Safer Prescribing and Dispensing of Medicines Consumer Research

Undertaken by Premium Research for Te Tāhū Hauora Health Quality & Safety Commission

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Executive Summary

Research Approach

- As part of the interagency programme of work to support safer prescribing and dispensing of medicines, Te Tāhū Hauora Health Quality & Safety Commission commissioned a research project to identify the medicine information needs of consumers and help health professionals better meet these consumer information needs.
- 56 consumers (and 2 support people) were interviewed via one-on-one interviews with Jude Varcoe (Premium Research). The sample had a wide range of respondents (in terms of medication experiences, health experiences and demographics).
- Overall, 27% of respondents said their medication information needs tend to be met well, 13% said they only received a limited amount of information, 38% said their experiences of receiving medication information was mixed and 23% said their experiences were poor.
  - Under-represented in ‘good’: European, respondents with mental health conditions, respondents with disabilities
  - Over-represented in ‘poor’: Auckland residents, women and respondents aged 40-59 years

Primary Information Needs (as identified by consumers)

Rationale	Options	Side effects	Interactions	Longevity	Administration
Why is this medication recommended?	The pros and cons of taking the medication	What are the potential side effects?	How this medication interacts with my other medications	How long will the medicine take to start working?	How much should I take?
How will this medication help my condition?	Why this medication works better than other options	How vulnerable am I to the side effects?	How this medication interacts with supplements/non-prescribed drugs	How long will the medicine work for me (will I plateau?)	How often should I take it?
Can the medicine cure my condition?	Is this medication really required?	Common and less common side effects	How this medication interacts with my other conditions	How long should I expect to be on the medicine for?	When should I take it (frequency and time of day)?
Why is this medication right for **me**?		Which side effects I should monitor for (and which ones can I disregard)	How this medication would interact with pregnancy	When will the medicine be reviewed?	What should I take with the medicine? (including food, drink and supplements)
How does this medication work?		When/where to seek help		What are the long-term effects of taking the medicine?	What should I avoid taking with the medicine?
Full disclosure with brand changes/supply issues				What would happen if I stopped taking the medicine?	How should I use devices for administering the medicine to the best effect?
				Is it a difficult medicine to stop taking (withdrawal)?	Consequences of missing a dose and what to do
				How best to come off the medicine	

The ideal approach to information dissemination would…

(as identified by consumers)

- Allow access to sufficient consult time
- Allow for informed choice/conversation
- Tailor format to consumer needs
  - Include written
  - Make the written information brief and jargon free
  - Combine modes (verbal and written)
  - Make use of email
  - Provide direction to credible websites (*“I’m going to google, so direct me to trustworthy sources.”*)

> *“Make sure that you are telling the full information to the person sitting opposite you so they can have informed consent and informed choice… only person who will be able to know what the right decision is, is the person sitting opposite the healthcare professional, because they're the one living their life, so they know what they can handle or not, but without having the full information, informed consent and informed choice cannot occur and it can have devastating results.”*

Information That Tends to be Missing

(as identified by consumers)

Side effects (the most common omission)	How the medicine works	Interactions	Administration	Timeframes
What the possible side effects are	What I should expect from the medicine and why	Interactions with my other medicines	Time of the day I should take the medicine	How long will I need to take the medicine?
What I should do if I experience side effects	What would happen if I didn’t take it	Interactions with non-prescribed drugs (legal and not)	Food and drinks that might interfere with the medicines	Will I need to take this for the rest of my life?
	What would stopping the medicine be like?	Interactions with my other conditions	Supplements I might require	What are the long-term impacts of the medicine if I do need to take it for a long time?
	What I need to be aware of if I stop taking the medicine	Interactions with pregnancy	What to do if I forget to take the medicine	When will the medicine be reviewed?
	Why the medication works as part of the suite of medications I am taking			

Cohorts

- Respondents were placed in the following cohorts (on the basis of their recent experiences) and were asked questions specific to the cohort

Respondent Category	# of respondents
CB: Change of brand	5
CBM: Change of brand for medication that required monitoring	4
CD Change of brand for medicine that has a different device to deliver the medicine	4
CT: Change of type of medication, but to treat the same condition	9
CS: Supply issue with a medicine	9
SM: Starting a medicine	9
SMM: Starting a medication that required monitoring	4
PC: Pregnancy – would consider becoming pregnant in the future and I am taking regularly prescribed medicines	8
PP: Pregnancy – have been pregnant in the past and either stopped or didn't stop taking my regular medicine	4

Pregnancy Cohort

Experience

- The responses were inconsistent. Ranging from no recall of having been told about how regular prescribed medicine could affect them or their baby if they became pregnant, through to comprehensive information provided.
- *Interviewer: Can you please tell me about any experiences you've had of being told about how regular prescribed medicine could affect you or your baby if you became pregnant?*
  Respondent: No, I haven't had any conversations like that.
  Interviewer: Do you recall when you've been prescribed medicine ever being asked, are you considering becoming pregnant? Do you recall if you've ever been asked that?
  Respondent: No, I don't think so.
  Interviewer: Have you ever been advised when you've been prescribed a medicine that you must stop it if you did become pregnant?
  Respondent: No.
- For some consumers, the lack of information had had serious consequences for their babies.
- Those who had been provided with information were largely satisfied with the way the information was provided. The information was provided by a range of professionals, primarily GPs, specialists and midwives. The information was mostly provided verbally. There was a mix of consumers proactively being offered information and consumers seeking the information out themselves.
- Consumers said if they wanted further information, they would primarily seek this from medical professionals (this is in contrast to responses about where people would seek more information about medications from – this was primarily 'Dr Google').

Ideal

- There was some inconsistency in terms of 'who' should be having the conversation with the consumer. Some preferring specialists, some GPs and some fertility experts. Good communication between the medical professionals was identified as an important part of informing the consumer and making good decisions for the consumer and their baby.
- The point in time the information should be shared was generally both at the point of prescription **and** at regular review points (recognising the changing stages of life experienced by the consumer while taking a long term medication). The information should be shared proactively.
- The primary content sought was the impact of the medicine on the foetus or person carrying the baby. The medication options and how to manage any medicine transition (stopping or changing) and associated impacts. Informed choice/consent was considered critical, as typically the consumer is needing to make a careful choice about which strategy they are most comfortable with, in terms of risks and benefits to themselves and their baby.
- Consumers were largely comfortable with a direct and proactive approach to asking them about whether they were sexually active and would consider having a baby.
- The information was sought in a combination of verbal and written format, from medical professionals. Accessibility was also raised, with some call for electronic format, including video.

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Starting a Medication Cohort

Experience

The key issues consumers raised in terms of their experiences of receiving information around a new medicine were:

- Limited/generic information provided and/or missing information
- Difficulty getting full and/or follow up information from specialists
- Information format issues (verbal and hard to recall, and/or inaccessible).

Ideal

The key suggestions consumers made in terms of the ideal experiences for receiving information around a new medicine were:

- Content related (sufficient for informed choice, rationale for prescription recommendation, what to expect and when, how long the medication will be needed, how best to administer the medication, side effects to monitor for, impact of not taking the medicine)
- Format related (include brief written material, ensure accessibility – email is best for blind people)
- Role related (role of the prescriber in informing the consumer is paramount, pharmacist also has a pivotal role for some).

Starting a Medication Requiring Monitoring Cohort

Experience

- 2 of the respondents received information about the new medication (requiring monitoring) while in a hospital setting. Both acknowledged that their medical conditions at the time made it difficult for them to take on board new information.
    - Both had some uncertainties about what information they had been given. In both instances there were negative consequences experienced after commencing the medication that were contributed to by the consumer not fully understanding the medication.
    - One relied on subsequent interactions with other medical professionals to provide a fuller understanding of the medication (both GP and pharmacist).
    - Neither had a good understanding of the need for and purpose of monitoring at the time of prescription.
- The two other respondents that were prescribed the medicine requiring monitoring by their GP had a limited understanding of the need for monitoring.

Ideal

- The respondents had mixed views on the ideal way of being informed about their new medication requiring monitoring. Suggestions included:
    - Their GP providing the detailed information, in writing
    - The hospital doctor being fully informed on the medication and able to give the full information to the consumer
    - Their GP giving fuller information on the rationale for monitoring
    - Their GP continuing to ensure the patient receives relevant information if their life circumstances change.
    - Providing upfront information about how long the consumer will need the medication for.

Change of Medication for the Same Condition Cohort

Experience

- Some consumers said the prescribing consultations felt very rushed/pressured and there was insufficient opportunity to get the information they needed.
- Some consumers had received very little, or no, information about the change in type of medication. The most common missing information was about side effects.
- Some consumers said they were well informed about their medication change.
- Some consumers had experienced mistakes in their prescription – which had impacted on their trust of the medical professional.
- Some consumers used 'google' to fill the information gaps. Some expressed interest in being guided on which websites would provide them with the most accurate information. Some noted that searching online had made them anxious about the medication.
- Some consumers had had experiences with medical professionals that were unfriendly.

Ideal

- Whakawhanaungatanga to ensure an open and trusting relationship between the prescriber and the consumer is sought by consumers. Within the context of an established relationship, consumers want to be given sufficient time and an appropriate atmosphere for an informed discussion about the medication.
- Some consumers want an opportunity to prepare for a discussion about a change in medication and would like their medical professional to also be well prepared. This included making sure medical professionals prepare well so they don't make prescription errors.
- Many of the consumers wanted to read more information after the consultation, in the format of email, paper and/or an online portal. The information sought is concise, clear and jargon free.
- Consumers want to be informed about the rationale for the change in medication, potential side effects and medication interactions. This includes when medication is prescribed by a specialist. Consumers also want medical professionals to communicate between themselves, so all relevant professionals are kept up to date on the consumers medication profile.

Change of Medication Brand Cohort

Experience

- Some respondents found out about the brand change when the medicine was dispensed to them, others from patient groups and others from prescribers. Those who had prior knowledge (pre-dispensing) about the change were more comfortable with the change.
- There was a mixed experience, with some saying they were sufficiently informed about the change in brand and others saying the communication was very limited.
- The strongest concern about brand change came from those who said they had experienced unexpected negative consequences as a result of the change in brand.

Ideal

- Consumers want proactive and upfront communication about any potential impact of the brand change.
- Consumers want full and accurate communication about brand change (*don't say it is the same if it is not).*
- Consumers want communication from the prescriber and the dispenser.
- Consumers do not want to be 'surprised' by brand changes (e.g. finding out after opening the box).

Change of Brand for Medication Requiring Monitoring Cohort

Experience

- Consumers had mixed of experiences of being advised of a change in brand of a medication requiring monitoring. One respondent had received a thorough explanation of the change from a specialist. The other respondents had found about the change when they picked up medicine from their pharmacist and were told little other than that medication would work the same as their previous brand had.

- There was frustration about the lack of communication about the change and one of the consumers attributed the brand change to serious consequences for their health.

- Consumers also had mixed experiences with information about the actual monitoring. Most of the consumers had some long-term experience with monitoring so learning about monitoring wasn't key to the change in brand. One respondent was new to monitoring and didn't understand the importance of regular monitoring, which resulted in a serious consequence for their health.

Ideal

- The primary change sought by consumers was having a consultation with the prescriber about the change of medication, rather than it being left to the point of dispensing.

- There was also interest in receiving information about how the medication is funded.

- One respondent also suggested providing consumers with a schedule to help them manage their monitoring requirements.

Supply Issue with a Medicine

Experience

- Experiencing supply issues with a medicine was a disempowering experience for most consumers. Most consumers were informed about the supply issue at the pharmacy and felt they had no choice but to accept the absence of medication or a replacement medication.
- Most were given very little information about the change of medication and any possible impacts.
- The supply issue had serious health consequences for one of the consumers.

Ideal

- Consumers want to be informed about supply changes in a timely manner, so they have the opportunity to seek information about the change and make an informed decision about their choice of replacement medication/treatment and arrange a replacement medication.

Change of Medicine that has a Different Device to Deliver the Medicine

Experience

- Overall, the experience of receiving information around a medication requiring a change in device were positive.
- Most respondents perceived they had been given the information they needed including sufficient guidance about how to use the device.
- There was one exception, with one respondent saying the medical professionals had assumed she knew how to use the device, when she didn't, and that this had had serious health consequences.

Ideal

- Most respondents were satisfied with their experience of receiving information around a medication requiring a change in device and didn't seek change in the approach.
- One respondent wanted the prescriber and dispenser to change their approach by giving direction about how to use the device effectively.

Support and Tracking

Support People

- Respondents were asked how they would like information about their medication to be provided to their personal support people.
- Most respondents said they personally wanted to take responsibility for relaying information to their support people. Many said that if they were to pass information on to their support people they would prefer to have the information in simple written form – to help avoid passing on incorrect information.
- A few respondents said they wanted/needed to have their personal support people involved in consultations and/or provided with information directly by the medical professionals involved. This tended to be older people, consumers in hospital settings and consumers with mental health conditions.
- We briefly interviewed two support people about their information needs as support people. Both support people felt they were appropriately informed (and didn't seek change in the approach to informing them), though one did note he needed to be proactive about seeking the information.

Tracking

- Many respondents said they had experiences tracking the impact of a medication on them. Some said they did so on paper, some using 'notes' on their phone and some memorised them.
- Some said they would be interested in having an app available for recording this type of information. This was generally the younger and more technologically savvy respondents.

Information Across Settings

There were noticeable differences in the expectations of consumers, depending on the setting they were in

Setting	Insights
GP	This is where consumers have the highest expectation of having an established relationship which allows an informed and holistic discussion about medication - that enables the consumer to make an informed decision. This includes taking into account consumer life stage (e.g. has pregnancy now become relevant?). Sometimes this expectation was met.
Hospital setting (mostly inpatient)	This is the setting where consumers feel the most vulnerable and are most likely to want to have a support person with them and to receive the information in writing. They also want expedient exchange of information about medication between medical professionals. Consumers receiving information about medication in a hospital setting often felt their information needs were not met (or if they were, they couldn't recall) or were not passed on expediently to their GP.
Specialist (mostly outpatient)	Experiences with receiving information about medication from Specialists was disappointing for many. Consumers often felt disempowered, hurried and unable to seek further clarification. There was also perceived to be a lack of good information flow between Specialists and GPs.
Repeat prescription online/phone	Consumers did not expect to be provided with information when ordering repeat prescriptions. But, some did note this was a missed opportunity to communicate about any changes in medication, new medication available and review the impact of medication.
Clinics	Some consumers spoke about the nurses/technicians working with them in clinics as being their most trusted source of information about medication.
Pharmacy	There were mixed views on the role of pharmacists in disseminating information about medication. Some consumers relied heavily on their pharmacist to inform them, others had little or no expectation of their pharmacists. Experiences with pharmacists (largely positive) featured heavily in the research, pharmacists clearly play a very important role as an information conjoint and safety-check for some consumers.

Advice to Medical Professionals

- Respondents were asked what advice they would give to medical professionals about how to inform consumers when prescribing/dispensing medicine The key themes were in the areas of:
  - Being upfront about the purpose of medication, possible interactions, side effects, what to look out for and longevity of medicine use
  - Engaging, listening, understanding, checking in and allowing informed choice
  - Building relationships, giving consumers time, giving consumers reviews/reminders
  - Being respectful to consumers
  - Tailoring format, language, presentation and accessibility to meet the needs of the consumer
  - Providing a Kaupapa Māori approach, being culturally aware and mindful of language choice
  - Improving communication between medical professionals
  - Enabling pharmacist safety checks.

Implications and Opportunities

- Consumers want medical professionals to build relationships with them, to give consumers time to engage, consumers want to be respected, heard, understood and empowered.

- Consumers want to have informed choice in their medications. They want to understand the rationale for the medication recommended. Consumers want to understand the pros and cons of the medication and they want to feel empowered to contribute to the decisions about the medication they are prescribed.

- Consumers want easier access to health professionals, so they have timely access to appointments and sufficient time within the consultations to make an informed decision about their medication.

- Consumers want to be provided with clarity about: the purpose of the medication, any possible side effects, interactions with other drugs (prescribed and not), how to use the medication (e.g. dosage, timing and foods to avoid) and the timeframe for the medication (e.g. how long they will need to use the medication for and when reviews will happen). There are exceptions to this, with a few mental health consumers saying anything other than a small amount of information can increase their anxiety about a medication.

- Consumers tend to want more thorough information about long term medications than they do for short term medications.

Implications and Opportunities cont.

- Consumers want information about medications to be tailored to meet their needs, in terms of format, presentation and accessibility. In particular, as well as verbal information, most consumers want brief written information, in simple language made available to them (and in electronic format to aid accessibility).

- Consumers do avidly ‘google’ for more information about medicines. Consumers suggested that this could be guided by providing links to trustworthy websites (though these links in isolation are not sufficient information).

- Consumers want to see a joined-up approach to informing them about medication. They want the information to be consistent and comprehensive across and between different parts of the sector (e.g. hospital registrar, external specialist, GP and pharmacist).

- Some consumers want medical professionals to demonstrate cultural competency, including providing a Kaupapa Māori approach, being culturally aware and mindful of their language choice.

- Some consumers want pharmacists to provide detailed information about medications. Including how to take the medication and possible side effects. Some consumers also expect pharmacists to maintain an overview of their medication and the ability to determine if any errors have been made at the point of prescription. It was clear that the strong relationships some consumers had with their pharmacists greatly enhanced their experience of receiving information.

Implications and Opportunities cont.

- Consumers want any changes in medication (e.g. supply issues, brand change so on) to be communicated proactively and with comprehensive information (as sought for new medications). Consumers do not want to feel cornered into accepting a change in medication when they collect their prescription.

- Some consumers identified patient support groups as being a viable and credible source of information about medication changes.

- Consumers want to be proactively and comprehensively informed about the implications of the medication for the consumer and baby in pregnancy. They want this to be proactively provided both at the point of prescription and throughout the lifecycle of the consumer (e.g. pregnancy may not be relevant at the time of initial prescription but may become so later).

Introduction

Background

- As part of the interagency programme of work to support safer prescribing and dispensing of medicines, Te Tāhū Hauora Health Quality & Safety Commission contracted a research project to identify the medicine information needs of consumers and help health professionals better meet these consumer information needs.
- This project aim is to undertake consumer research to understand the medicine information needs of consumers.
- We are specifically seeking to understand:
  - what information people want
  - how they want to get it
  - who they want to hear it from.
- The areas of focus are when consumers:
  - are first prescribed a medicine for regular use
  - have a change in regularly prescribed medication
  - potentially need to stop a regularly prescribed medicine during pregnancy.
- The purpose of this research to help health professionals better meet these consumer information needs and feed into the wider workstream activity.

Approach

- The research approach was qualitative.
- 56 consumers (and 2 support people) were interviewed via one-on-one interviews with Jude Varcoe (Premium Research).
- We allowed 45 minutes for each interview (some were longer and some shorter).
- The interviews were undertaken using either Zoom or phone (respondents' choice).
- All interviews were recorded and transcribed for analysis purposes.
- Respondents were recruited through the Commission’s Partners in Care team | He Hoa Tiaki an Expression of Interest (EOI) was released via the national Consumer Health Forum Aotearoa, the Consumer Advisor Group | Te Kāhui Mahi Ngātahi and the Consumer Network | Kōtuinga Kiritaki.
- A total of 159 EOIs were received, and a review process was undertaken in terms of scope of the project and eligibility. Following the review process 60 applicants were selected for interviewing representing a diverse group of consumers and 56 interviews were undertaken (4 selected participants were subsequently unable to proceed with the interviews). Two support people were also included.
- We appreciate the time and effort the consumers gave to participate, and for sharing their lived experiences.
- Details of the consumer sample profile follow.

Consumer Sample

Respondent Category	# of respondents
CB: Change of brand	5
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CT: Change of type of medication, but to treat the same condition	9
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Consumer Sample Profile

Age	
20-29	7
30-39	13
40-49	10
50-59	17
60-69	5
70-79	3
80+	1

Health condition includes:	
Disability	23
Mental Health	22

Gender	
Woman	37
Man	16
Non-binary	1
Takatāpui	1
Rather not say	0
DNR	1

Ethnicity (multiple response)	
European	33
Māori	18
Pacific peoples	10
Asian	3
Middle Eastern	0
Latin American	0
African	0
Other	6

Region	
Auckland	16
Bay of Plenty	3
Canterbury	7
East coast	2
Hawkes Bay	4
Nelson/ Marlborough	1
Northland	1
Otago	6
Southland	1
Taranaki	2
Tasman	1
Waikato	1
Wellington	9
West Coast	2

Overarching Information Needs

Overall

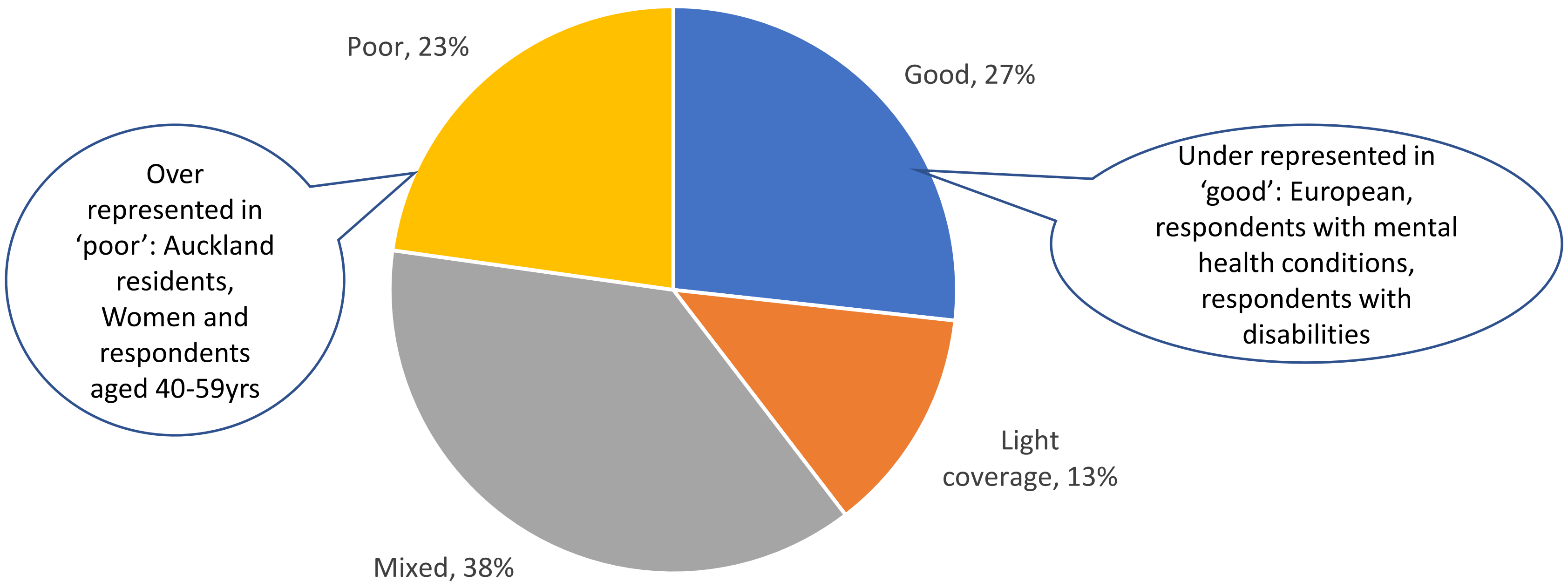
When health professionals prescribe medicines, they give their clients some information about the medicine. We want to learn about your experiences of receiving this type of information and how it could be improved. Thinking back to when you have been prescribed medicines…..

Overall, how well has the information you have been given met your needs?

How well has the information met your needs?

Respondents have been grouped into segments according to their top-of-mind responses to this qualitative question.

- Those in the 'good' segment (27%) were satisfied overall with how well their information needs had been met.
- Those in the 'light coverage' segment (13%) felt they had been given limited information but didn't express a strong opinion about this.
- Those in the 'mixed' group (38%) had had both positive and negative experiences.
- Those in the 'poor' segment (23%) said their information needs had not been well met.



Over represented in 'poor': Auckland residents, Women and respondents aged 40-59yrs

Under represented in 'good': European, respondents with mental health conditions, respondents with disabilities

See appendix for a more detailed demographic segment profile.

How well has the information met your needs?

Segment	Themes
Good	Strong relationship with GP I am capable at ensuring I am informed No surprises – was as I expected it
Light	Not given a lot of information proactively given and didn’t tend to seek more.
Mixed	Information was missing Inconsistency of experiences, depending on the medical professional involved Experience of adverse effects from medication
Poor	Information was missing Communication was lacking

Overall themes and quotes

- The overall themes in response to ‘how well has the information met your needs’ and associated quotes are outlined in the following slides:
  - Positive experiences
  - Transactional experiences
  - Mixed experiences
  - Missing information experiences
  - Adverse effects experience
  - Poor communication experiences
  - Other poor experiences

Positive experiences

Themes	Quotes
Strong relationship with GP	*I've been really impressed. I've been lucky to be able to have continuity with my own GP and that's been important. I think that's really important because if people are seen by several different health professionals when they have to be on medication, it can be overwhelming.* *I'm really trustworthy of our doctor. The doctor that we have, has been [with us] since we've started having children.* *For me, it comes down to the doctor and in the last three years, I've found a [good] doctor. He will tell me about the side effects, what the medication's prescribed for and all my medical stuff. He seems to know what he's talking about.* *It's been really good. I do have a doctor who's extremely good in talking and discussing things with you……He's a really good genuine doctor, one of the best. We're lucky, I think. Some of them clock watch, but he's not a clock watcher.* *I actually got prescribed a medicine yesterday and the doctor had been amazing. They called the pharmacist, checked for interactions, knew what the side effects were. Called me, told me all the side effects, told me to go to the pharmacy to talk to the pharmacist who knew what was going on. That was incredible because I know what I'm expecting, what it is, what it does, which blew my mind, and it shouldn't have blown my mind because that should be what happens.* *When they gave me the information, he explained what it was supposed to do. He showed me a diagram of the heart and exactly what my problem was to do with my condition and said, 'Well, this medication is going to dilate the pulmonary artery so that blood flow will go through it and these are the side effects. These are the pros and cons and we'll review it in x amount of time to see if we need to increase the dose.'* *Then, my GP, well, she's great. I can ask her anything. She'll just tell me straight.*
I am capable at ensuring I am informed	*Very well, I think, but I feel like I'm quite, how do I say, I'm quite onto it anyway, in terms of taking that information in.* *So, it has met my need because I understand and I have the ability to go and research and look up to make sure and to double check, but I can also see how it can't meet the need of people, if that makes sense.*
No surprises	*Yeah, pretty good. What the doctor has told me has actually happened as far as what the medicine was going to do for me. There's nothing surprising that's happened, so I've been quite well informed.*

Transactional experiences

Themes	Quotes
Light information	*I haven't really been given much information in terms of when I get prescribed medication.* *I guess not a huge amount unless I ask about the side effects.* *Okay, I would probably say minimum information has been given verbally.* *I think initially when the doctor prescribes medication, there's not really much information and depending on the pharmacists that we get, we might get more information, but maybe not any information.* *At my age, I listen to what the doctor says and you take other medication and it's only a problem when I start forgetting what one does and then I try to get the doctor to give me a review and explain what one does.*

Mixed experiences

Themes	Quotes
Different experiences from different medical professionals	*I'd say it's like for my general everyday GP that I usually go to, I would say generally the information is very good, very helpful, but on the occasions I've had to go to, say, the after-hours clinic or something, obviously they're extremely busy, the information tends to be a bit more lacklustre, to say it nicely….. I appreciate that they're really busy and they don't have the time to answer every single question, but yeah, a couple of months ago I ended up going to the after-hours clinic for something and the doctor and everyone was nice, but I just found the instructions for the medication were just sort of given to me verbally. And I'm like in the middle of a medical thing and I'm not going to remember that. So it was kind of pointless to tell me. I would've preferred if they wrote it down. That would've been a lot easier.* *If I start with general practice, very poor. The specialists, the oncologist and the eye specialist, outstanding, and the pharmacist really outstanding.* *I find the response from the prescribers has been quite varied. Sorry to say this, but I find GPs the least informed about prescriptions. Mostly, they go to their bible and check it out, what they're doing and how it would fit, whether it would be part of the family. Then, the hospital, when being released or discharged from hospital and you get your prescription list, they're not totally well informed, so a bit disappointed there, but I have had an excellent response from the pharmacists and they appear to be right up to date.* *I'd say it's been mixed bag, really. Often in my case, I've not been given details of the kind of impacts it could have, like side effects and what it's supposed to do.* *Inconsistent would be how I put it. The information sheet that is supposed to accompany medicines has been probably 50/50.*

Missing information experiences

Themes	Quotes
Missing information	*There's…..been times where I've started a medication and it's given me a side effect that was really scary. I hadn't been warned at all that it could be a side effect and I only find out as I start Googling, trying to find out what is happening to me... I'm just not warned by my doctors or my pharmacists that I should expect that or what to do if it happens.* *The other one I wanted to mention was a lack of advice and information when you are coming off a medication. There was a particular medication that we had to take me off faster than I think would've been ideal cos I had side effects and reactions to it that mentally needed to get me off it. My doctor just said that it would be a bit rough and to go down in small increments that she had figured out might be safe. I told the pharmacist I was coming down and they just agreed to go down in those increments and they said nothing else about it. It wasn't until I was halfway through the withdrawals for it that I found out that the drug I was on was notorious for causing horrific withdrawal symptoms, even if you stepped down incrementally. There was a lot of advice online, but in specific support groups, like a Reddit group specifically for coming off that medication saying that these are things you can do to try and ease it. This is what you're feeling. This is when to get worried, but none of the official information I could find really talked about it at all. It only ever said, 'Talk to your doctor before coming off this medication,' and nothing further. I think if I had been warned or I had seen anything about how difficult it was to get off that drug before I started it, I wouldn't have taken it.* *So, I was just going to say, it was a couple years ago and it was a type of SSRI. I got prescribed, but when I asked about side effects I got told, 'I don't want to tell you because it'll put things in your head.' To me, I found that quite problematic because (a) I like to know what's going on like everyone else does, but (b) it's my body. I need to know what could potentially happen and if I'm going to get side effects, what those would be, so I found that really, really hard.* *Something I did not realise and nobody warned me about is that there are other things that you can eat or drink or do that have the same effect on medicine as grapefruit does. There's actually other citrus fruits that have the same effect. I had no idea that things like CBD oil could also have that effect with medicine, which of course, nobody thought to warn me about because they don't tend to warn you about if you take this and you take this currently illegal thing with it, it could cause real problems for you.*

Missing information experiences

Themes	Quotes
Missing information cont.	*When they've made changes in my medication, they don't tell me any side effects or anything like that. I just have to take it and see what happens and then next time I come into contact with them, I'm just meant to say how I feel about the medication and whether or not it's working. [sectioned prescriptions]* *…..when I was prescribed different antidepressants, a lot of those risks or a lot of what was going to happen weren't fully explained. One of my experiences was with xxx, I had a lot of night terrors and sleep paralysis, which wasn't talked about….. They just give you the general idea of this is what it does, without going into too much detail, so you have to go home and Google things.* *I have been given medications and I've been given information sheets about them, but I feel that there hasn't been a lot of follow-up, or I guess consideration of other medications or supplements and things that I might be taking, and how they might interact with those things. What has also made that a little bit more awkward is that I feel like I have not had a consistent GP for the last several years because they keep leaving, so you don't get that consistency of understanding of my health, I don't think.* *Information he gave was extremely poor. Never explained how xxx works, what it does, anything like that. It was, 'Take this twice a day, once in the morning, once at night and it will improve your diabetes.'*

Missing information experiences

Themes	Quotes
Missing information cont.	*The other thing about it is, it's a tiny, tiny little white tablet and she said, 'You only need half of it each day.' So cutting these things in half is just crazy. They crumble into little pieces, and so I end up not even really knowing if I'm taking the right dose or not. I've probably been on it about six months now and I still don't know if it's working or not, because it's so hard to get appointments here that I haven't even had a blood-pressure check since I've been on it, so I'm just taking it and hoping for the best.* *Your GP gives you some information. Honestly, not much from the GP, usually, 'You have this condition, let's try this medicine, we'll try this dosage,' and nothing more than that. The rest of the information that I do pick up is from the pharmacy when they're prescribing it to me, which is usually just explaining things like when and how to take the medicine and again nothing really more than that, which means that I'm missing a lot of information about side effects or in general, what it should feel like when I'm taking the medicine, how to tell if it's working or if it's not working or if we need to change dosage. I'm also not really getting any information on things like interactions and…….especially things like what it would be like to come off the medicine.* *That's been a fairly common theme for just about all of the anti-anticonvulsants. Most of the time it's come through a specialist, but they don't give you any of these possible what could happen. Then, the one that I've been on for years, it wasn't until, as I say, I've been on it five years, that I find out that I should be drinking more water, because it can cause kidney stones… it is something I've noticed throughout the whole time, with the epilepsy ones in particular, they don't give information. They're trying to get to a point where your seizures are under control and, 'Okay, try that one.'* *Okay, no, I don't think highly of the GPs that I deal with, especially in the form of information about your medicines. They're pretty good at telling you to Google it, the ones up here. Google it is what you get told. You ask about side effects. They can't tell you so they're Googling it themselves... it'd make a big difference too if your doctors would explain a lot to you, but when they say to you, 'Google it', just goes to tell you, yeah, you're a number or a dollar sign. It's quite sad. You don't often come across a really genuine doctor that'll actually sit there and take the time out to actually explain stuff to you.* *How long you should actually be on it for, because some of us get put on medication and we're stuck on it for 20, 30, 40 years. There's got to be some long-term effect or at the end of the day, your body has got to get so used to that medication that it's not working anymore.* *They know to check drug interactions, but they don't know to check for seizure interaction.*

Missing information experiences

Themes	Quotes
Missing information	*I was prescribed a whole load of medication, some of them you will be familiar with not even being a doctor, so xx, xx, xx, xx, xx, xx and xx. I was given no information on any side effects they may have, no awareness around how serious those medications are in terms of they're quite strong…….All I was told was, 'It's going to help with the pain and don't stop taking it until the end of all of your prescriptions……I found that actually the side effects three of those medications they had me on were really quite serious and I had to stop everything. It's impacted on me, not only physically, but mentally. …. the impact it's had on me mentally is that I'm totally (excuse my language) shit scared of taking medication now. Whenever a doctor prescribes me something, I'm like, 'I don't wanna take it.' In terms of the information I was given, it was zero to none other than it will help with pain.* *From the GP, I got no information. There was no information given or anything. It was, 'This is going to help your back pain. It's for nerve damage.' That's the most I got.* *My first AED, which I was on for 10 years, I only found out that that makes you vitamin deficient after I'd been using it for 10 years and the neurologist said, 'You're on a really high dose. You need to be taking Vitamin D.' I was wondering why my teeth were like — I was going into the dentist and getting five fillings a year and I was like I'm looking after my teeth really good. That kind of thing I wish I'd been told when I very, very first got prescribed, even just to take a multi-vitamin to keep all the side effects not at bay.* *If I think of the two new medications that were introduced, one of them to this day, I don't know any of the side effects, because I haven't been given that information by the specialist who prescribed it or the healthcare professional.* *She [GP] didn't actually go into any of the side effects. I actually said to her, 'What are the side effects from taking this medication?' She glazed over and gave a few little things here and there, but it was very much a glaze.*

Missing information experiences

Themes	Quotes
Missing information	*That's been a fairly common theme for just about all of the anti-anticonvulsants. Most of the time it's come through a specialist, but they don't give you any of these possible what could happen. Then, the one that I've been on for years, it wasn't until, as I say, I've been on it five years, that I find out that I should be drinking more water, because it can cause kidney stones… it is something I've noticed throughout the whole time, with the epilepsy ones in particular, they don't give information. They're trying to get to a point where your seizures are under control and, 'Okay, try that one.'* *Okay, no, I don't think highly of the GPs that I deal with, especially in the form of information about your medicines. They're pretty good at telling you to Google it, the ones up here. Google it is what you get told. You ask about side effects. They can't tell you so they're Googling it themselves... it'd make a big difference too if your doctors would explain a lot to you, but when they say to you, 'Google it', just goes to tell you, yeah, you're a number or a dollar sign. It's quite sad. You don't often come across a really genuine doctor that'll actually sit there and take the time out to actually explain stuff to you.* *How long you should actually be on it for, because some of us get put on medication and we're stuck on it for 20, 30, 40 years. There's got to be some long-term effect or at the end of the day, your body has got to get so used to that medication that it's not working anymore.* *They know to check drug interactions, but they don't know to check for seizure interaction.*

Adverse effects experiences

Themes	Quotes
Adverse effects	*I've had an issue in a hospital once when I was given xxx, which I should have never, ever been given with epilepsy. They didn't mention it to me at all. I didn't find out until I was passed out on the toilet seat, because I'd been upright for a few too many seconds and passed out. From that, I was like, I definitely need to advocate for myself and actually ask the question to my doctor and to my pharmacist and say, 'Can you double check that this isn't going to contradict with these medications?' It would be probably quite helpful to be able to do some of that myself, but [I] shouldn't have to do it as well.* *'Oh, that one's been just ...' I can't remember if it was discontinued or Pharmac wasn't funding it anymore, '... and so now you're going to be on this one called xx,' and I think it's called xx. She said, 'Just swap it over and it'll pretty much be exactly the same, so don't worry about it.' But yeah, straight away the side effect that I got from the old one came back and they'd say, 'Oh, that's a shame.' Didn't know that was going to happen.* *When I had my first stroke, which was about 14 years ago, I remember going to the hospital. The medication they gave me, they probably told me what it was for, but I couldn't remember, but I do remember that it was quite a substantial amount that I had to take. It made me worse than what I felt actually. I stopped taking it and then I went to see my GP and she wanted to know why did I stop taking it? I told her that it made me feel like I was going a bit mental. …… You know when you come out of the hospital, they give you that form?......She [GP] asked me if I had that form and I did. I gave it to her and she asked me, why did I stop taking this particular drug? I told her what it was making me do. I was bumping into things. I had the shakes. It made me feel horrible. She had to look at the dosage and the dosage was quite high. I remember her saying to me, 'This dosage they've given you, they wouldn't even give it to a horse.'*

Poor communication experiences

Themes	Quotes
Communication (with consumer and between medical professionals)	*If I think of the brand switches I've had, and this has just occurred this year, it wasn't until I got the medication home, opened it up and was putting it into — I've got a pill dispensing container and I noticed that two of my medications had changed. One had totally changed in colour and shape and everything and the other one had totally different branding and everything. It's like, hang on, something's not right here. ……I went to the pharmacy and I said to the pharmacist, 'I've got two brand changes here and I'm actually sensitive to brand changes. It would've been nice to know about this earlier'.* *My GP liaised with the specialist who'd put me on it, and she said, 'Oh yeah, come off it.' There was no warning about how to do it. There was no guidance about how to do it in a way that was safe. It was just, my GP had to think on the fly about how to do it. She [specialist] saw me for all of maybe five minutes, if that, and then put me on this stuff, but she didn't have to put up with the after effects or how it was to come off it. I got no information about how to take it, I got no information about what the side effects might have been, and then she just went on her merry way.* *My neurologist will prescribe one thing, and then it goes back [to my GP]. I only see her [specialist] once every three months, but I see my GP every month and they don't seem to talk to each other about how that works. My GP will say, 'Well, I don't think that's a great drug,' and she'll change it to another one. Then, when I go back and see my neurologist, she'll say, 'Oh, why are you off this one now?' I've got to explain to the neurologist what the GP has done, and I might get it wrong. I think there's lack of communication sometimes between specialists. Well, the whole health continuum of care thing, I don't think they communicate well…. I think the biggest issue is Peter doesn't know what Paul's doing, and when you throw in Mary it's all over the show.* *……. It resulted in having too low blood pressure because the left hand wasn't talking to the right hand. In fact, this was a triple hand and they all weren't talking. The family of prescribers and people looking after me, got a lot of time for them, great people, but they didn't really communicate to each other what was going on, so I had double of this and under of this and whatever.*

Poor communication experiences

Themes	Quotes
Communication	*I was in ED, this person just came in and said, ‘Okay, we're going to add this one,’ and then left again……. she didn't even tell me how to start to do it, she just did the prescription and left. It was only through knowing how I'd been on medication previously, that I needed to be around people, I needed to do it gradually. I went to my GP to say, ‘Well, how do I actually go onto it?’ Because, the specialist had just said, ‘start it.’ It was quite a high dose to begin with, and I usually need to go gradual and slow. I went on it and I got the side effect. Again, I found out afterwards. My mood just dropped really badly and I became suicidal.* *I think you're only given a 15 minute slot GP, which is even though I've got a serious psychiatric disorder, I still get my medication through the doctor, through a GP and you have this really narrow 15 minute window where you've got to outlay the issue. Then they come up with what they think should happen. There's just not enough time to really sit and ask the questions that you need to ask. And for me, every time I'm prescribed something, I'll accept the prescription, but then I have to go and do my own independent research on it afterwards to make a decision from a more informed perspective that it's something I actually wanted to take….. there's not really a focus on holistic offerings or talking to family about what else is going on or anything like that. It's sort of I've got a problem, solve it with a medication, blindly take this medication. If you don't do your own research, then you don't actually have a lot of, I know informed consent's not the right word, but you're not informed as well as you could be. I don't think that the process works as well as it could.* *Actually, the one that prescribed my medication when I was being discharged, was a trainee. The consultant couldn't come to see me. The staff couldn't come to see me cos they were just so overworked and it was just chaotic and she had the script in her hand.* *I get to hear once and then I have to process and memorise that whole lot of information. That one conversation and take away and apply it to my life with no reference material, crap……I don't know anybody that takes in absolutely everything all day, every day and is able to say it back out verbatim.*

Other poor experiences

Other	Quotes
Other (confidence in GPs, relationships with GPs, brand changes, disempowered consumers)	*I have no confidence in doctors whatsoever when it comes to that they will give me information about medication they're prescribing. I have zero confidence whatsoever. I do not trust them. I will not even rely on them to give me the information. I will find it out myself.* *I keep going through GPs like crazy because they keep leaving on me. Each time a new one comes along, they try and prescribe me something that interacts. I know it's usually a seizure contraindication, but they don't think about that, because it's an easy way out to prescribe something and then I've got to go through it all again. No, I can't take that. It just seems like it's so easy to not think about these things.* *It's the younger ones [pharmacists], which led me to really wonder about the training they've been getting. But they were just spouting the Pharmac line. Seriously, it's like they'd been brainwashed. They were direct in quoting the Pharmac line about, 'Oh, it's no different. xxx no different to xx. It's exactly the same drug.' All this crap. Meanwhile at least seven or eight of our peers died and hundreds got pretty bad reactions and things and the likes but they were actually beautifully towing [the] Pharmac line and saying there's no difference, there's no difference. Then, I had another one try the same stunt with one of my other anticonvulsive drugs. They gave me the wrong one. I complained and I got, 'It's no different. It's exactly the same drug.' He said that to the wrong person.* *Well, I don't think some doctors understand what continuum of care actually means around medicines, because to me, that's a key thing. If I'm on a drug that works, I would like to stay on it, but I don't necessarily get the choice to do that. I've been told by some doctors, 'Oh, you're not a health professional. You don't know what it's going to do.' I'm going, 'Well yeah, but I've got to take the stuff. I would think I would know what it's about.'* *I had to get a new doctor. The practices there, you ended up just having to go to whoever. You couldn't have the same doctor, so I ended up changing practices mainly just for price, but it was the same thing. You don't get that real one to one anymore. That's why I say average cos I've experienced what it's like when you can be confident and be able to tell your doctor versus now it's like almost you have to explain yourself every time.*

What we want to hear

- Themes (see the table that follows for more detail)
  - Rationale (for the prescription)
  - Choices
  - Side effects
  - Interactions
  - Longevity
  - Administration

Primary Information Needs (as identified by consumers)

Rationale	Options	Side effects	Interactions	Longevity	Administration
Why is this medication recommended?	The pros and cons of taking the medication	What are the potential side effects?	How this medication interacts with my other medications	How long will the medicine take to start working?	How much should I take?
How will this medication help my condition?	Why this medication works better than other options	How vulnerable am I to the side effects?	How this medication interacts with supplements/non-prescribed drugs	How long will the medicine work for me (will I plateau?)	How often should I take it?
Can the medicine cure my condition?	Is this medication really required?	Common and less common side effects	How this medication interacts with my other conditions	How long should I expect to be on the medicine for?	When should I take it (frequency and time of day)?
Why is this medication right for **me**?		Which side effects I should monitor for (and which ones can I disregard)	How this medication would interact with pregnancy	When will the medicine be reviewed?	What should I take with the medicine? (including food, drink and supplements)
How does this medication work?		When/where to seek help		What are the long-term effects of taking the medicine?	What should I avoid taking with the medicine?
Full disclosure with brand changes/supply issues				What would happen if I stopped taking the medicine?	How should I use devices for administering the medicine to the best effect?
				Is it a difficult medicine to stop taking (withdrawal)?	Consequences of missing a dose and what to do
				How best to come off the medicine	

Rationale and choices

- Why is this medication recommended?
- How will this medication help my condition?
- Can the medicine cure my condition?
- Why is this medication right for ME?
- How does this medication work?
- The pros and cons of taking the medication (risks, benefits and consequences of not taking it)
- Why this medication works better than other options (including non-medicine)
- Is this medication really required?
- Full disclosure with brand changes (not saying the medication is the ‘same’ as the previous one it there are any differences)

Rationale and choices

That it's effective and specific to the issue that I have.

That it's relevant to me, that it's absolutely required and they're not putting me on something that I don't need to be on…

Starting a medication or being on a long-term medication, is it really worth it? Is it going to improve your life?

Sometimes the doctor will talk to you about benefits or the risks, but generally not together usually because there's not enough time or because they're just rushing you out of there sort of angling for you to take something so that that's the box checked and off you go. I mean, I guess I feel like it's quite risky to not manage the process well within your appointment time, because then people go and do independent research and for people that have psychiatric disorders, often we are looking for ways to not take something or a reason to not take something. It's quite dangerous not to allocate that time, to talk about those risks and benefits.

Knowing me and my situation and tailoring it to say, ‘This is why I'm recommending it and why, and if you don't have it, this is what that means’.

Exactly the part that's in my body that's receiving this medication, why it needs it, what will it do for me.

I need to know that taking a medication as an absolute, there are absolutely no other alternatives. I need to know all my options. I want all my options laid out. I want to know this isn't a quick fix for them.

Being well informed cos knowledge is very powerful. Knowledge is key and you have to be well informed to know that this is going to work for you. It's like buying a product. You wanna know it's gonna work for you right, so that’s why having all the information or the key information laid out from the get-go is important.

Side Effects

What are the potential side effects?

How vulnerable am I to the side effects (my personal risk)?

Common and less common side effects (NB: some only want to know about the most common)

What side effects I should monitor for (and which ones can I disregard)

What is normal and when/where to seek help

Side Effects

What point do I need to make an appointment and come in and see you and what do I need to be watching out for as signs that this isn't working?

It would be nice to know what the possible side effects are and even then, if somebody has to reassure me that, what's going to happen is not too bad. Well, at least then I would know not to panic.

What kind of things to look out for and what kind of things are common and you don't need to worry about some side effects and which are the ones where you do actually need to pay attention and talk to someone about it.

Things to expect, things that are really normal, like if you get a side effect but it's like that's okay, that's normal and maybe that will go away in time. Things that I need to avoid if I'm taking it.

I really should know the precautions that I have to take if I cut myself, if I hurt myself. I had to find that out the hard way and that wasn't very nice for me. I found out later on, after I had been through this experience of a bleed out, that they really didn't have… what do you call it? They didn't really have a medicine to stop me from bleeding.

Are there any [side-effects] that are specifically more likely to target me because I'm on other medication or because I am Māori or any other demographics

I don't really like being given the frighteners with something that is a one in a million and they write it on there because they have to do the legal disclaimer thing. I mean, it is, it's hard because I guess if I was the one in a million I'd wish I'd be told, so it's really tricky. It's a big issue.

My doctor …..did not tell me that one of the major side effects is if you have muscle pain that you must stop taking it straight away and go onto the next generation because it's affecting the heart and because it's a muscle. I went for eight to 10 months with significant muscle pain, before I spoke to a third party and they said, 'What the hell?' Then, my medications got changed, so my history is of suspicion.

Interactions

- How this medication interacts with my other medications
- How this medication interacts with supplements/non-prescribed drugs
- How this medication interacts with my other conditions
- How this medication would interact with pregnancy

Interactions

Top of the list will be interactions with other medications I'm on.

Because I'm on several different types of medications, I feel like no one actually really knows what happens when you put all those together.

I can't take anything with penicillin and some sulphates, so making sure that it's a medication that I've either had before or one that's not gonna interact with any of my other medications. As my doctor says, I'm quite complicated.

This one has interactions with these drugs. You're not on any of them but make sure you don't take any of these ones, whether it's an elicit substance, like alcohol or drugs/drugs rather than medicines,' because I think they look at me and assume …. I won't do that sort of thing.

Like I said, if I was able to have a baby, I'd be wanting to know about pregnancy as well.

You can never assume whether people are sexually active or not, for example, so the potential consequences within that as well.

If because I'm on so many medications, I'd want to know do they interact with each other in a negative way and if they're forever drugs because taking another pill a day isn't too much, but it's still certainly something you gotta remember and keep on track of.

Longevity

- How long will the medicine take to start working?
- How long will the medicine work for me (will I plateau?)
- How long should I expect to be on the medicine for?
- When will the medicine be reviewed?
- What are the long-term effects of taking the medicine?
- What would happen if I stopped taking the medicine?
- Is it a difficult medicine to stop taking (withdrawal)?
- How best to come off the medicine

Longevity

The biggest one is what it's going to be like stopping or when you gonna stop it. I've never had a GP say, 'This is gonna be a lifelong medication,' or 'This is a medication that we're looking at starting for six months.' Even though they've probably been thinking, you never have that conversation.

The long-term effects really, if there's any chance of me being able to get off them in the long run, what effect that's gonna have on other parts of my body, if any, if there's any hope of actually coming off them and leading your life without prescription medication.

An important one for me is when will it be reviewed? Of course, that's not only given because I think they should be reviewed anyway because people's conditions change, but there's so many new medications now available, pharmaceuticals available, that they're perhaps some of the ones where people are prescribed some years ago are now out of date or not as effective as others.

They don't tell you these things when you start taking them that a few decades down the track, they're going to pack up the rest of your body.

I am curious to know what the long-term effects are of taking certain medication. That's something that doctors don't have really the time to say, 'Well, this could cause certain side effects if you take it for too long'.

There's a big difference between something short term like an antibiotic and something long term. There's massive difference.

Administration

- How much should I take?
- How often should I take it?
- When should I take it (frequency and time in the day)?
- What should I take with the medicine?
- What should I avoid taking with the medicine?
- How should I use devices for administering the medicine to the best effect (e.g. inhalers)?
- Consequences of missing a dose and what to do (should I take more later?)

Administration

What it reacts with, what you can take it with or not, frequency and what happens if you forget and what are the consequences of forgetting.

What happens if I stopped taking it and even if you run out and you are out for a few days, is that a big issue or not?

Is it the two pills in the morning together or is it one in morning, one at night-time and because they use the bi-daily or their shorthand sometimes, I think they forget that not everyone remembers it.

It's really the timeline, so although my prescription might say, take two twice a day, it doesn't say when in the day to take them, or should I be taking paracetamol in the morning and codeine in the afternoon? There's not really a timeline.

What gets missed?

- What information tends to be missing (*when medicine is prescribed or dispensed to you*)?

Missing Information

- Side effects was by far the most common omission mentioned
  - What the possible side effects are
  - What I should do if I experience side effects.
- Other omissions that were often identified were:
  - How the medicine works
    - What I should expect from the medicine and why
    - What would happen if I didn’t take it
    - Why the medication works as part of the suite of medications I am taking (*“Why they’ve all been prescribed together.”*)
    - What would stopping the medicine be like?
    - What do I need to be aware of if I stop taking the medicine
  - Interactions
    - Interactions with my other medicines
    - Interactions with non-prescribed drugs (legal and not)
    - Interactions with my other conditions (e.g. *“Will this non-epilepsy related medication interact with my seizures?”)*
    - Interactions with pregnancy

> *I didn’t realise until a bit ago that three of the medications I’m on interact with each other and strengthen some of the side effects I’m getting.*

Missing Information

- Other omissions continued:
  - How to take the medicine
    - Time of the day I should take the medicine (including a schedule if there are multiple medications)
    - Food and drinks that might interfere with the medicines
    - Supplements I might require *("Vitamin D is a common deficiency if you're taking these drugs long term.")*
    - What to do if I forget to take the medicine ("*Can I take my dose later in the day?"*)
  - Timeframes
    - How long will I need to take the medicine?
    - Will I need to take this for the rest of my life?
    - What are the long term impacts of the medicine if I do need to take it for a long time? ("*When I'm 70 am I going to be suffering from the decisions I make today?"*)
    - When will the medicine be reviewed?

I think, one of the things that needs to be done is timeframes, explaining how long you're going to be on a certain drug. I think that gets left out quite a bit, and then you get the disinformation of, 'Oh, it'll only take a week to come off that drug.' I've never really known it, to come off a long-term drug, to do it in a week.

Missing information

- Other omissions that were sometimes identified were:
  - Kindness/ warmth from the prescriber (*“The last few times I have been to a specialist, it just feels like I am another number.”*)
  - Consultation time *(“The gap is them [the GP] having the time to sit down and talk with you.”*)
  - Benefits of taking the medicine (“*I don’t understand why there’s a focus on risk and not on the benefits because we really need to understand and have it reinforced why we should take something, I resist my diagnosis all the time.”*)
  - Refresher information – about long term medicine (“*I think there has been this assumption, you’ve been on this medicine for a wee while, you should know the ins and outs of if, whereas it would be really helpful sometimes to get that refresher.”)*
  - Alternatives to taking medicine (e.g. lifestyle changes)
  - Not checking in to see if you were trying to get pregnant *(“Particularly given that I do have quite clearly on my records a series of miscarriages and taking inappropriate medication at that time.”*)
  - Alerts about rebranding information *(“The consumer is the last person to know about it.”*)
  - Impacts of an overdose of the medicine
  - How the medication is funded *(“Will I have to pay for it?”)*

> *When you go to the doctor, you at best have 15 minutes... the medicine stuff tends to be left to the last and the prescribing.*

Improving communication

- Themes
  - Allow access to sufficient consult time
  - Allow for informed choice/conversation
  - Format:
    - Tailored to what works best for me
    - Include written
    - Make the written brief and jargon free
    - Combine modes (verbal and written)
    - Make use of email
    - Provide direction to credible websites (*I'm going to google, so direct me to trustworthy sources*)
  - Diverse views on the role of GP/Pharmacist
  - Brand changes - be proactive about informing consumers about brand changes and possible consequences
  - Other considerations

Theme: Allow access to sufficient consult time

Quotes

The way in which the health system is structured, it doesn't give health professionals, and I'm meaning GPs, enough time to adequately outline the information that's really important. I think our GPs are essentially trying to understand what the issue is, trying to solve it and then get you out the door as quickly as they can so they can see the next person.

Just you have to put a lot of faith into a practitioner or a clinician that you've met possibly for the first time in a 15 minute, 20 minute window and just take their word for it and particularly coming from a Māori perspective, there's some distrust for the medical framework in general.

I think what's missing, is that it's really hard to get another appointment. I don't like going back to the doctor just to ask a question. I wait now unless I'm really sick or really struggling with something before I make an appointment, whereas back in the good old days when there were enough GPs in places that I lived, they would usually give you a call back.

Yeah, just having the time, because I know that the doctors don't have much time, so I often feel like I don't have, I guess, the rights, which sounds funny because I'm quite proactive. I feel I'm an inconvenience if I ask too many questions, because I know they're pushed for time, so if I knew that my appointment was going to be longer than the 15 minutes, that I could actually have spent some time unpacking what the medication actually is, what it does, and what are the potential implications, that would be good.

Theme: Allow for informed choice/conversation

Quotes

It’s about being taken on a journey rather than being told this is what you should take, because I have all the power in this relationship and I make these decisions.

Most important thing is actually informed consent and informed choice.

I suppose to really put it to us, so we do understand. Any medication you take, it’s always nice to make sure that the client understands and knows for sure that what they're taking is the right medication for them.

It needs to start right from the person who's prescribing it because they need to provide the full information because otherwise I'm not going to get informed choice or informed consent.

For me, it's finding a GP that I trust and everything stems from him. I know I just need to talk to him. If I need a referral, he’ll get his nurse to do that or he'll refer me to a specialist that he recommends, but he’ll explain just about the medication.

I guess part of the ownership is it's a two-way street. I need to know myself as well and ask questions.

I guess it's important that you have a good relationship with your doctor, that you have that ability to be honest and can and feel like you can say no to something . If you’re not happy with that line of treatment, you should be able to say, ‘Actually, I'm not comfortable with that,’ and have everything fully explained. You shouldn't have to sit there and a script be written and handed to you and you just accept that that’s the only way it can be given.

Actually listening to what the patients are saying, not generalising them into the general box. Individualising what they're saying and not generalising of what's in the textbook.

Theme: Format

Sub theme	**Quotes**
Use multiple modes	*Me, I like the different modalities. I like having a conversation in person where I can ask questions, but also the amount of medicine I've had that's been dispensed that doesn't have the little foldout piece of paper, and that most people just throw away anyway. I've had an alarming number that doesn't actually have that in it and while verbal is great, having something that I can actually look, that is tangible and is researched, it's just helpful to know.*
Tailor to what works best for me	*I can't remember at any time anyone ever in the health sector or system saying to me… what is your preferred format for receiving information? They just start talking to the person you're with, and that's the guts of it. As a blind person, I have one way of receiving it. And [name] down the road, who's 80 with macular degeneration will have a different way of receiving written information. We're all different. It's individual, access is individual. If the health professional asked that question, then …… all of the problems go away, because they're giving information to me in a way that I consume it and the best outcome can be had, then they remove the barrier. I say to people, I am a person with a vision impairment who is disabled by print, but they don't understand that when they're handing something to you in print, that they're the problem. They're creating the barrier.*
Include written	*I think because I've got real memory problems, short term memory problems. I need to have specific instructions about things and I need them written down. Don't just tell me, but have them written down.*
Keep the written brief and jargon free	*That's where even something like a one-page sheet with something like the most critical points on it — I realise that a CMI has got a huge amount of information in there that a lot of people would probably switch off from, but a one page, even an A5 size, with just critical main points for people might be useful for people to walk out with and/or a barcode to scan to get that information….. At the bottom of something like an A4 page, you could have the website to go to get that further information for more detail.*
Use email to communicate	*If it was e-mailed as well. As I say, a lot of it is printed out and given to me at the time, and being a modern girl, it'd be quite nice to have just an email with it attached to it right from the start*
I'm going to ask 'Dr Google, so refer me to credible websites.	*If they can just flick me an e-mail with a link to all the information that I need, so that I know that when I'm Googling, I'm actually Googling the right person or the place with the most information.*

Theme: Diverse views on the role of the GP v Pharmacist in giving information

Other	Quotes
GP led	*By the time you get to the pharmacy, it's too late. I mean you've got to make an appointment, which will be three or four weeks' time…. There's not really much point in having a discussion about whether the side effects are worth it if you've already got the prescription.*
Pharmacist led	*Doctors can give you some information, but I think pharmacists are in a better position to provide that, because obviously they've trained in that particular field.* *The pharmacist is generally where I get a lot of that information from*
Multi-faceted	*I'd like a sequence where initially the GP or the practice nurse, whoever's prescribing it at source says, 'I'm going to put you on this or suggest you take this for these reasons,'……. I know pharmacists are very, very busy, but the pharmacist is the person who, in my opinion, can give you the authoritative information about that drug, how to take it, when to take it and of course they always put that on the script anyway and what should be avoided with that particular medication.* *I want to be able to have that discussion with the GP and feel confident in choosing that medication and then the pharmacist could be the little quick check at the end to make sure that we're not missing something in terms of my overall medications and how they're working with each other.*
Evolving pharmacy role	*I know I can get it free if I go to a pharmacy in The Warehouse or the Countdown supermarkets, but I would not any help if it was a change in medicine cos they wouldn't know who I was. I think staying with the same one [pharmacist], like I've done, has been very productive for me.*

Theme: Proactively provide information about brand changes

Quotes
If something looks different, well, you don't really want the pharmacy not to let you know that it's changed. *Another one for me, that's a real bug bear, I guess, is you never get told when they're changing, because one of my tablets, they stopped funding the particular brand. It became a generic one. I know again, through talking to people, but the amount of people who panic, because something's changed and you're never told about it.*

Other key points

Other	Quotes
Not overwhelming clients with information about risks that make them too anxious to take the medication	*They have to walk quite a balancing line really.*
Proactively review how medicine changes are working for clients	*I know if I react to a medication, I stop taking it, so instead of waiting three months, someone within that early period going, 'How's it going?'*
Keep complete patient records for seamless information between parts of the sector	*I want a national health record held that is data protected.*
Informing support people when appropriate	*The best way for me, because of my memory, they need to tell my children. My children need to know so that they can remind me, 'Mum, you gotta do this. You gotta do that,' because they do it now.*

Cohort Analysis

Cohort Analysis

- The following slides summarise our findings for each cohort.
- For each cohort we have:
  - Summarised the key themes in terms of the experience respondents in the cohort told us they'd had
    - ❖Used quotes to illustrate the themes
  - Summarised the key themes in terms of the ideal way the respondents in the cohort told us they would like to receive information
    - ❖Used quotes to illustrate the themes

Pregnancy

- Nineteen respondents discussed information experiences/needs in the context of past/current/future pregnancies:
    - *PC: Pregnancy – Would consider becoming pregnant in the future and I am taking regularly prescribed medicines (8 respondents)*
    - *PP: Pregnancy – have been pregnant in the past and either stopped or didn't stop taking my regular medicine (4 respondents)*
    - *Some female respondents from other cohorts (where time permitted), were also asked the pregnancy questions, or they spontaneously raised 'pregnancy' when asked about information needs (7 respondents).*
- All nineteen respondents have been grouped together for reporting as there were not clear divisions between the groups. For instance, several people commented both on PC and PP experiences.

Experience Themes

- Respondents were asked about any experiences they have had of being told about how regular prescribed medicine could affect them or thier baby *if* they became pregnant
- The responses were inconsistent. Ranging from no recall of being provided with any information, through to comprehensive information provided.
- For some consumers, the lack of information had had serious consequences for their babies.
- Those who had been provided with information were largely satisfied with the way the information was provided. With one exception, where the respondent said the approach a nutritionist took to providing the information was very blunt.
  - *“That's what he pretty much told me. ‘You need to stop it or you’re gonna kill an unborn child,’ just real ruthless. He doesn't work there any longer.”*
- The information was provided by a range of professionals, primarily GPs, specialists and midwives. The information was mostly provided verbally.
- There was a mix of consumers proactively being offered information and seeking the information out themselves.
- Consumers said if they wanted further information, they would primarily seek this from medical professionals (this is in contrast to responses about where people would seek more information about medications from – this was primarily ‘Dr Google’)

Lack of information

I was very early in my pregnancy, wasn't visually looking or presenting as pregnant. He never asked any questions. No consideration was given to the fact that I was a young female. There was no information given…… I'm assuming that had he known that I was seven/eight weeks pregnant, he wouldn't have prescribed that, hopefully, knowing the impact.

Interviewer: So none of them ever talked to you about potential impact if you were to become pregnant?
Respondent: No, never, and nobody ever even asked me the question, 'Am I sexually active?'

Interviewer: Do you happen to remember that, when you very first started taking the sodium valproate, were you given any heads up that that could affect a pregnancy?
Respondent: No, I wasn't. Given that I was 16 when I got diagnosed, that would've been the time to actually tell…… I think back to that time, and like I said to you, it was disempowering for so many reasons, because I'm believing the healthcare professional because I've put them on a pedestal because neurologists have an ego. You listen to them. If they say to do that, well, you're going to do it. They're very paternalistic, so, 'This is what you must do.' 'Okay, all right.' …….. I mean, this is where the whole thing of informed consent and informed choice keeps coming into it because if I had known all the risks, I would have made different choices cos there were different anti-seizure medications that I could have actually tried, but I did not have that option presented to me. I didn't have informed choice, which is evident.

I haven't heard any information about whether or not I should be taking it if I was to get pregnant.

Interviewer: Can you please tell me about any experiences you've had of being told about how regular prescribed medicine could affect you or your baby if you became pregnant?
Respondent: No, I haven't had any conversations like that.
Interviewer: Do you recall when you've been prescribed medicine ever being asked, are you considering becoming pregnant? Do you recall if you've ever been asked that?
Respondent: No, I don't think so.
Interviewer: Have you ever been advised when you've been prescribed a medicine that you must stop it if you did become pregnant?
Respondent: No.

Lack of information contd.

Interviewer: : Any medication for that matter, any discussions you've had with medical professionals about how medicine could affect you or your baby in pregnancy?
Respondent: I don't think there were any. I have [racked] my brain prior to talking to you today when jotting down those notes, but gosh, there must have been at least one. I don't ever recall being asked anything.

I have not been told anything by medical professionals. I've actually had to go to outside resources. There's this organisation called Foetal Anticonvulsant Syndrome New Zealand. They hand out information booklets about what to do if you're pregnant and how it will affect the baby and if you're planning on getting pregnant and talking about birth controls and everything, so that has really helped me.

Interviewer: Can you tell me about any experiences you have had of being told how regular prescribed medicines could affect you or your baby, if you became pregnant?
Respondent: No, I've never been told. It's always, 'Are you pregnant?' 'No.' 'Okay.' That's when the conversations end.

So my current GP, whether he knows I've got four children and my youngest is 11, but that's not a question that comes up at all…..Is there a likelihood that you could be pregnant?...... Actually, I haven't really thought, because I know I'm finished, but that doesn't mean that they [doctor] know I'm finished. Actually my partner and I were……considering, up until only maybe six months ago, whether or not we were done. I've not put into that puzzle my pain medication and what that would look like in terms of needing to not use certain types of medication. That's a really, really interesting thing to consider moving forward, for women in general.

Information provided

Yes, so I'm taking a Medicare drug through my specialist …... I'm taking that, but as soon as I get pregnant, I have to stop. I'm aware of that. It gets prescribed monthly to me. That, I was actually told in a nice way. That's why they're only giving it to me monthly at the moment.

So I've been on two long term xx medications in my life. One was xx, which is a Vitamin B12 inhibitor. I think it blocks it. That's quite crucial for pregnancy. My [specialist], who prescribed me, told me very, very clearly, and even I think made me sign a waiver, ….. that if you get pregnant during this medication, the baby will be quite heavily compromised and you will most likely need to go through diagnostic testing to make sure the baby's okay or opt to have an abortion. He talked to me through it for quite a bit of time, cos I think I was 16 when I was prescribed this medication and he took quite a bit of time to explain why I can't have babies while on this medication and that when eventually I do decide to get pregnant, we'll have to stop the medication for at least six months before trying to conceive….. I think personally they were handled quite well. I understood why I couldn't get pregnant on them, what it would do to the baby. …both specialists handled it very well and took me through why I can't get pregnant. They didn't go down to personal details of, 'Do you want to get pregnant?' They just said, 'You cannot regardless of whether you want to or not. You will have to stop the medicines because babies whilst on this medication will come out with encephalin or spinal tube defects.'

My doctor said to me, 'You're 30 now, are you planning on having children anytime soon because we need to have a look at your epilepsy medication?' I've had the same doctor since I was born, so she knows my medical history. She's really good like that.

I recall that that was a sensitive issue for me. I was really worried about how my depressive medication could impact on my pregnancy early on and the onset of the pregnancy. I remember that I had to ask the questions…….The midwife wouldn't or the doctor wouldn't initiate the conversation around it, but when I did ask the questions, they were good in providing the information I needed and to some extent, reassurance.

During the work up of the clinical trial, when they were talking about pregnancy and saying, 'You can't get pregnant,' I asked, 'How long do I have to stay off it before trying to get pregnant,' and knowing that my condition will get worse during that time, I was thinking, yeah, three months off it, nine months of pregnancy, assuming I get pregnant straight away, but then it could be a year or two of trying to get pregnant, so it could be a couple years off the medication? Can I go then back onto it? Can I breastfeed on it? I asked quite a few detailed questions like that. They said, 'We actually don't know cos it's a clinical trial drug.'

Ideal

- Respondents were asked about the ideal way for medical professionals to have a discussion with them about how regularly prescribed medicine could affect them or their baby *if* they became pregnant.
- There was some inconsistency in terms of 'who' should be having the conversation with the consumer. Some preferring specialists, some GPs and some fertility experts. Good communication between the medical professionals was identified as an important part of informing the consumer and making good decisions for the consumer and their baby. Some sought multidisciplinary input (e.g. GP, neurologist and psychiatrist) into the information that would inform their decisions (particularly when there is polytherapy).
- The point in time the information should be shared was generally both at the point of prescription **and** at regular review points (recognising the changing stages of life experienced by the consumer while taking a long term medication).
- The information should be shared proactively.
- The primary content sought was the impact of the medicine on the foetus or person carrying the baby, as well as how to manage any medicine transition (stopping or changing) and associated impacts. Informed choice/consent was considered critical, as typically the consumer is needing to make a careful choice about which strategy they are most comfortable with, in terms of risks and benefits to themselves and their baby.
- Consumers were largely comfortable with a direct and proactive approach to asking them about whether they were sexually active and would consider having a baby. There was also some acknowledgment that some people may be offended by being asked about pregnancy.
- The information was sought in a combination of verbal and written format, from medical professionals. Accessibility was also raised, with some call for electronic format, including video. Medicine labelling was also suggested as a vehicle for informing consumers about pregnancy risk.
- Other (non medical) possible sources of information on this topic were mostly not regarded as credible, for such an important situation. One consumer suggested a communication campaign and a few suggested using credible online sources.

Who

The thing is what you've gotta remember before I actually talk about what would be my ideal, a lot of people with epilepsy, if they get epilepsy when they're a teenager or something and they're stable, their GP is the one who keeps giving them the medication. So, the GP is gonna be the one who is going to be either assuming the specialist gave them the advice or they're not getting the information at all. For my ideal situation, I would actually be saying that the childbearing person needs to actually see their specialist because the specialist can then present options to them. This is like I said, informed consent, informed choice comes in because a GP cannot present different options. They would have to seek the advice of a specialist and especially if you're on the medication for, let's say, a mental health reason. In some cases, you can actually come off the medication if the right plans are in place. It's really dependent on what is right for that person.

If the woman is on more than one anti-seizure medication, there's more risks to a foetus. There can be more risks and that generally isn't being discussed either. Also, polytherapy, so say you've got multiple health conditions and you're on medications for these multiple health conditions, those medications can interact with one another. Again, we are not handling that well when it comes to pregnancy as well, so all of this needs to be looked at. To be honest, the consumers sitting in the seat, they probably won't know to ask about that. That's why that healthcare professional actually needs to look at all the medications that are being prescribed, even if it's other ones for other reasons and doing a multidisciplinary approach to it. Maybe actually that specialist is reaching out to say they have a psychiatrist involved. Maybe they are actually having a discussion together, which remember you need to include the consumer as well and actually all come up with a plan together. It's not okay to just work in isolation and silos. I would actually be saying have a preliminary approach to this, a more holistic approach.

That would probably be my GP having that conversation. I guess just asking or giving me some information about the impacts of taking that particular medication, whether it's fine to take, whether I need to stop, even just how it affects your health, how some of the, I guess, side effects of it might manifest in differently in pregnancy. So yeah, I have this side effect now, but with pregnancy and all of those kind of changes going on, is there going to be anything different in taking that medication? So, yeah, probably my GP, I don't know. I want to say a specialist, but I don't really know who I'd say. Yeah, probably GP.

Yeah, my GP. I know not everybody stays with a consistent GP. I find that problematic, but I know my GP and she knows me, so that keeps us both safe in a way. I mean probably me more than her, but there's a level of human connection.

Who contd.

There's the difference between what the GP is saying and what the specialists are going to do, and that's the problem. There'd be no way of knowing what they would do, because it's different doctors, you don't get to control that….. I think, just like my previous pregnancy …….there was a plan in place, so I had a plan with the GP to stay on my permanent medication. However, because the specialists are the next one up and they're dealing with everything, they didn't stick to the plan…… There wasn't enough written stuff on those notes, to give everyone a clear direction of where everybody was going. It was word of mouth and that caused a bit of confusion……..Ensuring that everyone understands where everything is should be their job. ……because I have a really good GP, and I thought we had a robust plan, but it was just changed because of what the different specialists understood. It was that miscommunication in that C category that was the big problem, because they didn't know if it was bad or good. Yet when I went to see the psychiatrist, they said it would be more damaging to come completely off the antidepressants to the baby, than it is to stay on…. [Ideally] I suppose it would be maybe ….. getting information from them [the specialist] before I even started trying…… but that's not possible, because I can't go to them [the specialist] and say I want to be pregnant, what do I need to do to prepare for it? My first port of call is the GP….

Probably my fertility specialist at the moment, not my GP. He doesn't always know what's going on until after it's happened, so I'd probably go back to him, but then it's always waiting cos they're always so busy…. I think cos we really want a baby, but we can't get pregnant. I guess we get all the information from him on the process of what's been happening for us to try and get pregnant. The GP hasn't had a lot to do with that, apart from in the beginning when we were getting testing done. I feel like he's probably more educated if that's the right word on our journey.

Point in time

It needs to be annual reviews as well cos things change and also information changes. We get more knowledgeable as the years go by.

Maybe not necessarily at the point when I'm just taking it, just being prescribed it for the first time cos I guess pregnancy was not on my radar then. Although I guess it will be for some people, but maybe at a check-in point at some point. Like 'Hey, you've been on this medication for six months. Has anything changed? Is that something that you want to talk about now that you've been on it for a little bit and you may be on it for a bit longer now?'

That needs to be initiated just when you are prescribed a medication, in terms of, 'Just by the way, this can cause deformities or whatever.' Sorry, that's personalised to my one. 'You'd need to talk with a doctor further about this medication if you became pregnant.'

One of the things I've been thinking about is whether there actually needs to be reminders of side effects and things like the pregnancy and so on at certain points. I've been on a medication for a hugely long time and I just electronically request another lot, and nobody ever talks to me. Maybe from time to time, you could do with a 'Hey, just a reminder …'

Content

The consequences of the effect that the medication would have on the baby or babies. I mean, for me, I've had the same GP for a long time, so it would be, 'What is it going to look like, a support network for me going off of a mood stabiliser that has really worked really effectively so what would a support network look like?' What would be danger signs that I'm not functioning?

is it a forever medicine or will I switch back after my pregnancy or is it just during pregnancy only and then after pregnancy, I'll be fine, does it need regular testing?

I would've appreciated information around the safety of what I was currently taking for the growing foetus, but not just say it's safe, but more comprehensive and evidence-based information, maybe in writing…. individualised information as well..

I'd want to know exactly what is the potential impacts that this would have on a pregnancy, both big and small, so big obviously is the most important, but little things can go a long way as well……Also, that really big thing of if my medication changes, how do I change that, because if it's a medication that I've been on long term, weaning off needs to happen and that's going to cause a whole different world of challenges, but also how to manage that when it has changed? Do I have to trial and error while trying to grow a tiny human? Do I have to do this beforehand? What would happen if a blessing should happen and I'd become pregnant without planning? Those would be my really big things because I'd want to know what was going to happen, what I need to look out for the baby, and what my partner would need to know what was going to happen, because if it's mood swings, they need to be aware, or if it becomes a risk of unsafe thoughts or suicidality or things like that, I need to be able to know that to protect myself and also have people around me protected and protect me.

The woman or child-bearing person needs to actually feel like there's a partnership happening and that they can explore different options and make the choice that is right for them…. The full information of the risk that could be to a foetus. Of course, they have to balance it up with the risks to you as an individual as well, but that's again where that person who's sitting in that consumer seat is able to make the choice that is right for them. It's not the healthcare specialist who is making the choice.

Approach

As long as it's an open, I'm not making assumptions that you want to have children or can have children and I guess there might be some people that you might miss by just targeting a certain demographic. It's hard but generally I think that's okay. You just have to be prepared that for some people you may be way off and for other people you may miss asking them when actually that is a concern for them.

For a lot of people that I know, they might be assigned female at birth, but that doesn't mean that they necessarily do want to carry a child and that doesn't mean they identify as she/her, so it's quite offensive for a doctor to make assumptions about what that person might wanna do with their body.

Not everyone is really comfortable with asking a hundred questions. If there are things that a patient needs to be informed of, the health professional should lead that conversation. I think it should work that way. Of course, some women who are pregnant will have a lot of questions and are more than comfortable and happy to fire them away, but some won't be. I think if it's related to your health or your baby's health, the health professional really needs to lead that conversation.

unless you're trying for a baby, you probably wouldn't sit in an appointment and then ask, 'Hey, by any chance if I was pregnant, is this going to affect me?' It would be neutral ground, if the professional could say, 'If by any chance you are pregnant, this could …' just as you do when you go for an x-ray. I mean at all the x-rays, of course, they say those things, which is always really good, so you wouldn't be the person to say around the other way type of thing. I think it needs to be led by the health professional.

Well, usually when I go to the doctors, they usually say, 'Are you sexually active?' I think if they stated off by saying a routine question like that, if they talk to me about, 'This is information I'm gonna prescribe you,' and then just saying, 'Are you sexually active,' and then going on from there?

I guess open, but honest at the same time. Specifically in my experience, because I have reproductive challenges and I'm in a same sex relationship, which means that would take a lot of money and a lot of planning, thankfully. I would want it to be realistic because I have been on some long-term medication and some of that is what I need to function at a level that I would like to, at a normal basis. If that was going to change, I need to know how I can take care of myself in other ways to mitigate that, because if I can't take care of me, I'm not going to try and bring a tiny human into the situation knowing that I can't take care of me in that process.

Format

Verbal and written down just in case I miss any information while talking or forget something.

Written is always good cos I can look back at it. You often forget when you're told in a phone call.

Written as well as talked over. Written to take away but talked through too.

I take in information if it's something physical, whether it's a booklet or like you said, in a newspaper cos usually if I read something physical, it gets in my head a bit better. I process it better.

Support Person Quote*: It could be the rehab coach or the OT she's working with for training for independence. She's more comfortable with them, so she's more likely to ask them questions.*

I would say verbal, but not just me in the room, but also written down, so talk me through it, but also let me leave with a thing written down so I can come back to it or clarify something.

Starting a Medication

- Thirteen respondents were asked in detail about receiving information when starting a medication:
    - *SM: Starting a medicine (9 respondents)*
    - *SMM: Starting a medication that required monitoring (4 respondents)*

Starting a medication

- Contextual note
  - 2 of the respondents re-started a medication
  - 2 of the respondents are blind
  - 1 respondent was assessed and treated under the Mental Health (Compulsory Assessment and Treatment) Act.

Experiences

- The key issues consumers raised in terms of their experiences of receiving information around a new medicine were:
  - Limited information provided and/or missing information
  - Difficulty getting full and/or follow up information from specialists
  - Information format (verbal and hard to recall, and/or inaccessible).

Experiences: Lack of information

There wasn't a lot of info, other than obviously it being a trial drug and again, there was nothing about side effects or long term use…..all I heard from him was, 'It's a new drug. It sounds like it's really good. Would you like to trial it?' I didn't really have time to think of any questions that might have been suitable to ask him….all I could hear was, 'New drug,' and it would help me. I thought, yeah, okay, because of where I was with my sickness. I thought, okay, let's do it.

Interviewer: Okay and what did the GP tell you about that medicine? Respondent: Nothing. He just said, 'It sounds like you probably need some xx to help with the xx.'

They just tell me that I'll be taking a different medication, because they don't actually know whether or not it's gonna work. They just trial me on different medications and ask me later on how I feel about that particular medication.

I didn't really have any idea how they connected. It seemed a ridiculous thing for me to have to take three tablets, but I did.

If you don't know what the side effect is or to look out for, then [you] don't know that the pain in your xxx today [is] from the new tablet that you've started taking a week ago. It all just becomes bit of a jumble.

The intention was clear, but the tablets at the other end wasn't that clear. It was boxes and bottles and just too much, too confusing, and on top of a huffer or something else. It's not often just that you're taking one, two or three tablets for your blood pressure, you're taking Laxsol for your bowel or you're taking a huffer or then you've got something else going on temporarily. It's a conglomerate.

….The name and the medication and the bottle. The doctor saying what it is and that information being available on the bottle. There's an absolute missing link there, and that's critical for me to understand. I could go into a pharmacy and they say, do you want the xxx? I've got no idea and you look stupid. Not because you are stupid, but because the information isn't in an accessible format and that's horrible.

When I'm dealing with pain, you just really want a resolution. In this particular time, it was very bad, so where I'm not able to walk. There isn't the capacity to question or really consider anything.

Experiences: Specialists

Then, I think the other thing that made it a bit more tricky in terms of being prescribed it and taking it was that it was actually prescribed by a specialist that I don't see often. I only see them once every six months or so, and I was just uncertain about, okay, if something was to happen, who do I contact? My GP, I can contact. I have a great relationship with my GP, but this isn't the drug that my GP's prescribed….. I felt like it took a combination of people to inform me, to make me feel like I was fully informed. The specialists generated all these questions. My GP was able to fill in the gaps a little bit but also the pharmacists when I picked it up and I asked questions there too.

I think what worried me the most was that this particular specialist was very non engaging. It was very much, 'Here's the prescription. I give you this. This is what's happening,' and then that's the end of. You don't speak to them. You don't have any engagement with them. The only engagement that you have with them is in the form of a follow up consult letter, but that goes to your GP. Then, if you have questions, there's no opportunity to ask questions. It's quite a process to ask questions. Basically, you have to get your GP to write to them officially before they would respond. It's things like that.

Experiences: Format

I find it sometimes a bit hard understanding when somebody's verbally telling me things and it's not sinking in. I'm not comprehending what he's actually saying. It's pretty much with just a whole lot of blah, blah, blah…..sometimes a diagram would help too, just to match his words to pictures that show what it does and just to more understand of what it does.

Ideal

- The key suggestions consumers made in terms of the ideal experiences for receiving information around a new medicine were:
    - Content related (sufficient for informed choice, rationale for prescription recommendation, what to expect and when, how long the medication will be needed, how best to administer the medication, side effects to monitor for, impact of not taking the medicine)
    - Format related (include brief written material, ensure accessibility – email is best for blind people)
    - Role related (role of the prescriber in informing the consumer is paramount, pharmacist also has a pivotal role for some)

Ideal: Content

I know that the doctor is doing their best to serve in the moment, and their intention is to help, but often decisions can be made and I don't have a choice. Well, not a choice, an option. Maybe they could say, ‘There's these three types of medications, these are the possible side effects for each of those. This one here has actually got a long-term effect of something, whereas this one not so.’ To be informed, to make informed choices in the medications prescribed, it would be good.

Probably just a little bit more detail and a better way of describing what it does, what it's going to do. …..really just narrowing down what this thing is going to do inside my body better than what the other prescription was doing. Again, back to the long-term thing for me. Will I be having to take this forever or is it going to stop the diabetes from increasing or decreasing or is it gonna plateau?

I would've been told specifically at the ideal time to take it, how to take it, what to be aware of in case there's side effects and how to monitor the side effects. If there are side effects, what to be alert for. …..When to actually take it? What time of the day to take it, when not to take it…. I would expect first and foremost, the GP and then the chemist…… In a written format.

I think it would've been beneficial to understand the use of the drug in other ways and the purpose it was to be used for specifically and why that particular drug was used.

Also, the different side effects and understanding a timeframe of how long I needed to be on it for and then what was going to happen if I didn't take it, the whole side effects thing for it. I didn't feel like that was fully answered by the specialist. Those were the things that I went back to the GP for.

Length and expected duration for the medication cos at the time, I didn't know. Thinking you were going to be on something long was pretty scary. I think I was just like, okay, but in hindsight thinking about it, I was just like, wait, what is long term?

How long I would have to be on that particular medication. I’d just like to know when exactly it is you end up becoming better after taking the medication and eventually come off

When to take it, whether to take it with food, what time of the day to take it and what are the side effects.

Explain the rationale why it is necessary and important to take it. And that there currently aren't any other options.

‘Now when you first start taking it, you are going to feel pretty awful and that's normal.’ They don't need to rattle off all the side effects because that'll scare everybody and to never touching the stuff. That's fine, but they need to tell somebody that they will feel very tired and just might feel a bit yuck for a while. Don't lead people to believe that they'll take pills and they'll feel all right because they won't. You don't give people false hope. You don't give people the wrong idea about something…… if people are going to feel really horrible from taking a new medication for a while, then they're allowed to know that, aren't they?

Ideal: Format

If it could have been written as a condensed high level thing, where I could just refer to or be familiar with, then that would've been really helpful.

Like I said with the pictures, instead of the words.

Ideally it would be in an accessible, written form, so that's either electronically or through an app on my iPhone, but that would also mean for me, it would be braille on the medication, on the packaging or the bottle, coupled with the electronic information.

I think initially it needs to be spoken, but they also need to ask, ‘Would you like me to write that down for you?’ Because when people are really overwhelmed, if they've just received a diagnosis of something or they're feeling really, really sick, you don't take it in or don't even ask, ‘Would you like me to write that down for you?’ Say, ‘I'll write that down for you or it'll be in your discharge notes,’ if they're in hospital, ‘I'll send a copy to your GP,’ or all the rest of it, but also make sure they've got written instructions, because a lot of patients, for whatever reason, you can hear stuff, but you don't take it in.

A pamphlet would be really useful, only because that's the kind of person I am. Being asked, do I have any questions or actually having the option to choose whether that was the medication I wanted to try.

Ideal: Role

I think all the information. I think given that the specialist was the prescriber, I think the specialist should be the one that should share all that information.

The information really does need to come from the person that prescribed it in the first place, whether it be a GP or a specialist.

I know that the pharmacist also sometimes has conflicting ideas about medication. I've got a longer relationship with my pharmacist than I do my GP. I weigh up the difference sometimes. I guess I'd probably trust both of them in different ways. Sometimes they'll question prescriptions. I'll be waiting and they'll say, ‘Oh, what did Dr … say about this, because we're not sure whether that's quite right for you.’ They've got a longer history of knowing my pain issues. They actually caught one time when I was prescribed a medication that they really questioned and didn't think was appropriate. Then when it went back to the GP, actually had prescribed me the wrong thing. That was a good save. This is different from the time I'm thinking of now. That's another example of where information kind of got a bit lost. My pharmacist is, I would believe, quite well informed. I trust what they've got to say about different things, and I'm happy for them to question things, and find things out. They always ask, ‘Have you had you used this medication before?’ Or they'll say, ‘Oh, you're familiar with this, aren't you?’ They have that little check in moment and then they just give you little reminders, make sure you have a big glass of water, and all that sort of stuff, so they do that. I guess that pastoral kind of care handover, whereas I find the GP is a lot more, he's more clinical, so it's not as personable.

Starting a medication requiring monitoring

- Contextual note
  - 2 of the 4 respondents were prescribed the medication in a hospital setting

Experiences

- 2 of the respondents received information about the new medication while in a hospital setting. Both acknowledged that their medical conditions at the time made it difficult for them to take on board new information.
  - Both had some uncertainties about what information they had been given. In both instances there were negative consequences experienced after commencing the medication that were contributed to by the consumer not understanding the medication.
  - One relied on subsequent interactions with other medical professionals to provide a fuller understanding of the medication (both GP and pharmacist).
  - Neither had a good understanding of the need for and purpose of monitoring at the time of prescription.
- The other respondents were prescribed the medicine requiring monitoring by their GP.
  - Both had a limited understanding of the need for monitoring.

Experiences

It was verbal. I remember it was verbal, but my son was with me…..Well, because I trust them so much [medical professionals], I think, well, you know what to do and whatever you give me, well, I'll take it as long as it makes me better, I suppose….. Well, I honestly believe that if the stroke team had told me some of the dangers of taking this medication, then I would've been aware of things that I had to be really careful about, like cutting myself or picking my nose or whatever……I found out later when I had the bleed out.

The registrar [prescribed the medication], he was a great guy. I got top service from him, apart from the medications and I suppose I was in a semi-drugged state or I wasn't totally aware, but he certainly told me what he was giving me, but he didn't tell me what I had to watch, whether I should take them once a day, before eating or with meals or whatever….

I'd asked [my GP] specifically for that medication …….after getting a recommendation from someone who had the same condition in the community. I asked if that would be a good option for me. He said, 'Yes, absolutely,' and said, 'This is how it works.' There were some warnings about it, particularly, how it's taken. It can't be mixed with something else and it's quite a severe reaction. …. In terms of improving my health, I was really happy with the description he gave of what it would do, the timeframe to expect it to work. Definitely, the side effects or precautions weren't thoroughly explained, but I didn't mind too much about that. I was pretty happy, again because I was trying to save time. I was happy that instead of using the time on that, instead discussing non-pharmacological options. I think too much focusing on that too might have made me like a bit like looking for those effects, so that was good.

I don't recall any discussions about risks or anything like that. Looking at it, there's definitely the risks of my seizures outweighed everything else so no regrets about being on it, but we definitely didn't have conversations about that kind of thing. We also never had a discussion about how that would interact with my epilepsy medication.

Experiences: Monitoring

Interviewer: Why do they test your blood?
Respondent: I don't know.
Interviewer: Would you like to know more about why they're testing your blood?
Respondent: Yeah.

We didn't get the total information. It was the third player and that was the GP, who rang when she got the discharge notes and rang to see me and said, 'You need to take blood tests….. Initially when the GP told me I did have to do blood tests to monitor the effect, I didn't know what it was for. I asked her, 'Was it to look at the kidney function?' She had told me it had to be monitored, but not the reason for it being monitored. I was able to guess what it was for and I was right.

Similarly, he mentioned about the monitoring and needing to go and get regular blood tests, which I was totally fine with…..to be honest, I don't actually really know what he's testing for, but I don't really mind because again, I trust him that it's fine.

Ideal

- The respondents had mixed views on the ideal way of being informed about their new medication requiring monitoring. Suggestions included:
    - Their GP providing the detailed information, in writing
    - Their GP giving fuller information on the rationale for monitoring
    - Their GP continuing to review the relevance of the information about the medication during the lifecycle of the patient
    - The hospital doctor being fully informed on the medication and able to give the full information to the consumer
    - Providing upfront information about how long the consumer will need the medication for.

Ideal

My GP, I suppose…….. The GP I've got now, he's very good, but it's hard to bloody get to see him. I need to have somebody with me…….I have asked him about [providing information in writing] and he said to me that the pharmacist should be writing on whatever, how to take the medication but they only tell you how many you gotta take really. They don't tell you the effect and how it helps you, so my GP should be telling me all that.

I presume the registrars are up to date cos they're newly trained and fresh, but I think……having a pharmacist in the hospital, come and talk to you about your prescriptions, a bedside chat about your prescriptions, what they're for, how to take them, when to take them, possible side effects, how they might interact with the rest of your prescriptions. That's an ideal world…. I think I should be told at source and even the registrar say, 'Your GP will arrange for you to be regularly monitored for this particular medication.'

I guess if he's searching for a difference in blood tests, maybe I could have asked, 'What are you looking for? Would there be any effects that I would notice to indicate that this blood test is out of whack?'

[Ideally] My doctor would prescribe it to me, give me information about why she's giving it to me, how to be taking it, any general other things that I need to know about the particular medication and confirm to me that it doesn't contradict with my key medications or if I've got something I take on and off, don't take them during that time, that kind of thing…. I always see the same GP, so I would expect that they should have that all. It's different if you've got different people all the time. You can't expect them to be up to date. I don't think I particularly expect much from my pharmacist unless I've specifically asked them for something. I'll often ask them to double check if it's something brand new, that it doesn't have a contradiction with maybe epilepsy medication.

It'd probably be the same to have a conversation at the start of it being prescribed just to just know what's going to have to happen ongoing, whether that's blood tests or check-ups or whatever it is, just when you know what you're signing up for and because that also helps me to know then if one of those monitoring things, the test came back negative that okay well then we'll have to do these things instead so you actually know what you're monitoring for.

Yeah, well now you're on it and that's it which is where I'm at now. I just have no idea how to get off it. I mean, I'm not going to be taking it 'til I'm 90, presumably. At some point, I have to come off it, but it is going to be a bit scary because my hormones affect my epilepsy so much. It's starting to worry me.

Changing a Medication

- Thirty-one respondents were asked in detail about receiving information when starting a medication:
  - *CB Change of brand (5 respondents)*
  - *CBM Change of brand for medication that required monitoring (4 respondents)*
  - *CD Change of brand for medicine that has a different device to deliver the medicine (4 respondents)*
  - *CT Change of type of medication, but to treat the same condition (12 respondents)*
  - *CS Supply issue with a medicine (6 respondents)*
- There were some overlaps in cohort groups, for instance a CBM respondent that also had a change in device. We have included the insights within the relevant section of the report (e.g. we have included the insights from the CBM respondent that are about the device change within the CD reporting).

Change of type of medicine (for the same condition)

Experiences

- Some consumers said the prescribing consultations felt very rushed/pressured and there was insufficient opportunity to get the information they needed.
- Some consumers had received very little, or no, information about the change in type of medication. The most common missing information was about side effects.
- Some consumers said they were well informed about their medication change.
- Some consumers had experienced mistakes in their prescription – which had impacted on their trust of the medical professional.
- Some consumers used ‘google’ to fill the information gaps. Some expressed interest in being guided on which websites would provide them with the most accurate information. Some noted that searching online had made them anxious about the medication.
- Some consumers had had experiences with medical professionals that were unfriendly.

Experiences

When I went to pick up the medicine, it was a different medicine, different branded medicine, but it's not the same active ingredient either. It's a slightly different active ingredient…. This particular condition, the medicine that I get for it has been one that I take a daily dose of to help prevent the condition coming back, but the actual medicine I picked up wasn't actually for that preventative action, it was for a treatment action, so the dosages were different. The dose quantity was different as well, so everything about it was different….. I looked at the medicine. It was different…. No info given….It was in a bag, so I didn't open it until I got home. I opened it up and I thought, oh, that's different and it was….. There was no consumer medicine information leaflet inside the box, so then I went online to look it up and the dosage I was prescribed was for three times a day and it was a higher dose than I've ever had before….. I modified it [the prescribed dosage] by breaking the tablets in two and taking half a tablet twice a day, instead of taking the whole tablet three times a day.

I was with my doctor, in for one of my three monthly check-ups. He said that one of the medications I was on was no longer being funded and that they were going to be changing me to a new medication that was being funded. He talked and said I could still stay on the old medication, but I would have to pay for it myself if that was something I wanted to do and then he took me through what the new medication was. He talked to me. He'd done some research himself on the medication and said from what he knew of the medication that it was going to be fine for me to take….. he did ask, 'Have you got any questions?' Well, I don't know anything about this medication, so I don't know what to ask. It wasn't until I got the medication that I was able just to have a read through it and then go back to him the next time.

I found that specialists especially are very good at talking very fast and saying very little . He suggested the new medication and told me that he expected that it would have less of the same side effects and would hopefully still work. That was about as much as he actually told me about the medication and the change other than what dosage we would be starting with….. From him, there was not really any discussion of the fact that this was gonna be a long term medication I'm on and what effect it would have on my body taking it long term or if we did need to switch it, what effect it would have when I came down off it again and absolutely no discussion with him about any major interactions, which that drug has quite a few…. I checked a few sites cos the pharmacist that I went through to get that medication gave no information when they dispensed it to me other than when to take it. I checked it on Health Navigator to see what was commonly there for side effects and all that kind of stuff cos at this point, I'd learnt. I did a quick check of the interactions with the other medications I take. I think it was just drugs.com. It's got an interaction chapter. I also did just a quick browse through its Wikipedia page to see if there were any huge side effects in that category. I also had a little look around on the Facebook page for the condition to see if anybody had said major things about that medication.

Experiences contd.

She [pacing technician] told me what it was for and why I did need it, how I was going to get it in pill form, and then she gave it over to the specialist. Well, she asked me a lot of things, but she asked if I was on this particular med and I said, ‘No.’ She said, ‘I've spoken with the specialist and he’s rushing a thing down to the GP,’ who in turn, just put one through to the chemist and I was to pick it up ASAP……Personally, I think they could have told me a bit more about what it's for and any side effects of it then as I was taking a whole lot of other meds as well. I’m still taking a whole lot of other meds as well as this one, but they lowered the dosage, so it’s panning out all right at the moment. At the time, they could have just told me about a lot more than what they did at the time. Even the pharmacist, I thought he was a dick, to be honest…. ‘Okay, here’s your meds. Take one a day. See ya.’ ….. I'm thinking he was having a hard day, but that's no excuse for being that cold.

It was really good, because I had information provided to me about the new medication….. I mean, this one was really good, because they'd also thought about how it would interact with the other ones I took…. They'd weighed it up and they'd worked out that, ‘No, it was worth it,’ and they'd explained all that. I was reassured as well, that they hadn't just picked one out off the shelf and thought, ‘Okay, that one will do.’….. He [the specialist] didn't just treat me like a dummy, he spoke to me as an adult, which was really good, but also my expectations, I guess, were very realistic, when he just said that ‘Well, we've got to wait and see what it's like.’

Okay, so I was prescribed a medicine to xxxx. It was done at the GP here in xx, but at my GP office, but it wasn't my GP. It was a junior doctor, who did his best job possible and prescribed me whatever it was. That didn't work. Went back. Then, next time around, I saw my GP and said, ‘Hey, this is not working. I obviously need something else.’ That occurred. Still didn't work…….. He [specialist] prescribed me the thing that did work, but what was probably the thing that alarmed me most was cos I took the two previous tubes of stuff with me and he said, ‘What on earth we are given that for? That crap will never work.’ I started to think, well, now I've got a bit of a confidence issue as to okay, if something happens similar, then am I gonna be prescribed the right thing?

It wasn't until I asked for the letter that was sent from her back to my GP, on there it actually said there is a possible side effect. Then, once I did that, then I did my own research and there was a side effect.

I just had to Google Dr Google, as we all do, and we shouldn't have to do Dr Google, but again, when I look at the packaging of this, it's a very plain box, so without the documentation in it….

Experiences contd.

I felt like it was actually pretty subpar. It was, again, a new doctor that I had seen. I haven't seen them again since. It felt rushed and pressured. I don't know if that's just part of the COVID environment we're in that everyone's seeing that many more people, but it felt like there wasn't a lot of time for various questions in that appointment. …… because it was a new GP, if they could have actually reviewed my file to a degree so that they were reasonably familiar with my other health issues, would've meant that they may have been better prepared for some of the questions I had around it. Therefore, there may have been more time to actually address other questions and concerns that didn't really have time to be dealt with in that 15 minute window….. Yeah, you're in and you're out. It feels like if someone doesn't have any clue about your health or background. ….. when I left that particular appointment, I didn't know of any risk or side effects that I should be concerned about.

He [specialist] said if I didn't have that, then the risks would be, if I was to fall pregnant, that it would cause severe damage to any foetus. I can't remember the other thing was said, so he gave me a sheet, an information sheet and we were Googling on … what do you call it? MedSafe, about interactions and stuff, what medications to avoid, how it would react to my allergies and stuff and what side effects I could potentially experience, what was normal, what was not.

I got a different psychiatrist who prescribed me something completely different and was quite short with me when I asked why and when I wanted to talk about it, they were quite impatient with me. …. It was just verbal. They were obviously really stressed. They had had other stuff going on because they were quite late for the appointment ……They breezed in and said, 'We've done a quick review. We're going to put you on this. You need to take it at this time. Do you have any questions?' Then, obviously I had questions and they were very short with me and quite snappy and just generally not interested in the questions, they just wanted compliance. …. It was a really unhelpful conversation. Actually they made quite a shitty comment, because I said, 'Oh, well I don't understand why I need to take this.' They said, 'Well, if you're suicidal, you should be willing to take anything.'

It was very much just a very quick conversation about, 'Yes, hi, Yeah, I understand. Yeah, we'll put the change through,' and gave the new medication without really discussing much of it. I mean, to be fair, it's like a very similar class of medication for the same thing. I suppose they probably thought it's not really worth going over it….

Ideal

- Whakawhanaungatanga to ensure an open and trusting relationship between the prescriber and the consumer is sought by consumers. Within the context of an established relationship, consumers want to be given sufficient time and an appropriate atmosphere for an informed discussion about the medication.
- Some consumers want an opportunity to prepare for a discussion about a change in medication and would like their medical professional to also be well prepared. This included making sure medical professionals prepare well so they don't make prescription errors.
- Many of the consumers wanted to read more information after the consultation, in the format of email, paper and/or an online portal. The information sought is concise, clear and jargon free.
- Consumers want to be informed about the rationale for the change in medication, potential side effects and medication interactions. This includes when medication is prescribed by a specialist. Consumers also want medical professionals to communicate between themselves, so all relevant professionals are kept up to date on the consumers medication profile.

Ideal

Ideally, my doctor would've come back to me and said, 'I'm going to be prescribing the medicine for you, but I'm going to change it to this other one because I think it's just a bit more effective and I'm going to be giving you this particular dose to treat this particular episode and then put you onto the maintenance preventative dose,' and that he would've also got the treatment dose correct at the beginning for the particular condition that I had…. Sometimes it's actually useful to have it written down too, because then if I forget something that he's told me or he forgets to tell me something, sometimes when we're writing something, it can make us more conscious about covering the different points sometimes.

it would've been really helpful to have had a heads up before the appointment to say, 'Just letting you know we're changing medication. I can explain it more when you come in,' instead of finding out at the appointment that it was happening, so some sort of precursor before would have been really good. Again, back to the wee fact sheet or something at the appointment to go, 'This is what it is.'

I think for me, I, would've been a bit more confident if the GP hadn't have said to me, 'I've done a little bit of reading on it and this is what I think of it.' It would've been really helpful if he had been really well informed himself first before passing that information on. For me, it was if he was confident and understood the medication really well and was able to go, 'I've done what I need to do. I can confidently say, "Take this"' whereas when that didn't come, it was like, right, I'll go and have a wee look myself .

I think again, going back to having some form of physical documentation of what he is saying would improve it a lot. It would've been better, I think, if instead of just generally saying, 'There's probably less side effects,' cos I'd already been worried about the side effects and that's why I had turned up, if he had been able to sit with me and say, 'Right, these are the common ones and what I would be expecting for you to be getting, these are the less common ones and if you get them, that means we need to change tack again,' kind of thing, and properly discussing and analysing the situation with me rather than just a very quick brief overview of it should be better.

I would've preferred to find out a lot of the information with the [specialist] as we were discussing whether or not to prescribe it and for that to have therefore been more of a conversation rather than just a statement, so I could be more informed and involved with the medications that I'm going on long term and again for him to have either sent me off with an information handout about the medication or if he had given me some sites to talk out to find information or written down the notes that he thought were important for me.

Initially, they [specialist] should have told me everything about it up front, I suppose…. He's the person who knows his particular profession…. Sometimes it's the attitude of the specialist….. The key things they would've told me would've been what are they, why I have to take them, what, if any, are the side effects and if there could be a reaction with any other of my meds….. Both [written and verbal] would have been good. My memory is like a sieve. Whether it's the meds or whatever, I don't know, but both. If I remember something later on that I didn't ask, then I can look it up.

Ideal cont.

Okay, she should have said, ‘I'm changing you from medicine A to medicine B and explained the reasons why but also explain that this particular medicine does have a side effect. That’s what she didn't do.

I think if they had access to that particular fact sheet, it would've been good. If you're doing something verbal, unless you're fully understanding everything else that's going on, it's too much information to take away…….either in paper or say, ‘Hey, what's your e-mail address? I'll e-mail you the details.’

I think they would've been familiar with my other health conditions, been prepared to provide me information about how this would relate to those and provide me with information to take away. Definitely, if there is some way to actually indicate beforehand that will be part of the discussion, would be helpful to prepare and improve the information sharing from both sides for that.

I think the language in certain things needs to be a little bit simpler because sometimes you're looking on MedSafe and it's all jargon that goes way over your head. I think the only thing that's really missing with information is more of layman's terms of how things work.

Basically having a bit more of a highlight on the things, interactions in particular for medication, like side effects, what's normal, what's not and I think clear information about normal side effects versus irregular side effects. I mean, I find when I get my flu jab or when I get any other vaccination, it's pretty clear when they've got the flow chart that's in front of you, I find that more helpful. It's not really like that when you get dispensed or change a new medication. There's no form that goes with it that a doctor could print off that’s not in medical jargon, so something a bit more simplified and access from your GP or doctor to where to look for the right kind of information.

what I need to know is the safety of it, length of time, is it long term or short term, what are the risk factors, do the benefits outweigh the risks, those kind of things are really essential when dealing with medications. There's a lot of misinformation out there. I think a place where somebody could just look up online that has got all the facts in an easy format for people to understand rather than like this drug … unless you actually have had some experience with reading that kind of jargon, you're gonna go, ‘What language is that?’ So, simplify it a bit, but get to the facts.

the benefits of taking the medication. I mean there's no point in being prescribed something if it's not gonna have a desired outcome. When you’re talking with your doctor about either starting a medication or being on a long-term medication, is it really worth it? Is it going to improve your life?

Ideal cont.

I think for me the whakawhanaungatanga is really important in terms of that trust and feeling like someone is there on your side to support you to flourish and to optimize your wellbeing…….. what could have been better was establishing that trust in the beginning so that I felt like I was talking to a trusted health provider as opposed to a person that saw me as an inconvenience and someone that I saw as an enemy…….I don't make decisions in isolation. I talk to my whānau about what's happening and I want to hear their opinions…… I think a verbal discussion with the upfront questions is great, but you need some written information to take away with you to discuss and then you also need a portal or a channel where you can go back and ask questions as well so that there's sort of more of a loop rather than just a transactional in and out…..I think when you're talking about medication for psychiatric disorders as well, they change the way that you feel, they change the way that you act, they change the way that you think about yourself. It's quite a significant medication. There's significant medications to go on. It's about having that space and time. That would be the ideal solution, I think for me, is establishing that trust, having a verbal discussion and then having the written information to take away and then, so you can come back with some questions afterwards.

With my specialist, he's usually the one that puts me on these medications. It would be nice to have a bit more directive about where to get further information cos hospital appointments can be very, very limited, and because you don't see your provider as often as what you'd see your GP, it would be nice to walk out of there with a bit more in the hand information about these kind of things, again written and simplified for people to easily understand, but also providing them with links of where they can look into it further, which will have the risks, the benefits, the contraindications, things like that, side effects.

So, it would be good if information between professionals was shared a lot faster, cos there's often a lot of delays between changes of medication, increase in dosage and things like that. When somebody goes into the next appointment, they go, 'I need some more meds,' they're like, 'When did you start that?' So, a bit more professional to professional communication would be good.

Access to a public link or a forum so that if there's questions that I've got come into my head when I've left the appointment, there's somewhere I can look to alleviate my anxiety. I think that would be the gap that's missing for me.

If there's clear bullet points about risks, benefits, simplified forms, I can actually absorb that a lot better than a whole bunch of words that all of a sudden I'm just struggling with.

I really needed to understand why the change in medication. I needed to understand what the justification for it was and why they recommended it and it's not that I didn't want to or I was resistant to it, or I needed to be convinced. I just needed the basic justification for it or rationale.

Ideal cont.

I mean, I think a good starting point would just be to go through the basic stuff with the GP. I think in this case, the pharmacist was obviously helpful, but again, I think it just comes back to what I've said again earlier, just getting the information in writing with the proper leaflet included with the medication I think is a really good place to start, especially when it's your first time with the medication, it's a new one. I think that's really useful.

The perfect scenario would be someone I have a really great relationship with, I'd be able to go in and talk openly and freely and say, ‘This is what's happening for me,’ deal with the immediate concerns and then be able to discuss any other health issues I might have instead of being rushed out the door. So, just having that time to be able to talk about all the things that might be worrying me about my health instead of, ‘You’re here for this purpose and now you’re gone.’

You Google it, and within two or three Google searches, you're coming across research articles which, of course, is not helpful to someone who's trying to just find out what it is they need to know. It would be awesome, if there was just something about, ‘Okay, here's the best place to go. It'll give you information.’

Change of brand

Experiences

- Some respondents found out about the brand change when the medicine was dispensed to them, others from patient groups and others from prescribers. Those who had prior knowledge (pre-dispensing) about the change were more comfortable with the change.
- There was a mixed experience, with some saying they were sufficiently informed about the change in brand and others saying the communication was very limited.
- The strongest concern about brand change came from those who said they had experienced negative unexpected consequences as a result of the change of brand.

Experiences

This particular time, I wasn't told there had been a change and it wasn't until I got home, I realised it was a change…. It went through my mind at the time, there's Pharmac changing subsidy again and I really didn't think more about it…. I started having problems, but I didn't at that time realise it was the medication…. The pharmacy, the pharmacist, they should then have advised that there were side effects and these were the ones to look for or even point out in the pamphlet that they give you, but it's a pretty standardised pamphlet. It doesn't really go into a lot of detail, that pamphlet they put in the medications….. I'd lost a lot of weight and I was really jaundiced, so when I went to see him [GP], he immediately started doing all sorts of tests. I then had a scan … …..I was sitting here one day and I thought that it was only after I started taking those pills. …. I said, 'I'm not taking them.' I was staving off going to hospital and I said to her, 'Just let me have another blood,' cos it was going every week for a blood test. I said, 'Well, let me just come in on Monday for my blood test and we'll go from there and I will make a promise to go and have it done if I have to.' By the time I went into the doctor's surgery on the Monday morning, I was virtually bouncing around and I said, 'I'm fine. I'm good. I'm as good as gold.'

Glaucoma New Zealand was my first point of contact regarding that change of medication. That's a support group for people with glaucoma. They communicated it a number of ways. E-mail was certainly one. I'm on their e-mail list, and also on their Facebook page….. Then, I discussed it with my specialist and he said that he would be very concerned with some changes of brand for medication, but he did not have concerns about this one and that I shouldn't notice any different or experience any problems, but to come back to him if I did…….I guess I was a little bit anxious because at that time, the epilepsy medication changes were in the news. You do feel anxious when you've been on a medication, which you've tolerated well, had no side effects really and then suddenly it's gonna change in four weeks' time. You do feel anxious about it, but I did feel reassured by what Glaucoma New Zealand were telling me and by what my eye specialist was telling me, that I shouldn't experience any major problems and I haven't….. For someone who wasn't tapped into Glaucoma New Zealand, for example, I don't know how they would've found out about it.

They prescribed the medication and he [GP] said, 'Look, it's just a generic, it's basically the same. It's really nothing to be concerned about. It's the same product.' 'Okay. Fine by me.' When I went to the pharmacist I did, and I asked him and he effectively confirmed what the doctor told me. It was pretty much at a good level of information provision that's for sure.

Ideal

- Consumers want proactive and upfront communication about any potential impact of the brand change.
- Consumers want full and accurate communication about brand change (*don’t say it is the same if it is not*).
- Consumers want communication from the prescriber and the dispenser.

Ideal

What I wouldn't have liked to have done is turn up at the pharmacy and the pharmacist just handed it over and say, ‘There's been a change of brand.’ That, I really wouldn’t have liked, but that didn’t happen for me.

Just potential side effects, length of time of taking it.

I think maybe they could have said to me, ‘Look, this is the change that's happening. There's no known side effects with this particular brand; however, if you do feel there is a change, come and see us straight away,’ something like that, or, ‘You can find information by contacting the pharmacist.’

Change of brand for medication that required monitoring

- Contextual note
  - 1 of the respondents spoke at a more generic level, about their experiences overall, rather than focusing on their CBM experience
  - 1 respondent appears to have combined their experiences of a change of brand of medication not requiring monitoring, with one that did require monitoring

Experiences

- Consumers had mixed of experiences of being advised of a change in brand of a medication requiring monitoring. One respondent had received a thorough explanation of the change from a specialist. The other respondents had found out about the change when they picked up medicine from their pharmacist and were told little other than that the medication would work the same as their previous brand had.
- There was frustration about the lack of communication about the change and one of the consumers attributed the brand change to serious consequences for their health.
- Consumers also had mixed experiences with information about monitoring. Most of the consumers had some long term experience with monitoring so learning about monitoring wasn’t key to the change in brand. One respondent was new to monitoring and didn’t understand the importance of regular monitoring, which resulted in a serious consequences for their health.

Experiences: general

Usually on the day I get it, the pharmacist will tell me that, ‘Oh, by the way, you're back on the same drug, but it's just been rebranded a different name.’ I don't like that way of doing things, because a lot of consumers from a mental health background, don't like change, because the medicine is the one thing that either keeps them out of hospital and alive.

It was the pharmacist who told us…..We were told, ‘It’s the same, it will work the same, you shouldn't have any problems,’ but that's all we were pretty much told, ‘It’s the same and it will work the same,’ and it didn't for either of us…..within a couple of weeks of me switching, I had made a plan to go and kill myself after being stable for about seven or eight years….. I switched back to xxx and it took me about 20 months to get back to where I was, so I had to also take xxxx because my anxiety got out of control because of the switch. Then, we had people like Keith Petrie saying, ‘You’ve got the nocebo effect.’

My pharmacist told me that the brand had changed…… Just that the brand had changed. It was the same medication, but the brand had changed….. The brands that I'd originally used were no longer being provided, so they changed the brand…….[it] wasn't until after I'd gone to a review meeting and said that I had diarrhoea and she said, ‘Probably from your xxxx.’ So they adjusted the amounts so that I wasn't experiencing diarrhoea so much.

She [oncologist] was very thorough in what she told me……it's an AstraZeneca drug, so I went onto the website because I was quite concerned about the side effects that I'd heard about, so I just wanted to be clear whether it was going to affect my quality of life. I mean, I didn't really have a choice as to whether I went on them or not, but I just want to know what I was in for.

Experiences: monitoring

It’s [monitoring] so that they can make sure that it's doing its job, from my understanding. I do blood tests once a month to keep an eye on levels and stuff like that. It’s on levels of different medications that I take…. They can adjust medication accordingly…. I've learnt to read the results and see where things are at monthly….. It's pretty clear to me at the moment.

I was supposed to have a blood test every four weeks, and then I knew I was seeing my oncologist two weeks after the fourth week came around. In my head, I was just, 'I'll just wait another two weeks.’ In those two weeks is when I fell over and the whole time I was thinking, well, I'm going to see her in two weeks anyway, so something's wrong, she'll sort it out, not realising if I'd had the blood test when I should have, then it would've been picked up way early than it was….. I don't think I realised the importance of why I had to have that blood test because it took me quite a while to tell them that I was in trouble, and then I was sent to A&E for an emergency blood transfusion. I just thought I wasn't feeling great, I didn't actually know that it would've been the result of the medication, to be honest, I just thought it was just getting over treatment or whatever. Whilst she told me that I had to do it, but I didn't realise the importance at the time, now I do.

I've had epilepsy since I was 10 years old, so I'm 51 now, so I've had it quite a while but I know I have to have the monitoring, but it should be on my GP or neurologist’s radar to do that for me as well…… I know that if I had a drop in my bloods, I could have a seizure, but since I've been in this country, I've only ever had one blood test and that's because I asked for it.

Ideal

- The primary change sought by consumers was having a consultation with the prescriber about the change of medication, rather than it being left to the point of dispensing.
- There was also interest in receiving information about how the medication is funded.
- One respondent also suggested providing consumers with a schedule to help them manage their monitoring requirements.

Ideal

The specialist should have given it to me, and they should have handed out something in writing. I mean, all of the pharmacists can create it. The prescribing specialist should be able to see from when they're looking at there, they have that drug book, they can see what are the side effects of having that medication.

I think a discussion with my GP would've been really good and also a discussion with the pharmacist who knows a bit more about drugs and the potential side effects…. When I filled out the first questionnaire, I initially thought I wanted my doctor to tell me, but I think the pharmacist knows more about the drugs, so I'm a bit torn. I'd rather probably have a conversation with both about it.

Only the funding side of it, probably where it came from and maybe the fact that it wasn't a common drug, like I discussed before. I don't think she really knew herself, to be honest. I think she was more like, 'Just go into your pharmacists and see what they know, what they can do for you,' and then we would've found an alternative if I had to, which is great, because that's the thing, that's where you rely on the pharmacy more to do, the dispensing side of it.

Maybe, I guess, maybe a schedule. I don't know, maybe so that it's like, you need to go for a blood test on this date and even now probably that's a good idea, because I'm quite diligent at putting things in my diary now, but I guess as life gets on, it's really easy to miss. I guess, even if they sent you a text or something, say your blood test is due, please, or you haven't had it or something like that, actually that'd be really good.

Supply issue with a medicine

Experiences

- Experiencing supply issues with a medicine was a disempowering experience for most consumers. Most consumers were informed about the supply issue at the pharmacy and felt they had no choice but to accept the absence of medication or a replacement medication.
- Most were given very little information about the change of medication and any possible impacts.
- The supply issue caused a serious health consequence for one of the respondents.

Experiences

A couple of months ago, I went to get it from the pharmacy and they're like, ‘There's nothing in the country.’ I’m like, ‘What? When's it gonna be back?’ ‘Don’t know, maybe August, maybe September, maybe October.’ I'm not supposed to just stop this, so that wasn’t fun. That was one of those medicines that you made you feel pretty awful when you abruptly stopped it as well……. Of course, we know the appointment to see my GP would've been three or four weeks away, so it wasn't a situation where I could just suddenly change to a different medication……Yeah and going to an after-hours or an urgent care doctor, they don't know you from a bar of soap, so not really in a good position to work out how to change things. It’s not quite that simple…….I did feel quite let down by the whole thing. You do your bit as a patient to try to do things in a way that’s suggested to you. You want to take it at the right time, so you get the best effect and you want to help out your own health, if that makes sense. Certainly, if you’ve got long term health issues, you do need to look after your health as best you can. You know what I mean. You've got to be motivated to look after your own health and do things right. You tend to be better off if you do that, so it was quite frustrating to find that you're doing all of those things yourself, but then all of a sudden, the system just drops the ball completely. I was pretty annoyed about that……Yeah, there was no information. There wasn't an information gap. It was just there was nothing……I jumped on Google, which is annoying because from the box, it says, ‘Don't stop this medication abruptly,’ but then I've got no choice and I don’t know what to expect.

…At the pharmacy, told that there was a substitution of medication…. the pharmacist says, ‘Hey, we don't have that medication. I'm gonna have to give you this one.’…I get no choice in the matter, so completely vulnerable. You’ve got no choice. Pharmac supply issue, you’re shit out of luck. You’ve just gotta take it on the chin……. it's disconcerting when you know that in the past you've had reactions to various medications. You do have questions……

….They couldn't get it into the country, so they put me onto a new tablet that had no water tablet attached to it. I told the doctor that something wasn't quite right and she asked me what. I said, ‘Well, I can't do number twos. I couldn't poo with it.’ …….She said, ‘Oh, we'll do it a month trial. Let it go.’ I kept saying to her, ‘I can't poo. Something's not right.’ …….it was a chemist that told me, because it had no water tablet attached to it, that made a big effect on my body…. They just tell you, ‘No, we've got to do this. We've got to recall this and replace it with this,’ but they still don't explain to you the side effects and everything that you want to know and stuff like that.

Experiences cont.

My chemist said, ‘Oh, we can't get such and such anymore. You're swapping….I said, ‘Well, what does that mean?’ ……they said, it acts in a slightly different way. I never felt reassured that whatever that slightly different way was, or no, it had slightly different components in it. I thought what components am I introducing that is going to change because it will change something in my body. But nobody was able to tell me what, so if the old one is working, then we can't get that anymore…….there wasn't any other choice I had to take it. . I felt backed into a corner over it. I took it. It's fine. It turns out….. Now, I could have insisted on that appointment [with the GP to find out more], but again, the pressures of the backlog of knowing a huge backlog for COVID on the health system meant that I didn't feel like having to that pressure. I took on some responsibility for the whole health system, not being able to cope, so I stayed away.

They actually didn't have supply in New Zealand for that particular medication, so the doctor rang me and told me that they were going to put me on a similar, like it had the same ingredients and stuff, but it wasn't the same pill. It was just a similar one, but they couldn't give me the one that I was on because there was no supply of that in the country at that time maybe cos of COVID and they couldn't get it in. That's when they switched me to another brand…. It was good because I could understand why and they weren't just going to stop it and leave me with nothing. There was a backup plan in place…. he didn't mention any side effects to look out for. I just assumed it would be the same.

Ideal

- Consumers want to be informed about supply changes in a timely manner, so they have the opportunity to seek information about the change and make an informed decision about their choice of replacement medication/arrange a replacement medication.

Ideal

I gathered Pharmac, or whoever it was, knew there was gonna be a supply issue a long way out. It seems strange that they've got all the information about who's taking it, who's prescribed it and they've got your contact details, but no one contacted me……Maybe if they'd sent out a text saying, 'Your next repeat, we're probably gonna have supply issues,' or something, 'Worthwhile catching up with your doctor before this.' …..I guess another thing is they could have notified the GP practice so that the GP could have contacted me or see if there was space available or something, if they'd actually communicated with the person who prescribed it, but again there wasn't any communication……The pharmacist was busy and stuff, but even if they had a sheet to give out or something, like this medication has been stopped, this is what you may notice. If this happens, call an ambulance or something.

Realistically, a bulletin through an e-mail because all the information is with the GPs, so I cannot understand how a GP could not send out the information. Also, that information is centrally stored, with the changes to the DHBs and things like that……What happens there? Maybe they can just send out e-mails to all concerned or involved people, customers and patients.

Well, you can't expect the GP to keep it, keep up with all the drugs anyway, what's available and what's not. It comes down back to the pharmacist to say, I think probably the pharmacist could work with one another because no doubt, some have greater stocks than others.

Change of medicine that has a different device to deliver the medicine

Experiences

- Overall, the experience of receiving information around a medication requiring a change in device were positive.
- Most respondents perceived they had been given the information they needed including sufficient guidance about how to use the device.
- There was one exception, with one respondent saying the medical professionals had assumed she knew how to use the device, when she didn’t, and that this had had serious health consequences.

Experiences: general

Interviewer: Okay, did you know about what the medicine might do for you?
Respondent: No, I didn't know, but they would have told me. I just forgot, I suppose.

My endocrinologist nurse, she was very good on explaining to me how much I needed and how I would arrive at taking the different amounts of insulin before food, with a scale that I use when I test my blood. She was very good at explaining when I would need to introduce more insulin, depending on the reading that I got from my meter.

I think this one was all good. I guess I asked about possible long term effects of steroid based ones, steroid based inhalers, cos I had seen an article somewhere about it, but the doctor discussed that and gave good info on that.

I was at the GP and I was actually just going for my WOF. That's when [GP] brought up the new inhalers. He said, 'I know that you've been on this for a long time. A new inhaler's come out now or a new preventer has come out now that I would like you to think about trying.' I mean, I can read and he gave me the new ethicals. He said, 'You can have a look if you want, cos I know you've got good understanding, so have a read. What do you think? Any questions?'….. I think it was fine. It was fully explained to me and I understood.

Experiences: Device change

You just twist the top to go and do the same thing…. It was easy…. He showed me. He showed me a dummy one and then it was real obvious.

They gave me a practice inhaler to show me whether I was doing the correct form and taking all of the medication in.

The doctor just explained it and it's simple enough that I could figure it out once I'd got it from the pharmacist.

It was very similar to what I already used. I mean, they have a … what do you call it? Like a mock inhaler or I guess a demo and they just showed me this is what you do, use a space or if you need to, so I was fine with the demonstration.

When I was given it, there was no, 'Unpack the box, this is what you need.' It was just, 'I'm gonna change it to something else.' It was just that and then really I was told, 'This might help you and it might be much better.' I don't recall him showing me this and I think I'm much more a visual learner. There was no unpacking the box or having an example in the GP office to say, 'This is what it is. This is how you use it.' …..Even when I went to the pharmacist, I waited for it and then they gave it to me over the counter, but there were no instructions. I remember having to go through the box, opening up the box, reading through the instructions and still not being very clear on how to use this device, which was quite different from the Ventolin inhaler. I have found that I've had to slowly understand better how to use it to get the most impact from it…. . I think at the time, they probably just assumed that the GP had given me all the information about the Breo, that I was then going to have. I think there's an assumption made that the GP has given you all the information, so they just dispense it essentially. I was fairly new to this pharmacist, so it was really, 'Okay, this is your medicine and it comes to you in the little paper bag,' all sealed up. They don't really go through this is what it's for and this is how you use it…. they just make an assumption that you know all of the stuff and you know where to find the information. It took me a while even just to understand cos again, I think I learn better when I'm shown things. I could pull out a pamphlet and it looks like Chinese, so that was the issue primarily. I wasn't sure how to use it. I felt really stupid going back. I mean I know it sounds really dumb, but I felt stupid going back to the GP. Again, you have to get a hold of the GP first and say, 'Well, actually, how do you use this?' I guess I could have gone back to the pharmacist and said I'm not really familiar with this new device, 'Show me how to use it.' The pharmacist was in xx and I live in xx, so that was not an option…. when using this device, there are certain things that you need to do, like ensure that after you've used, to rinse your mouth out properly cos the impact it can have too on your mouth. That was another piece of information that I wasn't aware of. None of that was communicated, so those were the gaps, the information not being broken down in a way that I understood what was important.

Ideal

- Most respondents were satisfied with their experience of receiving information around a medication requiring a change in device and didn’t seek change in the approach.
- One respondent wanted the prescriber and dispenser to change their approach by giving direction about how to use the device effectively.

Ideal

Put it on piece of paper, I would think.

Primarily from your primary carer, the GP, because that person is the one that dispenses, or I guess understands what you've told about your symptoms, so ideally from the GP would be really helpful, but on top of that, I could say the nurse that works in the clinic…..The other place would be….the pharmacist not to assume that the GP has given all of that information….. if you don't know what you need to know, then you can't ask.

Support People Information

How should any of your support people be provided with information about medicines you are prescribed?

Information for support people

- Respondents were asked how they would like information about their medication to be provided to their personal support people.
- Most respondents said they personally wanted to take responsibility for relaying information to their support people. Many said that if they were to pass information on to their support people they would prefer to have the information in simple written form – to help avoid passing on incorrect information.
- A few respondents said they wanted/needed to have their personal support people involved in consultations and/or provided with information directly by the medical professionals involved. This tended to be older people, in hospital settings and people with mental health conditions.
- We briefly interviewed two support people about their information needs as support people. Both support people felt they were appropriately informed (and didn't seek change in the approach to informing them), though one did note he needed to be proactive about seeking the information.
    - *It would be true to say that I may be seen as a third party at times. In which case, if I don't ask for the information, it may not be given to me, but I tend to be forward and asking questions…..I think the easy way around that is to have accompanying advice in some form that's accessible. …. Electronic, yes. Sent through the internet in an email form. I can read it, and it's quite useful if [consumer] can read it as well from her computer.*
    - *Her [consumer] medication information is quite confidential. Only if there is a change in medication or there supposedly could be a side effect, we are let know so we can keep an eye out for that. I think that works well right now because it also protects her privacy, but helps us keep an eye out for anything at worst that could possibly happen.*

Tracking

What would help you better track the changes and experiences you experience from the medication, to help you inform your health provider?

Tracking changes

- Many respondents said they had experiences tracking the impact of a medication on them. Some said they did so on paper, some using ‘notes’ on their phone and some memorised them.
- Some said they would be interested in having an app available for recording this type of information. This was generally the younger and more technically savvy respondents.

Settings

What do you think would be different about your information needs (both what you need to know and who from) if you were in the following settings (hospital discharge, renewal online/phone, GP).

Settings: As well as asking specifically about the different information needs in different settings, there was a lot of spontaneous discussion about experiences in different settings. The primary settings discussed were:

Setting	Insights
GP	This is where consumers have the highest expectation of having an established relationship which allows an informed and holistic discussion about medication - that enables the consumer to make an informed decision. This includes taking into account consumer life stage (e.g. has pregnancy now become relevant?). Sometimes this expectation was met.
Hospital setting	This is the setting where consumers feel the most vulnerable and are most likely to want to have a support person with them and to receive the information in writing. They also want expedient exchange of information about medication between medical professionals. Consumers receiving information about medication in a hospital setting often felt their information needs were not met (or if they were, they couldn't recall) or not passed on expediently to their GP.
Specialist	Experiences with receiving information about medication from specialists was disappointing for many. Consumers often felt disempowered, hurried and unable to seek further clarification. There was also perceived to be a lack of good information flow between specialists and GPs.
Repeat prescription online/phone	Consumers did not expect to be provided with information when ordering repeat prescriptions. But, some did note this was a missed opportunity to communicate about any changes in medication, new medication available and review the impact of medication (including possible pregnancy interactions).
Clinics	Some consumers spoke about the nurses/technicians working with them in clinics as being their most trusted source of information about medication.
Pharmacy	There were mixed views on the role of pharmacists in disseminating information about medication. Some consumers relied heavily on their pharmacist to inform them, others had little or no expectation of their pharmacists. Experiences with pharmacists (largely positive) featured heavily in the research, pharmacists clearly play a very important role as an information conjoint and safety-check for some consumers. As this was an often discussed topic we have included some quotes about the role of the pharmacist on the following slide.

Pharmacist

They’re [pharmacist] really busy, but on every occasion, they have said when there's been a change in the meds or things like that, they picked up on it and notified me. One of them, there was an error in the prescription and it was the pharmacist that picked it up and said, ‘Were you aware there is a change? The dosage has been doubled.’ I said, ‘It’s not supposed to be.’ That was quite fortunate we picked up on that error.

Yeah, they [pharmacist] actually have back sheets. They actually will go and get you a fact sheet on something and they will give it to you, which I found is really quite helpful too, which is quite neat because some people don't access or don't have access to the internet, especially here ….. A lot of people are still very old school and my generation, some of them don't have the privilege of these flash phones or the tablets or a computer. The information that you get from the chemist or the one that I deal with is, they are really fantastic.

I've had times where actually when the pharmacist said, ‘You shouldn't be taking these two things together,’ which I don't find helpful because then you're making me as a patient decide whether it's right to take them instead of maybe talking to the doctor to say, ‘Why have you prescribed these things together or asking me what's happening?’ Because then that just has made me go for my doctors who I've got the relationship with has told me these things. Now you're giving me a concern and I don't know what to do because obviously the expert in the medication is the pharmacist.

There's always a queue. Most times I get served by not the pharmacist, but the women who run the shop, do the shop part of it. They don't know. If you ask them a question about medicine, they go and find a pharmacist, but often, yeah, there's usually a queue so it's not that easy to just go up and ask a question. Yeah.

I guess it could be either the doctor or the pharmacist, but everyone's really busy. I think the fact that when you go to pick up the medicine, I think that's a good place to get that warning information. The pharmacists themselves are much more focused on the drugs and the ins and outs of them. Obviously, the doctors are too, but their main focus is what you've got, what can I give you to alleviate that and then I think the pharmacist is a good port of call.

I think pharmacists are probably the better place to go and get that information about the medication potentially, because, I mean, I guess they deal with it more often….. I would say so because pharmacists probably deal with the medication, like I said, more than the GP does. The GP prescribes it, but I suppose a pharmacist is more likely to know what the effects of it are.

Most of my information, I actually get from my pharmacist, who when he dispenses a medicine, explains to me what it's all about, tells me about the side effects and things like that. And I think they're really fantastic, the pharmacists from the chemist….. I give my ups to the chemists, the pharmacists who actually take the time out to explain to their customers, this is a medicine. This is what you've got. This is what it does. This is the side effects. And sometimes when they can't fulfil your medicines and they replace it with a replacement, they explain that to you too in really good details, which I think is very fantastic. So I've had more of a rapport with the chemist staff than the GP practice that I'm under.

Advice to Medical Professionals / Closing Comments

Themes

- Respondents were asked what advice they would give to medical professionals about how to inform consumers when prescribing/dispensing medicine.
- The key themes in the advice were in the areas of:
    - Being upfront about the purpose of medication, possible interactions, side effects, what to look out for and longevity of medicine use
    - Engaging, listening, understanding, checking in and allowing informed choice
    - Building relationships, giving consumers time, giving consumers reviews/reminders
    - Being respectful to consumers
    - Tailoring format, language, presentation and accessibility to meet the needs of the consumer
    - Providing a Kaupapa Māori approach, being culturally aware and mindful of language choice
    - Improving communication between medical professionals
    - Enabling pharmacist safety checks.

Purpose of med/interactions/what to look out for/longevity

- *Well, if I'm going to be informed by nurses or doctors, I want to know everything. I want to know what the medicine is, does it work, does it work on people, how long has this medicine been around. I want to know the side effects, what can happen and because every human being, their bodies are different, how it affects some people and not affect others. I suppose I don't want them to miss out on anything.*
- *They can't assume that their patients know as much about medication and side effects and interactions as they do, which is something I feel sometimes they forget cos if you spend so long in that knowledge, it's hard to remember that other people don't have that same starting point, but at the same time, just because the patient doesn't know or understand as much about the basics of the medicine doesn't mean that the patient shouldn't be having an informed opinion about how they are being medicated and treated......they need to help the patient get all the knowledge they need to make that decision properly and be well informed in making that decision.*
- *We shouldn't have to find the information ourselves and…... The doctors and the specialists, and even the pharmacists, they should be providing, or offering, the information.*

Purpose of med/interactions/what to look out for/longevity

- *I guess why the change is happening, what side effects I may experience and the significance of those side effects, how it might interact with other medications, particularly where you've got really diverse health conditions, what are the red flags as far as symptoms? You might have symptoms that are just quite routine and a bit of a nuisance, but you might have a really red flag that you should advice urgently.*
- *I would tell them that they need to spend time explaining the purpose of the medication. The possible, like I said, contraindications to any other medication you're taking, and really explain the side effects because it's a trial and error thing, but you can reduce side effects early, people don't have to endure the side effects thinking, oh, I'm old or it's my weight, if they give that information early.*
- *Any possible side effects, what the medication is actually used for and how long I will have to take it.*

Engage/listen/understand/check in/informed choice

- *Talk to your patient, ask them what they know and then give them the information again and make sure it's backed up with some written information for them to take away.*
- *Maybe just listen, don't assume. I don't know. I feel like sometimes that's the feeling that I get sometimes, a lot of assumption.*
- *I think you've got to include that it's okay to involve the patient. They know their bodies and their minds better than any doctor will do. I'm lucky my doctor at the moment, always asks me, what do I think of that particular idea? To me, that's showing me the mana that I've earned, because I don't know if all doctors give the patient the mana they deserve. I think that needs to be in your report is that, if you can enhance the mana of your patient when you're prescribing something, then the patient's more likely to take it. …….You enhance the mana of the person you're trying to help, then they're going to be more willing to seek help in the future.*
- *I think maybe really asking the patient, 'Did you understand all this or should we start again? Do you need to write this down?' Maybe providing time for the patient to write it down or note it down and ask questions back cos sometimes you just feel quite rushed in those appointments to be able to ask the questions, so just asking them to relay back what they've heard.*

Relationship/time/reminders

- *To build a really trusting, positive working relationship. If I think about myself and I think about a lot of my whānau, if that trust and that relationship isn't there and I think I like the word you used earlier, it just becomes transactional. If they really …. support, encourage and help us to be part of our own change, that's key......*
- *I feel sorry for the doctors [laughter]. They're just overloaded and it's understandable.*
- *Well, sometimes saying it once is not enough, because just about every time I think they should take the time to say, 'How's your list of all the different ones?' What it's doing for me and what they are seeing still functioning with the measures from the blood tests are saying this and that, that means those things are working well. It would be good to have reminders and not just to assume that I'm just taking what they prescribe and not thinking about it.*
- *Yeah, so I guess my advice would be, and it's a really tricky one because there's a whole structural issue with the way that the healthcare system works, where GPs especially are forced to deal with a lot of patients, but I just wish that when you see a GP, you could actually spend a bit more time with them instead of being forced out within 10 minutes. That would, I think, allow them to spend the time with a patient, make sure they really understand everything, like their condition, all their medications, what they're prescribed for, etc., rather than feeling maybe having no clue what the heck they're actually taking or what it's for. Especially if you're taking multiple things, you might have no freaking clue what you're taking.*
- *I think, taking the time is really important, and making sure that I feel okay about it. I don't know. It almost seems like luxurious these days to be saying these things because the GPs are under so much pressure, and so many people are really sick. It seems a bit luxurious to say, 'Well, can I please spend my 15 minutes calming my anxieties about taking a new medication?' You know, they might, 'Are you bleeding? Have you got COVID? Have you got a broken leg? Go. Get out of here.'*
- *I think that's where a lot of medical stuff gets lost because they don't have the time to explain it properly. You go to a GP, you get 15 minutes if you're lucky. You go to a specialist, you're lucky if you get 10 and yet they're prescribing life-changing drugs?*

Respect/tone

- *Don't talk from an ivory tower, the people that you’re talking with are human beings too and you’re a human being too. Just bear that in mind. I think that that speaks to a lot broader of the medical profession than just dispensing medication, that we're all human and bear that in mind and treat people with respect and ideally be treated with respect too.*
- *Don't patronise us, just because you've got a medical degree. Seriously, I know more about my drugs.*

Format/language/presentation/accessibility

- *Use……human or patient language, not medical. Quite often you'll get the name of the medicine and then you look at the prescription and it's nothing like what you thought you've heard them say to you. It's spelled differently, so that sort of thing.*
- *Probably to keep it simple and basic. You can get those fact sheets and you don't understand the words......The terms used are too clinical. If they just used basic English to explain it and maybe give references to where they can go to if they need extra advice or support.*
- *Make sure you know the person's preferred format so they can access the information. E-mail, large print, braille, audio. We must have it in our preferred format.*
- *Print me out something, hand me something, e-mail something. Just give me something to take away so that I'm not like, 'We had this conversation for half an hour and we talked about 50 things and here are 30 that I can remember and 20 that I just hope weren't important.'*
- *I think part of it is in building that relationship is getting to know what the best forms of giving information to someone is. For me, if it's in writing, perfect. For others, just knowing a bit more about what is it that'll make it easier for someone like me to receive that information, process it, comprehend it, and then be able to do what I need to do instead of looking at something and going, 'Okay, it wasn't that important. I'm not taking it.'*

Format/language/presentation/accessibility contd.

- *Asking each person what is your preferred method of communication. That's not just that can be around directions of dosage and directions of taking, side effects, all of that part of it, but also labelling and the medication.*
- *I think any explaining of what these drugs or what these medicines are going to be doing to your body, to have a diagram or something, like you can see what is actually happening to the body after these medicines are consumed, just to have more of a visual to the brain so they can understand more in-depth about what is happening inside them rather than words.*
- *I would say, 'Provide information in a language that the patient understands and make sure that they understand as well and provide them the opportunity to ask questions and not to be dismissive, but also not to be confronting.' By that, I mean some people go, 'Do you have any questions,' at the end? Of course, when you're asked that, you don't know, but allow them time for processing thoughts and allow them the opportunity to think about what they need to do and also who to contact if they have any further questions afterwards and also I guess where they need to go to collect their prescription or if there are certain things that they need to be aware of, if it's a drug that's not so common.*
- *It would be to make sure that you are telling the full information to the person sitting opposite you so they can have informed consent and informed choice…..The only person who will be able to know what the right decision is, is the person sitting opposite the healthcare professional, because they're the one living their life, so they know what they can handle or not, but without having the full information, informed consent and informed choice cannot occur and it can have devastating results.*

Kaupapa Māori/culture/language

- *I would really like them to explore Kaupapa Māori ways of doing things, because it’s not just advantaging Māori, but it's actually advantaging everybody. It's privileging upholding people’s mana and it's privileging a personal trust-based relationship, which is really hard to find, but when you're talking about maternal mental wellbeing or psychiatric disorders or things where humans are having very human experiences, they need to be met at a human level. I really feel like there's a lot to be learnt from te ao Māori ways of doing things.*
- *From my perspective, it's really important that health professionals understand the way in which non-Kiwis, non-New Zealanders, I guess non-mainstream people, understand or are able to communicate or understand information. I think that's really critical when we've got such a diverse population here in Aotearoa and the need to ensure that people have the right information in a way that they can understand. If that's about cultural competence, then I think it's really critical that they do that.*
- *I think certainly have cultural considerations around medicine use and understanding cultural beliefs and world views that may come into play and impact on the way that the client adheres to the treatment or the use of the medicine. So, I think cultural considerations and also looking at taking an individualised approach in the way that they provide the level of information to their clients.*

Communication between medical professionals

- *I think it needs everybody right from a person presenting at a general practice and seeing their own doctor, if they have to be referred into a bigger service or referred to hospital, that that information gets transferred with the patient and that that information is actually read by the treating team at hospital because I can hands up say it doesn't get read. You present, they look at the sheet to see why you're there and that's it. They don't look at the letters or the medication, unless you are somebody that can say, 'Hang on a minute, here's this letter. You need to read this.' That information just gets lost.*
- *Also, they [medical professionals] need to talk to each other a lot more, so there's no confusion. Yeah, read notes a bit more, listen to the colleagues a bit better.*
- *Particularly at hospital level to GPs, better form of communication if a specialist has adjusted a medication, because sometimes the reports can take up to about a month to get to your GP. If you're on a trial of medication, that can be quite difficult for your GP to catch up when they have to find the special authority and all that kind of things that go with it. So, ensuring if there's a change of medication, there's a form for professionals to fill out that will automatically go to the patient's GP to alert them that there's been a medication change and for what, so if this person loses their medication or needs the medication, there's not gonna be any delays in it.*

Pharmacist checks

- *To even the pharmacists, going down to the pharmacist, if they could just say to every single person, ‘Please read the side effects of this medication,’ if it is something which is an ongoing medication and also if there's any supplementation that anyone should be starting whilst taking that medication.*

Implications and Opportunities

Implications and Opportunities

- Consumers want medical professionals to build relationships with them, to give consumers time to engage, consumers want to be respected, heard, understood and empowered.
- Consumers want to have informed choice in their medications. They want to understand the rationale for the medication recommended. Consumers want to understand the pros and cons of the medication and they want to feel empowered to contribute to the decisions about the medication they are prescribed.
- Consumers want easier access to health professionals, so they have timely access to appointments and sufficient time within the consultations to make an informed decision about their medication.
- Consumers want to be provided with clarity about: the purpose of the medication, any possible side effects, interactions with other drugs (prescribed and not), how to use the medication (e.g. dosage, timing and foods to avoid) and the timeframe for the medication (e.g. how long they will need to use the medication for and when reviews will happen). There are exceptions to this, with a few mental health consumers saying anything other than a small amount of information can increase their anxiety about a medication.
- Consumers tend to want more thorough information about long term medications than they do for short term medications.

Implications and Opportunities

- Consumers want information about medications to be tailored to meet their needs, in terms of format, presentation and accessibility. In particular, as well as verbal information, most consumers want brief written information in simple language, made available to them.
- Consumers do avidly ‘google’ for more information about medicines. Consumers suggested that this could be guided by providing links to trustworthy websites (though these links in isolation are not sufficient information).
- Consumers want to see a joined-up approach to informing them about medication. They want the information to be consistent and comprehensive across and between different parts of the sector (e.g., hospital registrar, external specialist, GP and pharmacist).
- Some consumers want medical professionals to demonstrate cultural competency, including providing a Kaupapa Māori approach, being culturally aware and mindful of their language choice.
- Some consumers want pharmacists to provide detailed information about medications. Including how to take the medication and possible side effects. Some consumers also expect pharmacists to maintain an overview of their medication and the ability to determine if any errors have been made at the point of prescription. It was clear that the strong relationships some consumers had with their pharmacists greatly enhanced their experience of receiving information.

Implications and Opportunities

- Consumers want any changes in medication (e.g. supply issues, brand change so on) to be communicated proactively and with comprehensive information (as sought for new medications). Consumers do not want to feel cornered into accepting a change in medication when they collect their prescription.
- Some consumers identified patient support groups as being a viable and credible source of information about medication changes.
- Consumers want to be proactively and comprehensively informed about the implications of the medication for the consumer and baby in pregnancy. They want this to be proactively provided both at the point of prescription and throughout the lifecycle of the consumer (e.g. pregnancy may not be relevant at the time of initial prescription but may become so later).

Report available online at www.hqsc.govt.nz

Appendix

How well has the information met your needs?

Segment comparison by key demographics