Trainee Intern Health Care Evaluation Project

Patient and clinician attitudes to OpenNotes

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He aha ngā whakaaro o ngā tūroro rātou ko ngā nēhi, ko ngā rata mō te 'Pūkete Tuwhera'?
Patient and clinician attitudes to OpenNotes

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Nā
Te Tari Hauora Tūmatanui
Te Whare Wānanga o Ōtākou
Ōtepoti, Aotearoa

Word count/Ngā kupu = 7250

Unuhia te rito o te harakeke,

Kei hea te kōmako e ko?

Ka huri ki uta

Ka huri ki tai

Uia mai ki a au,

'He aha te mea nui?'

Māku e kī atu

'He tangata, he tangata, he tangata.'

If you remove the central shoot of the flax bush,

Where will the bellbird sing?

Turn inland

Turn seaward

Ask of me,

'What is the most important thing in the world?'

I will tell you

'It is people, it is people, it is people.'

ABSTRACT TUHINGA WHAKARĀPOPOTO

Objective: To assess patient and clinician attitudes towards OpenNotes

Design, setting, and participants: Cross-sectional survey across General Practitioner (GP) practices in Dunedin, Invercargill, Lawrence, Alexandra and Timaru, including 85 participants

Results: The response rates for patient and clinician surveys were 66% and 44% respectively. Regarding baseline characteristics for patients, the largest proportion were between 18-30 years old, of NZ European/Pākehā ethnicity, and of female gender. For clinician characteristics, the majority of responses came from nurses, and health practitioners with 10-20 years of experience in their clinical field.

Overall, the majority of patients and clinicians agreed (somewhat or strongly) with the benefits of OpenNotes. Concerning harms of OpenNotes, patients were more likely to disagree with compared to clinicians who tended to agree with potential harms. Overall, 75% of patients were for (somewhat or strongly) having OpenNotes used at their medical centres whereas clinicians were more evenly distributed between for and neutral, both receiving 47% of responses. A total of 37 qualitative responses were collected out of n=55 (67%) patient surveys and 19 out of n=30 clinician surveys (63%). Four main themes were identified across patient surveys and three main themes were identified across clinician surveys.

Conclusion: Overall, our survey demonstrated largely positive attitudes towards OpenNotes by both patients and clinicians. However, there were challenges with the methodology of the survey including a short data collection period. A small sample size limited the generalisability, and the results were likely impacted by non-response bias. Implications for future studies include a need for careful consideration of methods of data collection and a more in-depth analysis of a New Zealand perspective.

INTRODUCTION KUPU ARATAKI

The clinician-patient relationship is a concept that has become increasingly accepted among the medical community as a key determinant underpinning patient outcomes (1). Historically, this relationship reflected a predominantly paternalistic approach where the clinician was responsible for decision making for the patient. However, the model of mutual participation proposed by Szasz and Hollender (1956) argues that a sense of equality between patients and clinicians is mutually advantageous (2, 3). This model requires equal power, satisfaction, and independence, which may be reflected in the ongoing paradigm shift within medicine (3). Thus, patients now seek greater control over their health, particularly through active involvement in decision making and ongoing management.

To facilitate this more active patient role, General Practitioner (GP) practices in New Zealand have started to offer patients access to their health records through online patient portals. Through these portals patients are able to read notes from their consultations with clinicians, confirm their medical conditions and medication regimes, and view their laboratory and radiology results. This is based on a similar system adopted by other countries such as the United States of America, Australia, Norway, and Portugal (4). The ability of patients to read notes from consultations within their patient portals is facilitated by a movement called OpenNotes.

A number of studies have investigated the perspectives of doctors and patients towards OpenNotes access. The majority of patients supported being able to view their medical record (5, 6), and in a study where patients were given access, 99% recommended that this continue (7). Furthermore, several studies have found that patients who read their medical file report better understanding of their medical conditions, are better able to remember their care plan, feel more in control of their care, and have better medication adherence (4, 7-9).

Additionally, patients with access to their medical notes are able to share this information with care partners. One study demonstrated that from the three centres included in their sample, 20% of patients from two centres and 42% from another reported sharing their notes with others. This was associated with more informed discussions about the patient's care plan and better communication with clinicians (7, 8).

The most common concern of patients about OpenNotes access surrounds privacy. One study demonstrated that over one-third of patients reported privacy concerns (10), while another showed that almost 50% disagreed that records should be available online (6). Patients may be afraid of health information being disclosed to employers, government agencies, and unauthorised parties, preferring sensitive information to be coded or hidden.

Other potential risks of OpenNotes access include increased anxiety, misinterpretation of notes, and not understanding notes. Patients whose notes were not available to them were more likely to be concerned about these risks (5, 6) compared to those who had been given access (7, 8, 11). However, Bell et al. argue that health record transparency may mitigate some of these concerns, instead increasing patient understanding of the consultation and care plan and strengthening the trust of patients with their provider (11).

Conversely, clinicians were more likely to anticipate concerns about OpenNotes and less likely to agree with the purported benefits (5, 6). Clinicians anticipated that OpenNotes would yield an increased workload from clarifying their documentation and managing patient anxiety. Moreover, following the introduction of OpenNotes, some clinicians reported taking more time to write and edit documentation to reduce potential confusion and worry (7). However, Delbanco et al. demonstrated no significant difference in email volume associated with the introduction of OpenNotes, while a subsequent study reported only 7% of patients contacted the practice with questions related to their notes (7, 11). Hence, the literature remains conflicted regarding the potential impact of OpenNotes on clinician workload.

A limitation to the current literature on open access to medical notes is its international origin which may restrict applicability in a New Zealand context. Thus, this study aims to investigate the perspectives of patients and clinicians in New Zealand towards OpenNotes.

Additionally, it is also important that implications of OpenNotes must be considered for Māori. Lee and Sibley discussed demographic correlates with healthcare and noted that those of Māori ethnicity exhibited lower satisfaction (12). Thus, if acceptable to Māori patients and clinicians, OpenNotes may present a means through which healthcare satisfaction could improve. Signal et al. interviewed Māori patients living with multimorbidity and highlighted accessing appointments and sufficient consultation times as barriers in dealing with the health system (13). Te Karu et al. furthered these points by emphasising cultural, financial, and time barriers which impair healthcare access and understanding (14). However, Signal et al. also mentioned good communication and continuity of care from healthcare providers as being valued (13). Thus, OpenNotes may provide an avenue to further close a gap between healthcare experiences of Māori and non-Māori by improving communication and continuity of care. It may also potentially overcome some financial barriers by reducing the need to contact a GP practice directly with queries or points of clarification. Finally, Jansen et al. discussed inequitable experiences of Māori versus non-Māori in a general practice setting, where Māori are less likely to be offered choices, be seen on time, or be seen within their preferred time frame (15). Thus, OpenNotes has the potential to make a positive contribution to Māori experiences at GP practices through improving autonomy in healthcare decisions and improving access to medical information. Furthermore, this

literature further supports the notion that GP practices as an institution still act as a barrier to equitable health care for Māori. Thus, it is imperative that OpenNotes is acceptable to Māori so as not to exacerbate the current equity issues in existence in New Zealand.

METHODS TUKANGA

Participants

A total of 83 patients and 68 clinicians from Invercargill, Dunedin, Timaru, Lawrence, and Alexandra, New Zealand were approached to fill out the survey. In an attempt to recruit a generalisable cross-section of participants, several avenues were used for recruitment including face-to-face at GP practices, via personal emails, and contacting known WellSouth practices also through mass emails to the members of The Royal NZ College of General Practitioners (RNZCGP).

Inclusion criteria were:

- People aged 18 years and above
- Both those who had used OpenNotes and those who had not used OpenNotes
- Clinicians or patients within the Southern DHB or South Canterbury DHB region.

Patients were defined as persons who attended GP practices to receive medical advice or care.
Clinicians were defined as primary healthcare providers and included doctors, nurses, and nurse practitioners.

Exclusion criteria were:

- People aged 18 and below.

The study was approved by the Human Ethics Committee of the University of Otago, Dunedin, New Zealand, and Māori Consultation was sought via the Ngāi Tahu Research Consultation Committee.

Data collection

The cross-sectional survey was administered from April 2019 to May 2019. Surveys were administered both via an online version and on paper (hard copies). Consent and eligibility were established using check boxes (online version) that had to be completed before the participant was allowed entry to the survey, or using signed consent forms (hard copy version).

The survey

The survey questions were based on current literature (6, 7). The survey was designed and hosted using www.SurveyMonkey.com (Survey Monkey Copyright © 1999 - 2019 SurveyMonkey.com). A pre-test was electronically administered to five medical students to verify survey functionality and understandability and the survey was modified based on the pre-testing results. To assess that the survey was fit for purpose, feedback from the client (WellSouth) was also sought. Following this feedback

modifications were made to the survey including having an equal number of barriers and benefits within each survey.

Two online surveys were developed; one for patients (Appendix 1) and one for clinicians (Appendix 2). The surveys asked many of the same questions and followed a similar format of being divided into four main sections:

1. Demographics
2. Benefits
3. Harms
4. Overall opinion of OpenNotes

Description of OpenNotes included in the Survey

OpenNotes allows patients to access clinician notes written during consultations in their GP practice via a secure online patient portal (i.e. Manage My Health or Connect Med). The patient portal may also include laboratory test results, as well as a list of patients' medical conditions and current medications. This survey is on your attitudes about OpenNotes only, not on a patient portal overall.

Table 1. Overview of data collected in the patient survey

Survey section	Data collected
Section 1: Demographics	Participants were asked: age, sex, ethnicity, education, computer literacy, access to internet at home, how often they saw their GP, availability of Open Notes at the practice they attend, and access to Open Notes
Section 2: Benefits	Participants were asked if they thought they would: better understand their health and medical conditions, better take their medications, feel more in control of their healthcare, feel better prepared when visiting the GP, and feel doctor-patient communication is improved
Section 3: Harms	Participants were asked if they thought they would: worry more, find it more confusing than helpful, have decreased confidence in their health provider, worry about misunderstanding medical terms, and worry about privacy
Section 4: Overall opinion	Participants were asked: overall what they thought about Open Notes and if they thought Open Notes should be used at their current practice

Table 2. Overview of data collected in the clinician survey

Survey section	Data collected
Section 1: Demographics	Participants were asked: current role, years of experience in their profession, if their practice was using Open Notes, how often they use Open Notes, what percentage of patients they think use Open Notes, and if they would use Open Notes if it was available at their practice
Section 2: Benefits	Participants were asked if they thought patients would: better understand their health and medical conditions, better remember the plan for their care, feel better able to take care of themselves, be better at taking medications, feel more in control of their healthcare, and feel better prepared for consults
Section 3: Harms	Participants were asked if they thought: patients would worry more from reading their notes, patients find it more confusing than helpful, patients would feel less confident in their practice, patients would misinterpret their notes, there would be disruption of work due to patients querying about results and healthcare, and if they would worry about focusing too much on making notes patient-appropriate and therefore feel pressure to be less candid about clinical observations
Section 4: Overall opinion	Participants were asked: overall what they thought about Open Notes and if they thought Open Notes should be used at their current practice

Data analysis

Quantitative data analysis

Data was downloaded from Survey Monkey as a CSV. file and all data were analysed based on the question asked. For all information except ethnicity and the qualitative component, participants could select only one answer.

Information on ethnicity was collected using the 2006 NZ Census of Populations and Dwellings question as recommended by Statistics NZ. Participants who nominated two or more ethnic groups were assigned to a single group using the prioritisation system recommended by Statistics NZ, with the order of priority being (from highest to lowest): Māori, Pacific, Asian, Other, NZ European/Pākehā.

Exploratory analysis was carried out to investigate any apparent patterns among those who identified as Māori and their views on OpenNotes. Due to a very small sample size this was only exploratory in nature and no inferences have been drawn.

Questions on the individual benefits and harms were collated into graphs to display benefits as one graph and harms as another. This allowed visual comparison of responses to each benefit compared with other benefits and each harm compared with other harms.

Statistical analysis of the data was carried out to give descriptive statistics only. These are presented as number and percentage. No statistical inferences have been drawn from the data due to the lack of representativeness of the sample and, with respect to possible sub-group comparisons, the small sample sizes and subsequent low power.

Qualitative research arm

The survey also asked participants an open-ended question of 'Overall, what do you think about OpenNotes?'. The aim of this question was to collect qualitative information and allow a broader understanding of patient and clinician perspectives on OpenNotes. Themes were then identified from the manifest content (the visible, obvious components) of the qualitative responses. This analysis approach was used with the aim of extracting and reporting on the descriptive level of content and not to provide a deep level of interpretation and underlying meaning. These themes were, as far as possible, defined so that they were exhaustive and mutually exclusive. Each theme has been summarised and illustrative quotes are included.

RESULTS NGĀ OTINGA

A total of 151 participants (83 clinicians and 68 patients) aged 18 years and above across five GP practices in the Southern DHB and South Canterbury DHB regions were approached. Out of the 151 participants, n=85 (30 clinicians, 55 patients) completed the survey.

The characteristics of the patients that participated in the study are displayed in Table 3. Of the 55 patient responses, the greatest proportion were of the 18-30-year age group (n=19; 35%). There were slightly fewer in the 31-45-year age group (n=14; 26%) and equal numbers in both the 46-64 years and the 65+ years age group. The majority of the participants were New Zealand European/Pākehā (n=37; 67%), followed by Asian (n=11; 20%), Māori (n=4; 7%), Pacific (n=2; 4%), and Other (n=1; 2%). Of the 55 patient participants, 62% (n=34) were female, 38% (n=21) were male, and none were gender diverse.

A total of n=30 clinician responses were collected (Table 4) of which n=10 (33%) of the respondents were General Practitioners, n=17 (57%) were Nurses, and n=3 (10%) were Nurse Practitioners. The largest proportion of health practitioners had been working in their respective fields for 10-20 years (n=9; 30%). Data on clinician ages and ethnicities were not collected.

Most of the patients surveyed reported seeing their GP at least once per year (n=47; 85%) and n=8 (15%) reported visiting their GP less than once per year. Only n=11 (21%) of patients reported having OpenNotes available for use in their GP practice with n=7 (13%) having actually used OpenNotes. Of the patients who did not currently have access to OpenNotes, more than half (n=25; 54%) said they would use it if it was available. Forty-six percent (n=21) were unsure or would choose not to use it.

Of the n=30 clinician responses collected, six (20%) did not respond to the question 'On average, how often do you use/access OpenNotes?'. Evaluation of individual responses showed that five of the six non-responders did not have OpenNotes at their practice. It can thus be likely assumed that these participants did not think this question was applicable in their individual cases and as such left the answer blank.

Table 3. Characteristics of patients

Characteristic		n (%)
Age (years)	18-30	19 (35)
	31-45	14 (25)
	46-64	11 (20)
	65+	11 (20)
Ethnicity	Māori	4 (7)
	NZ European/Pākehā	37 (67)
	Pacific	2 (4)
	Asian	11 (20)
	Other	1 (2)
Gender	Female	34 (62)
	Male	21 (38)
How often do you see your GP?	Once per week	1 (2)
	Once per month	4 (8)
	Once every 3 months	14 (27)
	Once every 6 months	17 (33)
	Once per year	8 (15)
	Less than once per year	8 (15)
Do you have access to OpenNotes at your medical centre?	Yes	11 (21)
	No	41 (79)
Have you ever accessed OpenNotes?	Yes, more than once	6 (11)
	Yes, but only once	1 (2)
	No	48 (87)

Table 4. Characteristics of clinicians

Characteristic		n (%)
Type of clinician	GP	10 (33)
	Nurse	17 (57)
	Nurse Practitioner	3 (10)
Experience (years)	Less than 10	7 (23)
	10-20	9 (30)
	21-30	3 (10)
	31-40	8 (27)
	41+	3 (10)
Is your practice using OpenNotes?	Yes	16 (53)
	No	14 (47)
On average, how often do you use/access OpenNotes?	Daily/Several times per week	10 (42)
	Once per week	2 (8)
	Once every 3 months	1 (4)
	Once every 6 months	1 (4)
	Never	10 (42)
	Did not respond	6 (20)

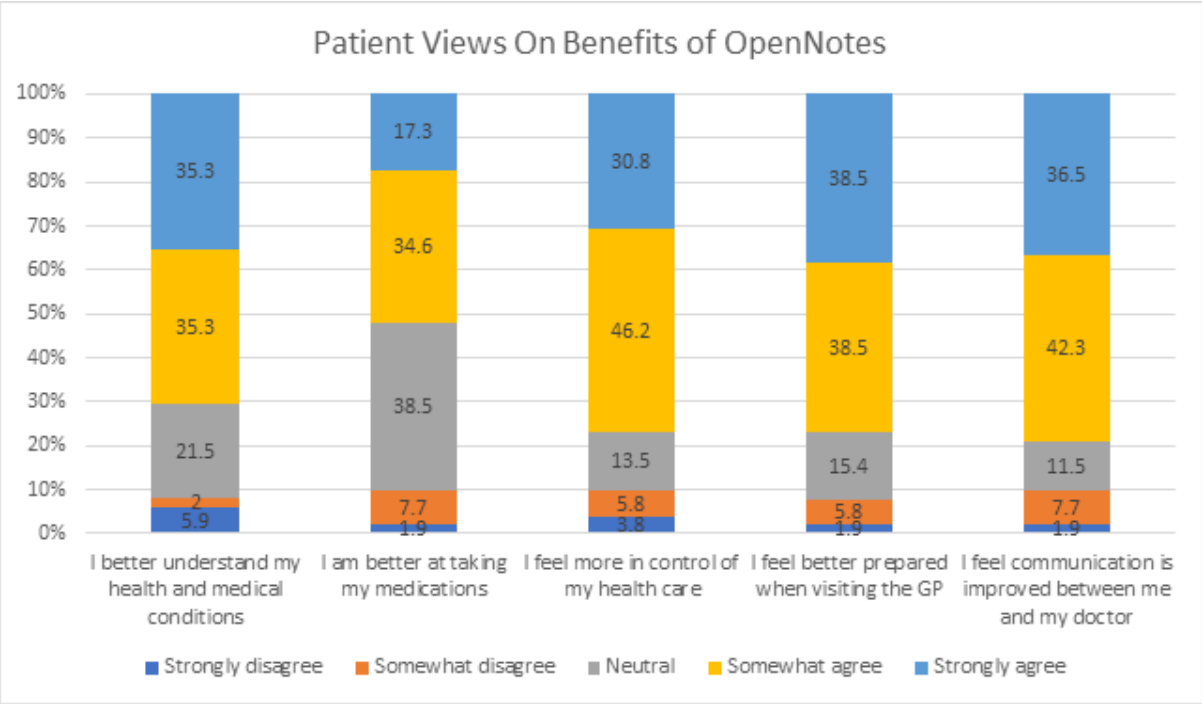

Figure 1. Patient views on benefits of OpenNotes

The results for patient views on the benefits of OpenNotes are displayed in Figure 1. Overall, patients to a large extent 'strongly agreed' or 'somewhat agreed' with the majority of the benefits of OpenNotes. For each benefit, a range of answers was reported by patients from 'strongly agree' to 'strongly disagree'. The spread of data for each benefit was surprisingly similar and each was weighed more heavily towards 'somewhat agree' and 'strongly agree' than 'somewhat disagree' and 'strongly disagree'. However, one result of note from the patient views on benefits is that substantially fewer patients strongly or somewhat agreed that OpenNotes enabled them to be better at taking medications (51%) compared to a range of 71-79% for the 'somewhat agree' and 'strongly agree' answers for all other benefits.

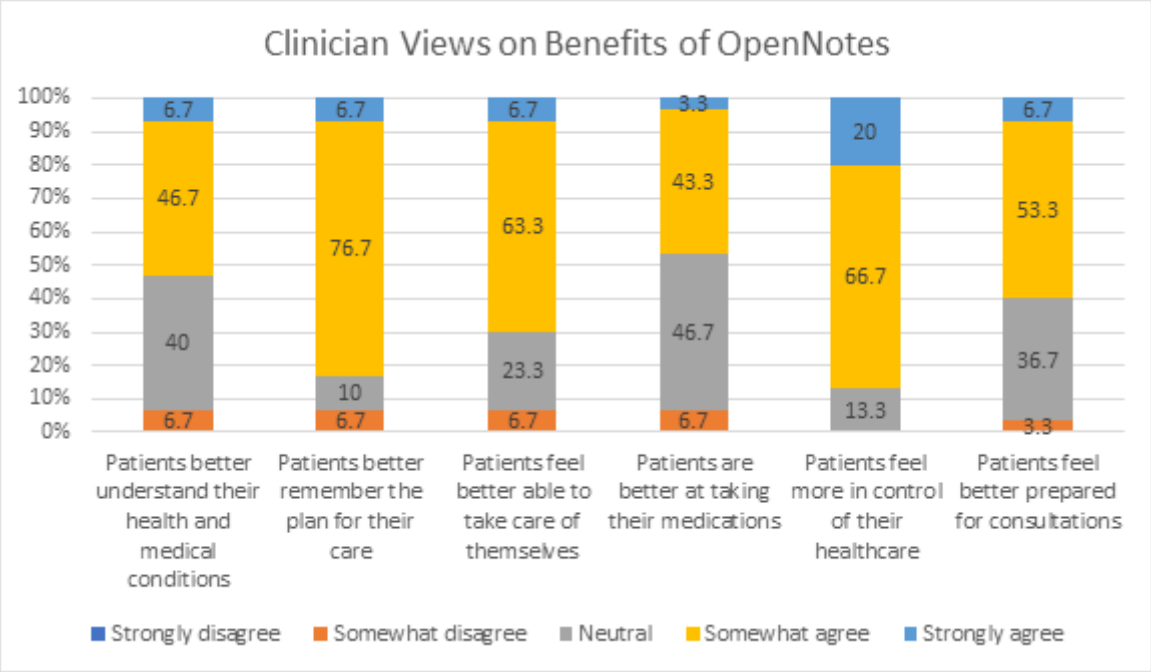

Figure 2. Clinician views on benefits of OpenNotes

The results for clinician views on the benefits of OpenNotes are displayed in Figure 2. Overall, clinicians were in agreement with or neutral about all benefits surveyed. No clinicians strongly disagreed with any of the benefits. One finding of interest from the clinician views on benefits of OpenNotes is that no clinicians 'strongly disagreed' or 'somewhat disagreed' that patients would feel more in control of their healthcare. In other words, they agreed or were neutral that patients would feel more in control of their healthcare. Furthermore, the 'strongly agree' category for patients feeling more in control of their healthcare was substantially greater (20%) than the 'strongly agree' category for other benefits (3-7%).

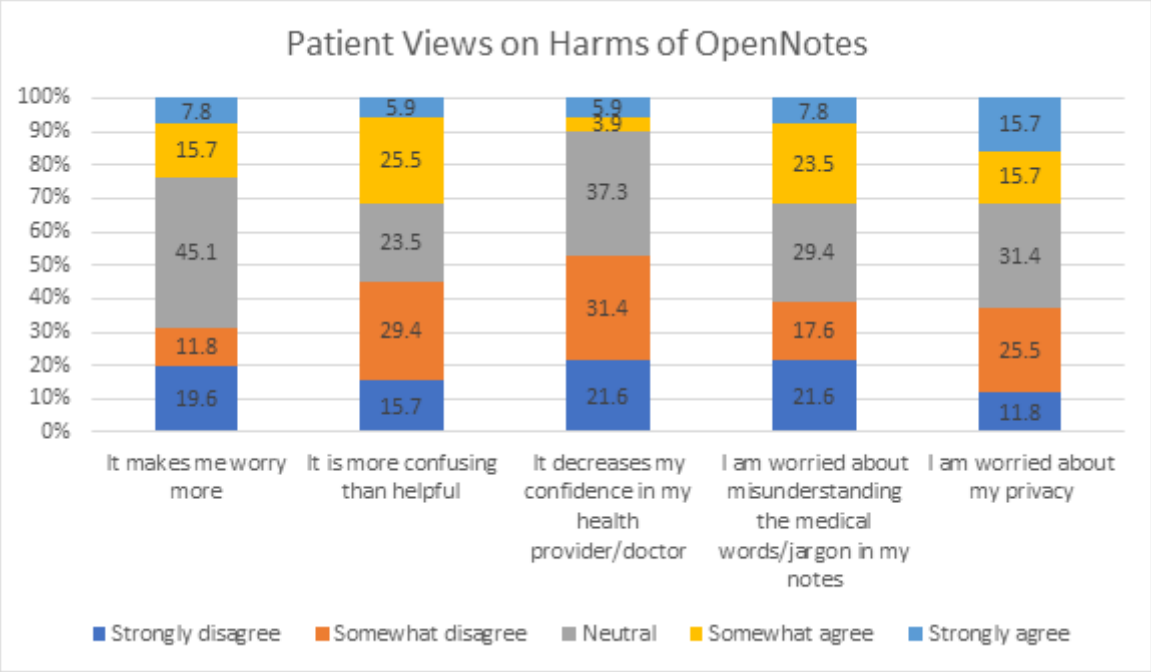

Figure 3. Patient views on harms of OpenNotes

The results for patient views on the harms of OpenNotes are displayed in Figure 3. Overall, patient responses to the harms of OpenNotes were more heavily weighted towards 'neutral', 'somewhat disagree' and 'strongly disagree'. Of all the harms reported in the survey, the harm that was reported as least likely to impact patients was 'it decreases my confidence in my health provider/doctor' as only a small proportion of patients n=5 (10%) either strongly agreed or somewhat agreed with this. However, all other harms reported a range of 24-31% in strong or somewhat agreement with the statements.

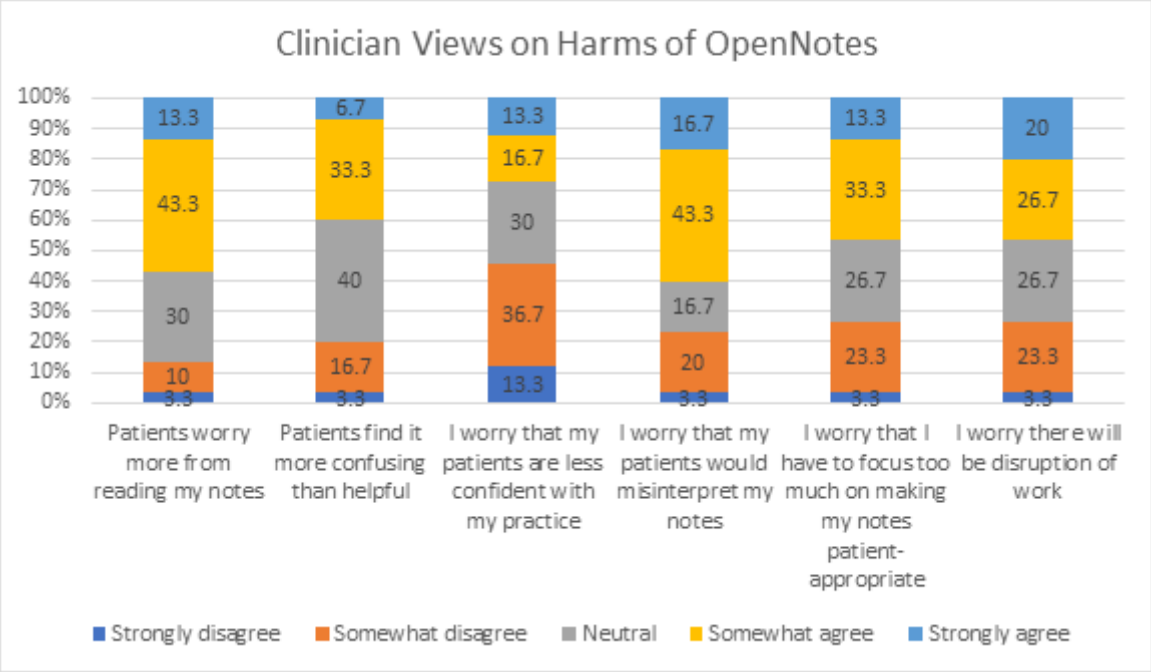

Figure 4. Clinician views on harms of OpenNotes

The results for clinician views on the harms of OpenNotes are displayed in Figure 4. The overall findings on harms of OpenNotes reported by clinicians showed that clinicians tended to agree rather than disagree with the harms of OpenNotes. The harm that clinicians most strongly disagreed or somewhat disagreed with (n=15; 50%) was that patients would be less confident with their practice with the availability of OpenNotes. This is in comparison to the other harms surveyed where rates of strong or somewhat disagreement ranged from 13-27%.

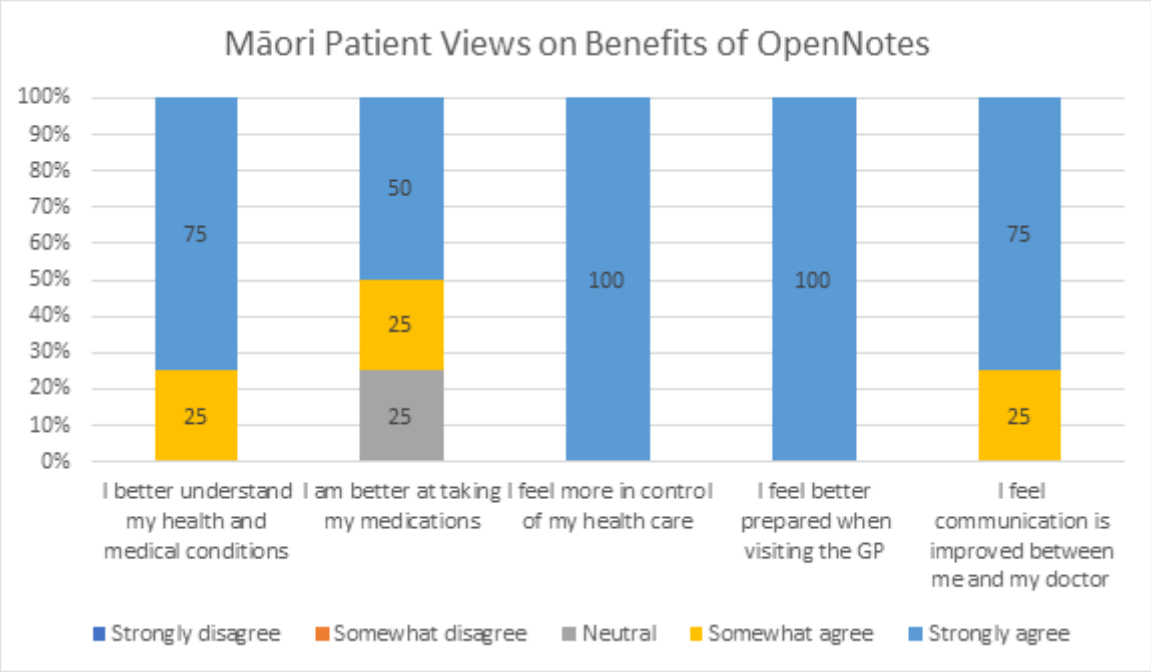

Figure 5. Māori patient views on benefits of OpenNotes

Figure 5 presents the results for the four Māori patients surveyed. The graph illustrates that all Māori participants were neutral or in agreement (somewhat or strongly) with all benefits surveyed. Furthermore, all Māori participants were of the view that OpenNotes would allow them to feel 'more in control of their health care' and 'feel better prepared when visiting the GP'.

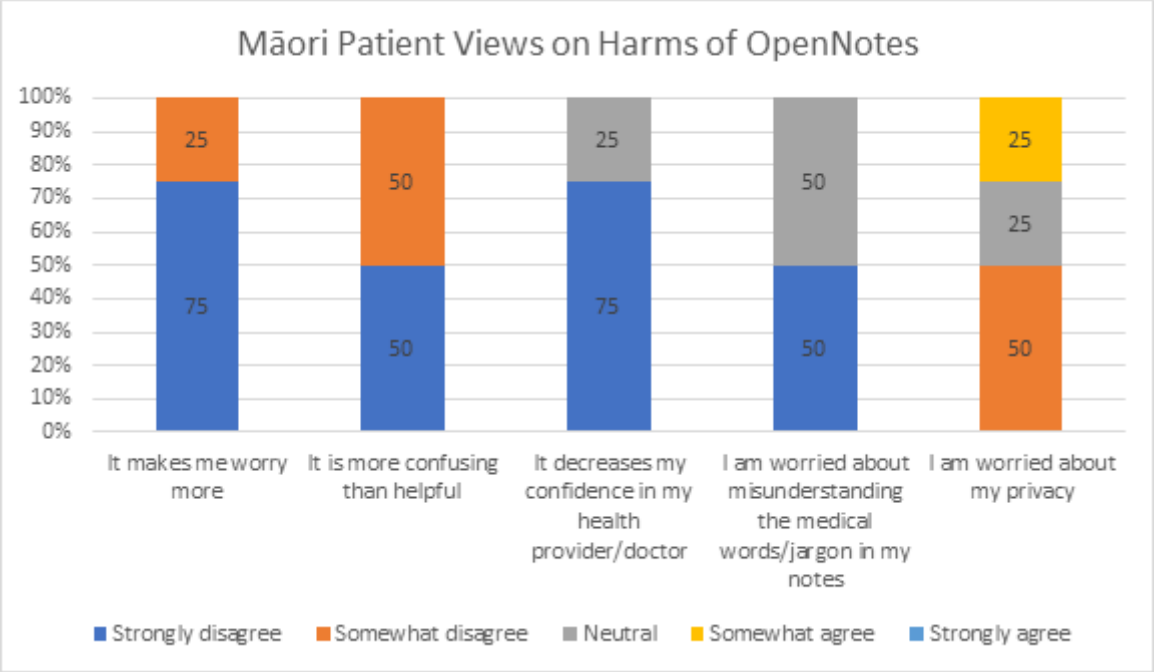

Figure 6. Māori patient views on harms of OpenNotes

Figure 6 presents the views on harms of OpenNotes for the four Māori patients surveyed. Overall, Māori patients disagreed rather than agreed with the harms of OpenNotes. However, no Māori patients reported strongly disagreeing with 'worrying about their privacy' in comparison to all other harms where at least 50% of patients reported to 'strongly disagree'.

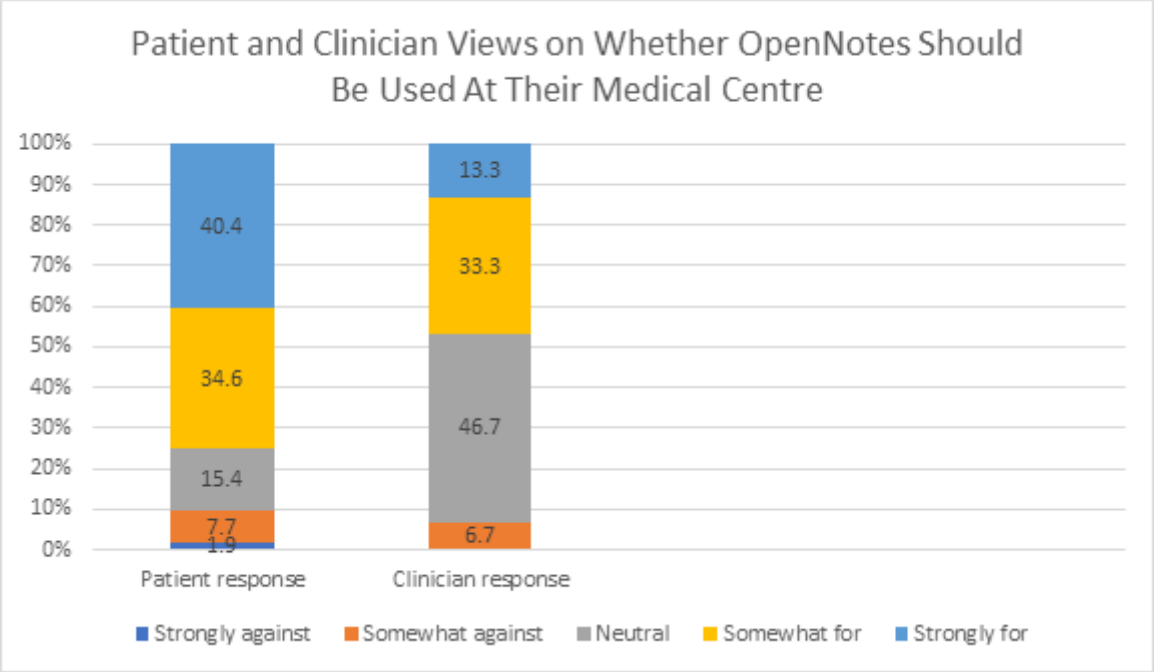

Figure 7. Patient and clinician views on whether OpenNotes should be used at their medical centre

Overall, patients were more in favour of having OpenNotes in their medical centre whereas clinicians tended to be largely neutral in their response, with almost half of clinicians either in support of OpenNotes (n=14; 47%) or neutral (n=14; 47%). A substantially low proportion of patients and clinicians were somewhat against or strongly against the use of OpenNotes.

Qualitative responses/Raraunga Kounga

A total of 37 qualitative responses were collected from 55 patient surveys (67%) and 19 from the 30 clinician survey responses (63%).

Patients

Four themes were identified among the patient surveys.

1. Privacy

   N=2 (5%) expressed concern about the breach of privacy of their medical information, in particular about who could be accessing their notes other than health practitioners involved in their care.

   [I would be] concerned about privacy, who would be able to see my notes.

   If it is 100% private then sounds positive.

2. Interpretation of medical information

   N=7 (19%) expressed worry about their ability to interpret medical terms or jargon in their notes, which could subsequently result in more confusion about their health conditions. Some of the participants who had a high level of education or came from a healthcare background were more confident than others in interpreting their notes correctly. However, most participants had a good trusting relationship with their health practitioners and felt that explanations given during consults were adequate.

   If I used OpenNotes I think it would confuse me because I wouldn't understand the medical jargon.

   Good for those who have some medical background. Not good and possibly harmful for those who do not have literacy in medical matters.

3. Communication and the clinician-patient relationship

   N=3 (8%) mentioned aspects of the clinician-patient relationship associated with communication. As some patients have complete confidence and trust in their clinicians, having OpenNotes may offer them little benefit.

Wouldn't be useful to me because I trust my health care provider and he is good at explaining things to me.

I think it would be helpful so I know where myself and the staff are at.

4. Patient autonomy and recall

   N=8 (22%) felt that having OpenNotes improved their autonomy, including better understanding of their own conditions, better management of their own health (i.e. making appointments when needed and remembering to take medication on time), and the ability to keep track of how their health has progressed through the years. They also mentioned the availability of OpenNotes helps them recall when their next appointment is and what was discussed during the previous consult.

   Could be useful for patient recall of what was discussed.

   Would give me an understanding in conditions/medical events that could occur.

Clinicians

Three themes emerged among health professionals.

1. Patient autonomy and recall

   Similarly to patients, clinicians agreed that having OpenNotes improved patient autonomy and increased patient participation in management of their own chronic conditions (n=5; 26%). In particular, most clinicians mentioned that patients have better recall of upcoming appointments or organizing their own appointments when needed. Another point made was that there is a reduction in clinician workload concerning patients being able to check their own results rather than phoning the practice.

   It is helpful for those who will attend to their healthcare e.g. they know when they are due for recalls and make their own arrangements.

   It has reduced the number of reception and nurse phone calls as patients can access results when it is convenient…helpful for doing recalls and patients are able to ask questions via email without coming to see me, so has reduced my workload.

2. Documentation

N=2 (11%) expressed potential issues with clinicians having to be more vigilant about writing their consultation notes in a more professional and non-judgmental manner. One respondent (5%) expressed that having OpenNotes has improved their practice by making their notes clear and easy to understand.

It has changed my practice in making clear, easy to understand notes and has reduced confusion.

It does mean clinicians have to be more careful with appropriate documentation.

3. Legal rights of patients

One clinician (5%) expressed their beliefs about patients having the right to access their information. According to the Code of Rights under the Health and Disability Act 1994, every patient has the right to receive written information should they request so, and this includes anything that was discussed in the consultation and any results of tests or procedures.

I think patients have the right to access their medical information easily, and open notes is a good vehicle for this.

DISCUSSION MATAPAKI

Findings/Tukunga Iho

Overall, 75% of patients supported the use of OpenNotes compared to 47% of clinicians. This general opinion was reflected in patients largely agreeing with the benefits of OpenNotes and showing a range of responses towards the harms, while clinicians showed mostly ambivalence or agreement towards both the benefits and harms. This contrasts with prior research by Delbanco et al. where over 85% of primary care physicians felt allowing patients access to clinician notes to be 'a good idea' (7). Unlike Delbanco et al., wherein all primary care physicians were using OpenNotes, only 53% of clinicians surveyed had OpenNotes at their practice. It is thus unclear whether this lower rate of positive opinion is due to negative experiences among users of OpenNotes, or a wariness among those not yet using the service. One may speculate that the overall opinion might change following the introduction of OpenNotes to more practices. Another noteworthy point of interest concerning patients and clinicians was the level of experience with OpenNotes. A total of 21% of patients reported that OpenNotes was available at their medical centre, compared with 53% of clinicians. Since many of the participants were recruited from the same practices, this may indicate a lack of patient awareness about availability of OpenNotes. However, we did not collect data pertaining to the distribution of clinician and patient responses, thus this discrepancy may reflect the differing proportions of OpenNotes access. This raises the question of whether exposure to OpenNotes would affect patients' overall attitudes and would be an interesting topic for further research. Despite less than half of clinicians being in favour of the use of OpenNotes in their medical centre, a greater proportion (67%) said they would use OpenNotes if it was available. In contrast, three quarters of patients were in favour of the use of OpenNotes in their medical centre, while only 54% of patients said they would use OpenNotes if available, indicating that patients want access to OpenNotes but may not feel the need or motivation to use them. The higher rate among clinicians on the other hand may reflect the consideration of clinical responsibilities and a potential obligation to use OpenNotes, should it be introduced to their practice.

According to Figure 1, patients mostly agreed with the proposed benefits of OpenNotes (better understanding of conditions, more in control of health care, better prepared for GP visit, better taking of medications, and better communication with their clinician). Furthermore, these generally positive patient attitudes to OpenNotes were supported by qualitative responses regarding communication and patient autonomy. When asked whether OpenNotes enabled better communication, 79% of patients somewhat or strongly agreed. Sixty percent of clinicians agreed that patients would be better prepared for consults. Qualitative responses also indicated that the improved access to information and communication could lead to improved and more aligned patient and clinician understanding. Given that OpenNotes can enable both patients and clinicians to review what they had previously discussed, the potential exists for more focused consultations and outcomes. Such findings are in alignment with

the previous literature. Delbanco et al. examined the views of 13,564 patients who received electronic access to their clinicians' notes, in conjunction with 105 primary care physicians. The study revealed 77-85% of patients agreed or somewhat agreed that access enabled a better understanding of their health conditions, while 76-84% perceived better recollection of their care plans (7). Interestingly, despite the indication that respondents felt communication and the clinician-patient relationship could be improved with OpenNotes access, our survey also showed that the trust and confidence that patients have towards their clinicians were unlikely to change based on the availability of OpenNotes in the practice, with 53% of responses either strongly disagreeing or somewhat disagreeing with the statement that patients have decreased confidence in their doctor with access to OpenNotes.

Figure 3 shows that patients were approximately evenly divided between agreeing, disagreeing, and feeling neutral about most statements concerning harms of OpenNotes (worrying more, more confusing than helpful, misunderstanding jargon, and worrying about privacy). The exception was that 53% of patients disagreed that their confidence in their provider was decreased. However, qualitative responses regarding harms of OpenNotes were less balanced and revealed three main themes, which were concerns around privacy, interpretation of medical information, and the clinician-patient relationship. Patients raised concerns around potential breaches in privacy and wondered who would be able to access their notes. Furthermore, patients expressed worry about interpretation of medical jargon, especially without 'literacy in medical matters'.

While patient concerns about privacy were anticipated based on responses in prior literature, this subject was not approached when interviewing clinicians. By including a similar question for clinicians, such as 'Do you believe your patients will have concerns with privacy?' or 'Do you believe your patients can responsibly manage confidential information?', it may have been easier to establish clinician perspectives. It is possible that patients may be better at managing issues than providers assume or may have specific concerns that providers were not aware of. Clinicians were also not asked as to their personal concerns about privacy. This may be an interesting perspective to explore in future studies, as Delbanco et al. found that 20-42% of patients shared their medical notes with another person, most often a family member or spouse (7). While the impact of clinician lapses in confidentiality is often discussed, there is potential for patient sharing of clinician notes to affect clinician practice and confidence in the security of their work.

Figure 2 shows clinicians were mostly in agreement with the benefits of OpenNotes for patients (better memory of care plan, taking better care of self, more in control of healthcare, and better prepared for consultations). However, clinicians were more ambivalent regarding the positive effects on patients understanding their medical conditions and better taking their medications. These responses reflect

responses from Delbanco et al., with only 38-45% reporting to agree or somewhat agree that OpenNotes access enabled improved patient understanding of health conditions. Clinician responses were similar regarding perceptions of improved care plan recollections by patients, with 41-46% reporting to agree or somewhat agree with the statement (7).

These generally positive clinician attitudes towards OpenNotes were supported by qualitative comments regarding a positive effect on patient autonomy. Clinicians commented that patients would be better able to independently coordinate matters related to their healthcare, such as checking recall due dates and querying results. Additionally, clinicians stated that OpenNotes serves as a good vehicle for fulfilling patients' right to easily access their own medical information. It should be noted that patients currently have the right to request their health information under the Code of Rights in the Health and Disability Act 1994, however this process is often more involved than simply accessing written notes online.

Figure 4 shows that clinicians were mostly ambivalent regarding most of the proposed harms of OpenNotes (patients finding it more confusing than helpful, focusing too much on making notes patient appropriate, and disrupting clinician work). While the majority of clinicians disagreed that patients would be less confident with their practice, the majority also worried that patients would misinterpret notes and would worry more. This theme was further elaborated on within clinician qualitative data regarding documentation. Clinicians stated that OpenNotes has changed the way notes are written, with one respondent commenting that it has created a need to document consultations more appropriately. This may align with 47% of clinicians strongly or somewhat agreeing that OpenNotes may be disruptive to their work. One would expect these disruptions may include revisions to notes written during consultations or explaining the meaning and implications of the content of notes to worried patients. Anecdotal comments from clinicians indicate that it can be difficult to write comprehensive and patient-friendly notes during busy patient lists where delays are commonplace. Clinicians also reported concerns that patients may worry more, with 57% in agreement, while only 24% of patients felt they would experience more worry. Patients expressed similar concerns including the misinterpretation of notes and relating to the use of medical jargon. These concerns were reflected throughout the literature, with patients across multiple studies reporting difficulties in interpreting their medical notes, inducing anxiety and confusion (6, 7). In a questionnaire-based study examining the attitudes of 601 patients and 564 physicians regarding shared medical records, 36% of patients and 49% of doctors agreed that doctors' notes would be confusing (6). Additionally, clinicians were particularly concerned that access to records would increase patient worry, with 81% in agreement. However, this was not as strongly reflected among the patient sample, with only 26% expressing concerns regarding increasing worry (6).

Although sample size made it unfeasible to perform sub-group analysis, we were interested in the Māori response in particular to inform further research. Out of the participant population a small cohort of respondents identified as Māori (n=4), whose responses reflected generally positive attitudes to OpenNotes. Figure 5 showed the majority of Māori patients agreed with the benefits of OpenNotes (better understanding of medical conditions, better at taking medications, more in control of healthcare, feeling better prepared for GP visits, and improved communication with their doctor). Similarly, Figure 6 illustrated that the majority of Māori patients disagreed with most harms of OpenNotes (increasing worry, feeling more confused, and decreased confidence in their health provider). However, half disagreed with worrying about misunderstanding jargon while the other half were neutral. With regards to privacy, one Māori patient raised concerns while one felt neutral and two disagreed. The qualitative data was similarly positive, with one Māori patient stating it was a 'great idea' and another commenting that OpenNotes is a 'good concept'.

Strengths and Limitations/Ngā Painga me Ngā Ngoikoretanga

To our knowledge, this is the first study performed in New Zealand investigating attitudes of patients and clinicians towards OpenNotes, thus providing an insight into the views of New Zealanders. Unlike previous studies performed overseas, our study was more likely to be representative of the demographics of Southern and South Canterbury DHBs and may be of value to those interested in opinions about OpenNotes in said areas. While many findings of our study were consistent with those of previous studies, our study suggested a lower rate of support than found overseas, though reasons for this were unable to be fully established.

The number of responses to the surveys was low overall, with 55 patient and 30 clinician responses. This number of recruited participants meant that it was not feasible to undertake sub-group analysis, for example comparing patients and clinicians with and without access to OpenNotes. We were interested to learn the opinions of Māori, so conducted a simple exploratory analysis for this demographic, however were unable to fully compare the responses of this group with non-Māori survey responses. Higher survey numbers would facilitate our ability to draw inferences from the data.

The response rate overall was low, especially among clinicians, and therefore our study potentially suffered from non-response bias. For clinicians and patients the response rates were 44% and 66% respectively. Reasons for clinicians declining to participate included being too busy caring for patients, disliking filling out surveys, being against the concept of OpenNotes, failing to fill in or return the survey, and unfamiliarity with OpenNotes. Possible ways to improve clinician uptake in future investigations would be to have a longer study period, approach more GP practices, send widespread

recruitment emails, recruit clinicians on occasions when they have more time such as at conferences or training days, or further incentivise participation with rewards.
Similarly, there were logistical issues with Trainee Interns distributing surveys to patients in their educational placements at GP practices without having substantial time allotted specifically for this purpose. The short data collection period was further shortened by the Easter holiday period, further limiting responses.

Generalisability appeared to be limited in our study. Of particular note was that older patient age groups were under-represented in the participant population, with only 20% of respondents being aged over 65 years and 20% aged 45-64 years. Data from the NZ Health Survey indicates patients aged 65 and over have the highest rate of primary care visits annually. One would expect from this that a significant number of patients attending GP practices each day would be in this age group. Our survey instead had its highest response rate from those aged 18-30 (35%). Reasons for this are unclear, but may include a willingness among those aged 18-30 to engage with the interviewers, all of whom were in a similar age group, being more comfortable in answering questions related to electronic/online records, or confidence in answering the survey in the often brief time available. This may have biased the results because, anecdotally, older patients have higher levels of trust in their medical providers and lower levels of computer literacy, so the number of patients against OpenNotes may have been underestimated in our study. To better capture this demographic, recruiters could sit with patients and guide them through the survey, or alternatively use a focus group methodological approach that would allow for a longer period of discussion. Other ways to increase patient responses in general include prolonging the study period and incentivising participation.

Another limitation concerning the survey was that questions asked to patients were not completely reciprocal to those asked to clinicians. While certain survey questions related specifically to the roles of patients and clinicians, some questions relating to both groups were not posed to both. This meant that possible comparative data was lost. One such example involved clinician ethnicity not being collected, thus preventing analysis of experiences specific to Māori clinicians. Another example addressed above related to the opinions of respondents about privacy. Clinicians were not asked their opinions on patient privacy, nor their concerns on this affecting their practice. Obtaining such information may have helped evaluate the difference in overall opinion between clinicians and patients.

A further limitation of the study was that certain questions did not explore the full range of patient responses. For example, patients may have 'agreed' or 'disagreed' that their confidence in their provider is decreased, but this does not take into account whether patients may instead feel more confident in their provider. Allowing patients to express the full spectrum of opinions may have yielded different

responses and allowed a greater range of the positive and negative implications of OpenNotes to be more apparent. The use of question-specific scales, rather than a simple 'strongly agree' – 'strongly disagree' scale may have been a viable solution. However, the decision to simplify and limit the number of questions was a pragmatic attempt to avoid making the survey too cumbersome for participants and thereby maximise the response rate. On careful consideration, we justified that the survey was simple enough to facilitate responses while detailed enough to provide useful data for analysis.

Our survey included a single qualitative question at the end. This question was included to allow patients and clinicians to express opinions that were not covered in the previous sections. However, the design of the survey may have inadvertently restricted the response to the question. The question was generalised and open-ended, and as such did not prompt many nuanced responses. The addition of more specific questions, such as splitting the question into positive and negative opinions, may have allowed respondents to offer more in-depth opinions. However, this would have required significantly more time for data collection and may have also turned out to be ineffective for ambivalent respondents, which a sizeable proportion of the study population was. Furthermore, the placement of this question at the end of the survey may have affected the response. Given many of the respondents, especially patients, had not used OpenNotes, questions they had answered in the previous sections were highly likely to influence or bias their answers. An ideal solution would be to place the question at the beginning of the survey. However, respondents would require more initial time and explanation to form an opinion on OpenNotes. Unfortunately, due to the method of delivery of the survey, dedicating more time per respondent would have been unfeasible.

Implications/Hīraunga

Clinician and patient attitudes are such that the role of OpenNotes in General Practices should be investigated with further research. However, the methodology of such research should take into account the challenges encountered in this study. For example, low survey response rates call into question the appropriateness of this method of data collection and potentially highlight the low acceptability of surveys to clinicians and patients. As such, the presented limitations should be carefully considered to better streamline the process and to improve the quality and generalisability of the results. In future studies, collecting data from a wider geographical area and a greater number of medical centres may also be likely to better represent the New Zealand population.

While the presented results show a generally positive trend, the data is not of sufficient quality to allow for robust statistical analysis of patient and clinician attitudes towards OpenNotes. Furthermore, the role of qualitative research was trialled in this study and yielded useful results and insights into attitudes in a way which was potentially more representative than quantitative research. Thus, future efforts at

discerning patient and clinician views may consider incorporating focus groups to allow for more structured and systematic qualitative data collection.

Careful consideration of the impact of OpenNotes on Māori is paramount in ensuring that it does not serve to further worsen inequities in experiences with GPs. Thus, collecting sufficient Māori responses from both clinicians and patients in a culturally safe and acceptable way will form an important aspect of any future research in this area in a New Zealand context.

Conclusion/Whakapaunga

Patient and clinician attitudes towards OpenNotes appear to be generally favourable, however this study has highlighted some clinician concerns with OpenNotes and key points of difference in views between the two groups. These findings are limited by a small sample size, methodological weaknesses, and inability to conduct statistical inferences.

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