

Discussion outputs from DIGITAL HEALTH LEADERSHIP SUMMIT, March 2021

Topic 9: Patient outcome measures and experience measures: How do we harness the power of consumer feedback?

This topic was discussed by groups in Auckland, Wellington and Christchurch.

Auckland delegates' responses

Challenges/barriers	<ul style="list-style-type: none">• Service dependent – rate differently across speciality• Experience/satisfaction• PROMS/PREMS routinely collected• Poor job of presenting data back over time:<ul style="list-style-type: none">○ Patient at the centre and show data○ See that change has happened○ Comparison data vs. patient/those like me• Clinical view vs. patient view – finding expectations of patient from beginning and track• Patient centred – make experience #1 priority and back everything against that• Belief that only those who are on the edges, answer• Yelp doctor/Yelp hospitals – data sovereignty• Comparisons against all healthcare – what are the barriers to sharing data?• Clinicians seem happy to share if they have it• Multiple leases – cross speciality, when is there validity in the data?• Response rate issues still a barrier• Robust clinical outcome measures:<ul style="list-style-type: none">○ Managed based on patient○ Not so good at doing the quality○ Harnessing can provide better service• How do you not over-survey patients?• Regularly following up
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- Outcome and experience data:
 - What is the outcome that the patient wants?
 - Do not collect outcome (unless unfortunate)
 - Collect input – utility – barrier to changing service
- Experience:
 - Goal to have patient define key points for experience
 - Paper to digital – response rate dependent on person’s enthusiasm presenting to patient – more familiar/quicker on paper unreliable:
 - Trust issue/to be identified
 - With gaps – patient must understand digital platforms ... Affects experience
 - Barrier for interpretation – bias. Translating is difficult
- Overcome collection barrier – with defined outcome. Patient/clinician/funder
- If we do collect – what are the benefits at the patient level?
 - Benefit/how does it change the system?
 - Better navigation
 - Service delivery gap. Expectations vs. feedback
 - “Who is there with me when I need help”
- Quantitative vs. qualitative feedback:
 - F Test for Statistical analysis– very subjective
 - Physical Activity Questionnaire PA... - questionnaire – long use data
 - Symptom based measures- difficult to validate
 - Too much quantitative – becoming a barrier
 - Feedback bias – need to confirm/validate preconceived/ideas – previous relative experiences
 - Outcome data shouldn’t be experience data:
 - Health – assessment – QOL
 - Patients need to see their data being used
 - Data needs to follow the patient:
 - They need to be constantly asked what is important for them
- Patients need to redefine expectation based on what is achievable
- Co-design – informing through to empowerment – lots of assumptions:

	<ul style="list-style-type: none"> ○ System level measures need a patient voice ○ System not invested in listening to consumer groups because of commercial agreements and investment of dollars – people’s careers at stake ● Consumer feedback: <ul style="list-style-type: none"> ○ People don’t worry about their health until they are unwell ○ Subjective – not recognised by health system as measures are standardised ○ Pain cannot be measured for example ● Structure of feedback: <ul style="list-style-type: none"> ○ C3b form doesn’t work with current generation ○ Lots of detail from small group → less detail from → ↑ group ○ Need to do something with the feedback ● Expectations – process of deciding to go ahead with surgery: <ul style="list-style-type: none"> ○ Use consumer feedback to find out what is important ● Whānau: <ul style="list-style-type: none"> ○ They need to be involved ○ How do we be transparent? ● Some people would rather be happy and not worry about their health in the future – but there are those that want to live longer ● Funding is based on the injury itself: <ul style="list-style-type: none"> ○ It needs to be measured and work out the problem after ○ Historical ignorance on a clinical level <ul style="list-style-type: none"> ▪ Resistance from physicians ▪ They need to be open to unknown vs knowns ▪ Experts are protected ● Collection of data – barriers: <ul style="list-style-type: none"> ○ Interest in patient’s perspective ○ Funding consumer funding model <ul style="list-style-type: none"> ▪ Funding consistent and maintained – risk management approach → cap the amount of money – longitudinal approach, rather than single point in time ● Not measured at clinical level:
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	<ul style="list-style-type: none"> ○ Measured by number of patients, not outcomes ○ More and more procedures ● Funding: <ul style="list-style-type: none"> ○ Healthcare model – not set up for people with the right skills to do extended roles, i.e., patient care that is under-resourced. If this was enabled, a care model/co-design could change ● Feedback is collected but is a power orientated choice of words – co-design is more relevant: <ul style="list-style-type: none"> ○ Capturing the goal of the patient. This doesn't happen to all patients ○ Feedback is typically reactive – retrospective – not realtime ○ What consumer wants should be considered ○ Shared care planning – a tool that the acute team can have access to that gives the whole picture/outcomes that the patient cares about ○ By attempting to measure what we are doing we are going to find out if we are doing the right thing ○ Goal is to have the patient's choice a key factor in clinical pathway ● Its driven only on a medical model, not outcomes
Ideas/solutions	<ul style="list-style-type: none"> ● Standardise question sets/treatment specialty ● Patients to be able to view data vs. cohort ● Multi party measurement – measure once and share between funders, providers, clinicians ● What's the 1 thing a health system could do to make the collection or feedback? <ul style="list-style-type: none"> ○ Use the community to gather the data ○ Joining up the journey ● Asking questions that are relevant to the patient, not clinical group ● Helping them navigate their health journey ● Challenge status quo of what we spend money on. Some of the spend is not valuable for the patient ● It must be focused on DHB's funders and ACC ● It needs to be outcome focused and publicly reported ● Health professionals need to be open to sharing information and sharing experience ● First and foremost, it must be what patients want: <ul style="list-style-type: none"> ○ Only then manage funding around it ○ Is funding based on longitudinal measures? ● Model – for certain patient groups they should have different funding models:

	<ul style="list-style-type: none"> ○ Majority of patient care is in the community ○ Longitudinal studies in road planning and infrastructure – direct cost and lifetime costs – ACC have data ○ Intervene early in childhood – learning ○ Funding ○ Personal experience: <ul style="list-style-type: none"> ▪ Conveyor belt – wait list initiatives ▪ No time spent with patients ● Requirements: <ul style="list-style-type: none"> ○ Mealtime data captured – prospective – mandatory ○ Change incentives – currently the patient doesn't have a choice: <ul style="list-style-type: none"> ▪ Funding model incentivises more procedures ▪ If a patient is sent home successfully with no issues/readmission – it should then be funded ○ Data needs to be available first – patient goals, expectations – needs ○ Pull the data into clinically relevant information ● Community programmes: <ul style="list-style-type: none"> ○ Heart health example – nurses in the community – requires funding ● Big need – change the model of care ● New national EMR system – urgent infrastructure requirement <ul style="list-style-type: none"> ○ Patient -/ + write access ○ Trust comes through transparency ○ Health navigator ○ Open notes – more compliance – help them formulate questions ○ Digital literacy ○ Health promotion – instigate routine appointment ● Better outcomes: <ul style="list-style-type: none"> ○ Measuring wellbeing ○ What matters to you ○ Whanau engagement – involve cultural groups
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Christchurch delegates' responses

Challenges/barriers	<ul style="list-style-type: none"> • Survey fatigue – how to understand silent consumer • How do we learn from what's going well? • The feedback loop – change? • Availability – equity of access? • People get tired of being asked the same questions • How do we consistently use tools to capture all parts of care? <ul style="list-style-type: none"> ○ Working groups? ○ Diversity? ○ Stakeholders? • How do we capture the true voice of the population? How representative are we being? • One size does not fit all! • How to engage consumers outside groups/representatives (those outside the targeted group) • If you touch the system at some stage: <ul style="list-style-type: none"> ○ All users? ○ Potential users? • Surveys don't fully capture stories/journeys/experiences – ethnography has validation • Staff wellness and monitoring performance – how to capture “thanks” • We are not always the right person to ask the questions • How to gather quality, meaningful data with feedback loops and measurable change • What do we do to show we have listened, especially if we don't/can't change? • Can't integrate text – digital transformation • How do you capture all the little bits? • Deliver on current systems: <ul style="list-style-type: none"> ○ Already feel stressed coming into process ○ Patients feel disempowered to feed back (consumer advocacy?)
Ideas/solutions	<ul style="list-style-type: none"> • Standards • Experiences: Known and shared goals, expectations, understanding • Databases

- How to engage: Qualitative vs. quantitative
- Clinician vs. consumer centric – “what matters to me”
- Conversations
- How – quick wins: Tokens, buttons
- Training to listen – process – passing
- SLMs analytics “so” into “so what?”
- Interface: In person, right skills
- Consumer engagement/membership governance
- Telling your story (right person): Sharing stories, visibility
- Accessibility to change agents → understanding who to
- Allow time and good triage when listening – resource for skilled person
- Social governance model – “everyone’s responsibility”
- Outcome vs. experience:
 - How you make people feel important
 - Hospital Siri to capture positive feedback – on app?
 - Taking care of our staff – positive feedback loop
- Funding models:
 - Sustainable funding and resource
 - Responsive to change
 - Commitment to sustaining change
 - Treating things as a product and not a project (measurement)
 - Allow failure (measurement)
- Maintaining good relationships:
 - Governance models
 - Whole of system relationships
 - Established values
- Safety in sharing with honesty and trust (known people):
 - Delivered
 - Time
 - Investment

	<ul style="list-style-type: none"> ○ Transparency ○ Demonstrate integrity ● Patient defined vs. clinician defined – “what does good look like”? ● What matters to me? <ul style="list-style-type: none"> ○ Give partners choice: when, how, where ○ Fund community led groups, cross sector to lead consumer engagement ○ Build into digital clinical systems, e.g., d3 post op ○ Build into patient owned apps – feedback whenever you want ○ Start dealing with feedback well: <ul style="list-style-type: none"> ▪ Listen ▪ Make change ▪ Be proactive in monitoring data and deep dive early ● Prioritise the importance of the experiences of community and community engagement ● Who does this? Lived experience community ● What is the why? ● Social determinants ● Social governance: <ul style="list-style-type: none"> ○ Partnerships, connections and relationships ○ Central part of truth ○ Empowering community partners to have a voice and being active change agents ○ Power needs to be addressed – accessibility ● The value is in the complexity: <ul style="list-style-type: none"> ○ Disengaged ○ Survey ○ Qualitative ● Learn from what’s working well ● Patient reported experiences and outcomes should be captured in an appropriate way for the community ● Good quality information takes time – we then need to do something with this ● How do we ensure our community feels heard? <ul style="list-style-type: none"> ○ Tell our story
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- Share our story
- See change
- Consumer councils – (part of organisation) and NGO to capture stories of our community
- Resource for time to listen and action
- Feedback:
 - → dashboards
 - Experiences, not complaints
 - Need to see the why of collecting feedback
 - Capture the disengaged
 - Design with patients
 - Share good practice
- Capture good and bad – from good to great
- Technology can enable consumer feedback, e.g., monitoring/analysing conversations via video
- Quick and easy monitoring
- Monitoring proactively and deep dive
- The feedback loop → do something with the data
- What matters to you? Patient/whanau centred feedback
- Engage community iwi leaders:
 - Leaders to the voice to the DHB
 - Supporting and enabling, rather than telling
- Give \$ + power to community to engage with
- Getting feedback: Community to community
- Experience and be in the system
- Outcome vs. experience
- Experience surveys
- Feedback boxes – “share your comments”
- Specific thank-yous
- Comments to chief executives and MPs
- Social media
- Specific feedback in design – who?

	<ul style="list-style-type: none"> ○ Patient ○ Whanau ○ Staff ○ Consumer council ● Health literacy – quality feedback to aggregate quality data ● Speaking the same language in a conversation → medium of transporting feedback ● Train to monitor themes and know when to deep dive ● Ethnography is a powerful evidenced-based tool! ● Invest in listening
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Wellington delegates' responses

Challenges/barriers	<ul style="list-style-type: none"> ● Current systems limited capture/data ● Consumers need to know their voices are heard ● Data needs to connect, e.g., between primary and secondary care ● Are we measuring the right variables to make a difference? ● Currently not a loop back in response ● Possibly need to rebuild trust from previous negative experiences, fatigue ● Be wary of shaping our system on our current engagement ● How do we engage those who are currently well? ● Who is implementing the solutions that have been decided on? ● Closed-loop feedback for patient intervention need to be fail-safe → feedback loops need to be tight
Ideas/solutions	<ul style="list-style-type: none"> ● Feedback should be agile ● Start small ● 'Analyse the why' – utilised AI etc. ● Co-design critical: <ul style="list-style-type: none"> ○ Patient outcome ○ Patient experience ● Ability to cater for different populations

- Equitable access to provide feedback, i.e., not just an App platform
- Feedback loop for continuous improvement
- Multi-disciplinary review
- Information needs to be valuable to consumer
- Showing that F/b has an effect
- Engage with the feedback given
- Use different ways to collect feedback, e.g., speech recognition, use AI
- Need to know whole picture with feedback
- Understand why we are measuring
- Giving up-front time expectations
- Look at Bots as a route for feedback
- More flexibility in time etc. as options
- Ability to co-design survey with consumer
- Be flexible in solutions driving from feedback
- Acknowledgement of participation
- Trust
- Establish a baseline to compare results
- Limit patient burden in providing their information
- Feedback loop system
- Important to capture whole picture as to what leads to a survey response
- Need to consult and correct stakeholders in design
- Holistic viewpoint
- Important to trial/pilot initial systems
- Have a variety of feedback platforms
- Multiple data collection options
- Have simple feedback options, e.g., 'happy face'
- Need accountability in using information
- Importance of consulting before just making change
- Need a breadth of feedback

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| | <ul style="list-style-type: none">• Consider the process to how feedback is gained• Bring feedback into patients' ongoing journey/health experience• Need to leverage other industry, e.g., marketing• Consider need for consent• Information needs to be usable for its applied setting• Apply AI to simplify questions per consumer• Don't make it hard to give feedback• Measure us on more advance scorecards• "Measures" should be: Response to engagement• Need longer-term thinking• Looking at "Life course" experience – mindful of using the right terms, e.g., use of "patient"• ↑Digital will = ↑ data to analyse• Utilise clinical input in design• ↓ Barriers for consumers to provide feedback, e.g., time/travel• Possibility to incentivise giving feedback• Post telehealth survey "pop-ups", e.g., Zoom• Intelligent use of patient outcome data |
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