Discussion outputs from DIGITAL HEALTH LEADERSHIP SUMMIT, March 2021

Topic 13: Apps & wearables: How do we utilise citizen science for health outcomes?

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

Auckland delegates' responses

Barriers/challenges	• Quality of user-generated health information • Worried well • Previous hesitancy to integrate into Cloud • Incentivisation better in other countries • Defining data sets • Quality control and interpretation • Ensuring that the data was accurate • Consumer grade vs. medical grade wearable • Duality of growth • Tech now different to tech in future • Big brother "privacy" • Trust • Device capability / infrastructure • Fear = Facebook, WhatsApp – consumerisation of data • Trust and that people understand what this can do → patient – certified funder • Victorian system/workforce challenges • Access to the social determinants of health – access Wi-Fi, cell phone • Accessibility of data at present • Finding the 'signal' in the noise • Technology design can introduce bias • Behavioural information – bias • Self-management of individual – all about system, rather than patient

	• Data validity – around consumer grade wearables • Data as a commodity • Integration with other platforms • Cost of non-adherence • Governance because unregistered. Need stronger enforcement of Privacy Act 2020 • Data quality and capture • Access to the social determinants of health • Liability – who is responsible? • How do I make sure that the vulnerable patients are well taken care of – not a tech problem, but rather a model of care • HIPPA/GDPR – stronger enforcement than that emphasised in the Privacy Act 2020 • Biggest burn of cost – other issues, e.g., non-compliance • Distracted focus • Big tech players going to be big players – ensuring their incentives are aligned with that of health / generating wellness • Informed consumer – who are the professional advisors? • Volume of health informatics – how do you mitigate worried well? • Health literacy of conversation – ensuring rich conversation • Privacy/ethical questions – personal information shared with insurers • Medico-legal risk • How will the data be used with humans? • Wearable another piece – privacy – “sign away rights” • Recognised we need to post questions to data • Trust in data • Privacy concerns • Control where the data goes – how? Who? What? • Potential risky concept if not clearly defined • Liability of an AI-based information presentation – if the doctor can’t understand the algorithm, who is liable? • How do we make sure that the inputs/outputs are correct? • Design may introduce bias • Missing piece in wellbeing sector – Wi-Fi access can be more intelligent/targeted

	• Not usually an open portal – data unstructured as all over the place • Facebook/Google has view of ‘citizen’ – science in analogy • Potential equity implications, particularly for older population/digital literacy • Don’t utilise data particularly well. Security, governance, validity. Needs to generate insight • Cyber/hacking potential. • Trust/understanding • Ethics, interpretation – nothing is for free. Data/taken and stored. • Fundamental drivers of big data companies. Concerned about framing is citizen science and about data collection • Con artist potential indicating ‘we are data scientists’ – unclear terminology • Is the Ministry a trusted source? People who have different incentives may insert themselves in the mix • Tracking health information from wearables – patients need to establish a baseline first, as we are all different • Digital literacy of the current workforce • No immediate value exchange for the citizen • Trust issues: ○ Use of data ○ Use of information ○ Value of usefulness • Cynicism of big tech • Dynamics/changes: ○ Speed ○ Specifications ○ Needs • Punishment of lower SES for behaviour choices • Privacy, clinical buy-in, trust • Over-connected sensors • Skills shortage for data analysis • Digital disparity/poverty: ○ Lack of money ○ Lack of awareness – “why should I use one”?
Solutions/ideas	• When wearable integrated into model of care / workflows – would enhance clinician uptake

	• Enabling preventive approaches to healthcare intervention • Sharing with whanau: ○ Framing ○ Bringing in whanau overseas • Investment in infrastructure • Enabling patients to be supported better at home through enabling model of care changes e.g., early supported discharge, chronic disease management, early intervention etc • Assessment first – enabling choice • Wearables are an addition to models of care changes • Changing funding model to support digital technologies, such as wearables • Inform what is right / wrong – consumer budgets • Integration of wearable / app-based devices • Data standards • Interoperability • Clinicians on board • “Own” data • AI/digital navigator to make sense of data • Patient collaboration – information shared care plan: ○ Navigator ○ Assign roles • Better identifying patient deterioration • Prevention, predictive models • Input given guide to right resource – enables choice • Enabling early Internet – login the field measures/how much • Citizen science – non-clinical approaches to telehealth – “offbeat” interventions • New sources of health data. Approach should be shifted from “diagnostic” to “preventive” and “wellbeing” oriented approaches • Wearables could help predict health conditions in advance. This shifting emphasis from clinical diagnosis to preventive interventions – cut down burden on hospitals and clinics • Incentive structure – need commissioning for outcomes

	• Focus on wellbeing – cost to consumer and system • Integrate wearables and apps. • Open standards. • Utilising GIS. • Navigators to access choice – improved clarity of system / model of care • Singapore gave free Fitbits for all citizens – could be a pilot? • Incentivise models around outcome, not profit – Commissioning. • Integration into models of care • Telehealth uptake during COVID-19 highlighted we CAN innovate / change • Increasing ability to gain/capture data and generate insight • Crowd sourcing – desired outcome is change – organic way of gathering data • Research – enabling prevalence/overlying trends – e.g., zoning of fast food / alcohol outlets to enhance public health responses. • Mental health apps – already showing evidence of supporting improved outcomes • Value proposition of citizen science – continuous snapshot • Tech needs to be set up with “purposeful” information / method of capture • Public health responses improved to enable preventive approaches / intervention • Targeting care delivery. Enabling personalisation of healthcare intervention • Improved data sharing with clinicians – integrate with models of care – telemedicine • Moving towards value-based healthcare • “People like me” – creating self-management communities • Whānau/navigator care roles – information shared with GP (if alert) • Improved understanding of data – improved decision-making • Citizen science – co-design new ways of doing things • Triage – access to data – integrate into care plan • Predictive intervention – useful data • Encrypted NHIs – needing to let consumers know that their data wouldn’t go to ‘big brother’ • Data needs to generate insight – generating value from unstructured data • Improving digital health capacity / capability within the healthcare workforce

	• Interesting that there is hesitancy around the use of intelligence – happy to give app data to FB etc. Needing to frame the VALUE correctly to society. • Prospective clinical trial - … trial and can see insight – instead, model is just going “6 months later, are you any better”? • Crowd sourcing wellbeing data for research – would make this evident to consumers that this is happening • Promote citizen responsibility: o Example of genome o Could give to citizen science ‘Cert’ • More education because some are unaware of what they are giving up to system • Legal/policy standpoint = secure and trustworthy. Clearly define and ensure transparency of data us • Trustworthy and clear communication from all involved • Personalised healthcare. Bettering health outcomes – self management. Talking about reframing a system that already exists • Gains vs. loss? Benefit outweighs harm of trialling • Efficiencies: o Guidelines o LOS/outcomes • Enable people to value better health and wellbeing decisions • Trust matters – understand why, what and how • Showing people consequences of decision – ↑health literacy and active participant • Education – best way – interaction, particularly health/children • Individual health. Population health outcomes. Innovation/longevity • Social wellbeing and productivity – making a better world • Support platforms for patients/individuals (motivating outcomes) • Increased self-management of health and wellbeing by the general population • More data, more w… (about spurious items), mental health issues or overload health system with more queries • Integrity of data • Harnessing the power of citizens in clinical tech trials and policy development • Education – changing the health landscape of NZ in 10 years • Early, proactive intervention. System integration to have a broader, more informed decision • Create clear interfaces that show patient trends

	- Public health intervention/research – overlay with the social determinants of health information

Christchurch delegates' responses

Goals/observations	- Hook them and get them 'on the wheel' - Incentives - Budget - Need to upgrade - Technology moving fast - Open up closed access to date
Barriers/challenges	- What is the purpose and what are the benefits? - Another distraction among the digital grab for attention - Is the data being used for good by agreement - Do users know how data is being used? - Trust: ○ In app/device ○ In how data is used - Confidence in app/device as a clinical intervention - Where does data go and who is responsible for action? - How is 'health' enabling innovation? - Equity: ○ Accessibility ○ Cost of data - Behaviour driven by app developers - Risk of obsession with health and associated pitfalls, e.g., anxiety - Trust and fear of 'big brother'/security - Continuity of service - What do clinicians do with plethora of data? - Access/equity – who is wearing them?

	• Getting people to use them • Integrate with health data to make it meaningful • Dated technology in health sector to integrate/infrastructure • Digital literacy: ○ CRAs/other processes ○ How do healthcare providers verify/rate apps? • Reliability of devices • Anxiety in interpreting data • Are the worried well putting more stress on health system? Yes – filling valuable GP slots, impact on equity of access • People who don’t want to engage in health system • Fear of sharing data • Extensibility/technology changing • How to share data with others? • Interoperability • Who owns data? • ‘Walled garden’ • How to regulate? • Quality and validity of data • Verifying source of data • Equity of access • Use of data, e.g., insurance • Health literacy – what is the value in using this? • Defining and verifying quality/standard of apps • Understanding their purpose – why? • Data anxiety • How to choose app/device? ○ Too much choice ○ No standard • Capability/capacity of health sector to prescribe • Trust

	• Security and privacy • Equity and affordability • Fear of ‘big brother’ • Accuracy of data • How to bring consumer and clinical data together • Creating/causing problems, e.g., investigating things that will never be a problem
Solutions/ideas	• Nurse Blake😊 • Library of apps for my condition/s • Standards/ratings for apps/devices • Patient compliance of meds adherence • Public health working in partnership with app developers, e.g., dental health for kids → tell the story • Quality control over more regulation • Integration with clinical access to clinical data expertise • Analogous to mobile • Give them away! • Link ‘life’ data with ‘clinical’ data • Streamline processes to remove barriers to innovation • Look globally for best practice in verifying apps • Digital prescribing • Fail fast • Gamification • Government op-ex • Summary data tailored for clinicians • Tailored forward-planning healthcare • Gamification • Government to provide wearable, for free • Health Hub to assist users to correctly capture data • Prescribing wearables – lifestyle interventions help • Data standards

	• Funding for those that meet standards • Neutrality of those caring for data • Population analytics • Prescribing devices • Integration with home devices, e.g., Alexa • Digitally capable clinical workforce • Pharmacists to take leadership in promoting and prescribing – trusted health professional • Ministry to create app/s as ‘source of truth’ • Role of central government to lead and lay foundations for this to work • Deliberate targeting of evidence-based apps/devices • Post discharge monitoring • Focus the ‘citizen science’ on specific chronic conditions • Government fund targeted apps/devices • Dementia and early cognitive impairment apps/devices • Validate and regulate apps – ‘standard’ with rating

Wellington delegates’ responses

Goals	• What do we want to use the data for? o Preventative care o Increase the data available for use in the system for population-level analysis, and build intelligence across the system o Research: ▪ Disease specific ▪ Measure health outcomes and influence clinical process → change the model of care ▪ Develop a case for new interventions • It must deliver value to patients and give back to them in order to maintain buy-in • What outcomes do we not want? o We don’t want to create competition, or limit access to services based on providing or not providing data

	○ It should be socially focused, not commercially focused ○ It shouldn’t be a replacement to clinical decision making – it should support clinical decision making • Use to assess what staff are doing / introduce new models of care • Opportunity to deliver data for background monitoring and interventions – may be particularly helpful for the demographic who don’t want to get help • Important to use devices/data that patient chose • Use apps that improve experience (both for patient & clinician) e.g., for translation • Measure patient experience to improve care/delivery • Should avoid creating silos (resolve this by driving interoperability) • Value to patient is key - why should they care about providing their data? • Monitoring of specific/targeted patient groups would be higher value compared to general population monitoring • Group questioned the definition of citizen science. Some in the group felt citizen science was the use of citizen-led research [facilitator focused more on the use of citizen data from apps/wearables in questioning] • Need to understand how/who has access to technology • Will inform future service delivery / care pathways • Group suggested the solutions should be centrally funded but locally distributed • Group wanted challenged the system to consider: Can we lead the way globally in a nationally co-ordinated approach? • Use data for pre-emptive treatment and corrective interventions • Should consider whether the benefits outweigh the consequences? • Can we make the most of data which already exists vs introducing totally new data? • Education is important – do people realise the power of the data they hold? • On the table, we had people who specifically said they wouldn’t want the data – already have enough data to assess • Questioned what the value proposition is for using the data? ○ Link to something they already do in their practice ○ Offer cash? • Need to build trust: ○ Could do this through provider recommendations ○ Provider needs to be literate ○ What are the different groups we’re targeting and what is the desire? • If intervention-based, have a set of principles:

	o What’s the definition where it becomes / requires an intervention o Balance of what has evidence vs what people engage with • Could use data for prioritisation • Specific suggested use-case was step counts used for physios o Could prioritise care based on this / intervene based on step count o E.g., in the lead up to surgery or for patients in hospital. Work with patients who don’t have a sufficient step-count, leave those who are mobile
Barriers/challenges	• Data: o Governance ▪ Necessary to build trust with those providing data – who has access, what do they have access for, and why ▪ Developing permissions and access models o Quality and accuracy of data e.g.: ▪ Is the data from the person we think it’s associated with (e.g., have I attached my Fitbit to the dog)? ▪ Is the data available on a consistent basis? ▪ Can the data be skewed / are ranges equal across the population? o Huge range of devices available to consumers in the market o Data inoperability – partly due to the number of devices, but also willingness of commercial providers to develop solutions which integrate • Standards: o Are there any available now? o Is it even possible to create/enforce standards? • Differences between communities e.g., re expectations, use of technology, measurement/scale of data • Data sovereignty and consent issues • Need to future-proof the solution for policy changes • Really important to consider human behaviour and potential unintended consequences of the use of data • Group highlighted a significant existing bottleneck in IT teams approving the use of new technology with ~15 approval steps • Privacy and security could be a barrier, but group were keen those developing solutions shouldn’t be limited by these and to think about opportunities • Group questioned why we default to traditional/physical models of care

	• Question about who is responsible for monitoring the data / where does liability lie and is this a risk? • Development of standards would be challenging, and establishing a range of ‘normal’ may not be possible – example given re heart rate monitoring where normal range for exercise can vary between individuals • Education necessary on the use of these types of data/technology • Does it move us towards a place of equity and are we promoting this? • If we built a library of apps, we be aware that ultimately consumers will be driven towards apps they like – therefore need to balance open market with the implementation of standards/equity • Not just about technology – what are the culture/funding changes needed • Large part of workforce aren’t digital natives • Would need to manage the worried well and ensuring they don’t block access • Lack of trust in tech, especially where vendors/s are not designed for health • Can the system set standards? In general, felt this tended to be driven by the app/device developers • Challenge with managing app/device version control and updates – e.g., do patients keep their device up to date, does it matter? • Need to balance value vs. time required for approvals – one of the group pointed to an example of mental health apps in Australia [facilitator doesn’t have the details on these apps] • Noted one difference in drug approval is that Pharmac have control over drug availability, vs apps/wearables which are readily available to consumers • Digital literacy is a <u>key</u> enabler • Does the use of apps/wearables increase the digital divide? But can it also improve access? • In the group it was highlighted that we likely underestimate how digital our society is – COVID tracer has shown the lack of access to tech. Therefore, a strategy around this would need to be for the long-term • More data doesn’t equal better – need to build maturity around data which already exists and develop intelligence on existing datasets before we can move to accepting app/wearable data • No standards exist for accessibility – how do you adapt for different communities? • Value will not be universal – need to understand stakeholder groups and how this might differ • Sign up process for patients and organisations – experience from one of the group was that the registration process put them of using the app / suggesting it for patients • Process of change • False positives:

	○ Is the range accurate? ○ Does it change for the individual? • Data governance is key • Commercial organisations block access, e.g., Facebook • PMS systems aren’t building capabilities • Clinical trust • Patient trust • Unintended consequences • Potential for coercion of patients • How do we make it equitable – would prescribing help? • Issues w data accuracy – especially if “cheap” technology • Ethical question re wearable data e.g., for at risk groups. Do you target based on this? • Would be unethical to screen without intervention available • Would need to develop awareness for patients re what devices are available • Change in tech is coming fast • Keeping up with technology changes is hard with an approvals process • Can apps capture the nuances of health? • Adoption rate [facilitator can’t remember what this was, it may have been that the general trend is users collect a lot at first, but slowly the use of device/wearables trails off over time] • At the moment, data collection is uncontrolled – would need to target – i.e., via consumer marketing
Solutions/ideas	• Co-design: ○ Identify needs/value for the consumer ○ Design for this • To overcome trust issues the group suggested a solution which collects data from individuals but only evaluates that data at a population level. ○ Present back to patients in a way that means they don’t feel singled out ▪ Individual uploads data ▪ System reflects learnings from pop-level analysis back to consumer ○ Noted it is worthwhile testing what level of analysis/evaluation could be undertaken re social licence; this may be a barrier to overall usefulness/uptake

	• Have the ability to share across other groups e.g., whanau • Types of data which would be relevant: ○ Physical ○ Environmental ○ Mental health • App/device types ranked according to reliability of data: ○ Implants (most) ○ Wearables ○ Apps with manual data input (least) • Communicate with communities – ensure focus on social objectives and not commercialising • Approval of apps nationally: ○ Don’t stifle innovation at local level but share experience ○ Share across sectors, including private ○ Include accreditation which considers privacy and efficacy ○ Should be evidence-based ○ Builds trust both for consumers and sector ○ Should work to enforce standards ○ Is there a way it could be generic approval for a type of tech (i.e., not tied to specific device or app)? • Engage with commercial sector: ○ Develop approval process which drives compliance ○ Develop understanding of how data should be interpreted • Also consider the use of other reviews alongside approval by the centre (e.g., https://www.commonsensemedia.org/): ○ Consumer driven ○ May include diff types of review e.g., clinical, community leader, consumer ○ Democratise • Important to simplify approval process (especially re medical device) to enable rapid innovation • Make sure it’s not a burden to developers and innovators – e.g., tiered approval as in Germany where suppliers can get a preliminary approval prior to obtaining evidence • Also, would want to reduce the burden on the sector re approvals process • Suggested driving standards through an approval process. Check:

  - Clinically safe
  - Technically safe
- Use national platforms as a gateway to drive standard adoption
- Buy consumers the device if it is going to deliver value to service
- Use subject-matter-experts to review
- Should be the vendors responsibility to get approval – like for drugs or food (i.e., self-certification) – to reduce burden on the system
- Use “data free sites” for certain approved tech to support adoption
- Can we get approval from trusted overseas sources?
  - Does that fit for equity?
  - Is it safe?
  - Does it fit for our system?
  - Is the interpretation of the data accurate?
- Build trust by being very specific of use of data/need of data
- Patient would have control over data – thought that may have clinical implications e.g., may not get the whole picture
- Accessibility and equity – should take a blended approach and not one-size-fits-all
- Apple are developing interoperability – opportunity to use this data
- Align/focus around a particular intervention – start small
- Use a top-down MoH approach
- Don’t stop patients using their choice of app
- Anonymity builds trust – more likely for patients to provide all their data rather than just the data which paints a good picture
- Could you use a robot to respond, to encourage patients to provide data?
- Should include different levels of permission e.g., sharing data with whānua
- Develop an integrated view of person – look at determinants for health
- Enable patient to self-regulate
- Suggested focus areas:
  - Stroke:
    - Currently must admit to monitor. Instead, could do remotely via apps/wearables
    - Check treatment/outcomes vs. postcode

	○ Blood pressure ○ Glucose monitoring • Don’t necessarily make data public, but available to the system to improve • Look for trends i.e., aggregate • Need explicit consent about sharing: ○ Establish use cases for this ○ What is the health outcome? ▪ Is it vendor-led or provider-led? ▪ Should use a partnership approach with industry • Expect that technology will get cheaper over time • The wild west supports innovation • Patients may establish their own outcomes – basis for sharing • Look at Strava as example of open data/APIs • Use targeted data collection for outcomes to build trust with patients • Develop warning flags • Create targeted patient education programme – designed for different patient groups