The Evidence-base for Using Ontologies and Semantic Integration Methodologies to Support Integrated Chronic Disease Management in Primary and Ambulatory Care: Realist Review

Contribution of the IMIA Primary Health Care Informatics WG

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Summary

Background: Most chronic diseases are managed in primary and ambulatory care. The chronic care model (CCM) suggests a wide range of community, technological, team and patient factors contribute to effective chronic disease management. Ontologies have the capability to enable formalised linkage of heterogeneous data sources as might be found across the elements of the CCM.

Objective: To describe the evidence base for using ontologies and other semantic integration methods to support chronic disease management.

Method: We reviewed the evidence-base for the use of ontologies and other semantic integration methods within and across the elements of the CCM. We report them using a realist review describing the context in which the mechanism was applied, and any outcome measures.

Results: Most evidence was descriptive with an almost complete absence of empirical research and important gaps in the evidence-base. We found some use of ontologies and semantic integration methods for community support of the medical home and for care in the community. Ubiquitous information technology (IT) and other IT tools were deployed to support self-management support, use of shared registries, health behavioural models and knowledge discovery tools to improve delivery system design. Data quality issues restricted the use of clinical data; however there was an increased use of interoperable data and health system integration.

Conclusions: Ontologies and semantic integration methods are emergent with limited evidence-base for their implementation. However, they have the potential to integrate the disparate community wide data sources to provide the information necessary for effective chronic disease management.

Keywords

Ontology, general practice, chronic disease, semantic web, knowledge management

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Introduction

Chronic Care Model (CCM) a Holistic Approach to Chronic Disease Management (CDM)

Chronic non-communicable disease is rising and is a global priority, with much of that disease managed or capable of being managed in primary care [1, 2]. The chronic care model (CCM) provides a holistic care model, in contrast to much chronic disease management (CDM), which is carried out as if chronic diseases were mutually exclusive [3]. The CCM suggests that a wide range of community, technological, care team and patient factors contribute to CDM [4, 5]; effective care pathway management is complex and best run by integrated teams working in partnership with patients and their communities [6].

Data and Information Requirements to Support CCM

The data and information sharing required to support the implementation of the CCM is complex; and gaps in information system (IS) provision are a limitation on delivering effective care. Whilst the CCM provides many opportunities to apply technology [7], including the use of social media for patients to interact and provide support [8], and data collected from multiple monitoring devices, so called “ubiquitous computing” [9]; it is challenging to link

these disparate systems. In several disease areas, including cardiovascular disease [7], cancer [10], and diabetes [11] IS development is suboptimal and fails to provide the timely information required for care. Further, for many nations there is almost a complete absence of effective information and other systems [12].

Approaches to Managing Complex Health Information

It has been recognised that to provide more personalised health care we need active knowledge management, reasoning systems, and semantic interoperability with ontology based models [13]. New information and communication technology (ICT) tools such as ontologies are needed to build federated information infrastructures [14]. However, such approaches have hitherto largely limited themselves to the scope of the data within the computerised record, often defined by archetypes and represented within standard terminologies such as the systematised nomenclature of medicine, clinical terms (SNOMED CT) [15, 16]. Similarly, approaches to messaging have not focussed on considerable challenges of achieving semantic interoperability between data held in separate clinical data silos [17]. Whilst we fully support the importance of existing work, we see the data requirements for implementing effective CDM, using the CCM, as much broader.

Ontology:

An ontology is a specification of a conceptualization (Gruber 1993)
It can also be described as a set of concepts and their relationships within a given domain.

Semantic interoperability

Interoperability: The capacity for two or more systems or components to exchange information and to use the information that has been exchanged. [73]

Semantic interoperability: The ability of different information technology systems, software applications and networks to communicate and exchange data accurately, effectively and consistently so providers can use the information as they care for patients. (National Alliance for Health Information Technology (NAHIT) <http://www.nahit.org>)

Semantic Web

The Semantic Web, is an extension of the World Wide Web (www) providing a common framework to allow data to be shared and re-used across application, enterprise, and community boundaries. (<http://www.w3.org/2001/sw/>)

Box 1 Key definitions

There is a challenge in balancing the usability of a coding system, particularly inclusion of diverse synonymous terms, with the need for accurate capture of discrete concepts. Classifications may be less flexible in daily use, but allow for more accurate capture and categorization of unique concepts and for improved interoperability of information. Accurate mapping of ontologies, with their often ambiguous concepts, to classifications is a challenge and may require a “second step.” [74] Ontological approaches are used to address semantic interoperability issues, flexibility of information management and integration, and complexity of information models [18]. In practical terms, an ontology defines the concepts and their relationships within a given domain, in our case CDM, allowing their specification (Box 1) [19]. *Semantic integration methods* should enable the seamless interchange of information across the health enterprise to achieve effective CDM, as set out in the CCM. The semantic web (Box 1) forms a common approach to this challenge. Medical semantics are crucial because they

Fig. 1 Heterogeneous data sources relevant to the management of a person with diabetes

Fig. 2 The elements of the chronic care model (Bodenheimer et al., 2002)

stress the importance of preserving meaning as data are passed between different parts of the health enterprise [20].

Objective:

This study explores the evidence base for the use of ontologies and other semantic integration methods to support CDM.

Method

Overview

We carried out a realist review [21]. The process of a realistic review is to determine

what mechanism acts within a particular context to produce an outcome.

Context + Mechanism = Outcome

For the purpose of this review we have looked at the context of research identified; and identified a mechanism, either an ontology or a semantic integration methodology that produces an outcome. We have carried this out for the six elements of the CCM (Fig 2).

Search Strategy

We searched PubMed, Science Direct, and Scopus databases using the terms “Chronic

disease” and “ontolog*” - the wild card capturing ontology or ontologies - or “semantic integration” repeating the same searches substituting each element of the CCM. The six elements of the CCM are: (1) Community resources; (2) Health system; (3) Self-management support; (4) Delivery system design; (5) Decision support, and (6) Clinical IS (Fig 3). The results, numbers of papers identified, obtained from the searches are shown in Table 1, with duplicate results removed.

The search result abstracts and titles were reviewed for relevance to primary and ambulatory care, and chronic conditions. We excluded publications related to genetic data as they are beyond the scope of this review. We also excluded the use of ontologies or semantic integration tools within a single computerised medical record system, as the purpose of this review is to explore using data between systems and across a community implementing the CCM to improve CDM.

Context:

We report the context in terms of the health system within which the relevant implementation took place; this is either reported in the text or can be identified from the relevant references.

Mechanism:

The mechanisms we describe are either the use of ontologies or some form of semantic integration. We include within semantic integration:

- Semantic interoperability, the ability of computer systems to exchange data with unambiguous, shared meaning (Box 1).
- Knowledge management, processes to accelerate learning and improve decision making [22]
- Other re-use methodologies, which can't be readily classified in one of the other categories.

Outcome:

We used the Donabedian evaluative hierarchy to look at outcomes in terms of creation of structures/IT or informatics infrastructure, processes and true outcomes [23]. Ideally, we would have liked to have found implementation of ontologies and other semantic integration tools that resulted

Fig. 3 Search strategy

in hard outcomes, for example classifiable using the Cochrane Effective Practice and Organisation of Care (EPoC) Group taxonomy of outcomes [24], likewise with strength of evidence and recommendations using commonly accepted evidence-based medicine tools [25]. However, the level of maturity of ontological development is such that we had more modest expectations [19, 21]. We therefore included outcomes where the structures/infrastructure to support ontologies and semantic integration tools are in place; and also where there are processes involving their use.

Results

Introduction

The results are presented reporting the use of ontologies in the six domains of the chronic care model: (1) Community resources; (2) The health system; (3) Self-management

support; (4) Delivery system design; (5) Decision support; and (6) Clinical IS. We describe what evidence we ascertained and its outcome. Each element identified, potentially contributing to care (Fig 1) belongs to one or more of these six categories. A cross-tabulation of how they relate to each element of CCM is shown in a supplementary data file (Table S1) [1]. The literature on ontologies seemed to sit firmly within the medical model. There was very little literature about how the factors such as limitations on driving, potentially high insurance premiums, diabetes charities, policy makers, and professions allied to medicine, podiatrists, optometrists, and ambulance services, might integrate their information into broader patient care.

1. Community Resources

We found little evidence of the use of ontologies to support this element of the CCM. Community support is important in CDM

Table 1 Search results from selected bibliographic databases

Areas of chronic care model (CCM)	PubMed		Science Direct		Scopus	
	All	Since 2009	All	Since 2009	All	Since 2009
1. Community Resources	3	1	167	81	2	2
2. Health system	14	8	983	521	18	14
3. Self-management support	16	9	124	86	2	2
4. Delivery system design	7	3	72	45	0	0
5. Decision support	26	16	493	265	49	32
6. Clinical information system	2	2	197	83	6	2

but there is little evidence of the use of ontologies or semantic integration methods; current systems require reworking [26] and there are prototypes [27] and a pan-European project in progress [28]. The disparate nature of IS in the community is highlighted in a study of the risks associated with older people transitioning between health providers and settings [29], and descriptions of very different implementations of integrated care in the Netherlands [30]. Telemonitoring is increasingly proposed as a way for monitoring people with chronic diseases and optimising therapy in the community. There are however proposals on how ontologies might be used to harness these data [31].

2. The Health System

We found little evidence of a health system implementing a systematic approach to ontologies or semantic integration processes as part of health system redesign from a structural perspective. One exception is the NHS (National Health Service) Data Model and Dictionary, which whilst firmly rooted in clinical practice is an attempt to codify multiple concepts [32]. This provides an ontological mechanism for getting data to support business decisions about which services should be offered to a community (called commissioning health care) in the English NHS. In the NHS Data Model the elements are divided into data collections, classes and attributes. Its principal objective is to support usable commissioning datasets. For example, enabling national definitions of care-groups that might be hard to consistently identify from complex data; for instance the use of readily reproducible methods for identifying emergency admissions and what constitutes an admission of a person

with chronic obstructive pulmonary disease (COPD) [33, 34]. The Australian GP Data Model and Core Data Set was started with similar goals but not maintained.

The majority of ontology and semantic integrative initiatives are for supporting processes of specific diseases. Across health systems proactive teams appeared to be empowered by simple well established processes including the use of the plan-do-study-act (PDSA) cycle [35] and joining innovators together into collaboratives [35].

Patient empowered care is being promoted through personal health records (PHR) and through electronic patient record access; again we found little use of ontologies. When implemented in the context of an appropriate business model this has led to a decrease in face-to-face consulting and more “Virtual visits” [37]. However, without this stimulus these initiatives may fail [38]. There is emergent use of ontologies in PHR [39].

Outcome related initiatives include the UK health system interoperable pathology, prescribing and primary care data to underpin the implementation of pay-for-performance (P4P) in the quality and outcomes framework (QOF) [40]. The use of these has been illustrated in chronic kidney disease (CKD), where recognition and management of the condition has been enabled through these mechanisms [41]. Within this P4P scheme pragmatic ontologies (though not referred to as such) are created for what represents a case (to be included in the disease registry), and what represents good care [42]. An ecological study suggests an association between improved primary care disease management and variation in incidence of transplant and dialysis [43]. Registration based systems with an accurate denomina-

tor facilitate the development of ontologies to define cases, prevalence and quality of care. Similar levels of interoperability have been achieved in Denmark, Netherlands, Australia and New Zealand [44]; providing a data environment which should facilitate the development of data driven ontological approaches. The patient-centred medical home, as proposed in the USA, will generate more data in and out of the hospital setting but a strategy to integrate these data is not apparent; an ontologically rich approach could be effective [45].

3. Self-management Support

Self-management support is a broad concept stretching well beyond the medical domain, to a range of community resources (Fig 1, Supplementary data file Table S1); and broader partnerships providing input may for example improve care in diabetes [46]. Such multi-faceted data sources may lend themselves well to ontological exploration.

In hypertension, an ontology has been developed to improve hypertension prescribing [47], patient information requirements in COPD [48], and continuity of care in heart failure [49]. Ontologies have also been developed to help improve the quality of decision making about progression from CKD to renal replacement [50]. The ontology acts in these cases as a mechanism for tying together complex datasets to measure the quality of care, progression of disease or health outcomes.

Self-management support has also shown benefit in a number of studies, though ontologies and other semantic integration technologies do not appear to have underpinned these training of professionals in shared decision making, to improve patient self-management support. Self-management support has been shown to be effective; for example a randomised trial tested this in COPD, diabetes, and irritable bowel syndrome (IBS) [51]; and a systematic review has found evidence of improved outcomes in diabetes and hypertension, with some evidence for arthritis and less clear evidence for asthma and COPD [52]. Interventions in self-management support are diverse, with little evaluation of their effectiveness [53]; circumstances which may lend themselves

to an ontological approach. Again there is only emergent recognition that ontological approaches might form an appropriate method to link complex relevant data [54].

4. Delivery System Design

Ontologies have been developed to support computerised cognitive behavioural therapy (CBT) [55].

A systematic review has described how delivery-system design interventions including multidisciplinary team care have positive effects on both provider behaviour and some patient outcomes, particularly for diabetes, hypertension and lipid disorders [54]. This includes demonstrating the value of practice nurses in European primary care [56, 57] and of case management [58]. There are few methods used to assess the effectiveness of the delivery system. Patient Assessment of Chronic Illness Care (PACIC) demonstrates that it is possible to assess patients' quality of life, and the range of factors that contribute also lend themselves to an ontological approach [59]; though improving completion rates and linking it to health outcomes remain limitations [60].

5. Decision Support

Computing methodologies used for implementing decision support systems include Bayesian networks, neural networks, rule-based systems, heuristics, and fuzzy systems [61]. Recently there has been a shift in the methodologies used for developing such systems: moving from more traditional rule-based systems to semantically-rich knowledge based systems taking advantage of the "connected" nature of modern health IS. Ontologies have been viewed as more effective way of representing the clinical knowledge used for the decision making process. However, the methodologies used for emulating the decision making process are those listed above. Ontological reasoning engines are being used to add deduction capabilities to these systems [62]. The commonest use of decision support is the diagnosis of disease decision support and it is increasingly used for detecting the risk of disease, prescribing or other intervention decisions and prevention [63-65].

6. Clinical Information System (CIS)

At a structural level, one of the most common objectives of ontology and semantic integration initiatives has been to improve data quality of CISs in order to facilitate effective sharing and data reuse. Improved data through ontology mediated data dictionaries and datasets have enabled better care management and quality improvement initiatives [66]. High-quality data has also enabled primary care providers to monitor the quality of their care and the longitudinal impact of policy [67, 68]. One of the main contributions from ontology facilitated CIS has been improved data coding. For example, the US Veteran's Administration's use a lexicon, a subset of terms, within a defined set of terminologies [69]. All the unresolved terms (i.e. clinical record entries that could not be coded) in their Decentralized Hospital Computer Program (DHCP) are sent to a central registry [70]. SNOMED CT provides a comprehensive coverage of these unresolved clinical expressions [71]. This improved process of data management should enable more effective disease management.

Processes improvements from ontology designed CISs have been at many levels. First has been the improvement of specific clinical processes such as decision support for chronic disease such as diabetes [72].

Second has been the use of ontologies for the development of disease registries, which have improved care delivery as well as facilitating research in children with arthritis [73].

Outcomes from ontology based CISs have included improved care in diabetes [74] as well as better access and adherence to evidence-based guidelines and educational training for health professionals.

Summary

Ontologies and semantic integration can act as mechanisms for improving CDM; this emerging phenomenon is summarised in table 2.

Discussion

Principal Findings

Ontologies and semantic integration methods underpin much of what has been achieved to develop more integrated care. However, very often these approaches are not directly recognised as such. The mechanism by which they appear to act is at the level of providing a better integrated primary or ambulatory care record, that supports more holistic care. This better integrated record not only allows the

Table 2 Emerging themes how ontologies and semantic integration can act as a mechanism to improve chronic disease management

Areas of CCM	Main Mechanisms	References
1. Community	Supporting complex care Care in the community, Linking services that affect outcomes (e.g. social care with medical care), Telemonitoring	27-33
2. Health system	Measures to support interoperability and integration	34-47
3. Self-management support	Self-management tools (though due to their diversity it is hard to identify the mechanism)	48-56
4. Delivery system design	Shared data registries Health behaviour modelling, Knowledge discovery Patient assessment of care	57-62
5. Decision support	Computer-assisted medical diagnosis, Care pathway planning/allocation	63-67
6. Clinical information system (CIS)	Integrated health information systems, Interoperability of data Consistent clinical coding of key data Data quality	68-74

health care professional access to the required data at the point of care, it also enables clinical audit and other mechanisms to benefit care. However, the level of sophistication of such approaches has been limited. There are no report of problems with patient safety associated with using more ontologically rich records.

However, there are also important gaps in the use of ontologies and semantic integration methods that required further research (Table 3). These gaps might be present because linking these datasets is considered too hard. Our assertion is that data driven ontological and semantic integration methods should enable more selective linkage of data and consequent improvement in patient care.

Implications of the Findings

Until more sophisticated methods of semantic integration are piloted and tested for their effects on health outcomes the evidence base for these technologies will remain limited. Consequently, the evidence for the use of ontologies and semantic integration methods is limited by current CIS.

Better use of ontologies and semantic integration has the potential to support the CCM and improve CDM. It could be that progress could be made using the Donnabedian approach; with initial emphasis on creating the right informatics infrastructure; then building processes that fill in the gaps, for example in the areas of community support and delivery system design; with finally empirical studies conducted to see if this infrastructure and processes improved health outcomes.

Comparison with the Literature

Others have grappled with the difficulty of modelling holistic health [75]. Although the scope of the CCM is community wide, we recognise there are challenges in coding data, to make them more readily interoperable. Coding can be challenging in itself [76, 77], some systems do not routinely record reason for encounter [78], and other factors can distort coding. Coordination between professionals is also thought to be important in delivering effective CDM [79], and again the creation of richer records might help underpin this process. Whilst we could not find literature about the use of ontologies

Table 3 Gaps in the current evidence-base for ontologies and semantic integration technologies that need to be filled

Areas of CCM	Gaps in using ontologies and semantic methodologies
1. Community	Concepts related to mobilising resources are not defined. Many community resources do not integrate with other health data
2. Health system	Little evidence of any systematic approach for implementing ontologies with provision for integration. Best examples at national or integrated care provider level.
3. Self-management support	How to achieve better continuity of care by synchronised information flow across the health enterprise
4. Delivery system design	Lack of leveraging semantically integrated information for managing care pathways.
5. Decision support	Data-driven enrichment of clinical knowledge for improved decision support.
6. Clinical information system (CIS)	Semantic integration of clinical concepts between clinical information systems, and across the health enterprise, beyond sharing imaging and pathology data

and semantic integration for optometry or podiatry, other literature points towards the value of linking data they hold. Eye disease can be associated with worse blood pressure control in diabetes [80], and lower limb complications are often associated with problems with other areas of diabetes control [81].

Limitations of the Method

The principal limitation of the method is the lack of experimental work, about how ontologies and semantic integration methods might improve CDM. We also did not explore the potential to link primary care data with genetic or other databases, something of enormous potential benefit [82] and currently the subject of research [83].

Additionally, restricting our search to ontologies implemented in more than one system may mean we failed to consider ontologies implemented in a single computerised medical record system. Possibly excluding pilot studies that might have added to our understanding in this area; for example we excluded some studies of the use of ontologies in decision support, which might have broadened our perceptions of their role [84, 85].

Call for Further Research

Ontologies and semantic integration technologies recognise that these are approaches in their relative infancy, and requiring further research and development rather than mature technologies ready for deployment [19, 21].

Conclusions

Interoperability of data and information has been achieved in many primary and ambulatory care settings; particularly to enhance self-management support. However, the benefits have largely been achieved for single conditions, and largely in a medical context. Further development of ontologies should enhance semantic interoperability across the health enterprise. Ontologies should enable more robust integration of data, including patients' reasons for encounter, and hence improved potential to manage chronic disease.

References

1. WHO Preventing chronic diseases: a vital investment. World Health Organization, Geneva; 2005.
2. De Maeseneer J, Roberts RG, Demarzo M, Heath I, Sewankambo N, Kidd MR, et al. Tackling NCDs: a different approach is needed. *Lancet* 2012 May 19;379(9829):1860-1.
3. Lalonde L, Goudreau J, Hudon E, Lussier MT, Duhamel F, Bélanger D, et al. Group for TRANSIT to Best Practices in Cardiovascular Disease Prevention in Primary Care. Priorities for action to improve cardiovascular preventive care of patients with multimorbid conditions in primary care—a participatory action research project. *Fam Pract* 2012 Dec;29(6):733-41.
4. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA* 2002;288(14):1775-9.
5. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA* 2002;288(15):1909-14.
6. Cramm JM, Nieboer AP. In the Netherlands, rich interaction among professionals conducting

- disease management led to better chronic care. *Health Aff (Millwood)* 2012;31(11):2493-500.
7. Siminerio LM. The role of technology and the chronic care model. *J Diabetes Sci Technol* 2010;4(2):470-5.
 8. Roblin DW. The potential of cellular technology to mediate social networks for support of chronic disease self-management. *J Health Commun* 2011;16 Suppl 1:59-76.
 9. Bott OJ, Ammenwerth E, Brigl B, Knaup P, Lang E, Pilgram R, et al. The challenge of ubiquitous computing in health care: technology, concepts and solutions. *Methods Inf Med* 2005;44:473-9.
 10. Campbell MK, Tessaro I, Gellin M, Valle CG, Golden S, Kaye L, et al. Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network. *J Cancer Surviv* 2011 Sep;5(3):271-82. d
 11. MacLean CD, Littenberg B, Gagnon M, Reardon M, Turner PD, Jordan C. The Vermont Diabetes Information System (VDIS): study design and subject recruitment for a cluster randomized trial of a decision support system in a regional sample of primary care practices. *Clin Trials* 2004;1(6):532-44.
 12. Mendis S, Al Bashir I, Dissanayake L, Varghese C, Fadhil I, Marhe E, et al. Gaps in capacity in primary care in low-resource settings for implementation of essential noncommunicable disease interventions. *Int J Hypertens*.2012;2012:584041.
 13. Hwang KH, Chung KI, Chung MA, Choi D. Review of semantically interoperable electronic health records for ubiquitous healthcare. *Healthc Inform Res* 2010;16(1):1-5.
 14. National Research Council (US) Board on Research Data and Information; Uhler PF, editor. *Designing the Microbial Research Commons: Proceedings of an International Symposium*. Washington (DC): National Academies Press (US); 2011.
 15. Cimino JJ. Collect once, use many. Enabling the reuse of clinical data through controlled terminologies. *J AHIMA* 2007 Feb;78(2):24-9.
 16. Garde S, Chen R, Leslie H, Beale T, McNicoll I, Heard S. Archetype-based knowledge management for semantic interoperability of electronic health records. *Stud Health Technol Inform* 2009;150:1007-11.
 17. Dolin RH, Alschuler L, Boyer S, Beebe C, Behlen FM, Biron PV, et al. HL7 Clinical Document Architecture, Release 2. *J Am Med Inform Assoc* 2006;13(1):30-9.
 18. Liaw ST, Rahimi A, Ray P, Taggart J, Dennis S, de Lusignan S, et al. Towards an ontology for data quality in integrated chronic disease management: A realist review of the literature. *Int J Med Inform* 2013;82(1):10-24.
 19. Gruber T. A translation approach to portable ontologies. *Knowledge Acquisition* 1993;5(2):199-220.
 20. Groen P, Wine M. *Medical Semantics, Ontologies, Open Solutions and EHR Systems Virtual Medical Worlds* 2009. URL: <http://www.hoise.com/vmw/09/articles/vmw/LV-VM-09-09-6.html>
 21. Pawson R, Tilley N. *Realistic evaluation*. London: Sage; 1997.
 22. de Lusignan S, Pritchard K, Chan T. A knowledge-management model for clinical practice. *J Postgrad Med* 2002 Oct-Dec;48(4):297-303.
 23. Donabedian A. Evaluating the quality of medical care. *Milbank Q* 2005;83(4):691-729.
 24. Cochrane Effective Practice and Organisation of Care (EPOC) Group taxonomy of outcomes. URL: <http://epoc.cochrane.org/>
 25. Atkins D, Best D, Briss PA, Eccles M, Falck-Ytter Y, Flottorp S, et al; GRADE Working Group. Grading quality of evidence and strength of recommendations. *BMJ* 2004;328(7454):1490.
 26. Plumb J, Weinstein LC, Brawer R, Scott K. Community-based partnerships for improving chronic disease management. *Prim Care* 2012 Jun;39(2):433-47.
 27. Paganelli F, Giuli D. An ontology-based system for context-aware and configurable services to support home-based continuous care. *IEEE Trans Inf Technol Biomed* 2011;15(2):324-33.
 28. Rosso R, Munaro G, Salvetti O, Colantonio S, Ciancetto F. CHRONIOUS: an open, ubiquitous and adaptive chronic disease management platform for chronic obstructive pulmonary disease (COPD), chronic kidney disease (CKD) and renal insufficiency. *Conf Proc IEEE Eng Med Biol Soc* 2010;2010:6850-3.
 29. Enderlin CA, McLeskey N, Rooker JL, Steinhauser C, D'Avolio D, Gusewelle R, et al. Review of current conceptual models and frameworks to guide transitions of care in older adults. *Geriatr Nurs* 2012 Oct 31. doi:pii:S0197-4572(12)00278-9. 10.1016/j.gerinurse.2012.08.003.
 30. van der Linden BA, Spreuwenberg C, Schrijvers AJ. Integration of care in The Netherlands: the development of transmutal care since 1994. *Health Policy*.2001;55(2):111-20.
 31. Martinez-Lopez R, Millan-Ruiz D, Martin-Dominguez A, Toro-Escudero M. An Architecture for Next-Generation of Telecare Systems Using Ontologies, Rules Engines and Data Mining, Computational Intelligence for Modelling Control & Automation, 2008 International Conference 2008;31-6.
 32. NHS Data model and Dictionary Service. URL: <http://www.connectingforhealth.nhs.uk/systemsandservices/data/nhsdms>
 33. Gunther S, Taub N, Rogers S, Baker R. What aspects of primary care predict emergency admission rates? A cross sectional study. *BMC Health Serv Res* 2013 Jan 7;13:11.
 34. Agboado G, Peters J, Donkin L. Factors influencing the length of hospital stay among patients resident in Blackpool admitted with COPD: a cross-sectional study. *BMJ Open* 2012 Sep 1;2(5).
 35. Berwick DM. Developing and testing changes in delivery of care. *Ann Intern Med* 1998;128:651-6.
 36. Kilo CM. A framework for collaborative improvement: lessons from the Institute for Healthcare Improvement's Breakthrough Series. *Qual Manag Health Care* 1998;6:1-13.
 37. Baer D. Patient-physician e-mail communication: the kaiser permanente experience. *J Oncol Pract* 2011;7(4):230-3.
 38. de Lusignan S, Seroussi B. A comparison of English and French approaches to providing patients access to summary care records: scope, consent, cost. Accepted for publication EFMI STC 2013, Prague (Ref: 51).
 39. Kokkinaki A, Chouvarda I, Maglaveras N. An ontology-based approach facilitating unified querying of biosignals and patient records. *Conf Proc IEEE Eng Med Biol Soc* 2008;2008:2861-4.
 40. de Lusignan S, Mimmagh C. Breaking the first law of informatics: the Quality and Outcomes Framework (QOF) in the dock. *Inform Prim Care* 2006;14(3):153-6.
 41. Stevens PE, de Lusignan S, Farmer CK, Tomson CR. Engaging primary care in CKD initiatives: the UK experience. *Nephrol Dial Transplant* 2012;27 Suppl 3:iii5-iii11.
 42. de Lusignan S. Informatics as tool for quality improvement: rapid implementation of guidance for the management of chronic kidney disease in England as an exemplar. *Healthc Inform Res* 2013 Mar;19(1):9-15.
 43. Dhoul N, de Lusignan S, Dmitrieva O, Stevens P, O'Donoghue D. Quality achievement and disease prevalence in primary care predicts regional variation in renal replacement therapy (RRT) incidence: an ecological study. *Nephrol Dial Transplant* 2012;27(2):739-46.
 44. Protti D, Bowden T, Johansen I. Adoption of information technology in primary care physician offices in New Zealand and Denmark, part 5: final comparisons. *Inform Prim Care* 2009;17(1):17-22.
 45. Tufano JT, Ralston JD, Tarczy-Hornoch P, Reid RJ. Participatory (re)design of a sociotechnical healthcare delivery system: the Group Health Patient-Centered Medical Home. *Stud Health Technol Inform* 2010;157:59-65.
 46. Lee A, Siu CF, Leung KT, Lau LC, Chan CC, Wong KK. General practice and social service partnership for better clinical outcomes, patient self efficacy and lifestyle behaviours of diabetic care: randomised control trial of a chronic care model. *Postgrad Med J* 2011 Oct;87(1032):688-93.
 47. Mabotuwana T, Warren J. An ontology-based approach to enhance querying capabilities of general practice medicine for better management of hypertension. *Artif Intell Med* 2009;47(2):87-103.
 48. Borycki E, Kushniruk A. Development of a virtual self-management tool for COPD patients: towards a user needs ontology. *AMIA Annu Symp Proc* 2007:879.
 49. Eccher C, Purin B, Pisanelli D, Battaglia M, Apolloni I, Forti S. Ontologies supporting continuity of care: The case of heart failure. *Comput i Biol Med* 2006;36(7):789-801.
 50. Harwood L, Clark AM. Understanding health decisions using critical realism: home-dialysis decision-making during chronic kidney disease. *Nurs Inq* 2012;19(1):29-38.
 51. Fullwood C, Kennedy A, Rogers A, Eden M, Gardner C, Protheroe J, et al. Patients' Experiences of Shared Decision Making in Primary Care Practices in the United Kingdom. *Med Decis Making* 2012 Nov 5.
 52. Dennis SM, Zwar N, Griffiths R, Roland M, Hasan I, Powell Davies G, et al. Chronic disease management in primary care: from evidence to policy. *Med J Aust*. 2008;188(8 Suppl):S53-6.
 53. Johnston S, Liddy C, Mill K, Irving H. Building the Evidence Base for Chronic Disease Self-management Support Interventions Across Canada. *Can J Public Health* 2012;103(6):e462-7.

54. Protheroe J, Rogers A, Kennedy AP, Macdonald W, Lee V. Promoting patient engagement with self-management support information: a qualitative meta-synthesis of processes influencing uptake. *Implement Sci* 2008 Oct 13;3:44.
55. Lenert L, Norman GJ, Mailhot M, Patrick K. A framework for modeling health behavior protocols and their linkage to behavioral theory. *J Biomed Inform* 2005;38(4):270-80.
56. Vrijhoef H, Spreeuwenberg C, Eijkelberg I, et al. Adoption of disease management model for diabetes in region of Maastricht. *BMJ* 2001;323: 983-5.
57. Ahgren B. Chain of Care development in Sweden: results of a national study. *Int J Integr Care* 2003; 3: e01.
58. Gravelle H, Dusheiko M, Sheaff R, Sargent P, Boaden R, Pickard S, et al. Impact of case management (Evercare) on frail elderly patients: controlled before and after analysis of quantitative outcome data. *BMJ* 2007;334:31.
59. Schmittiel J, Mosen DM, Glasgow RE, Hibbard J, Remmers C, Bellows J. Patient Assessment of Chronic Illness Care (PACIC) and improved patient-centered outcomes for chronic conditions. *J Gen Intern Med* 2008 Jan;23(1):77-80.
60. Rick J, Rowe K, Hann M, Sibbald B, Reeves D, Roland M, Bower P. Psychometric properties of the patient assessment of chronic illness care measure: acceptability, reliability and validity in United Kingdom patients with long-term conditions. *BMC Health Serv Res* 2012 Aug 31;12:293.
61. Waghlikar KB, Sundararajan V, Deshpande AW. Modeling paradigms for medical diagnostic decision support: a survey and future directions. *J Med Syst* 2012;36(5):3029-49.
62. Abidi S. A conceptual framework for ontology based automating and merging of clinical pathways of comorbidities. *Knowledge Management for Health Care Procedures* 2009;55-66.
63. Verma A, Fiasché M, Cuzzola M, Iacopino P, Morabito F, Kasabov N. Ontology Based Personalized Modeling for Type 2 Diabetes Risk Analysis: An Integrated Approach. In: *Neural Information Processing*. Berlin/Heidelberg: Springer; 2009. p. 360-6.
64. Verma A, Fiasché M, Cuzzola M, Morabito F, Irera G. Knowledge Discovery and Risk Prediction for Chronic Diseases: An Integrated Approach. *Engineering Applications of Neural Networks* 2011;270-9.
65. Rodríguez-González A, Mayer MA, Alor-Hernandez G, Gomez-Berbis JM, Cortes-Robles G, Lemos AL. Using ontologies and probabilistic networks to develop a preventive stroke diagnosis system (PSDS). In: *Computer-Based Medical Systems (CBMS). IEEE 23rd International Symposium* 2013;370-7.
66. de Lusignan S, Liaw ST, Michalakidis G, Jones S. Defining datasets and creating data dictionaries for quality improvement and research in chronic disease using routinely collected data: an ontology-driven approach. *Inform Prim Care* 2011;19(3):127-34.
67. Campbell S, Roland M, Middleton E, Reeves D. Improvements in quality of clinical care in English general practice 1998–2003: longitudinal observational study. *BMJ* 2005;331:1121.
68. Murray J, Saxena S, Millett C, Curcin V, de Lusignan S, Majeed A. Reductions in risk factors for secondary prevention of coronary heart disease by ethnic group in south-west London: 10-year longitudinal study (1998-2007). *Fam Pract* 2010;27(4):430-8.
69. Lincoln MJ, Weir C, Moreshead G, Kolodner R, Williamson J. Creating and evaluating the Department of Veterans Affairs electronic medical record and national clinical lexicon. *Proc Annu Symp Comput Appl Med Care*.1994:1047.
70. Eagon JC, Hurdle JF, Lincoln MJ. Inter-rater reliability and review of the VA unresolved narratives. *Proc AMIA Annu Fall Symp* 1996:130-4.
71. Penz JF, Brown SH, Carter JS, Elkin PL, Nguyen VN, Sims SA, Lincoln MJ. Evaluation of SNOMED coverage of Veterans Health Administration terms. *Stud Health Technol Inform* 2004;107(Pt 1):540-4.
72. MacLean CD, Littenberg B, Gagnon M. Diabetes decision support: initial experience with the Vermont diabetes. *Am J Public Health* 2006;96(4):593-5.
73. Natter MD, Quan J, Ortiz DM, Bousvaros A, Ilowitz NT, Inman CJ, et al. An i2b2-based, generalizable, open source, self-scaling chronic disease registry. *J Am Med Inform Assoc* 2013 Jan 1;20(1):172-9.
74. Benedetti R, Flock B, Pedersen S, Ahern M. Improved clinical outcomes for fee-for-service physician practices participating in a diabetes care collaborative. *Jt Comm J Qual Saf* 2004;30(4):187-94.
75. Rossi Mori A, Mazzeo M, Mercurio G, Verbicaro R. Holistic health: Predicting our data future (from inter-operability among systems to co-operability among people). *Int J Med Inform* 2012 Oct 31.
76. de Lusignan S, Wells SE, Hague NJ, Thiru K. Managers see the problems associated with coding clinical data as a technical issue whilst clinicians also see cultural barriers. *Methods Inf Med* 2003;42(4):416-22.
77. Soler, JK, Okkes I, Wood M, Lamberts H. The coming of age of ICPC: celebrating the 21st birthday of the International Classification of Primary Care. *Fam Pract* 2008;25:312-7.
78. Soler JK, Okkes I. Reasons for Encounter and symptom diagnoses: a superior description of patients' problems in contrast to medically unexplained symptoms (MUS). *Fam Pract* 2012;29:272-82.
79. Cramm JM, Nieboer AP. Relational coordination promotes quality of chronic care delivery in Dutch disease-management programs. *Health Care Manage Rev* 2012 Oct-Dec;37(4):301-9.
80. Styles C, Timlin H. The relevance of blood pressure measurements in patients attending a diabetic eye clinic: the use of an electronic patient record. *Eye (Lond)* 2007 Nov;21(11):1450.
81. Brem H, Sheehan P, Rosenberg HJ, Schneider JS, Boulton AJ. Evidence-based protocol for diabetic foot ulcers. *Plast Reconstr Surg* 2006 Jun;117(7 Suppl):193S-209S; discussion 210S-211S.
82. Bioinformatics: towards new directions for public health. *Methods Inf Med* 2004;43(3):208-14.
83. de Lusignan S, Krause P, Michalakidis G, Vicente MT, Thompson S, McGilchrist M, et al. Business Process Modelling is an Essential Part of a Requirements Analysis. Contribution of EFMI Primary Care Working Group. *Yearb Med Inform* 2012;7(1):34-43.
84. Kawazoe Y, Ohe K. An ontology-based mediator of clinical information for decision support systems: a prototype of a clinical alert system for prescription. *Methods Inf Med* 2008;47(6):549-59.
85. Corrigan D, Taweel A, Fahey T, Arvanitis T, Delaney B. An ontological treatment of clinical prediction rules implementing the alvarado score. *Stud Health Technol Inform* 2013;186:103-7.

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