RESEARCH NOTE

BETTER HEALTH THROUGH BETTER DATA

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Her master's degree in public health from the University of Auckland provided her with an excellent grounding in both public health in general and specific knowledge of the health system in New Zealand. In 2015 she set up a new GP practice, which within nine years was providing care to approximately 8,500 patients with a multi-disciplinary staff all within custom-designed premises. This has equipped her with a wealth of first-hand experience and knowledge of health policy, strategic planning, and management within healthcare.

She has since left full-time general practice to focus on medical advisory roles to plan, deliver and maintain quality healthcare for all New Zealanders.

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Executive Summary

New Zealand’s health system faces growing pressure. Demand keeps rising, money is tight, and the workforce is stretched.

Most New Zealanders first meet the health system in their GP’s clinic, but this is also the part we understand the least. Without good information about what happens in general practice, it is hard to know whether people can get care when they need it, whether that care is coordinated, or how much difference it makes.

Other countries have already learned that better data lead to better health. When doctors can see patterns in their own work – for example, how they prescribe medicines or manage chronic conditions – they can make improvements that help patients directly. When policymakers can see what works across the system, they can invest where it matters most.

New Zealand already has a powerful tool for linking data across government, called the Integrated Data Infrastructure (IDI). It connects information from health, education, income, housing and other areas.

The one missing piece is data from general practice. Adding this would give us a full picture of how health care works for people in their communities.

The report recommends a simple, practical plan:

- **Start with trust:** Build a system owned and led by clinicians, with strong privacy rules and clinical governance.
- **Use clear standards:** Make sure data can be shared safely and used for approved research and learning.
- **Deliver value early:** Give GPs useful tools, such as dashboards and feedback, that make their work easier.
- **Grow carefully:** Begin small, expand step by step and include all communities so that the data is a true representation of the New Zealand population.

Privacy concerns are real, but they can be managed through design. Data would be de-identified, patients could opt out, and every use of the data would be logged and approved.

If done well, this would let New Zealand track what truly matters: continuity of care, safe prescribing, avoidable hospital stays, patient experience, and equity across different groups.

In short:

Better data will not treat patients on its own – but it will help those who do. It will let doctors spend more time caring and less time guessing. It will help government focus on what works. It will make the health system fairer, safer, and more effective.

Better health begins with better data.

Introduction – from blurred vision to a clear line of sight

Policy is the art of choosing under constraint. In health, the constraints are relentless. Demand rises. Money is finite. The workforce is stretched. Choices are made every day in clinics, in ministries and in Cabinet rooms. The quality of those choices depends on our depth of understanding.

General practice is where most New Zealanders encounter the health system. It is where diseases are first diagnosed, where treatments are started, where conditions are watched over time, and where referrals are made or avoided. If we cannot understand what happens there, we cannot govern the system with confidence. We cannot readily determine whether there is access to care, whether continuity of care is occurring or whether that care is coordinated and comprehensive. We also cannot tell how this care is benefiting the health system. We cannot tell if prescribing is safe and effective. We cannot know whether chronic disease is optimally managed, and we cannot see where there are gaps in care.

The strongest lesson from comparable countries is simple. Health systems built on strong primary care data make better policy. They learn faster. They target better. They protect clinician and patient trust by design.

New Zealand has a structural advantage that few others enjoy. The Integrated Data Infrastructure (IDI) can already link de-identified microdata across health, education, income, justice and housing at the population scale under strong controls.[1] Primary care clinical data are the missing piece. Adding them would enable us to better understand the place where the majority of health care occurs, link it to the rest of the system, and evaluate reforms across sectors with precision. This is not about surveillance for its own sake. It is about learning what works in the public health care system for whom, and at what cost.

1. Why primary care data matter – from the consultation to the Cabinet table

The case for better data begins in the consultation, not in a spreadsheet. A GP who knows their patient population can spot who is overdue for a review. A GP practice with a simple continuity index can see whether it is supporting the building of vital longitudinal relationships between its clinicians and its patients. Audit-and-feedback can show where antibiotic use is off course or where there is variation in asthma care.

When data support care, clinicians engage. When they engage, the data improve at the source. Once that loop is in place, the system can ask bigger questions. For example, are continuity of care and access to comprehensive and coordinated care in general practice improving for high-need groups? With more services established in primary care, or improvements to housing or income, are ambulatory-sensitive hospitalisations falling?[2]

Good policy needs a balanced view. Inputs like workforce and buildings matter, as do processes and outcomes. However, patient-reported outcomes and experiences are also key. These health system measures use a population level collection approach. Internationally, there has been a steady shift toward measuring what matters to patients, not only what is easy to count. That is why patient-reported indicators now sit alongside clinical measures in health reform programmes.[3]

Effective international examples include: QRESEARCH from the United Kingdom,[4] the Canadian Primary Care Sentinel Surveillance Network (CPCSSN)[5] and Health Data Coalition in British Columbia[6] which excel in primary care chronic disease surveillance and research through networks extracting data from diverse Electronic Medical Records (EMRs). Australia's Practice Incentives Programme Quality Improvement (PIP QI) demonstrates a model for encouraging data quality and continuous quality improvement at the practice level, supported by Primary Health Networks (PHNs) and a national data custodian.[7]

Scandinavian countries (Norway, Sweden, Denmark) showcase the benefits of high digital maturity, national eHealth strategies, unique patient identifiers, and integrated patient portals, fostering strong continuity of care and enabling comprehensive data linkage for service planning and research. The United States, through various Centres for Medicare & Medicaid Services (CMS) initiatives like the Comprehensive Primary Care Initiative (CPCI)[8] and Accountable Care Organisation (ACO) models,[9] offers valuable lessons in multi-payer collaborations, value-based care experiments, and the use of data for risk stratification.

The most effective methodologies involve a combination of robust EMR systems, secure patient portals, integrated telehealth data, and adherence to international data standards such as SNOMED CT for clinical terminology[10] and HL7 FHIR for interoperability, with effective approaches to coding that do not burden clinicians.[11] On the patient-reported side the OECD's PaRIS initiative provides a shared template for patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in primary care so that countries can compare and learn from one another.[12]

These technologies, coupled with strong data governance and privacy protection, clear policy objectives, and clinician engagement, enable the collection of high-quality, longitudinal data. This data facilitates advanced analytics, real-time monitoring through performance dashboards, and comprehensive evaluation of interventions. This in turn enables evidence-based funding to occur.

2. What good looks like: governance first, then data standards, then tools that help clinicians

Sound governance and privacy by design are needed if a primary care data network is to be successful in improving patient care and supporting clinicians to practice well. The network must be designed to build trust and engagement from patients and clinicians. Resource support should be provided for data collection. Common standards are needed so that data can flow and be used again. Time and care must go into producing quality data. This requires data cleaning, mapping and case definitions. Value should be given quickly to general practices through tools that save time or make improvement easy. Data linkage and evaluation must be planned for at the start, not at the end.

Standards turn information extracted from individual patient records into re-usable data. HL7 FHIR[13] provides a modern way to exchange health data. SNOMED CT[14] provides a common vocabulary so that a diagnosis means the same thing everywhere. Standards do not do all the work, but they make clean extraction and faster harmonisation possible. On top of that, a common schema can absorb data from different EMR products and map diagnoses and medicines to standard classifications.

Finally, the system must show its value to clinicians by making it easier for them to provide the best possible care to their patients. Peer-group feedback processes which are easy to implement so that patient care improves, and safety signals that prevent harm from occurring add value to clinicians.[15] These are the things that turn data collection from a chore into a tool.

Based on its relevance and adaptability to New Zealand, the CPCSSN from Canada is used as an exemplar and explored in detail.[16]

3. The Canadian Primary Care Sentinel Surveillance Network – a clinician-led network that makes learning possible

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) began in 2008 with a clear aim.[17] Build a national chronic disease surveillance system from primary care EMR data. The country is federated, provinces run their own programmes, and there are numerous EMR vendors.[18] A single system was not on offer; however, a single network was.[19]

The CPCSSN is governed by clinicians. Patients are provided the opportunity to opt out of having their data included in the dataset. The network built extractors for a wide spread of EMR products. It de-identified data at source, transferred them securely, and implemented a national schema.[20] It mapped diagnoses to ICD-9 and medicines to ATC classifications.[21] It developed and validated case definitions for conditions using data from multiple fields.[22] It created a secure environment for approved research, with each query reviewed by the governance group and access limited to only the fields needed to answer the question.[23]

These measures were strong enough to win an international privacy award.[24] Clinicians got something back from the start. Feedback tools let them see, for example, their patterns of prescribing, compare them with peers, and generate lists of patients who needed review.[25]

Scale followed naturally. More than 1,500 clinicians across many learning and research networks have contributed data covering nearly two million patients. Representativeness has been an issue. Early participation skewed toward academic practices and this limitation was reported.[26] Recruitment has since widened, and analysts were urged to adjust for differences in age and sex.[27]

Impact has been both direct and indirect. Direct, when feedback on antibiotic prescribing supported antimicrobial stewardship by clinician groups.[28] Direct in assessing whether there were changes to patient care during the COVID pandemic.[29] Direct, when gaps in asthma care were made visible in ways that practices could act on.[30] Indirect, when the national neurological conditions surveillance system could draw on a consistent primary care dataset.[31] Indirect, when research on multimorbidity and polypharmacy became possible at a scale that mattered.[32]

Canada's most important lesson is practical. Extraction is only the start. The work that turns extracts into evidence is vital – mapping, cleaning, harmonising, maintaining case definitions, checking quality, reporting limits and the protection of privacy. It was important that this work was undertaken by people with a sound understanding of the nature and primary care context of the data. This is the work that makes policy better because it makes learning possible across a whole country rather than only inside a single EMR vendor's product or a single province's programme.[33]

4. New Zealand's advantage – add the missing piece to the IDI

The Integrated Data Infrastructure (IDI) is a national asset. It links de-identified microdata from many agencies in a secure environment, with clear rules for access and analysis. Health-related datasets in the IDI include: immunisations, laboratories, hospital discharges, pharmaceuticals, maternity, and mortality.[34] Beyond health, the IDI holds education and training, income and work, housing, benefits and social services, justice, people and communities, and core population data.[35]

General practice clinical data at scale is not yet included. That is the gap that matters. If we add de-identified extracts from general practice under strong governance, we can see in detail the sector in which most patient health care encounters occur and the pathways that flow from it. We can evaluate reforms with power rather than inference. We can look at equity with a sharper lens. We can move capitation funding to fairer formulas that reflect real patient needs. We can also examine how education, housing and work interact with clinical care for specific cohorts over time.

The aim is not to build a giant new database for anyone to browse. Instead, it is to establish a clinician-led national network that de-identifies at source, makes data useful to clinicians, and then contributes de-identified extracts for approved research questions. The IDI can then be the place where cross-sector learning happens, under controls that people can understand and trust.[36]

5. Risks, realities and how to manage them

Anxiety about privacy is legitimate. Comprehensive public engagement and consultation are vital. A recent survey from Australia shows that people view data held by general practices as being different to other health data. As a result, people surveyed were more conservative in the data sharing purposes they supported, with reticence about data sharing for government analysis.[37] The response must be operational, not rhetorical. That means privacy must be enforced in practice, not just promised in principle.

The NHI system has been in place in New Zealand for over thirty years and can be used to anonymise patient data.[38] Data transfers must be encrypted and de-identifying at source must also occur so that clinicians cannot be identified. The key can be held by local networks. Data analysis must occur in a secure environment. It is important that patients can choose to opt-out from having their data included in the network. A published register of approved uses is needed. It is also important to record who accesses the data, what they did with it and when. This is how leading networks, such as the CPCSSN, already operate. It is also how Stats NZ operates the IDI.

Vendor and clinician incentives must be managed. EMR products and GP practices are not charities. Some vendors monetise data for private research. Contracts for extractors need to be clear about public-good use at no cost to practices. Data standards also help to prevent the need for GP practices to be tied to using particular EMR providers. A public custodian can coordinate technical work across products. Ownership and governance should remain clinician-led so that purpose does not drift.

Data quality is a constant task. Raw EMR data are messy. Coding habits and recording fields differ across systems and regions. Case definitions must be validated and maintained. Quality reports must be public so that users can see limits and improvements. A data extract should not be used when it cannot answer the question being asked of it. Representativeness will not happen by accident. Early participants are often atypical. Recruitment must be active. Analyses must adjust for differences. Coverage maps should be published as a routine matter.

Lastly, if participation means more time spent on paperwork and less time with patients, clinician participation will fade. The huge advancements in artificial intelligence (AI) technology should mean that data transcription and coding will become easier and less time-consuming for clinicians, as should data extraction and the process of turning the data into evidence.

6. A practical roadmap – pace, sequence and proof

There is no need for a big-bang build. What is needed is a solid base. The sequence matters because trust is cumulative.

Start with governance. Create a clinician-led body with clear decision rights. Give it a public charter and clear mandate. Make purposes explicit. Set rules for access and publishing. Bring independent privacy and security expertise to the table. Put the patient voice in the room. Publish minutes and a register of approved questions. Begin small but begin visibly.

Lock in privacy by design. De-identify at source. Move data through encrypted channels. Analyse only in a secure environment with role-based access control. Grant access only for approved non-commercial use questions and only to the minimum fields needed. Prevent ad-hoc extracts and private copies. Audit everything. Then write publications about methods used and oversight.

Adopt standards before scaling up. Require HL7 FHIR for interoperability and SNOMED CT for clinical terms. Agree on a minimum dataset and a common schema. Fund the mapping and the cleaning. Build validated case definitions for conditions that will anchor early work, such as diabetes, hypertension and chronic obstructive pulmonary disease (COPD). Negotiate extractor obligations into vendor contracts so that practices are not charged to serve the public good.

Return value to clinics quickly. Deliver simple dashboards that show continuity of care, chronic disease management and safety signals. Provide case-based, evidence-supported peer-group feedback that leads to conversations rather than compliance. Integrate patient group management lists into existing workflows. Use automated transcription and coding where it saves time without risk.

Expand deliberately. Start with willing practices, Primary Health Organisations (PHOs) and existing research or learning networks.[39] Make representativeness a goal. Recruit rural and high-deprivation areas on purpose. Publish coverage and gaps. Report sample characteristics and adjust analyses. The network will earn its scale by being useful and fair.

Link and evaluate in phases. For approved questions, link de-identified extracts to hospital, pharmaceutical and mortality data. Use the IDI to study cross-sector outcomes where primary care is part of the story. Build a monitoring and evaluation frame before you scale, with baselines and comparisons, so that every expansion generates evidence. Tie incentives to participation and improvement.

The example of the CPCSSN shows that work that is measured and steady and which is underpinned by clinician-led governance with meticulous attention to privacy will have the most chance of success.[40]

7. What to measure – small, sharp and meaningful

Measures must be few, linked to goals and useful to clinicians. The aim is not to build a museum of indicators. The aim is to produce a bottom-up (rather than top-down) approach of providing data to inform and guide clinical practice. Data should primarily serve to help inform GPs about their prescribing practices, clinical outcomes, and care patterns, enabling them to improve the care they provide their patients.[41] Ongoing and lifelong learning by clinicians should be the major impetus to quality improvement. Clinicians should be part of a system-wide effort to engage them in studying their own practices regarding degree of patient improvement in health, variations in outcomes across their patients and patient populations, overprescription of medications, such as antibiotics; occurrence of unintended consequences of treatments (including adverse ones); and support for acceptable deviations from standard practices.[42]

Continuity matters because relationships matter. Practice-level continuity indices are needed. Increased continuity of care in general practice is associated internationally with safer prescribing, better chronic disease control and lower costs.[43]

Prescribing safety shows whether a system protects patients from harm. Antibiotic use for respiratory infections is a reliable measure. It responds to feedback and peer comparison.[44] It protects people from harm in the present and from antibiotic resistance in the future. It is a concrete example of how a data-driven audit can change behaviour.

Avoidable hospital use is a system lens. Ambulatory-sensitive hospitalisations are not a perfect measure, but we know they improve when there is better access and management in primary care.[45] They are meaningful to clinicians and ministers. They have the advantage of being visible in existing administrative data.

Patient-reported outcomes and experiences humanise care. They show whether services help people live the lives they want to live. The OECD's PaRIS work offers instruments that allow international comparison.[46] If New Zealand uses compatible tools we can learn from others, and they can learn from us.

Equity should not be viewed separately. It must instead be incorporated into every measure. Age, sex, ethnicity, deprivation and geography must be visible. We must ensure that the way these measures are presented does not serve to discourage clinicians from working in high-needs areas. If gaps are not closing, the policy is not working.

Conclusion – a clear case and a workable path

Data do not treat a patient. People do. But people do better when they can see and understand clearly. Our line of sight into general practice is clouded. We have a world-class linkage platform in the IDI. We have decades of experience with patient enrolment. We have clinicians who want to improve, and a public that wants a fair system that works.

Other countries have shown what works. Canada has built a clinician-led national network that takes messy EMR records and turns them into a platform for surveillance, research and quality improvement.

The next step for New Zealand is straightforward. Put specialists GPs in charge of a national primary care data network with privacy by design. Require standards that make extraction clean and reuse safe. Fund the unglamorous work that makes evidence possible. Deliver useful feedback to practices early. Link under strict governance to the IDI for approved evaluations. Measure a small set of meaningful indicators which have equity measures built in. Publish methods and results. Learn in public.

Better data is the cheapest reform with the highest return because it makes every other reform smarter. It turns debate into learning. It lets ministers see whether policy is working rather than hope that it might. It helps clinicians spend time where it counts. It helps patients receive care that is safer, more continuous and more effective. The case is clear. The path is workable. It is now time to act.

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