

## A Continuum of Sociotechnical Requirements for Patient-Centered Problem Lists

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### Abstract

*Specific requirements for patient-centered health information technology remain ill-defined. To create operational definitions of patient-centered problem lists, we propose a continuum of sociotechnical requirements with five stages: 1) Intra-disciplinary Care Planning: Viewing and searching for problems by discipline; 2) Multi-disciplinary Care Planning: Categorizing problem states to meet discipline-specific needs; 3) Interdisciplinary Care Planning: Sharing and linking problems between disciplines; 4) Integrated and Coordinated Care Planning: Associating problems with assessments, tasks, interventions and outcomes across disciplines for coordination, knowledge development, and reporting; and 5) Patient-Centered Care Planning: Engaging patients in identification of problems and maintenance of their problem list.*

### Keywords:

Problem List, Care Planning, Patient-Centered, Sociotechnical.

### Introduction

Health Information Technology (HIT) systems that assert patient-centeredness have varied levels of functionality and integration across professional clinical disciplines (e.g., nursing and medicine) and with patients. Problem lists may be a simple list maintained by one provider, or a tool that coordinates priorities and goals among all disciplines, specialties, and patients. We argue that problem lists fall on a continuum of patient-centeredness and this continuum is characterized by increasingly challenging sociotechnical requirements (STRs). We use the term STRs based on Coiera's approach [1], defined as the technical translation of insights about the sociotechnical nature of clinical work into design specifications. There is overlap between the knowledge of different clinical disciplines in the inpatient setting [2]. The intradisciplinary work of each discipline and the differences that exist between discipline-specific standardized terminologies require explicit linkages of knowledge concepts to establish common ground between clinicians at the point of decision-making [3–6]. Problem lists that fail to explicitly link interdisciplinary and patient-centered knowledge will propagate isolated care planning, leading to poor communication and outcomes [5,7].

Patient-centered problem lists (PCPLs) are evolving from a list of medical diagnoses toward shared, interdisciplinary, patient-centered electronic applications with standardized, coded problems from nursing, medicine, other clinical disciplines, and patients [7,8]. While, engagement of patients as active contributors to their problem list is not widespread, it is an

identified goal of PCPL [9,10]. Shared problem lists that enable active alignment of interdisciplinary care priorities can be used for identification of patients' priorities. The problem list summarizes a patient's clinical state after an episode or transition of care and provides a comprehensive overview of the patient's condition and needs for future care [11]. The collaborative activity of documenting on a shared patient problem list introduces complexity as the documenting clinician may not be the direct beneficiary of the information in the future, and differing perceptions of responsibility and rewards may exist [11]. In this paper, we make the case that known challenges for problem lists (e.g., competing documentation needs of medical specialties [11]) will expand exponentially for problem lists used by multiple clinical disciplines and patients with distinct but overlapping needs.

The collaborative nature of the shared problem list has profound implications on its design [11]. The design of a computer-based encoded problem list must define the characteristics of the terminology it employs [12] and adoption of a reference terminology is a critical step toward interoperability [10]. SNOMED CT is a well-recognized standard reference terminology recommended for use in encoded problem lists [10,12,13]. This vision paper aims to understand the STRs for PCPLs. We propose a continuum of STRs that sets the stage for in-depth analyses of approaches, such as our recommended ontological infrastructure to represent the shared but distinct diagnostic concepts between clinical disciplines, as well as patients. Innovative and incremental solutions along our proposed continuum, as a central component of coordinated care, may facilitate evolution toward patient-centered care delivery.

### Materials and Methods

We reviewed the literature and sought expert opinions from our team of informaticians (SC, TH, RR), terminologist (HKN), and knowledge engineers (KT, DD) involved in interdisciplinary problem list work since 2008 at Partner Healthcare System (PHS). We searched PubMed from 1990 through June 2012 for the terms: problem list, interdisciplinary, intradisciplinary, multidisciplinary, patient-centered, problem-oriented documentation, SNOMED CT, physician/medical, and nurse/nursing. We reviewed English-language publications that discussed *interdisciplinary* and *intra-disciplinary* system requirements for the development of a computer-based problem list. We excluded system-generated problem lists since our focus was on STRs [9]. SC performed thematic analysis of the literature to identify STRs. These themes were iteratively analyzed by the research team to establish our continuum of STRs for PCPLs.

## Results

Thirty-three out of 647 studies met inclusion/exclusion criteria: 2 systematic reviews, 1 randomized controlled trial, 26 case studies, and 4 expert opinions. Five themes for STRs emerged: [a] Viewing and searching for problems by discipline [2,4,9,10,13–21], [b] Categorizing problem states to meet discipline-specific needs [4,9,10,12,15,16,18–26], [c] Sharing and associating problems between disciplines [4,9–11,19,21,22,24,25,27–30], [d] Associating problems with assessments, tasks, interventions and outcomes within and across disciplines for care coordination, knowledge development, and quality reporting [7,9–11,14,16,18,19,24,25,28,29,31–36], and [e] Engaging patients with PCPLs [4,9,21,37,38]. Analysis of each theme in the context of achieving patient-centered care revealed variability in the difficulty of implementation among the 5 requirements. We propose that each requirement belongs along a continuum with 5 incremental steps: [a] Intra-disciplinary Care Planning, [b] Multi-disciplinary Care Planning, [c] Interdisciplinary Care Planning, [d] Integrated & Coordinated Care Planning, and [e] Patient-Centered Care Planning (see Figure 1). A detailed description follows.

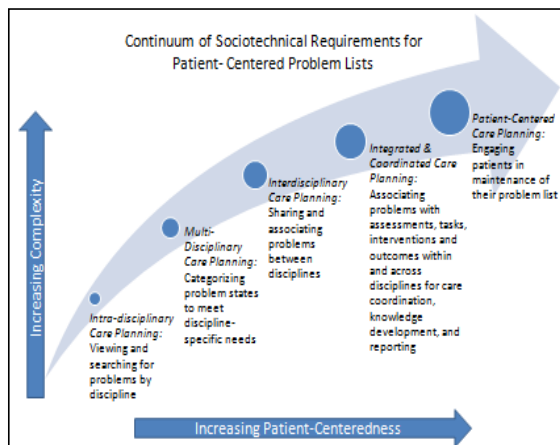


Figure 1 - Continuum of Problem List Requirements

### Viewing and searching for problems by discipline

Successful adoption of PCPLs is dependent on users' ability to efficiently enter problems in electronic form and willingness to do so [9,15]. Creating and using specific "views" of the list are methods to improve desired functionality and efficiency [9]. Campbell et al argued that problem lists should "offer features that allow tailoring of presentation suited to the clinical needs of the current user" [14]. Matney et al articulated that problem lists are a method to organize a patient's problems so that clinicians can view, at a glance, all of the patient problems from a multidisciplinary perspective to ensure that clinical treatments do not conflict across disciplines [13]. Yet, each discipline is also responsible for list management according to their respective scopes of practice, i.e., physicians manage the medical diagnoses, nurses manage the nursing diagnoses, and so on [13]. Therefore, tailored sorting and viewing are vital [9,21].

Enhancements of search functionality to enhance precision and recall should support consistency in choosing the correct or most specific problem [10]. Commonly used diagnoses vary among clinical disciplines; this variability requires multiple lookup groups or subsets of problem list entry choices to optimize clinical workflow and data capture [10]. The classification of problems into useful clusters and the development of

personalized "lists of favorites" may enhance the desired precision of search retrieval [9,17,18]. It is important to note that restricting users from selecting problems outside of their discipline is not an identified requirement from the literature or our work at PHS and that care should be taken to ensure that functionality is not restrictive. STRs for viewing and searching for problems by discipline pose design implications due to content overlap between nursing and physician problem lists and discipline-specific subsets offer a solution [4,13]. The infrastructure of a PCPL will require the flexibility to support and maintain content overlap between disciplines, as well as the functionality to meet the specific searching and viewing requirements of each discipline [2,4,13].

### Categorizing problem states for discipline-specific needs

We know that designing one system that supports all use cases across provider types and care settings is a challenge [9]. Varying STRs for medical problem lists between primary care, specialty, and emergency providers have been identified and provide insight into handling varying needs between all professional clinical disciplines [10]. A sharable PCPL should provide a mechanism that meets all clinicians' needs for documentation of the conditions on the problem list, such as categorization of problem states, to facilitate problem list management and decreasing "problem list clutter" [10]. Examples of problem states throughout the episode(s) of care include "active," "resolved," "modified," "re-activated," and "sub-problems" (subsumption), as well as categorizations such as family history problems [4,15,18,19,25,26]. Meta-categorizations include the ordering of problems to communicate priorities [9,15]; yet, these priority rankings may appropriately vary between discipline and specialty [17]. Viewing one's own priority ranking and others' priority rankings allows clinicians to visualize and understand another clinicians' perspective of patient-care goals [9,21]. These collective and specific views may advance patient-centered care by visually aligning intra- and inter-disciplinary responsibilities, actions, and plans [22].

Increasing user types, views, and categories of problems places the list at risk of clutter. Sources of clutter may be symptoms, acute care diagnoses, and other types of transient problems [9,10,16]. The capability to separate problems by type (e.g., acute vs chronic) can facilitate the user experience. Automated tools could facilitate the resolution of problems based on inferred state, such as alerts to resolve acute problems after a hospitalization [10]. However, the conceptual differences between medical diagnoses and nursing diagnoses require tailored functionality to capture useful problem states because: a) medical diagnoses relate to pathological disease processes, and b) nursing diagnoses relate to a patient's physical, sociocultural, psychological, and spiritual response to an actual or potential illness or health problem [21]. For example, the use of SNOMED CT modifiers for post-coordination of medical diagnoses are well accepted [12,23]. At PHS, SNOMED CT procedures were automatically post-coordinated with a "status post" modifier to enhance physician list management. The approach met physician requirements for documenting past procedures on the past medical/surgical history section of the problem list. However, the automation did not work for nursing. The model prevented nursing diagnoses that addressed planning for a "future state" discharge problem, or caring for a patient pre-procedure. Others have cited misclassifications when post-coordinating with SNOMED CT modifiers [39].

Pre-coordination of SNOMED CT nursing diagnoses is useful as an interface terminology. From a terminology management

perspective, the International Standards Organization (ISO) 18104 Reference Terminology Model (RTM) for nursing diagnostic concepts provides the utility to dissect pre-coordinated nursing problems by concept type [40]. Dissection could facilitate grouping problems for problem list management and decision support. For example, one ISO nursing diagnosis concept is “potentiality”. Potentiality allows for grouping of nursing diagnoses as actual problems indicated by signs and symptoms (e.g., “Impaired parenting”), potential problems indicated by risk factors (“At risk for deficient parenting”), and readiness problems indicated by the patient’s desire to improve health (“Ready for enhanced parenting”). Future work could determine types of problems (e.g., potential versus actual) that are useful to infer expected chronicity to tailor problem list management alerts. Finally, PCPLs must also account for uncertainty as part of the differential diagnostic process. A system must be able to handle actual, potential, and transient problems, as well as uncertainty and conceptualizations that differ between disciplines [9,16,21,24].

### Sharing and linking problems between disciplines

The American Health Information Management Association recommends changing signs and symptoms to a more accurate diagnosis once one is identified [10]. Changing and refining problems has been discussed in the literature since the 1990s [14,30]. However, an interdisciplinary problem lists poses new challenges because each discipline may change the same signs or symptoms to a different discipline-specific diagnosis, necessitating the need for linkages, historicity, and policy to govern amendments by multiple types of providers [9]. At PHS, we define refinement as superseding (“resolving”) a problem list entry that contains a sign or symptom concept with a new instance that contains a diagnosis concept, but with a transparent audit history indicating to the user the related sign and symptom that resulted in the formalization of the diagnosis. Our refinement is consistent with the NANDA definition of a nursing diagnostic statement including three components: 1) problem or health state, 2) etiology or related factors, and 3) associated signs/symptoms [41]. The requirement to resolve a sign or symptom is well-established [14]. Designing an interdisciplinary problem list that can handle refinement of problems is a challenge because signs and symptoms are shared problems that may be refined to a more accurate medical diagnosis *and* a more accurate nursing diagnosis. Moreover, each discipline may refine signs and symptoms to an appropriate diagnosis for that discipline at variable points in the patient’s episode of care due to workflow or workload differences. Resolving problems in the context of an interdisciplinary problem list introduces two important challenges: 1) Discipline-specific links between problems and 2) Temporal evolution of these links. An analysis to address temporal challenges is outside this paper’s scope, but is important future work.

We know that knowledge sharing, such as linking problems between disciplines, is needed to support the alignment of intra- and inter-disciplinary responsibilities, actions, and plans [21,22]. In 1994, Henry et al., provided the example of linking the patient-generated problem of shortness of breath, the nurse-generated problem of impaired gas exchange, and the medical diagnosis of *Pneumocystis carinii* pneumonia [4]. Linking problems from multiple sources through relationships such as ‘secondary-to’, ‘caused-by’, and ‘associated-with’ was proposed to facilitate long term maintenance of a unified, non-redundant problem list and included providing users with the ability to view either the entire problem list or receive a tailored view [4]. Development of tailored views that account for problem linkages and workflow variability is a great challenge.

Transparency of linkages will be critical for continuity of care [28] and to satisfy users expectations of information provenance [11,21]. We propose that the ownership and tracking of problem associations be met with a technical approach, while the responsibility for maintaining the problem list is more appropriately addressed as a governance decision. In 1998, Campbell used a social governance approach that defined the maintenance of the problem list as a shared multi-disciplinary activity owned by the care team, and not by a single individual or role [14]. For shared responsibility and interdisciplinary linkages to occur, a problem list must be perceived as useful to each individual’s practice, consistent with the language and concepts of the user’s discipline, integrated into clinical workflow, and resulting in discrete data that can be processed by computerized clinical decision support tools [9,14].

### Associating problems with interventions and outcomes

Value-based care requires links between care provided and outcomes achieved. The nursing and medical literature have separately discussed intradisciplinary problem list capabilities for patient-centered care since the early 1990s [17,25]. Problem list-clinical workflow integration is cited as a method to facilitate care planning by associating assessments, goals, interventions, tasks/to-dos, outcomes, plans and temporal knowledge with each problem [10,14,18,19,28]. The problem list could serve as an index to the medical record by linking to source documents [9]. Yet, within current EHR infrastructures, problem lists may force clinicians to “double document” patient information [18]. To prevent double documentation, Zhou et al., describe a vision of problem lists that could provide links (pointers) to referenced information to tell the patient’s story, versus a laundry list of discrete clinical processes [11]. Others describe how the problem list can facilitate longitudinal care processes by utilizing triggers and links with “to-do’s” and “tasks” as critical reminders to complete protocol-directed activities or results follow-up [9,18,34]. Other work cites the potential to leverage links between ordered interventions and problem lists for the detection of drug interactions, automated surveillance, and advanced decision-support.[16]

However, much of the problem list literature falls short of the ideal of interdisciplinary care planning and is more consistent with the conceptual view of multidisciplinary care planning, case management, and disease-oriented critical pathways [28]. Most available knowledge bases to direct interdisciplinary care planning employed by EHRs remain disease focused [42], rarely involving nurses, allied health, and physicians. Within the nursing domain, criteria to describe problem-oriented care is consistent with the cyclical nursing process, which is modeled after the scientific process: [a] assessment, [b] problem/diagnosis, [c] goal, [d] intervention, and [e] outcome/evaluation [7,32,33,43]. The critical components to documentation of the nursing process are the internal relationships, or linkages, between the five steps [32,33]. For example, nursing outcomes should be internally related to the diagnosis stated and to the interventions performed for that diagnosis [31]. In the medical domain, criteria critical to facilitate collaborative care planning in the hospital setting are shared task-lists, which may be an artifact of the problem list [34].

Our work indicates problem list entries should be intentionally associated with the assessments, goals, interventions, tasks/to-dos, outcomes, and plans identified for problems, across user types (i.e., by discipline or specialty). Associations would facilitate a problem-centric search for patient data, which is contrasted with existing note- or author-based information retrieval processes in many EHRs. Associations will also enable doc-

umentation workflow enhancements, such as carry-forward of data (with critical validation steps and tracking) from nurse to nurse, or physician to physician. Finally, clinicians are lacking evidence-based interdisciplinary care planning knowledge at the point of care. Analytics can leverage explicit problem-based associations as part of a learning system and knowledge development. Previous and ongoing work done related to the ISO RTM for Nursing Action can be leveraged to capture these associations [44–46]. The development of a generic and flexible information model *and* the use of discipline-specific terminology models may provide a means to index knowledge concepts and link to external knowledge sources, such as care plans or order sets. Further, discipline-specific terminology models will allow mapping to atomic SNOMED CT concepts to prevent inconsistencies that arise when pre- and post-coordination are used to describe similar concepts [23].

### Engaging patients

Electronic PCPLs could increase patient engagement through communication and decision support functionality and linking patients to clinical trials and online patient communities [9]. Patient engagement may improve the quality of problem lists by increasing identification of problems particularly for past significant events or procedures [37]. Physicians have excluded patient-identified signs and symptoms from lists in the past [37]; yet, patients identify psychosocial problems that are not identified by a nurse or physician [4]. Lawrence Weed described the problem list as including established diagnoses and all other unexplained findings, including psychiatric, social, and demographic problems [47]. Evidence strongly suggests that PCPLs should include patient-generated data including “patient perspectives”, such as preferences regarding end-of-life care [38]. Patient-generated data requires the use of consumer health vocabularies, mapping of patient’s descriptions of their signs and symptoms to standardized taxonomies, and data management tools that incorporate clear policies and procedures that consider the patient and the care providers who are serving the patient as the primary customers [9,48]. Investigating when and how to target patient engagement is a priority. We offer the idea of challenging assumptions about where a PCPL should reside and investigating the pros and cons of a shift toward patient-controlled problem lists within personal health records (PHRs) as the “source of truth”. A centralized list would provide a visualization of competing and misaligned priorities *faced by the patient* - a natural starting point for patient-centric shared-decision making conversations.

### Conclusion

The development of a problem-list with functionality that meets a minimal set of STRs for computer-based PCPLs is a first step toward standardized, useful, cooperative, and patient-centered interdisciplinary care planning. Functional requirements of PCPLs will call for flexible and customizable software, as well as standard policies and guidance for use to support efficient entry, access, and maintenance. The continuum of STRs for PCPLs provides guidance for minimum functionality standards and incremental advancement along five stages toward achieving patient-centered care.

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