenging decisions that are being made if they aren’t happy.

- “I am the expert of me. I can consult with doctors and nurses who will provide me with excellent advice, but I’m the one who has to manage the conditions I have. So we need to empower patients to become the experts, I think” (staff member, Nelson).
- “People should be encouraged to speak up, rather than carry on, if they’re not happy” (patient, Waikato).

According to cultural advisors from Tātou, providing prompts and encouraging greater engagement from Māori, aligns well with the principle of participation embedded in the Treaty of Waitangi. There is also particular value in empowering whānau, who can then advocate for the patient.

- “Within te ao Māori (the Māori world), it will be the family that will advocate, will make sure mum takes her meds, will take her to the doctor, and down to the laboratory to get bloods – so that’s a shared responsibility” (staff member, Nelson).

Patients can formulate their questions over time

Patients often need time to figure out what they know, where the gaps are in their understanding, and what they want to ask, before they come face-to-face with busy ward staff. That’s where these prompts come in handy.

- “I think . . . giving the patient a little bit more time. Generally they’ll be like, ‘do you have any questions?’ and you’ll be like ‘No’, and then once they’ve gone, that’s when you’ve got a question to ask” (patient, BOP).

- “I think they [the staff] appreciate people being assertive, and taking responsibility for their own health as well. Like I had to sort of think, sit there, and not feel sorry for myself, but think of a good set of questions to ask the doctors, and take a proactive stance on my own behalf” (Māori female patient, Waikato).

6.11C | WHAT COULD BE IMPROVED?

Recognise the barriers

Empowering patients is an admirable goal. However, there are still significant barriers that must be recognised, if we are to design a prompt that actually empowers patients. We will briefly run through the key barriers that we noted during our site visits.

“Doc knows best”

Many patients will not ask questions about the care they are provided, because they assume that ‘Doc knows best’.

- “Those people [the hospital staff] know what they’re doing – I just have to trust them” (patient, BOP).
- “There are still some patients out there that say ‘he’s the doctor, I’ll do what he says’” (staff member, Northland).

These views are more common amongst older patients.

- “It’s difficult, because a lot of patients don’t take the initiative to be involved in their own care – especially when they’re a bit older, and they maybe have just got into the habit of the GP will just prescribe them things, and not really discuss things” (staff member, Waikato).
- “Younger people, generally, can speak up for themselves, and they’ll ask the questions – whereas the older person probably is more accepting” (staff member, Waikato).

Staff members acknowledge that “people are in quite a vulnerable position, with health professionals” (staff member, Nelson), and that as the specialists, they generally have the final say:

- “I think there’s also a question around moving the discussion from ‘what’s the matter with me?’ to ‘what matters to me?’ . . . because again I think that’s something that will potentially avoid re-admissions, and enhance the quality of care. You know, actually I don’t want to take 20 tablets, I want to go home and I want to sit with the cat.”
“We get that all the time!”
“And what do we do? Oh, you must take the 20 tablets!”
(laughing)
(focus group, Nelson)

However, there is a difference between asking questions to find out more information, and asking questions because you disagree with the course of treatment that has been chosen. We are primarily recommending that patients are given prompts so that they understand key points about their medication and condition management, before going home.

“I don’t want to cause a fuss”

Because of the power imbalance that exists, patients may not feel comfortable ‘bothering’ busy staff members:

- “Sometimes if you approach patients after the doctor’s ward round, and . . . they won’t know what’s happened . . . [and] they’ll say, ‘no they looked too busy, I didn’t dare ask’” (staff member, Waikato).

Staff members acknowledge this issue – that empowering patients to ask more questions will require an investment of staff time.

- “It is a con for the doctors. It’s time. It’s always time” (staff member, Waikato).

Beyond the staff-patient dynamic, there are broader cultural issues here, as Kiwis are known for ‘going with the flow’, rather than being more assertive and asking questions:

- “Us New Zealanders are very shy . . . it’s ok to speak up, it’s ok to ask, and to enquire. You just go to the doctor, get your meds, don’t ask any questions . . .” (patient, Waikato).

We may even avoid asking questions, for fear of annoying the people in the bed next to us:

- “Even for elderly - I don’t want to annoy that patient across the way who’s in more pain than me, so I’ll just sit and be quiet” (staff member, Waikato).

“I don’t want to look stupid”

Another barrier that may stop patients from asking questions is the fear of looking stupid.

- “I always say there’s no such thing as a silly question. Because I think that puts a lot of people off. ‘Cause they think they’ll think I’m an idiot if I ask that” (pharmacist, Northland).

Patients with less social power are more likely to be defensive of their social status, and relatively unwilling to ask questions. Likewise, asking questions may be difficult for patients of Māori descent – who will be keen to avoid the feeling of whakamā, which can be loosely translated as shame, inadequacy or inferiority. Finally, patients may struggle to ask questions on ward rounds, when confronted by a large team of medical specialists:

- “The surgical ward rounds can be quite big. And so if you’re lying there in bed, and there are 8 people standing around you, that’s quite an intimidating environment” (staff member, Waikato).

There’s a language barrier

Some patients will refrain from asking questions if there is a language barrier – for instance, if they speak English as a second or other language.

“I didn’t notice the prompt”

The final barrier is that on the wards, patients and family members may not notice a prompt that encourages them to write down and ask questions. The ward is a high-stress environment, and unless the prompt is front-and-centre, it is likely to be overlooked.

Address these barriers & optimise the prompt

We have the following suggestions, to remove the barriers discussed and optimise the prompt.

On the ward

Firstly, we believe there is value in having a relevant nurse attend the ward round, so they can hear what is said, and answer any follow-up questions that patients have immediately after the round.

As a second point, ward staff should explore cost-effective ways to encourage patients to note down their questions. For instance, a whiteboard could be provided, or a small notebook could be attached to the bedside table.

In the Discharge Lounge

We believe the Discharge Lounge is the optimal time and place to prompt patients (and family members) to ask questions, before going home. In this context, patients are feeling relatively healthy, and they have time, as they wait for their discharge paperwork.

Therefore, we recommend that the Commission develop a ‘Home safe’ checklist, printed on an envelope, which can be used to:

- Encourage patients to ask the right questions
- Ensure patients receive, and can keep track of, all the right paperwork

This suggestion is based on the successful ‘Discharge to rest home’ envelope, which has a checklist on the outside, and which has been proven to “minimise errors and delays during transfer of care” (Waitemata DHB Quality Accounts, 2012/13).

The checklist could start with a reassuring statement, and then include a simple list of questions for patients to review. A mock-up of the 'Home safe' checklist is included in Chapter 7 of this report.

A copy of the 'Home safe' checklist could be placed on each chair in the Discharge Lounge, first thing in the morning, and whenever a patient vacates a chair.

Once a patient has worked through this checklist, the information can be reviewed by the Discharge Lounge team, who can fill in as many of the 'knowledge gaps' as possible, before the House Officer arrives. The House Officer can then fill in the remaining gaps.

By following this process, we should be able to remove many of the barriers discussed:

- Putting the checklist on all Discharge Lounge chairs helps to establish a social norm. Patients will all notice the prompt, and they will feel more comfortable asking questions, because everyone around them is being encouraged to, and because this is a formalised hospital process. In this context, there is no shame in asking questions, and patients are less likely to feel they are 'making a fuss'.
- Having the Discharge Lounge nurses review the checklist, and fill in as many gaps as possible, means that patients will not feel like they are 'bothering' the House Officer with so many questions.

6.12 | IN THE COMMUNITY – FOLLOW-UP FROM COMMUNITY PHARMACISTS OR GPs

As we have noted throughout, community-based pharmacists and GPs play a key role in patient education. That is why we have recommended (a) that patients are more formally 'referred' to appointments with pharmacists and GPs, as part of the discharge summary for patients, and (b) that the discharge summary includes more information about the changes made to a patient's medicines, so pharmacists and GPs can check that newly prescribed drugs are safe when combined with the existing regime.

Beyond this, we are wary of relying on pharmacists and GPs to act as a 'safety net', by filling in knowledge gaps that patients may have about their medication or condition management. Having a safety net may create a culture of complacency in the hospital – and the aim of the National Patient Experience Survey, and this project in turn, is to improve information sharing within public hospitals. Therefore, we have focused our suggested improvements on what can be changed *within* the hospital context – rather than what could be changed in the community.

6.13 | IN THE COMMUNITY – FOLLOW UP FROM WARD STAFF

Recall that in the NPES data, patients gave very positive responses when they received a proactive follow-up phone call from their hospital care team. Given this, our final suggestion is for wards to explore how they could proactively follow-up with patients after discharge, via a phone call.

No doubt this would be resource intensive. However, evidence from previous research in the AT&R and medical wards in Nelson has indicated that being more proactive with patient follow-up leads to a statistically significant drop in re-admission rates - "and one of the things that was the most beneficial, was phone follow up" (staff member, Nelson).

Amongst the staff members that we spoke to, the idea of proactive follow-up calls was generally well received:

- “they must have been pretty sick to require to be in hospital . . . And they might well have an outpatient appointment, but that’s probably 6 weeks, 12 weeks away . . . So you have this window, where the patient goes from very intense care, to just being at home. And I think there’s a real opportunity to start filling that in” (staff member, Waikato).
- “Maybe we can do more with the phone call. Ring them up after 24 hours and see how they’re doing . . . I think the phone calls would be really good. Because some of them they go home and they don’t want to bother us” (staff member, Nelson).
- “Would it be conceivable for the team’s registrar to have 2 hours allocated one afternoon, to contact all their discharge patients?”

“Absolutely – ”

“. . . just touch base with them and make sure everything is fine. And that would be good education for the hospital teams, to get feedback on what’s happening.”

“And you can imagine, in a surgical setting, it might be the nurse specialists that work within those services . . . or any other, same sort of idea, but slightly different format”

(Focus group, Waikato).

SUMMARY

In this section, we have outlined the key results from our on-site research at 4 DHBs. In terms of medication side effects and condition management, we have reviewed what information is shared, who shares it, when and how. We have outlined what is working well, and the areas where improvements could be made.

In the next section, we will demonstrate how these various improvements could work together, in order to optimise the patient journey, and improve scores on the Medication Side Effects and Condition Management questions of the NPES.

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RECOMMENDED INTERVENTIONS

CHAPTER 7

The Results section of this report outlined a number of changes that could be made, to improve how staff members share information about medication side effects and condition management, and to help patients retain more of what they are told.

To understand how these improvements would work together, we compiled all the suggestions, and mapped out what an **improved** patient journey would look like, and what an **ideal** patient journey would look like. These process maps are included in Appendix 1.

Off the back of this, we developed 6 recommended interventions.

There are **3 quicker wins** – or changes that could be made relatively quickly, without a significant increase in resource. These changes could be classified as ‘nudges’ – small changes which have a significant impact on behaviour.

Then there are **3 big wins** – which require more resource investment, but which should help to drive significant improvements in patient care, and subsequently improve responses to the NPES questions. These are not ‘nudges’, but they are still informed by behavioural science.

We will now run through these, and explain how they align with MINDSPACE, EAST and other behavioural science best practices.

3 Quick Wins

- 1) Focus on ‘down side’ medicines
- 2) Optimise the discharge summary for patients
- 3) Use the Discharge Lounge as an education safety net
 - a) Introduce the ‘Home safe’ checklist
 - b) Scale up the use of multi-sensory education

3 Big Wins

- 1) Provide follow-up phone calls
- 2) Increase pharmacy resource
- 3) Continue to roll out technology-based solutions

QUICK WINS

1) Focus on ‘down side’ medicines

The ultimate goal of this project is that patients stay safe and well, at home. To help achieve this goal, and improve scores on the Medication Side Effects question, we recommend that DHBs complete the following steps:

- Develop a uniform list of the ‘down side’ medicines – that is, medicines with very common or very serious side effects.
- Develop a process to:
 - > Formally flag a patient in the hospital system, if they are to be prescribed a ‘down side’ medication.
 - > Prompt nursing staff to hand out a short information sheet to patients, before any ‘down side’ medicines are administered or prescribed. Sheets should be stockpiled in the ward, or compiled in a central database, to enable this step.
 - > Prompt a pharmacist to follow up with the patient – highlighting the key side effects, providing balanced risk information, and actively encouraging patients to ask questions.

Behavioural science elements

- **Suitable messenger (M of MINDSPACE)**
Pharmacists are best-qualified to explain medication risks to patients, given their specialist knowledge.
- **New default (D of MINDSPACE)**
Previously, staff members only gave out written information about medicines when they were asked to by patients. Here we are recommending a new process, in which patients receive information by default, rather than having to ask for it.
- **Timely information (T of EAST)**
Patients need time to digest information, and think of any questions that they have. In this process, there is a lag between patients receiving the information from the nursing staff, and having the information explained by the pharmacist. In this lag-time, patients can formulate their questions.

2) Optimise the discharge summary letter

In the Results section, we outlined a large number of ways to optimise the discharge summary for patients. This includes splitting the document in 2 – with one section specifically for patients. Then, the following changes should be incorporated into the discharge summary for patients:

- Simplify information about medication
 - > Use plain English rather than abbreviations
 - > Present new medication regime in a simple table, complete with information on side effects
 - > Explain any changes made to baseline medicines
- Simplify information on condition management
 - > Provide warning signs
 - > Use if-then scenarios
 - > Use do's and don'ts lists
- Improve follow-up
 - > Provide a contact number
 - > Direct to websites / videos
 - > 'Prescribe' apps
 - > More formally refer people to community pharmacy / GPs
 - > Nudge patients to book their follow-up appointments
- Make use of best-practice communication devices
 - > Use language signposts (i.e. subheadings in the same language as the NPES)
 - > Use visual devices
- Standardise the content
 - > Prompt staff to include key content
 - > Use auto-populated text when possible, to save time

We have prepared the following mock-up of a discharge summary for patients (see next page), to illustrate how these changes might look, in practice.

Note: Once the discharge summary for patients is optimised, it is still important that staff members read through this document with patients and family members. This will help patients to absorb the content, and the face-to-face contact (kanohi ki te kanohi) will be particularly valued by Māori patients.

Behavioural science elements

■ **Easy to understand (E of EAST)**

By simplifying the discharge summary for patients and making the information more visual, we have made it much easier for people to understand the contents of this document. In particular, the use of visual devices will benefit people with limited health literacy.

■ **Attractive (A of EAST)**

People are more likely to pay attention to something if it is attractive and draws them in. The newly formatted discharge summary for patients is more visually appealing than its predecessor.

Discharge summary for patients

Please read this information, and carefully follow all instructions.



Patient information

Patient Name Miss Elizabeth Jane Smith	Phone number +64 21 335 695	Admitted on 03/04/2017
Date of Birth 20/01/1986	GP Dr M. Knowler Allan Street Medical	Discharged on 03/04/2017
Address 8 Fishburn Ave, Whangarei		Ward/Location Short stay surgical

Your hospital stay

- ▶ You were admitted to Whangarei hospital on 4 April 2016, because your appendix burst.
- ▶ While you were here, you had your appendix removed with keyhole surgery. You also received antibiotics to prevent infection, and painkillers.
- ▶ You are now being discharged home. To keep yourself safe, please read all information on this sheet, and carefully follow the instructions.
- ▶ If you have any questions, please ask a staff member.

How to stay safe at home



Take your medication regularly

- ▶ You have been prescribed the following NEW medicines.
- ▶ [Include explanation of changes made to baseline medicines].
- ▶ If you have questions once you leave hospital, please talk to your community pharmacist.

Drug name	Daily dose	What it's for	Number of tablets to take				Key side effects to watch out for*	Special instructions
			Breakfast	Lunch	Dinner	Bedtime		
Tramadol 	200mg max/day	Reduces pain	1	1	1	1	May cause constipation, drowsiness.	Take Laxsol to prevent constipation. Do not drive within x hours of taking tramadol.
Laxsol 		Prevents and treats constipation				1-2	May cause severe stomach pain or nausea.	

You received your last dose of medication at:
DATE & TIME

You should take your next dose at:
DATE & TIME

*If you experience any of these side effects, please contact a medical professional immediately.



2

Stick to your care plan

- ✓ DO record the amount of liquid that is coming out of the drain.
- ✓ DO follow the recommended diet plan for 3-4 days.
 - Eating soft, bland foods such as potatoes, rice and chicken.
 - Avoiding spicy, greasy, fatty foods.
 - Avoiding gas-producing foods such as lentils.
- ✓ DO regularly take your medicines.
- ✗ DO NOT lift anything heavy for 6 weeks. By 'heavy' we mean anything that requires 2 hands to lift.

3

Ensure you receive the right follow-up services

District Nursing

We have arranged for a District Nurse to come and check your wound and the drain.

Your appointment details:

Date & time:
.....

Visiting your address:
.....

If you need to change this appointment,
please call (01) 234 5678.

Outpatient clinic

We have arranged an outpatient appointment for you, so that your drain can be removed.

Your appointment details:

Date & time:
.....

Clinic name & address:
.....

Please make sure you attend
this appointment.

If you need to change this appointment,
please call (01) 234 5678.



4

Know your warning signs

- ▶ If you have a fever
- ▶ If you have blood in your urine
- ▶ If your wound becomes red, hot or swollen.
- ▶ If you experience any of the medication side effects listed above.
- ▶ If you are consistently feeling severe pain of 7/10 or higher (with 10 = worst pain imaginable).
- ▶ If you experience mild-to-moderate pain for up to 6 weeks, this is normal.



Go immediately to your local A&E.



Call your GP immediately.

If you cannot get through, or it is after-hours, phone Healthline on 0800 611 116.



Keep following your care plan.

For more information

Websites

The following websites contain useful information:

- ▶ Health Navigator – www.healthnavigator.org.nz
- ▶ Website 2
- ▶ Website 3

Contact phone numbers

If you have general questions about your health, you can contact:

- ▶ Healthline – phone 0800 611 116
- ▶ Your GP
- ▶ Your local community pharmacy

3) Use the Discharge Lounge as an education safety net

The Discharge Lounge is an ideal 'education safety net' or site to:

- a) introduce the 'Home safe' checklist
- b) scale up the use of multi-sensory education

3a) The 'Home safe' checklist

Firstly, we recommend introducing the 'Home safe' checklist in the Discharge Lounge. As noted in Chapter 6, this would be a checklist printed on an envelope.

Every morning, the checklist would be placed on each chair in the Discharge Lounge. When patients come into the lounge, they would be prompted to answer the questions on the checklist, to indicate whether they understand key points about their medicines, condition and ongoing care. Discharge Lounge nurses would then fill in as many information gaps as they could, either by providing information themselves or directing people to online multi-sensory resources, before the House Officer arrives and fills in any remaining knowledge gaps.

The checklist would also help patients to keep track of their paperwork, as they could 'check off' when they had received certain documents.

On the next page we have included an example of the type of prompts the Home safe checklist could include.

We recommend that this tool be refined further, through a co-design process with staff members and patients. It could then be pilot tested at a number of DHB sites.

YOUR 'HOME SAFE' CHECKLIST

Before you leave the hospital, we need to make sure that you understand the next steps in your care. Please read and answer the following questions, by circling Yes, No, or n/a (not applicable). It's important that you answer honestly, so we can share the right information with you, and get you home safely.

	<i>Please circle</i>		
Do you know why you were admitted to hospital?	Yes	No	
Do you know how the medicines you are going home with differ from the medicines you came to hospital with?	Yes	No	n/a
Do you know the side effects of any new medicines that you are being prescribed?	Yes	No	n/a
Do you know what you should do, and not do , to manage your condition at home?	Yes	No	n/a
Do you know what follow-up care you will receive? (including further tests, appointments, etc.)	Yes	No	n/a
Have you received the equipment that you need, to manage at home?	Yes	No	n/a
Do you know the warning signs to look out for?	Yes	No	n/a
Do you know a contact phone number you can call, if you experience any of these warning signs?	Yes	No	n/a

YOUR QUESTIONS

Please write down any other questions that you have, here:

THIS ENVELOPE CONTAINS:

- My discharge summary letter
- My pharmacy script
- Etc.

Behavioural science elements

■ **Makes question asking a norm (N of MINDSPACE)**

The fact that the 'Home safe' checklist is placed on every chair in the Discharge Lounge, and that all patients are encouraged to complete it, means that asking questions suddenly becomes a social norm in this environment. Because we are social creatures, we are more likely to perform a behaviour if we think it is a norm.

■ **Ego protection (E of MINDSPACE)**

Patients may not wish to ask questions in the hospital environment, for fear of looking stupid. The 'Home safe' checklist helps protect patients from 'whakamā' or potential shame, by making question-asking part of a formalised hospital process – not something left to the discretion of the individual.

■ **Taps into the omission-commission bias**

The omission-commission bias is the idea that we feel more responsible for negative outcomes that result from our actions (commission) than we do for negative outcomes that result when we are passive (omission).

This is relevant in the hospital context, because at the moment, patients can passively imply that they understand what is going on. But the 'Home safe' checklist removes the option of being passive – as patients must actively answer, and indicate whether they understand aspects of their care, or not. With this set-up, patients are less likely to 'lie by omission', and more likely to tell staff members where the gaps in their knowledge are. This, in turn, means staff members can ensure that relevant information is shared.

■ **Makes it easy for staff members to share the right information (E of EAST)**

It can be difficult for staff members to remember to tell patients all the key information they need, prior to discharge. The use of a checklist makes it much easier for staff members to 'cover their bases'.

■ **Makes it easy for patients to keep track of paperwork (E of EAST)**

By printing the 'Home safe' checklist on an envelope, we can make it easier for patients to store and keep track of all of their paperwork.

■ **A suitable messenger shares the information (M of MINDSPACE)**

The process we have suggested involves drawing on the knowledge of Discharge Lounge nurses as much as possible, rather than House Officers. We have made this suggestion as patients are more likely to feel comfortable asking questions of the nursing staff, who are perceived to be in less of a hurry than the House Officers.

■ **A timely prompt (T of EAST)**

The timing of an intervention matters. When patients reach the Discharge Lounge, they are in a relatively better state of health than they have been, on the ward. This means they will be in a better headspace to review what they know, and what they need to know, before they go home.

3b) Use of multi-sensory education

Throughout this report, we have noted that patients find it easier to take in information when it is multi-sensory – aural, visual, audio-visual, or demonstrated in a hands-on way. According to cultural advisors from Tātou, using multi-sensory learning tools is particularly beneficial for Māori patients, who have a bent towards visual and kinaesthetic or hands-on learning styles. As such, we recommend that the Discharge Lounge become a place of multi-sensory education.

After completing their ‘Home safe’ checklist, and indicating where the gaps in their knowledge are, patients could be directed to an online library of multi-sensory, educational resources, like videos and short information sheets.

If patients don’t have their own device (like a smartphone), the Discharge Lounge could look to provide handheld devices. These could even be attached to the Discharge Lounge chairs, in a similar way to in-flight televisions on international flights.

In order to roll out this change, we recommend that DHBs collaborate and add to the stockpile of online resources held by existing sites, like Health Navigator.

Behavioural science elements

■ **Makes learning attractive (A of EAST)**

Information is more interesting and attractive when it is presented via multi-sensory formats. People are also hard-wired to process images more rapidly than we process words, and so, by relying more on video-based content, we can make it easier for patients to take information in.

■ **Timely provision of information (T of EAST)**

As we noted earlier, by the time that patients reach the Discharge Lounge, they are in a relatively healthy state, and thus, they should find it easier to absorb what they are learning.

BIG WINS

1) Provide follow-up phone calls

In an ideal world, all patients would receive a follow-up phone call from the ward, within a certain time period after discharge. Feedback from the NPES suggests that this would be very well received – and staff members acknowledge that this would help patients to safely transition from hospital-based care to life at home.

Adopting this change system-wide would require significant resource. Therefore, we recommend that the Commission pilot test the intervention in a handful of wards, before considering a wider roll-out.

Behavioural science elements

- **Support provided in a timely way (T of EAST)**
Both the Medication Side Effects and Condition Management questions relate to how well people can manage, once at home. Therefore, it makes sense to provide patients with more support, and to help them get the answers they need, once they are at home.
- **Changes default, which benefits disempowered patients (D of MINDSPACE)**
At the moment, patients will only seek medical attention at home if they are very concerned about their condition, or if they are particularly active participants in their own care. In simple terms, the set-up is that ‘the squeaky wheel gets the grease’. This is not ideal from an equity perspective, because disempowered patients are less likely to seek out, and receive, follow-up care.
By changing the default, and ensuring all patients receive a follow-up call, we can help even disempowered patients to get the input and care they need.

2) Increase pharmacy resource

We believe there would be significant benefits in increasing the number of FTE pharmacists, in public hospitals.

With more pharmacists on board, it should be possible to:

- Formally include pharmacists in the multi-disciplinary team, ensuring that higher-risk patients receive the input they need, prior to discharge.
- Provide the medicine reconciliation service to more patients.
- Prepare medication cards for more patients.
- Have relevant sections of the discharge summary written or reviewed by pharmacists.
- Improve handover processes between the hospital and community pharmacy.

Behavioural science elements

- **The right messenger for the job (M of MINDSPACE)**
Pharmacists have specialist knowledge about medication, and so they are best-placed to educate patients about drugs and their side effects.
- **Timely input (T of EAST)**
With pharmacists formally included in the MDT, there can be more certainty that patients will receive the input they need from this specialty service, before discharge.

3) Continue to roll out technology-based solutions

Throughout the Results section of this report, we noted a number of technological solutions that the Commission are already rolling out, in order to improve information sharing around medication and condition management. This includes:

- Electronic medicines management – covering:
 - > Electronic medication prescribing & administration
 - > Electronic medicine reconciliation (eMR)
 - > Electronic pharmacy (ePx)
- Shared workstations between hospitals & community pharmacies / GPs
- Directing patients to apps (e.g. SmartHealth, Patient Portals)

When mapping out the ideal patient journey, it became clear that many of the optimised processes involve a significant technology component. Therefore, our only suggestion in this space is to continue to roll out these ‘tech’ solutions!

Behavioural science elements

- **Makes information sharing easy (E of EAST)**

The obvious, key benefit of the aforementioned technology-based solutions is that they make information transfer easier, facilitating sharing between hospital staff, patients, and community pharmacies/GPs.

CONCLUSION & NEXT STEPS

CHAPTER 8

The objectives of this project were:

- 1) To understand why patients are giving relatively negative responses to the Medication Side Effects and Condition Management questions in the National Patient Experience Survey.
- 2) To design a series of cost-effective interventions which DHBs can roll out, to improve patient ratings on these two questions.

During the research phase of the project, we conducted a secondary analysis of the NPES data, and primary research at 4 DHBs around New Zealand.

Through our secondary analysis, we identified the factors that negatively or positively impact on how patients answer the Medication Side Effects and Condition Management questions. Through our primary research, we were able to determine what, when, and how information is being shared with patients, and who is doing the sharing. We identified what is working well, and where there were opportunities for improvement.

Using the results from our primary and secondary research, we developed a series of recommended interventions, all of which should help to improve patient ratings on the Medication Side Effects and Condition Management questions of the NPES. Our interventions are based on robust behavioural science frameworks, including MINDSPACE and EAST, and they have been reviewed by cultural advisors from Tātou.

The interventions are as follows:

3 Quick Wins

- 1) Focus on 'down side' medicines
- 2) Optimise the discharge summary for patients
- 3) Use the Discharge Lounge as an education safety net
 - a) Introduce the 'Home safe' checklist
 - b) Scale up the use of multi-sensory education

3 Big Wins

- 1) Provide follow-up phone calls
- 2) Increase pharmacy resource
- 3) Continue to roll out technology-based solutions

From here, we recommend that the Commission review the results and recommended interventions outlined in this report. Some recommendations may not be feasible, due to constraints that our research team is not aware of. Other recommendations could be adopted and pilot-tested in a number of DHBs, so that the effectiveness of the interventions can be reviewed, before a wider roll out.

The changes have been primarily designed to improve scores on the Medication Side Effects and Condition Management questions of the NPES. But they should also have a wider impact – helping to reduce re-admission rates and healthcare costs, and improve patient outcomes, nationwide.



APPENDIX

MAPPING THE IMPROVED & IDEAL PATIENT JOURNEY

APPENDIX | MAPPING THE IMPROVED & IDEAL PATIENT JOURNEY

Chapter 6 of this report outlines a number of changes that could be made, to improve how staff members share information about medication side effects and condition management, and to help patients retain more of what they are told.

To demonstrate how these improvements would work together, we have compiled all the suggestions, and mapped out what an **improved** patient journey would look like, and what an **ideal** patient journey would look like.

Of course, modelling the patient journey from admission, to treatment, to discharge and back into the community, is very complex. So we have isolated the moments in the patient journey when patients receive information about their medication, or condition management. From there, we have highlighted the improvements that could be made, and noted whether the improvement requires a process change and/or a new technology, and whether the resource implications are moderate or significant.

Key

-  Significant resource required
-  Moderate resource required
-  New technology required / beneficial
-  Process change

Medication Side Effects – page 1

	CURRENT	IMPROVED	IDEAL
On admission			Pharmacist completes a medicine reconciliation for all patients (Note: already a focus of the Commission) 
On ward	Doctors mark all medication changes on patient charts		Doctors mark all medication changes on the medicine reconciliation sheet
At discharge	House Officer writes list of new medicines, which patient is given script for. Information is written in short-hand for pharmacist.	House Officer prepares short-form medication table , as part of discharge paperwork. This outlines: <ul style="list-style-type: none"> All changes to a patient's medicines (stopped, started, changed) Why the medication has been prescribed Dosage How often to take Side effects to look out for Plus a statement so patients know how their baseline medicines have changed 	Pharmacist prepares optimised medication card , as part of discharge paperwork. (Sections of this are auto-populated, e.g. the side effects section) This outlines: <ul style="list-style-type: none"> All medicines patients need to take, categorised by indication Why the medication has been prescribed Dosage How often to take Side effects to look out for A picture of what the medicine looks like 
In community	Community pharmacy view script in isolation. This leads to confusion about what changes have been made. Can lead to follow-up calls to hospital.	Community pharmacy view script, and ask patients for the medication table . They act as a safety net – contacting the hospital if they are concerned about drug interactions etc. 	Community pharmacy view this medication card , which gives them the context for the script. They act as a safety net – though unlikely to be required, as script prepared by pharmacist. 
			eMedicines reconciliation is completed * See health.govt.nz/our-work/ehealth/other-ehealth-initiatives/emedicines/emedicines-reconciliation 
			All medication changes logged on tool
			Patients receive auto-populated medicine reconciliation (potentially reviewed by pharmacist)
			Community pharmacy has shared workstation, can view updated eMedicines reconciliation

Medication Side Effects – page 2

	CURRENT	IMPROVED	IDEAL
On admission	Ward team determine whether patient requires input from a pharmacist.		Pharmacist is included in MDT meetings, and they determine whether a patient is likely to need their input. 
On ward	Pharmacist provides services as required, for example: <ul style="list-style-type: none"> Education about new medicines like warfarin Preparing a medication card 	<p>Patient starts on a high-risk medication – one with common or risky side effects. This is formally flagged in the system. Pharmacist is alerted that patient will need education. </p> <p>Nurse gives patient an A4 print-out about the medication, and asks them to read this. On the print-out, patients are prompted to write down any questions they have for the pharmacist, who will follow up. </p> <p>Pharmacist follows up – going over key content, including side effects to watch out for. <ul style="list-style-type: none"> Balanced risk information is provided There is time for patients to ask questions </p>	<p>Patient starts on a high-risk medication – one with common or risky side effects. This is formally flagged in the system. Pharmacist is alerted that patient will need education. </p> <p>Pharmacist explains new medicines using videos, diagrams and other educational resources which appeal to people with different learning styles. <ul style="list-style-type: none"> Balanced risk information is provided There is time for patients to ask questions </p>
At discharge	At times, patients are discharged before receiving required input from a pharmacist.	Pharmacist must 'sign off' that patient has received appropriate education. 	Like other members of MDT, pharmacist must clear a patient for discharge , before they leave the ward. 
In community	On an ad-hoc basis, hospital-based pharmacists may call community pharmacy and ask them to give more education / assistance to patients who are struggling with their medicines.		If deemed necessary, hospital-based pharmacists can formally refer patients to community pharmacy , for further education / assistance. 

Condition management – input from ward staff

	CURRENT	IMPROVED	IDEAL
On admission	Patient admitted to ward		
On ward	<p>Patient receives key verbal updates from the consultants, during ward rounds. Ward rounds are often:</p> <ul style="list-style-type: none"> Fast – the team are with each patient for a few minutes Relatively public – updates may be given in a shared room (albeit behind a pulled curtain), and with a large consulting team present (e.g. 8 people on a surgical ward round) Delivered at a time when family members are not present <p>In this context, it may be difficult for patients to ask questions.</p>	<p>Where possible, verbal updates are supplemented with written materials, videos or websites</p> <p>Patients are given a notebook or whiteboard, or asked to provide this, to record any questions they think of.</p> <p>Ward team answer these questions over time</p> <p>A member of the nursing team attends ward rounds. In this way:</p> <ul style="list-style-type: none"> They hear the key updates, and can deliver a consistent message to the patient They can re-visit the patient at a quieter time, and see if they have any questions. <p>Family members are included in ward rounds. This could be achieved if:</p> <ul style="list-style-type: none"> Family members are called and put on speakerphone Patients are given time to record key points (on their phone, or on paper) 	<p>All patient updates are:</p> <ul style="list-style-type: none"> logged in an app / online system that the patient can access written in layman's terms
At discharge	<p>House Officer briefly reads through discharge summary, pointing out content that is most relevant for patient. This will include:</p> <ul style="list-style-type: none"> Any equipment provided by MDT Any referrals to community-based services, or follow-up tests Advice (e.g. avoid heavy lifting for 6 weeks) Warning signs (e.g. if wound becomes hot, red, or swollen, seek medical attention) <p>Patient is asked if they have any questions – often when they have waited a number of hours to receive discharge papers.</p>	<p>House Officer writes and reads through optimised discharge summary. This will include:</p> <ul style="list-style-type: none"> Specific scenarios Expectation setting around pain management Follow-up appointments & dates these should be completed by When & how to get more help Visual communication tools <p>In the Discharge Lounge, patients are given a checklist which outlines the paperwork they should receive, and the key points they need to understand, before they go home.</p> <p>Patients note any areas where they would like more input.</p> <p>A nurse from the Discharge Lounge reviews the patient's checklist and provides relevant information (e.g. directing to online videos, or giving print-outs), prior to the House Officer's visit.</p> <p>The House Officer then fills in any other knowledge gaps.</p> <p>Family members also included in discharge discussions. Ideally they will be there in person, if not, then called and put on speakerphone.</p>	<p>App records all discharge information, referrals, appointment times etc.</p> <p>Patient can be directed to relevant videos and online content.</p> <p>Patients work through discharge checklist, confirming that:</p> <ul style="list-style-type: none"> they have the right paperwork for discharge they understand the key points about their condition & medication They can attend all their appointments (bookings made by staff, in conjunction with patients) House Officer also signs off discharge checklist, before patient leaves hospital.
In community	Patients may not know who to call, if they have questions	If patients have questions once at home, their discharge summary includes useful resources / key numbers they can call	<p>Patients can ask questions via the app (e.g. Smarthealth)</p> <p>Ward staff proactively call patient to follow up</p>

Condition Management – input from MDT

	CURRENT	IMPROVED	IDEAL
On admission	Members of MDT decide whether patient requires their input.		
On ward	<p>Patient receives a visit from an MDT member (e.g. a physio). Team member:</p> <ul style="list-style-type: none"> Completes assessments Determines what information, equipment and support services the patient needs Verbally explains key information to patient Uses demonstrations and written resources on an ad-hoc basis 	<p>Patient receives current level of service (on left).</p> <p>PLUS whenever MDT member provides education, there is a formal process to ensure patients also receive:</p> <ul style="list-style-type: none"> Written resources from a central repository, or Links to relevant videos, websites etc., all compiled in one place 	<p>Patient receives improved level of service (on left).</p> <p>PLUS all education resources for patient, including written resources and videos, are stored on a single app / online system</p>
At discharge	<p>MDT members:</p> <ul style="list-style-type: none"> Provide equipment that patient requires to manage at home Refer patients for support services (e.g. home help), as required Give out exercises / advice about how to manage at home 	<p>Patient receives current level of service (on left).</p> <p>PLUS MDT members provide patients with the contact phone numbers of support services</p>	<p>Patient receives improved level of service (on left).</p> <p>PLUS MDT members liaise with patient to confirm the date & time of support services first visit</p> <p>App records all discharge information, referrals, appointment times etc.</p>
In community	<p>At times:</p> <ul style="list-style-type: none"> Patients do not hear from support services Patients have questions / concerns but do not know who to talk to 	<p>Because of the changes in the discharge summary:</p> <p>Patients can call support services directly, if the service provider does not follow up.</p>	<p>Nominated MDT member (or ward staff member) proactively calls patients shortly after they get home, to check that they can manage, and to see if they have any questions.</p> <p>Patients can ask questions via the app (e.g. Smarthealth)</p>

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