

Practical applications and discussions

An 'integrated health neighbourhood' framework to optimise the use of EHR data

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ABSTRACT

General practice should become the hub of integrated health neighbourhoods (IHNs), which involves sharing of information to ensure that medical homes are also part of learning organisations that use electronic health record (EHR) data for care, decision making, teaching and learning, quality improvement and research.

The IHN is defined as the primary and ambulatory care services in a locality that relates largely to a single hospital-based secondary care service provider and is the logical denominator and unit of comparison for the optimal use of EHR data and health information exchange (HIE) to facilitate integration and coordination of care. Its size may vary based on the geography and requirements of the population, for example between city, suburban and rural areas.

The conceptual framework includes context; integration of data, information and knowledge; integration of clinical workflow and practice; and inter-professional integration to ensure coordinated shared care to deliver safe and effective services that are equitable, accessible and culturally respectful.

We illustrate how this HIE-supported IHN vision may be achieved with an Australian case study demonstrating the integration of linked pseudonymised records with knowledge- and evidence-based guidelines using semantic web tools and informatics-based methods, researching causal links between data quality and quality of care and the key issues to address. The data presented in this paper form part of the evaluation of the informatics infrastructure - HIE and data repository – for its reliability and utility in supporting the IHN.

An IHN can only be created if the necessary health informatics infrastructure is put in place. Integrated care may struggle to be effective without HIE.

Keywords: data analytics, EHR, integrated health neighbourhood, medical homes

INTRODUCTION

Persisting systems gaps and fragmentation of care within and between health care teams in primary and secondary care are the key issues being addressed by most national health systems, examples being the Australian primary health care (PHC) strategic framework,¹ NSW State Health Plan² and eHealth blueprint.³ The long-suffering patient has to deal with fragmented roles and responsibilities compounded by poor communication, fragmented programs and services. This fragmentation extends across interfaces for care, information provision, identification and handover, guidelines use and standards, access to their own records and privacy compliance.^{4,5} Fragmentation leads to poor and unsafe care and inappropriate use of emergency and hospital services, which are often preventable. Continuity and coordination of patient-centred care requires effective communication, coordination, teamwork and judicious use of information and communication technology^{4,5} within a medical home⁶ and across the health neighbourhood.^{7,8} This requires the effective use of electronic health records (EHRs), personal health records and electronic decision support tools to collect, share and use good quality information to provide safe, effective and coordinated care along 'patient journeys' and 'care pathways' in the health and social care system. However, while there is consensus about how EHRs and informatics structures and processes support good quality care, there is less agreement about implementation.⁹

Observational EHR data are also increasingly being mined, linked, aggregated, cleaned and used for audit, continuous quality improvement, health service planning, surveillance and epidemiological study, evaluation research and measurement and monitoring of quality of care, particularly of patients with chronic diseases. Fundamental questions about observational EHR data include:

- (i) What are the data types?
- (ii) How good are the data and metadata?
- (iii) How good are the data tools and systems?
- (iv) Is the information fit for purpose?
- (v) Can poor data lead to poor care?

Despite improved informatics capability, data quality (DQ) in primary care¹⁰ and hospital systems¹¹ has serious deficiencies. However, ontological data management methods can maximise its potential and ensure as far as possible fitness for purpose.^{12,13} Tools to collect/extract data and assess and manage DQ are often inconsistent and should be validated in a transparent manner within a robust data and clinical governance framework.^{11,14} There is also a *de facto* failure among primary and secondary care clinicians to share data beyond the traditional referral letters, clinic letters and traditional structured documents such as discharge summaries.¹⁵ Key issues and research questions exist around whether there are causal relationships between good data and good care, inter-professional relationships, information-sharing, health literacy and patient engagement/empowerment.

This paper describes our vision of an integrated health neighbourhood (IHN) underpinned by a community wide health information exchange (HIE) using a model of multi-level integration of data, information, clinical practice and disciplines to support inter-professional coordinated care across primary, secondary and tertiary care settings. The care must be safe, evidence-based, continuous, coordinated, accessible and equitable. We see the IHN as a learning organisation using complex collections of EHR data optimally for service provision, education and research. The data presented in this paper form part of the evaluation of the informatics infrastructure – HIE and data repository – for its reliability and utility in supporting the IHN.

Context for the vision

The context includes the regulations, policies, strategies and resources available to governments, funders, planners and implementers to achieve the mission of equitable access to well-coordinated safe and evidence-based care.

Primary health care framework: The Australian PHC strategic framework¹ describes:

- i. a consumer-focused integrated PHC system;
- ii. improved access and reduce inequity;
- iii. health promotion, prevention, screening and early intervention;
- iv. quality, safety, performance and accountability.

Interactive model of access and equity: Access is an interaction and a balance of demand and supply.¹⁶ Demand includes the burden of disease and attributes of the population such as knowledge, attitudes, skills, capacities and self-care practices. Supply includes location, availability, cost and appropriateness of the services. The supply and demand provider-user dyads include:

- i. approachability – ability to perceive;
- ii. acceptability – ability to seek;
- iii. availability/accommodation – ability to reach;
- iv. affordability – ability to pay;
- v. appropriateness – ability to engage.

Access and equity is further complicated by increasing health costs and demand arising from increased expectations of health and the ageing population with increased morbidity.

Purpose of EHR and information systems: EHR data would be used for:

- i. accurate identification of an individual;
- ii. supporting managerial functions and integration of data and systems;
- iii. supporting clinical care and coordination;
- iv. supporting care of populations;
- v. supporting research, evaluation and audit to inform DQ, governance, business models, policy and practice;
- vi. creating a real-world evidence base around the management of complex comorbidity and frailty in an ageing population.¹⁷

Expanded chronic care model: The chronic care model (CCM) (Figure 1) incorporates the policy, clinical and managerial systems and processes that must be in place to provide safe, effective and coordinated care to individuals and populations.¹⁸ The health care team needs to be activated and proactive to engage meaningfully with the activated and empowered patient to guide them through the health system to ensure access to and appropriate use of health services. This requires the integration of data/knowledge, clinical service and inter-disciplinary teamwork across the health neighbourhood.

Multilevel integration to support care: Figure 2 summarises the key levels of integration and the standards required at each level:

1. data and information system;
2. knowledge and evidence;
3. clinical services within the medical home;
4. inter-disciplinary team work across the health neighbourhood.¹⁹

The vision is an IHN and an information enhanced learning organisation.

Integrated health neighbourhood: For translational and health services research, the IHN is the logical unit of data collection and denominator for data analysis. With the understanding of general practices as medical homes, the health neighbourhood is described as the actor network and information ecosystem²⁰ created by secondary care health and hospital services and the surrounding primary care, community health and general practice services.

The complexity of the EHR data collected from the IHN includes time and space dimensions, which we believe will require innovative ontology-based approaches to optimise their use.¹² The IHN concept needs record linkage to enable the tracking of individual patients across different services in the IHN. This also enables the elimination of duplicates in prevalence/incidence studies. The Fairfield IHN (FIHN) uses GRHANITE™ for probabilistic record matching and linkage through pseudonyms created by the hashing of personal identifiers.²¹

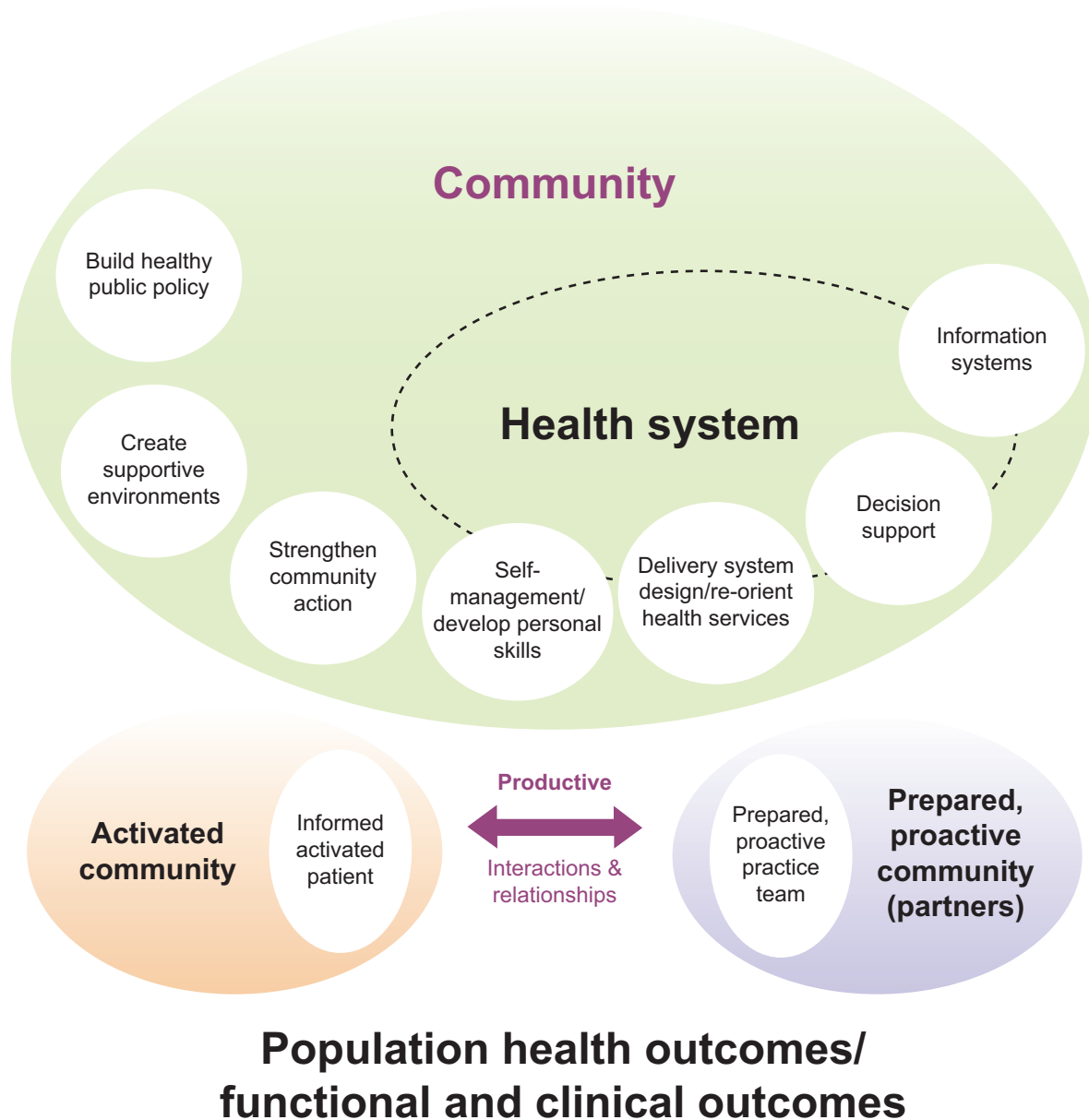


Figure 1 Expanded Chronic Care Model (used with permission)

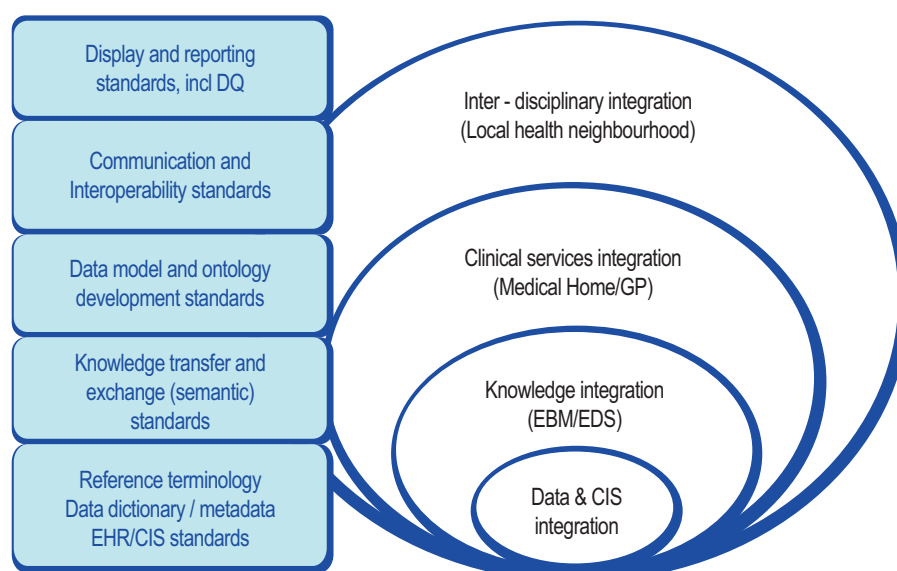


Figure 2 Levels of integration and relevant standards

(Note: CIS = clinical information system; EBM = evidence-based medicine; EDS = electronic decision support; and GP = general practice)

Case study: The Fairfield IHN

Methods: We established the FIHN (Figure 3) with support from the local hospital/health services and the local UNSW general practice-based research network. The informatics infrastructure – an electronic data repository, which links and manages data extracted from the Fairfield hospital admissions, emergency department and diabetes clinic (★) and ten general practices (●) in the Fairfield local government area – was installed.

Standard operating procedures are in place for DQ management and governance to ensure compliance to quality, privacy and security standards. We focused initially on DQ assessment and management,¹³ validation of data extraction¹⁴ and management tools,^{10,11} and exploring the use of ontologies to collect, link, manage, store and analyse complex personal clinical data from these multiple disparate EHRs.^{22,23} The FIHN database architecture was established with ontology-based data access, using tools like SPARQL, to complement relational database access²² with algorithms to create cohorts and to integrate data, information, practice and disciplines in the medical home and across the IHN. This work is ongoing to establish automated protocols to improve the DQ, through structured DQ reports (SDQRs) and feedback,²⁴ to enable accurate epidemiological and cohort studies.

Findings: In the following section, we describe examples of basic, informatics and applied projects to illustrate the systematic approach to developing and testing the tools to establish an informatics infrastructure to achieve this vision.

Example: Phenotyping and case finding: The accuracy of the FIHN phenotyping algorithm for Type 2 diabetes mellitus (T2DM) in the data repository was assessed using both biostatistical (sample size) with ontological (combination of attributes) methods.²² In addition to acceptable accuracy of the case finding tool, we also confirmed the common understanding that

accuracy increased with increased sample size and increased number of attributes used in the query (Tables 1 and 2).

Comment: At this point, we would not recommend unsupervised use of the data for patient care. With some caveats on the DQ, especially the completeness and representativeness, the data repository can be used for research, education and quality improvement purposes.

Example: Record linkage and patient journeys: The FIHN pseudonym-linked datasets²¹ enable the tracking of patients journeys through primary care services in the neighbourhood (Table 3). This shows there is significant number of patients using a number of general practices in the neighbourhood, usually for access reasons. On the other hand, it could be an indication of doctor shopping.

Similarly, patient journeys can be tracked through primary and secondary care services in the FIHN through linkage of general practice, diabetes outpatient and hospital data sets (Figure 4). We have defined a cohort of 5186 patients with T2DM (estimated prevalence of 3.5%) in the ten general practices ($N_{\text{all ages}} = 151,616$). There were 5049 in the diabetes clinic, of these 2428 had at least one admission into the local hospital.

Developments are ongoing, using ontology-based methods, to embed an assessment of temporal and spatial variations in the patient journeys across the health system. This enhancement will improve the relevance and validity of the data for modelling, predictive and longitudinal studies.²⁵

The data linkage is highly accurate as tested by both computer-based and manual (i.e. checking with the general practice) methods. The main problem was similar and sound-alike names, especially with some ethnic communities in the FIHN, one of the most multicultural local government areas in Australia.

Example: Integrating data quality assessment: Ontology-based methods have been developed to embed an assessment of DQ in the management and analysis of the FIHN

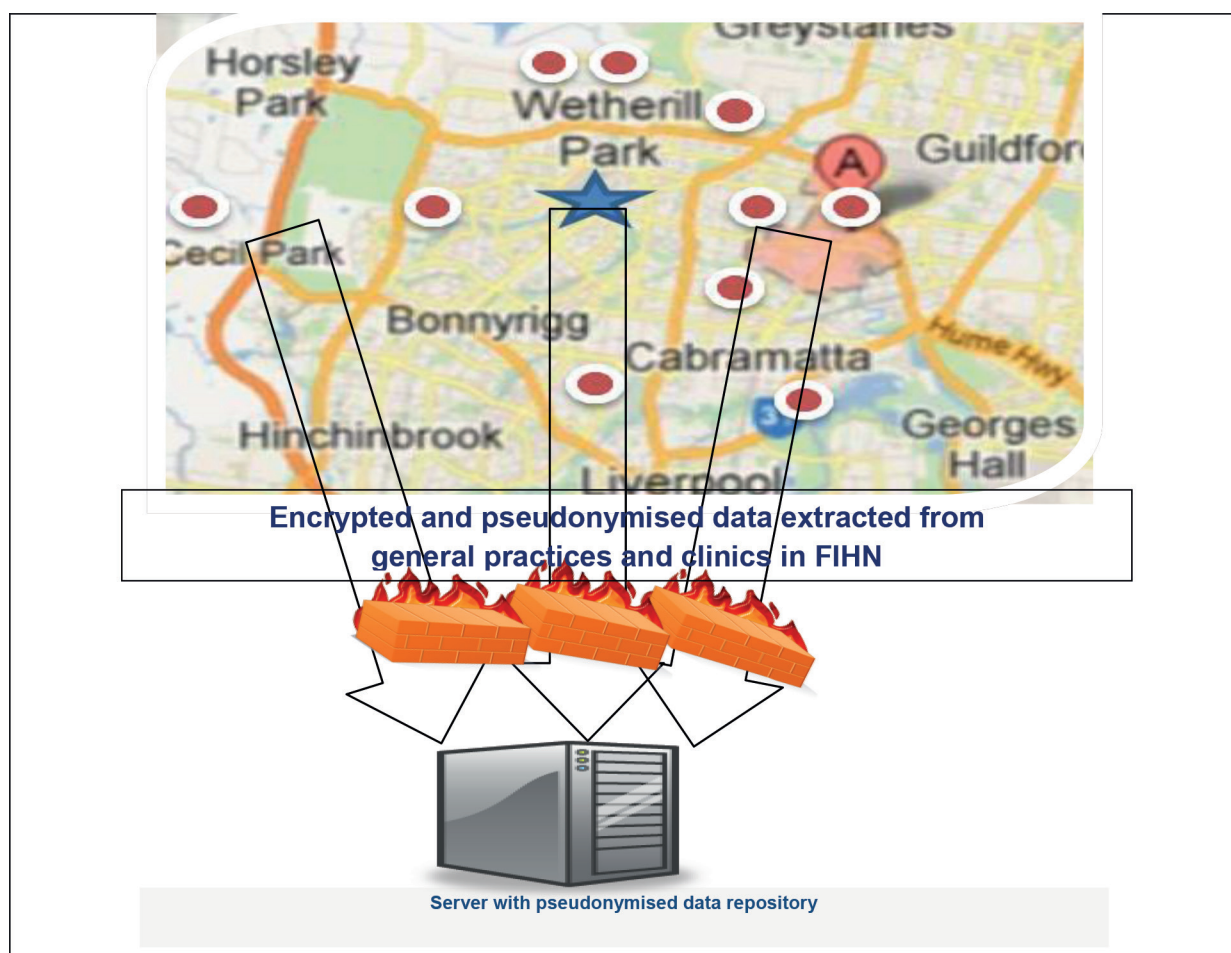


Figure 3 Fairfield IHN showing the informatics infrastructure and flow of data

Table 1 Accuracy increases with sample size

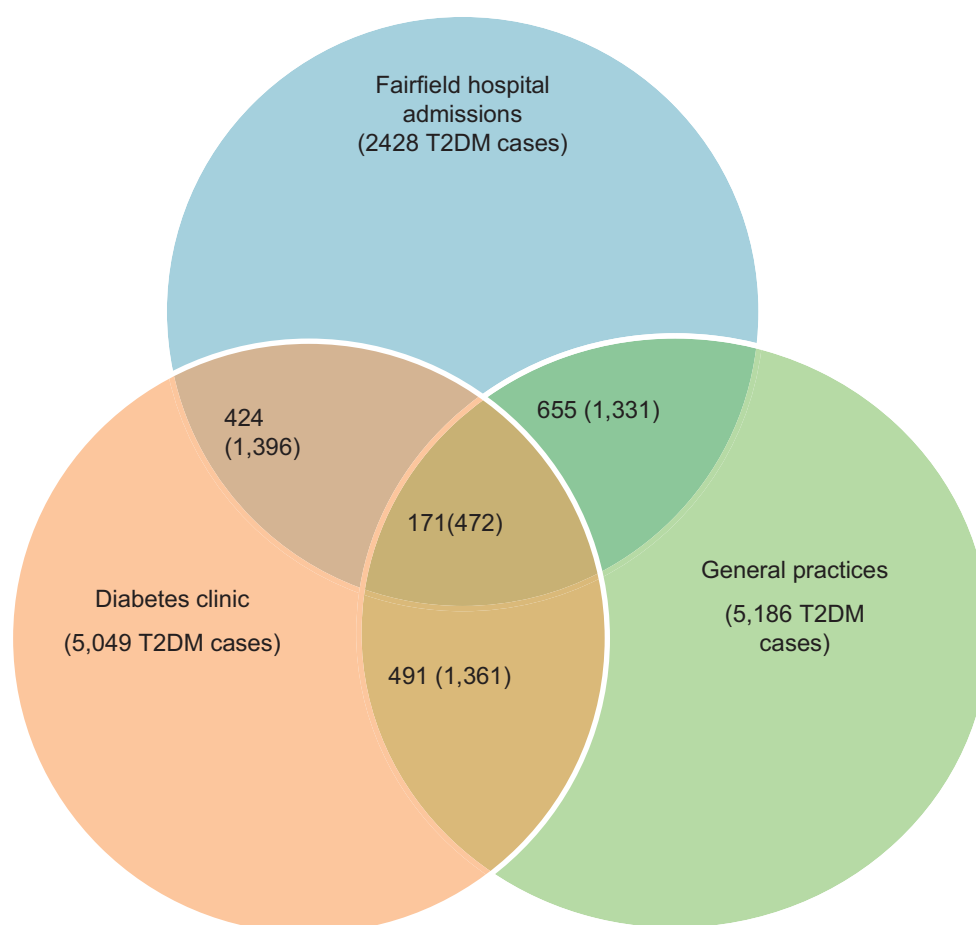
Accuracy measures	Practice 1 (N = 927)	Practice 2 (N = 3699)	Practice 3 (N = 7110)	Practice 4 (N = 12057)	Total (N = 23793)
Sensitivity	100.0	100.0	100.0	100.0	100.0
Specificity	98.0	99.8	99.8	99.8	99.7
Positive predictive value	57.1	98.3	96.9	97.4	96.4
Negative predictive value	98.2	100.0	100.0	100.0	100.0
Accuracy	98.1	99.8	99.8	99.8	99.8

Table 2 Accuracy increase with the number of attributes

Accuracy measures	True positive	False positive	True negative	False negative	Sensitivity	Specificity
Reason for visit (RFV)	2216	1263	145120	3017	42	99
RFV+ Medication (Rx)	5016	207	146176	217	96	99
RFV+Rx + Pathology	5233	183	146200	0	100	100

Table 3 Record linkage among practices in the FIHN – indicating shared patients

Suburb (postcode)	Practice 1 (N=3863)	Practice 2 (N=7028)	Practice 3 (N=23162)	Practice 4 (N=30717)	Total (N=64770)
Practice 1 (2176)	XXXXX	172 (3%)	142 (1%)	405 (13%)	722 (1%)
Practice 2 (2164)	173 (4%)	XXXXX	327 (1%)	691 (2%)	1191 (2%)
Practice 3 (2171)	139 (3%)	333 (5%)	XXXXX	3011 (10%)	3483 (5%)
Practice 4 (2176)	400 (10%)	692 (10%)	3005 (13%)	XXXXX	4097 (6%)
Total	712 (18%)	1200 (17%)	3474 (15%)	4107 (13%)	9493 (15%)

**Figure 4** T2DM cases linked across care settings

data repository; it has been shown to be feasible and accurate.²³ The accuracy and robustness of the model is currently being refined conceptually and testing with larger data sets, including natural language processing of text data.^{26–28}

Example: Integrating the patient dimension: This is being implemented with feedback and reflection at the professional and practice organisation levels, using practice-focused and patient-centred SDQRs as the basis for discussion. This is a RACGP-recognised quality improvement and professional development exercise, in collaboration with patients. Neighbourhood-constrained online strategies are being developed to engage patients and their carers in their care.

DISCUSSION: SOME KEY ISSUES TO ADDRESS

Workshops with Australian²⁹ and international collaborators³⁰ highlighted common issues:

- DQ, interoperability and fitness for use;
- fragmented data and information governance;
- proprietary software and transparency;
- business model and sustainability;
- multiple ethical perspectives;
- cognitive load on patients and clinicians from managing comorbidity and associated polypharmacy.¹⁷

Solutions proposed include transparency, integrated DQ management and governance, sharing of tools, data and metadata, and partnerships to achieve consensus rules for sharing. This scenario is evolving and will be informed by this work on optimising the use of observational EHR data for clinical and population health purposes. Our work to date demonstrates the need for caution with data extraction tools; probabilistic data linkage is accurate, reliable and secure; and that unsupervised information exchange is not recommended for clinical purposes. However, recognising the limitations of data completeness, our program of work suggests that quality improvement activities and cohort studies can be conducted with confidence, especially if combined with technical solutions, governance and organisational protocols.³⁰ The ultimate solution to improve data quality is a culture change in clinical and managerial practice plus good design of health information systems to embed good documentation into the clinical and managerial workflow, with a focus on the safety and quality of patient-centred care.

CONCLUSIONS

The IHN and HIE are being systematically achieved through the informatics infrastructure and development and validation of automated tools to extract and use EHR data for clinical, organisational, systems and population health research. The

focus of the FIHN is on primary and integrated care research, using cohorts to link models and processes of care to patient and health system outcomes. Replicating the FIHN across the health system, nationally and globally, will enable comparative effectiveness research to be done logically and cost effectively.

The limitation of this publication is that it is based on a single area, though the experiential learning of the authors is that this approach and its principles are likely to be generalisable. However, we fully recognise that not all areas have a single hospital hub or in big cities, very large hospitals may have such large catchment areas that they support more than one community-based areas. In rural or underpopulated areas, other solutions may be required.

Notwithstanding the need to the inevitable customised solutions for localities, the approach described here is needed if we are to address the clinical and managerial challenges of optimal care for an ageing population with increased and increasing multimorbidity. Integrated care requires integrated health data, integrated systems, integrated services and integrated clinical and eHealth interventions.

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