Does Informatics Enable or Inhibit the Delivery of Patient-centred, Coordinated, and Quality-assured Care: a Delphi Study

A Contribution of the IMIA Primary Health Care Informatics Working Group

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Summary

Background: Primary care delivers patient-centred and coordinated care, which should be quality-assured. Much of family practice now routinely uses computerised medical record (CMR) systems, these systems being linked at varying levels to laboratories and other care providers. CMR systems have the potential to support care.

Objective: To achieve a consensus among an international panel of health care professionals and informatics experts about the role of informatics in the delivery of patient-centred, coordinated, and quality-assured care.

Method: The consensus building exercise involved 20 individuals, five general practitioners and 15 informatics academics, members of the International Medical Informatics Association Primary Care Informatics Working Group. A thematic analysis of the literature was carried out according to the defined themes.

Results:The first round of the analysis developed 27 statements on how the CMR, or any other information system, including paper-based medical records, supports care delivery. Round 2 aimed at achieving a consensus about the statements of round one. Round 3 stated that there was an agreement on informatics principles and structures that should be put in place. However, there was a disagreement about the processes involved in the implementation, and about the clinical interaction with the systems after the implementation.

Conclusions: The panel had a strong agreement about the core concepts and structures that should be put in place to support high quality care. However, this agreement evaporated over statements related to implementation. These findings reflect literature and personal experiences: whilst there is consensus about how informatics structures and processes support good quality care, implementation is difficult.

Keywords

Patient-centred care, clinical informatics, healthcare quality assurance, computerised medical records, patient participation

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Introduction

Most technology we frequently use as individuals (i.e. smart phones, web browsers) are personalised to cater our specific information needs. The growth of internet services, the infrastructures that host them, and the associated technologies have enabled us to transmit and store virtually all data produced in our personal lives. This has led to a paradigm shift on how information is processed and utilised in most information domains, including health care.

The US Institute of Medicine has highlighted well-designed information systems as key supports in the delivery of patient-centred care [1]. The availability of patient electronic data has revolutionised health care in many positive ways, although it can also be seen as an obstacle to the personalised approach necessary in patient-centred care [2]. Big data technologies have now matured and laid a platform for patient-centred care (as defined by Stewart)[3] to be taken to the next level. Nevertheless, harnessing novel informatics techniques should be done strategically without impeding the relationships between the health care provider and the patient [4].

The Primary Health Care Informatics (PHCI) Working Group accepts a concept-oriented definition which characterises informatics as a science [5]. This definition, created by Van Bemmel and Musen, defines "informatics" as "the science that studies the use and processing of data, information and knowledge" [6]. In the context of primary care, we have contextualised this definition as "the scientific study of data, information and knowledge, and the way they can be modelled, processed or harnessed to promote health and develop patient-centred primary medical care" [7].

The work presented in this paper describes a review we carried out to explore whether informatics enables or inhibits the delivery of patient-centred, coordinated, and quality-assured care. The elements of the study comprised:

1) A literature review to identify themes, health care settings, and technical foci of publications related to patient-centredness and informatics.
2) A consensus building process to identify informatics factors that enable or inhibit patient-centred care.
3) A mapping process to link the themes emerging from the consensus process with the results of the literature review.

Methods

Literature Review

We carried out a literature review to identify published research work related to patient-centred care and informatics. We searched PUBMED/Medline, Scopus, Web of Science, CINAHL and the Cochrane Database for publications related to this topic. The search terms used included "pa-

tient-centred care" (or "patient-centered care") and "informatics".

An overview of the literature review is given in the adapted PRISMA flow chart shown in Fig. 1. Research papers published between January 2000 and November 2014 were taken into consideration. We limited the literature search to publications written in the English language.

The initial search results from all sources yielded 817 publications, which was then reduced to 252 after removing duplicates. By conducting a title and abstract review to eliminate publications that were not relevant, we further reduced the number of publications to be used for the final in-depth review to 128 articles.

The literature was mapped to the four themes identified during the consensus development process, which will be described in the next section. Certain publications were mapped to multiple themes, and we identified the health care setting and technical focus for each of the papers reviewed. The PHCI Working Group searched for ontological methods to improve semantic interoperability in various health care settings [8]. Therefore, we also searched for evidence of ontological approaches for enhancing patient-centred care.

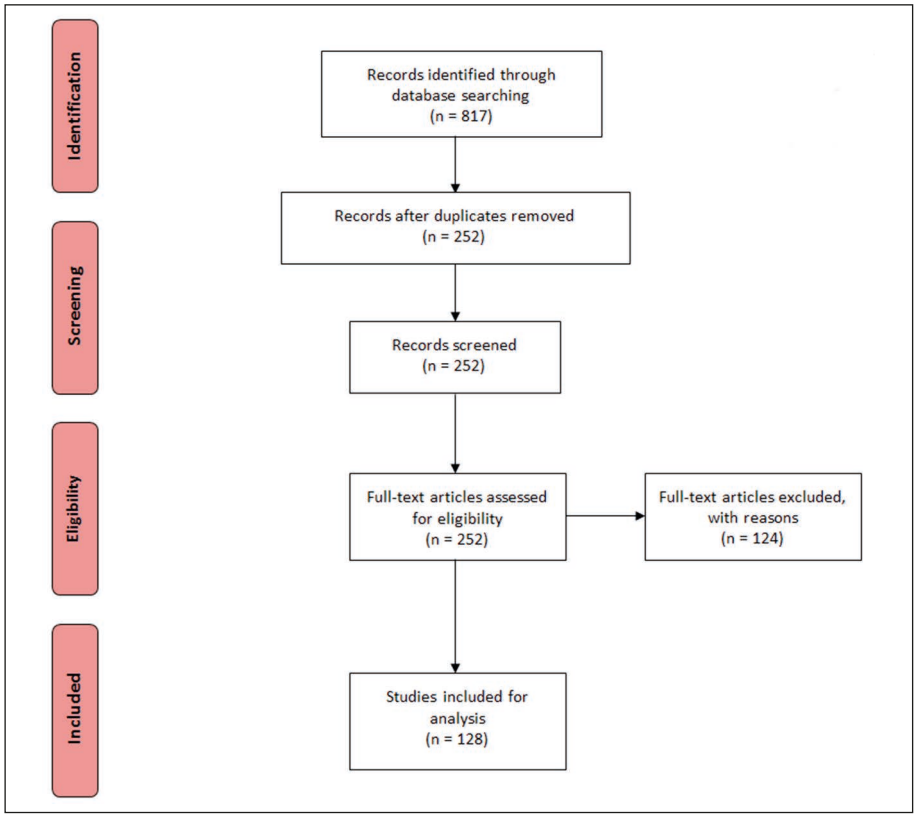

Fig. 1 Adapted PRISMA flow diagram

Consensus Exercise

We engaged the PHCI Working Groups of the European Federation of Medical Informatics (EFMI) and the International Medical Informatics Association (IMIA) by conducting a three-round consensus development process. The process involved consulting an international panel of five clinicians and 15 informatics experts from six countries, including Australia, Canada, Croatia, Spain, South Africa, and the United Kingdom.

a. *Round 1 – Identifying informatics factors enabling/inhibiting patient-centred, coordinated, and quality-assured care*
The initial round intended to explore how the use of computerised medical record (CMR) systems at the point of care (i.e. using a computer in a doctor's office consultation) changes the delivery of patient-centred care. We invited the panel to list enablers and inhibitors of delivering patient-centred, coordinated, and quality-assured care. This round was conducted in the form of an online survey instrument. It was an inclusive round seeking to identify key issues related to the research topic. When analysing the responses from this round, we were able to distinguish issues across four distinct themes (Fig. 2, and full description on Box 1):
   i. CMR systems
   ii. Patient communication and engagement
   iii. Health care provider communication and information sharing
   iv. Standards and quality

   These issues were then used to develop consensus statements for Round 2.

b. *Round 2 – Rating of statements using the RAND/UCLA appropriateness method*
The second round of the study was focused on achieving consensus about the appropriateness of the issues identified in the initial round. We enquired about the appropriateness of each statement developed using the responses of Round 1. Twenty-seven statements across the four themes were included in this round. We achieved 75% response rate from the panel for this round. The respondents for this round included three clinicians and 12 informatics experts while non-respondent included 2 clinicians and 3 informatics experts. The final list of statements is given in Box 2; this round was also conducted using an online survey instrument. We replaced the standard terms used in the RAND/UCLA appropriateness scale, "Highly inappropriate" and "Highly appropriate", with "Strongly disagree" and "Strongly agree" to improve the usability of the instrument.

c. *Round 3 – Discussion of the findings by a panel of experts*
The final round of the consensus process was conducted in the form of an online

Fig. 2 The four themes of informatics factors that affect patient-centred coordinated care

Box 1 Four themes of informatics factors enabling or inhibiting patient-centred care

Computerised medical record system	Factors focusing on the functionality and clinical decision making tools available to the clinician within the computerised medical record system. Similar terminology for this theme includes Electronic Health Record (EHR), Electronic Medical Record (EMR) or Electronic Patient Record (EPR).
Patient communication and engagement	Factors focusing on the engagement of patients with their online medical record, and on the limitations or advantages of communicating clinical concepts to patients effectively via an electronic medium.
Health care provider communication and information sharing	Factors focusing on the integration of workflows and safe sharing of data across different health care providers, for the purpose of providing coordinated care to patients.
Standards and quality	Factors focusing on the use of informatics for surveillance and other quality monitoring activities in health care, and on the necessary training and support for clinicians to use informatics effectively.

panel discussion. Two separate online meetings were organised, in order to engage panel members in different time zones. Eight experts participated to this final round. The results of the two initial rounds were communicated to the expert panel, and acted as a basis for discussions. The feedback received is incorporated to the discussion section of this paper.

Results

Literature Review

Publications issued from the literature review were mapped onto the four themes that emerged during Round 1 of the consensus process (results are shown in Fig. 3). Although some papers were related to multiple themes, the majority of the papers focused on CMR systems, particularly on studies evaluating the effectiveness on patient health outcomes of using a clinical decision support system [9-12]. The second most common theme across the literature was patient engagement and communication, especially the use of online patient portals to clearly and succinctly communicate complex clinical information to patients, and engage them in self-management [13,14,15].

Papers focusing on health care provider communication and information sharing were less common, and their focus tended to be on building effective health care models to support coordinated workflows across different providers [16,17]. Finally, the least common papers were those on standards and quality, and the focus tended to be on clinician education and training to use informatics appropriately [18,19].

The health care setting varied, but primary care and nursing were emphasised since informatics provides essential support to general practitioners and nurses [20]. Further, patient-centred medical homes, which will be expanded on in a later section, were a setting often studied in the papers reviewed (see Fig. 4). The technical focus of the papers was mostly on building the organisational infrastructure necessary for integration (see Fig. 5).

Consensus Process

The degree of consensus for the statements is summarised in Fig. 6. The panel of experts strongly agreed on 15 statements, while nine statements were considered to be equivocal. There were three statements with which they disagreed. Within the RAND/UCLA method, non-agreement does not denote that the experts considered the statements inappropriate, but rather that expert expressed different opinions. For

Box 2 Statements from Round 2 of the consensus process, divided by theme (SAT- Strongest Agreement in Theme, SDT- Strongest Disagreement in Theme)

A. Computerised medical record (CMR) systems

Enabling factors

S1. Accurate and complete data on patient circumstances, health, and health care is available in the information system/CMR to aid the clinical decision making process [Agreement].

S2. Use of electronic clinical decision support, with strong international, contemporary evidence base [Agreement].

S3. Easy access to relevant and appropriate health care delivery using the information system/ CMR [Equivocal].

S4. User friendly and functional information systems/ CMR are essential in the delivery of patient-centred quality-assured care [Agreement][SAT].

Inhibiting factors

S5. Paper based communication between medical carers is still commonly used [Agreement].

S6. Computerised medical record (CMR) systems that are not user friendly, or which have poor functionality, that detract from efficient care delivery [Agreement].

S7. Looking up clinical terminological terms for recording patient details is inefficient when using a CMR system [Equivocal].

S8. Information/ CMR systems are in constant change, and it is difficult for clinicians to keep up-to-date on how to use them [Disagreement][SDT].

B. Patient communication and engagement

Enabling factors

S9. The use of technology allows the engagement of patients in the clinical decision-making process [Equivocal].

S10. Individualised advice and education for the patient is facilitated by a comprehensive and structured electronic medical record [Agreement][SAT].

S11. Providing patients with access to their own computerised medical record (CMR) online can help with engagement and effective communication [Agreement].

S12. The information/ CMR system can facilitate communication, by using accessible language in explaining clinical concepts [Equivocal].

Inhibiting factors

S13. Low health literacy in patients could result in online access to their computerised medical record being irrelevant or even detract from care [Equivocal].

S14. Low patient engagement often poses an obstacle in involving patients in the clinical decision-making process [Equivocal].

S15. The interruptions in the consultation resulting from recording data in the information/ CMR system can detract from effective communication with patients [Disagreement][SDT].

C. Health care provider communication and information sharing

Enabling factors

S16. The sharing of the computerised medical records (CMR) across health care providers can enable integrated patient-centred care [Agreement][SAT].

S17. The interoperability of information/ CMR systems allows for the coordination of care across multiple health care providers [Agreement].

S18. The safe sharing of electronic patient data to ensure patient confidentiality is maintained is a priority in patient-centred care [Agreement].

S19. The information/ CMR system allows informational continuity, which in turn is key in ensuring the best quality of care is provided [Agreement].

Inhibiting factors

S20. It is difficult to merge different workflows from various health care providers into a single integrated workflow for clinical decision making [Equivocal][SDT].

S21. There may be resource conflicts between health care providers, which impede the coordination of care [Equivocal].

S22. Different information/ CMR systems often result in silo working across health care providers, rather than coordinated care [Agreement].

D. Standards and quality

Enabling factors

S23. The use of the information/ computerised medical record (CMR) system can lead to clear standards for coding of key clinical data, and these data can be used to ensure quality-assured care [Agreement].

S24. Where patient data are readily available this facilitates regular audits of indicators of quality of non-communicable diseases (especially long term conditions) [Agreement][SAT].

Inhibiting factors

S25. The use of the information/ CMR systems requires clinician competence and this is difficult to achieve [Equivocal].

S26. Health professionals are time poor, and the use of information/ CMR system requires a large time investment in training and education [Disagreement][SDT].

S27. There are low levels of investment in the equipment and education needed to ensure that information/ CMR systems are used routinely [Agreement].

example, statement S15 ("The interruptions in the consultation resulting from recording data in the information/CMR system can detract from effective communication with patients") is reported as "disagreement", which means that responses were irregularly distributed across the scale from 1 to 9. In contrast, statement S20 ("It is difficult to merge different workflows from various health care providers into a single integrated workflow for clinical decision making") is reported as equivocal, which means that responses formed two groups: a group of high ratings and a group of low ratings.

In Box 2, we have indicated the statements that had the strongest level of agreement/disagreement for each theme. The panel tended to agree on the technical advantages and limitations of the CMR system itself. Equivocal statements mostly focused on the level of patient engagement and the improved access to information. Finally, the statements where the panel disagreed on referred mostly to the clinician-computer interaction.

Ontological Approaches to Support Patient-centred Care

In a previous article produced by the PHCI Working Group [21], we reviewed evidence of the use of ontologies and other semantic integration methods to achieve semantic interoperability across disparate health systems. However, from the perspective of patient-centred care, we found only few instances where ontological approaches have been leveraged. A review on implementation challenges for process-oriented, patient-centred health information systems found a general trend to adopt formal, clinical, and organisational ontologies, and the use of workflow management systems [22]. There is also evidence of using ontological approaches for representing organisational and situation-specific work patterns and practices to facilitate cross-boundary decision support [23]. Despite the limited number of ontological applications, we recognise that there is widened scope for the use of ontologies to link the big data, generated by wearable devices and other sensors attached to patients, with other health care systems [24].

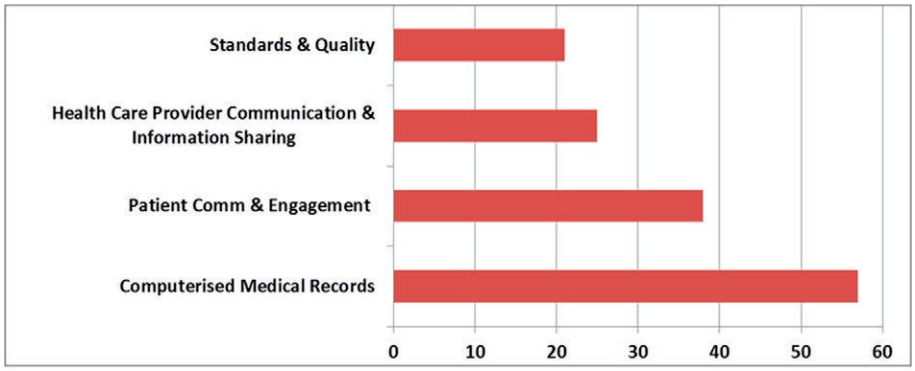

Fig. 3 Number of publications mapped to the four identified themes (Note: certain results map to multiple themes)

Fig. 4 Word cloud for health care setting mentioned in publications analysed

Fig. 5 Word cloud for technological focus mentioned in publications analysed

Key messages found on both the literature review and the consensus exercise, with respect to the identified themes, are given below.

a) Information Systems/Computerised Medical Records

These tools have an increasingly high relevance in a context where patient-to-health-professional ratio becomes larger, which may lead to poor decisions when less time has been spent with the patient, and not all the necessary information has been obtained. The use of informatics such as clinical decision-making support tools can provide the health professional a summary of key patient data as well as recommendations using a strong evidence base.

CMR systems and any associated clinical decision-making support tools are essential in the delivery of effective patient-centred care. The poor functionality of CMR systems has been reported as a key obstacle in their usage by health care providers which affects the clinician-patient interaction [25]. Conversely, the availability of strong evidence-based clinical decision-making support tools allows clinicians to enhance the quality of patient-centred care [26].

b) Patient Communication and Engagement

A key consideration in the use of CMR systems during medical consultations is the communication and engagement with the patient. The use of an electronic tool might deteriorate from effective communication with the patient [27], although the various online channels can encourage the patient to engage in self-management [28,29]. This is, of course, highly dependent on the computer literacy of the patient and her/his willingness to engage with self-management tools outside the traditional health care channels [30]. Development of user-friendly interfaces for CMR systems increases the motivation of patients to engage in their health care [31].

A key health care setting found in the literature was the patient-centred medical home (PCMH), since this is a realm where the enabling force of informatics to deliver patient-centred care is most evident [32]. This is a key reform of the primary care system, which occurred mostly in the United States, and which has a number of core principles around the provision of integrated and well-planned care, as well as the engagement of patients in self-management. Although informatics is considered as vital for the functioning of these settings, it is thought that many of the currently available technologies do not provide the high level of integration and coordination necessary to satisfy the aims of the PCMH [33].

c) Health Care Provider Communication and Information Sharing

The sharing of patient data across health care providers allows for the opportunity to approach health care from the patient perspective. The continuity of care provided by connectivity across health service providers creates a more personalised health care experience for the patient. As the person-centred approach suggests, the spheres

of care surrounding the patient should be jointly involved in the management of the patient's health [34]. Although the data across providers may be integrated, there may be difficulties in the integration of the different workflows [35,36].

As mentioned previously, the PCMH is a setting that most appropriately harnesses informatics in delivering patient-centred care. The key advantage of the PCMH is that there is a high degree of integration and coordination across the health care providers that surround the patient. While informatics is unable to generate an integrated workflow, once this organisational reform occurs, it becomes an essential support tool that facilitates the integration [37].

Fig. 6 Level of agreement achieved for statements across the four themes (n= number of statements)

d) Standards and Quality

Electronic patient records allow for the collection of key data that can be used in the monitoring of chronic conditions [8], drug adherence and adverse effects [38], among others. Data quality is a major issue [2]; further education and training of health care professionals and their support staff is needed, in order to ensure that data quality and use meet the necessary standards to deliver effective patient-centred care [39,40].

The field of nursing informatics has been developed around the need of bringing informatics closer to a profession that involves a high degree of patient-centred care [41]. This is especially the case in an acute care setting where a high degree of monitoring patients with complex conditions is required, and real-time and easy to use informatics tools become an essential support. Emerging technology has been viewed as a solution to compensate the need for increasing patient-to-nurse ratio [42]. Furthermore, nurses will need to develop new skills to ensure that they effectively use emerging technologies without compromising patient safety [43].

Discussion

Principal Findings

Though the key messages extracted by themes were rather varied, most of them supported the role of informatics in the delivery of patient-centred care. It is acknowledged that informatics merely acts as a support for clinical decision-making, but it cannot solely achieve the goals of patient-centred care. In principle, the role of informatics is recognised as positive, but the operational details of how to implement it effectively are still subject to discussion.

Clinicians agreed on the strengths and limitations of existing CMR systems in providing data. There was no agreement on how CMRs might improve access to health information. There was a disagreement about what limited clinicians to effectively use their CMR system, and how to overcome the barriers.

The nature of information systems, and the technical details associated with them, are largely uncontroversial. However, there was a wide disagreement regarding the integration of workflows and implementation, particularly across different contexts. It was highlighted that the level of support and training, and the interoperability across systems, varied drastically depending on the country and the health care setting. This was confirmed in the findings associated with CMR systems we extracted from our literature review.

Moreover, clinicians and non-clinicians had different views on a number of statements, particularly related to the implementation. Clinicians had stronger views on patient engagement, as they are in direct contact with patients, and were able to assess the impact of informatics on patient engagement more directly.

Some criticisms of informatics, such as the distraction of having to input data, were accepted to be existing issues of medical practice, which was actually mitigated by the ease of use of some computer systems. Overall, it was widely accepted that informatics had a positive impact on patient-centred care, but the implementation differs across contexts.

Implications of Findings

The positives and negatives of CMR systems to support care appeared limited by data quality and the level of semantic interoperability between data silos. Coordination should not necessarily be based on a single record system, but rather on the full integration of different workflows into a patient-centred framework.

Clinicians may need different types of support to encourage more and better computer use. This is highly dependent on context, particularly on the infrastructure and training available, and on the speciality of the clinician. Further consultation with clinicians is needed to understand how the clinician-computer interaction happens, and where key interventions are needed to improve this process.

Quality improvement trials are needed to demonstrate how access to health information or computer-mediated consultations

results in improved outcome. Results from these trials should give a precise indication of the required characteristics of a system, and serve as the foundation for a strongly-evidenced implementation strategy of informatics in the local system, with the aim of providing patient-centred quality-assured care.

Comparison with the Literature

A systematic review about how health information technology enables patient-centred care produced substantial evidence to confirm health information technology applications across a series of components, ranging from health care processes to patient satisfaction [44]. Another review on the role of informatics in patient-centred care identified issues related to cost of, access to and comfort with technology, as well as privacy and security, health literacy, feasibility, and social inequality as the key barriers to facilitate better interactions between health care providers and patients [45]. However, we still observe a gap in understanding how health information technology impacts patient encounters and patient-centredness of health care delivery.

In addition, many reviews are focused on specific themes of patient-centred care. A systematic review on patients' online access to their electronic health records and related online services suggested business processes need to be redesigned in order to effectively engage health professionals with patients through these media [46]. However, there is no clear evidence of medical report quality improvement due to the involvement of patients in the management of their medical records [47].

Limitations of the Method

Observed disagreements may reflect the different health systems that the contributors worked with, rather than fundamental disagreements on the statements. Contributors highlighted that two-part statements may have generated equivocal responses.

Conclusions

The consensus exercise and the literature review demonstrated that the context of implementation is essential for understanding if informatics enables or inhibits patient-centred care. In principle, there appears to be a good understanding of the technical limitations and advantages of informatics within patient-centred care, but there is much disagreement and lack of understanding on the clinician-computer interaction, patient-computer interaction, and how this can enable or inhibit patient-centred care.

The health care system, the profession or speciality of the care provider, and the level of patient engagement are factors, among others, that can heavily impact the effective implementation of informatics in the purpose of providing patient-centred quality-assured care. Informatics on its own does not necessarily enable or inhibit care, but in the right context, it can serve as an essential support to the delivery of patient-centred, coordinated, and quality-assured care.

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