Chapter 6
An Ontology for Capturing Pervasive Mobile Solution Benefits in Diabetes Care: Insights from a Longitudinal Multi-country Study

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6.1 Background

Globally, two key and unconnected trends are evident: (1) the prevalence of diabetes is increasing exponentially (Help4Diabetes 2012), and (2) the adoption of pervasive mobile solutions is increasing rapidly (Degusta 2012). Globally, diabetes mellitus [diabetes] is one of the leading chronic diseases (Geisler and Wickramasinghe 2005). The total number of diabetes patients worldwide is estimated to rise to 366 million in 2030 from 171 million in 2000 (Wild et al. 2004). Contemporaneously, conservatively, over 6.4 billion mobile internet subscriptions are predicted by 2019, and by 2030 everyone is predicted to be using mobile banking.

In Australia alone, an estimated 275 individuals develop diabetes daily (Diabetes Australia 2016) making Australia a significant contributor to this projected global trend. Further, an estimated 700,000 Australians, representing approximately 3.6% of the population, were diagnosed with diabetes in 2004–2005. Further, between 1989–1990 and 2004–2005, the proportion of Australians diagnosed with this disease more than doubled from 1.3% to 3.3% (Diabetes Australia 2016). Additionally, between 2000–2001 and 2004–2005, Australian diabetes hospitalization rate increased by 35% from 1932 to 2608 per 100,000 people (AIHW 2008). Hence, most agree that diabetes is one of the fastest growing chronic diseases in Australia (AIHW 2008; Catanzariti et al. 2007; Chittleborough et al. 2007).

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In addition to the unpleasantness of this disease to its sufferers, it must also be kept in mind that diabetes and its complications incur significant costs for careers, governments, and the entire health system (Geisler and Wickramasinghe 2005; Colagiuri et al. 2002). In the United States, in 2010–2011, costs associated with diabetes were US$174 billion ($116 billion direct medical costs and at least $58 billion indirect costs) (Help4Diabetes 2012), while in 2004–2005 direct healthcare expenditure on diabetes in Australia was AU$907 million, which constituted approximately 2% of the allocable recurrent health expenditure in that year (AIHW 2008; Catanzariti et al. 2007; Chittleborough et al. 2007; Colagiuri et al. 2002; Wickramasinghe et al. 2013). Further costs include societal costs that represent productivity losses for both patients and their careers (Colagiuri et al. 2002).

In Germany and China, diabetes is also a significant healthcare issues and represents a national concern for these two countries whose combined spending (with the United States) contributed 60% of the total global health expenditure on diabetes as of 2015 (International Diabetes Federation 2015). Given that China is the most populous country, it currently is home to the largest number of adults living with diabetes. According to International Diabetes Federation (2015), both countries had 10.6% diabetes national prevalence as of 2015, while China had a higher diabetes age-adjusted comparative prevalence (10.6–10.9%) compared to 8.7% in Germany.

Further, the prevalence of gestational diabetes mellitus (GDM) increased in both Germany and China during the last 15 years. While more cases have been diagnosed with GDM in China as compared to Germany (adjusted for population differences), the two countries have similar trends in the prevalence of GDM, with slightly higher rate in Germany than in China. Specifically, the adjusted prevalence of gestational diabetes mellitus increased by 2.8 times during 1999–2008, from 2.4% to 6.8% ($P < 0.0001$ for linear trend) (Zhang et al. 2011); the highest rate was in the age group 30–34 (11.3%), and the lowest was among women aged 25 and under (1.2%). A similar trend can be seen in Germany, over a period of 11 years (2002–2013); the documented prevalence of GDM increased 2.9 times (compared to 208 times in China) from 1.5% to 4.4% (Kleinwechter et al. 2011; AQUA 2013).

In the United States, 29.1 million people or 9.3% of the population have diabetes; 21.0 million people have been diagnosed with diabetes, with estimated 8.1 million people with undiagnosed diabetes (Centers for Disease Control and Prevention 2014). Further, The prevalence of gestational diabetes mellitus (GDM) in the United States may be as high as 9.2%, with 1–14% of pregnant women in the United States could develop GDM annually (DeSisto et al. 2014). According to Centers for Disease Control and Prevention (Centers for Disease Control and Prevention 2014), the total medical costs and lost work and wages for people with diagnosed diabetes is USD 245 billion.

Recognizing the growing problem of diabetes as well as noting that simultaneously there has been an exponential rise in the penetration, use, and uptake of mobile phone solutions and applications, it seems logical to investigate the possibility of developing a pervasive mobile solution to support and facilitate better care of individuals with diabetes. As diabetes is a global health concern, this longitudinal study examines the use of the proffered pervasive solution in several countries, namely, Australia, Canada, China, German, Sri Lanka, and the USA. In Australia, Germany, and the USA, the focus of the patient cohort is on GDM (gestational diabetes), while in Canada, China, and Sri Lanka the focus is on type 2 diabetes. To understand the use of the proffered pervasive solution then, it is first necessary to understand the key aspects of chronic disease management and diabetes self-care as well as the case of GDM as the following describes. Then we present the insights to date from the longitudinal multi-country study. However, in conducting the multiple studies and examining the insights collected to date, an important void became apparent to us, the need for a universal framework to examine the benefits of pervasive mobile solutions for various populations of patients with diabetes. We address this void by developing an ontology for diabetes care which is presented in the discussion section of the paper.

6.1.1 Diabetes Care and the Importance of Self-Management

Currently, there is no cure for diabetes. Recommended treatment protocols require effective and ongoing lifestyle management, together with particular attention and monitoring by healthcare professionals and patients (Britt et al. 2009). In order to be effective, it is essential that patients are both informed and be active participants in their treatment regimen (AIHW 2008, 2007). Thereby, continuous self-management is an essential part of prudent diabetes care (ICIC 2008; Colagiuri et al. 1998; Poulton 1999; Rasmussen et al. 2001; Wellard et al. 2008).

Nevertheless, self-management is time-consuming and requires significant self-discipline (Russell et al. 2005). Current support strategies include regular assessment, goal setting, action planning, problem-solving, and follow-up (ICIC 2008). However, since effective self-management often requires ongoing patient interaction with their healthcare professionals (Knuiman et al. 1996), difficulties often arise when diabetes sufferers encounter problems ranging from making appointments to needing to travel to many locations (Wellard et al. 2008; Van Eyk and Baum 2002; Zgibor and Songer 2001). There may be temporal gaps in appointment, geographical gaps due to travel distances, and informational gaps due inadequate communication.

Solutions for supporting self-management to date (Chau and Turner 2007; Rudi and Celler 2006) have not always been effective, as they have been complex and awkward for patients to embrace easily (Reach et al. 2005). It has been noted that computer-assisted telemedicine can help diabetes sufferers improve both their self-management (Balas et al. 2004) and their relationship with healthcare professionals (Bodenheimer et al. 2002; Downer et al. 2006), and thus the use of a pervasive mobile solution would appear to have merit.

6.1.2 Gestational Diabetes

The global problem of diabetes is well documented, and public health agencies globally are trying to develop appropriate awareness, education, and treatment programs to address this silent crisis (Help4Diabetes 2012; Geisler and Wickramasinghe 2005). These discussions, however, tend to focus only on type 1 and type 2 diabetes; less attention is given to gestational diabetes mellitus (GDM) (Geisler and Wickramasinghe 2005). GDM is also an important consideration when examining the chronic disease of diabetes, and thus we endeavor to include it in many of our trials.

Gestational diabetes mellitus (GDM) is a form of diabetes which presents in pregnancy, and is usually detected by routine screening in asymptomatic women (Wickramasinghe et al. 2013). Typically, incidence is 4.6% of pregnancies, i.e., greater than 12,400 women per year, in Australia (Templeton and Pieris-Caldwell 2008). Some women, especially those in whom the diagnosis of GDM was made early in pregnancy, may have pre-existing undiagnosed diabetes. In Australia and New Zealand, universal screening for GDM is recommended by the Australasian Diabetes in Pregnancy Society (ADIPS) (Hoffman et al. 1998); however, the uptake of the recommendation is rather variable (Rumbold and Crowther 2001). Most commonly the diagnosis of gestational diabetes is made following routine screening at 24–28 weeks gestation, with smaller numbers of women diagnosed earlier or later in pregnancy. Maternal complications of GDM include polyhydramnios and premature labor, preeclampsia, and perineal trauma (Hoffman et al. 1998). Perinatal complications include macrosomia, shoulder dystocia, bone fractures, and nerve palsy (Crowther et al. 2005a). It recurs in subsequent pregnancy in 30–80% of women, the incidence varying with ethnicity, being lower in Caucasian women (Kim et al. 2007).

Treatment of women with GDM aims to control maternal, and therefore fetal, hyperglycemia and the associated tendency to fetal hyperinsulinemia. They are at the root of the fetal complications (Metzger et al. 2008). Critical to the treatment of women with GDM is careful and systematic monitoring of maternal glycemia and appropriate adjustment of lifestyle, dietary, and pharmacological therapy (Crowther et al. 2005a; Metzger et al. 2008; Crowther et al. 2005b).

6.1.3 The Development of a Pervasive Mobile Solution

In order to develop the solution, it was first necessary to understand the key elements of chronic disease management as set out by Rachlis (2006). Integral to this model is the interaction between an informed patient and a proactive care team. Both of these are possible only with solutions that can facilitate better management and monitoring (Goldberg 2002a, 2002b, 2002c, 2002d, 2002e; Wickramasinghe and Goldberg 2003, 2004).

To develop such a solution, a user-centered design (UCD) approach was adopted. UCD can be considered in general terms as a type of user interface design (Vredenburg et al. 2002). In addition, it is a process where attention is given to the needs, wants, and desires of end users of a product or solution and is characterized by a multistage problem-solving process including planning and feasibility, requirements, design, implementation, test and measure, post release, and analysis (Vredenburg et al. 2002). In the case of the design and development of a pervasive mobile solution, this included a 30-day e-business acceleration project in collaboration with many key players in hospitals, such as clinicians, medical units, administration, and IT departments. At the completion of this e-business acceleration project, a scope document to develop a proof-of-concept specific to the unique needs of a particular environment was delivered.

The web-based model (Fig. 6.1) provided the necessary components to enable the delivery framework to be positioned in the best possible manner. It can facilitate enacting the key components of the chronic disease model successfully. In addition, the web-based model is designed to be flexible and dynamic. It can be adapted to suit the complex nature of healthcare environments by iteratively, systematically, and rigorously incorporating lessons learnt from data into healthcare processes to ensure superior healthcare delivery. This method not only maximizes the value of past data and learning but also makes processes amendable as complex needs and requirements evolve.

What makes this model unique and most beneficial is its focus on enabling and supporting all areas necessary for the actualization of ICT (information communication technology) initiatives in health care. By design, the model identifies the inputs necessary to bring an innovative chronic disease management solution to market (Rumbold and Crowther 2001; Crowther et al. 2005a; Kim et al. 2007; Metzger et al. 2008; Crowther et al. 2005b; Rachlis 2006; Goldberg 2002a). These solutions are developed and implemented through a physician-led mobile e-health project. This project is the heart of the model that bridges the needs and requirements of many different players into a final (output) deliverable, a "wireless healthcare program."

Succinctly, the final technology solution works as follows. The individual takes their blood glucose readings. These are then either directly transferred to the mobile device or manually entered and then sent to the designated member of the clinical care team who on reading the information can send a message back to the patient.

6.2 Methods

Given the preceding, we set out to investigate the possibility of applying the pervasive mobile solution in several countries. Specifically, we wanted to investigate the benefits of a pervasive technology to facilitate and enable superior self-care for patients suffering with diabetes. As highlighted in Table 6.1, in some of the countries, we only focused on GDM (gestational diabetes mellitus), while in other

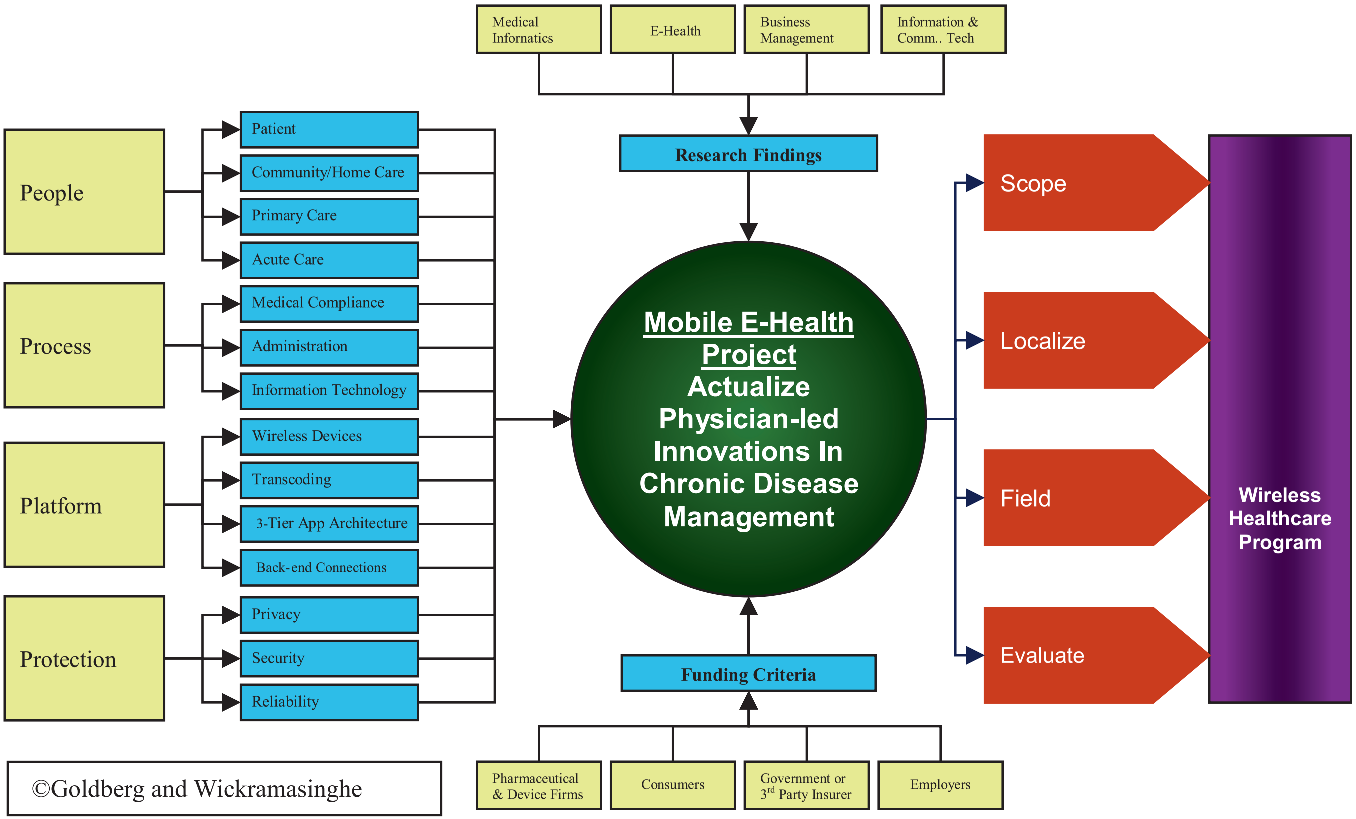

Fig. 6.1 Depiction of the underlying conceptual model and delivery framework. As can be seen the emphasis is on four key inputs of people, processes, platform and technology. The project is always clinician led. Moreover, it also captures the dynamic nature of health care by continually enabling latest research findings to be incorporated. The sustainability of the solution is ensured through the multiple sources of funding. These all support the four key aspects of the delivery framework; namely, scope, localize, field and evaluate

Table 6.1 Summary of results

Country	Stage	Comments
Australia—GDM	Completed	All patient and clinical users preferred the technology solution, and usability, fidelity, and usability were established
Canada—type 2	Completed	Pre and post levels of HbA1c were recorded to monitor glycemic control. The study showed that all patients using the technology solution recorded their blood sugar daily indicating a higher level of self-management which in turn led to better glycemic control
China—type 2	Recruiting	Currently the recruiting process is proving to be difficult since culturally Chinese do not like to take blood sugar four times a day as required, and some patients have been trying to sell the test strips
Germany—GDM	Tailoring the solution	Several bespoke requirements have been requested by the hospital, and these are being considered and integrated into the mobile solution
Sri Lanka—type 2	Recruiting	We are in the process of finalizing the recruitment stage
United States—GDM	Recruiting	We are in the process of finalizing the recruitment stage

countries we focused on type 2 diabetes. In any single trial in a particular context/country, we did not mix type 2 and GDM patients. Thus each trial was either made up of a GDM patient cohort or a type 2 diabetes cohort.

Research Design The DiaMonD (Diabetes monitoring device) study used the established techniques adapted by Wickramasinghe and Goldberg (Goldberg 2002a, 2002b, 2002c, 2002d, 2002e; Wickramasinghe and Goldberg 2003, 2004, 2007) to date, i.e., the AMR (adaptive mapping to realization) methodology. In addition, a crossover style unblended RCT (randomized control trial) was utilized which means that the control group at a predetermined time converts to using the technology solution, while the intervention group at this same point in time then reverts to the traditional solution. This strategy is deemed appropriate in studies of this nature so that it is possible for patients to compare with/without technology scenarios.[1] We note that for GDM trials crossover was set at 4 weeks while for the type 2 trials crossover was set at 3 months.

Established qualitative and quantitative techniques have been employed to analyze the collected data. Specifically, from the qualitative data, thematic analysis was performed in accordance with standard approaches described by Boyatzis (1998) and Kvale (2009), while simple regression techniques and exploratory data mining techniques will form the major focus for the quantitative part.

[1] www.implementationscience.com/content/4/1/69.

6.2.1 Data Collection Strategy

The data collection strategy included collecting data at the start, at the cross over point, and at the end of each respective patient's participation in the trial via an interview and the administration of open-ended questionnaires. In addition, clinician data would be captured at the start and conclusion of the project via interview and the administration of open-ended questionnaires.

6.3 Results

The results to date of this research in progress are summarized in Table 6.1.

As can be seen from Table 6.1, the study is at various stages of progression across the different data sites in each country with the trial completed in Australia (focusing on GDM) and Canada (focusing on type 2). In addition to the relative stages of the actual trial, the study has also established an appropriate delivery framework and web-based conceptual model that were tailored to each context, namely, Australia, Canada, China, Germany, Sri Lanka, and the United States. This was an essential first step in order to successfully apply the pervasive mobile solution. From this, it was possible to then program the solution to the required local processes and requirements. Once the solution was approved by the clinicians and ethics clearance received, it was then used in the technology arm of the trial.

6.3.1 Key Insights

From the Australian case results, we are able to note that whether patients started with standard care and then migrated to the technology arm or vice versa, all patients interviewed have preferred the technology solution over the standard care approach. The standard care approach in the Australian context essentially consisted of keeping logs of blood sugar readings and food intake and when required insulin usage. One patient noted (and all patients to date have expressed similar sentiments):

> …as a busy working person I have no time to note things down but with the mobile solution I can record things as I go so easily. I cannot believe this solution has not been used yet…. (patient 3)

Patients also commented about the benefit of the solution in a geographic sense, since they did not have to drive for regularly checkups but could through the technology solution transfer key data and be advised when they must come in for a checkup.

All members of the healthcare team (obstetricians, diabetic educator, and endocrinologists) were supportive of the technology solution. They claimed it enabled them to provide a higher quality of care in a timely fashion to their patients. When the findings were discussed with hospital administration, they were supportive of the solution to improve quality of care for patients but were also focused on if there were more labor requirements for members of the clinical team especially if scale increased to manage the backend and provide timely replies and feedback.

From the Canadian study, patients reported that the technology solution facilitated them to record their blood sugar regularly which in turn led to higher levels of self-management with the result of higher compliance. This was considered to be of value to the patients and also the clinicians.

In all the trials to date, the focus has been on monitoring and self-management; however, when we look at the literature around diabetes care, one is also aware of other important aspects such as coaching and education (Wolever et al. 2013; Mullins et al. 2012).

6.4 Discussion

Even though this longitudinal multi-country study is in progress, to date we have not had any patient prefer the standard care over the technology solution. However, a more pressing void than the access to a pervasive technology solution per se has been uncovered, while we have been conducting the respective trials and working with the clinicians and hospital administrators in order to move forward with our respective trials. Specifically, we realized that a void in the literature is the presence of a universal framework of diabetes care to facilitate maximization of the benefits of a pervasive technology solution in the context of supporting the delivery of superior care in diabetes exists. We believe this is particularly important today given the global problem of diabetes and the variety of technology solutions that are now being developed to support various aspects of diabetes care. For example, studies on diabetes management such as (3,4,13,50,51) discuss only a subset of all stakeholders, many do not discuss GDM even though this is a recognized type of diabetes, and some do not discuss the geographic angle or traveling. Thus, to address this void, we constructed the following ontology (Fig. 6.2) and discuss key aspects of it below.

6.4.1 Ontology of Diabetes Care

Figure 6.2 presents the ontology for diabetes care that was derived by combining our literature review with results to date from the current longitudinal multi-country study. To understand the ontology, it is first necessary to realize that it is difficult to effectively present the full complexity of diabetes care using linear natural (English) narrative as the narrative would not only be too voluminous but also increase the risk of simplification and the bias of selection in its description. On the other hand, a structured natural English representation using an ontology can be parsimonious

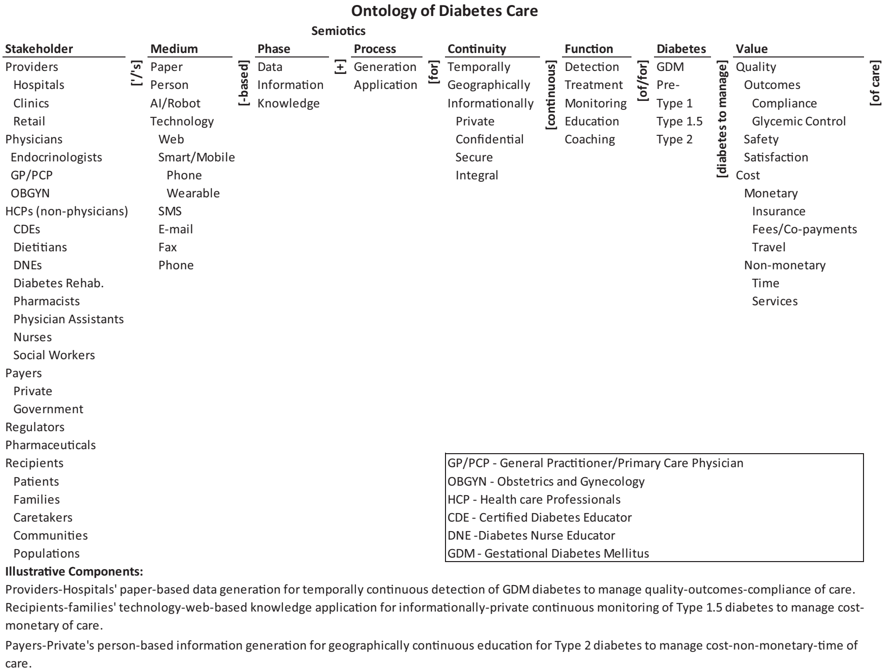

Fig. 6.2 The proposed ontology

and effective in capturing the complexity of diabetes care and making it visible and comprehensible. The ontology then serves as a combinatorial, visual, natural English representation (Churchman 1967; Ramaprasad and Syn 2014; Ramaprasad and Syn 2015; Cimino 2006). (It can be in other languages too.)

Thus in developing the presented ontology, we deconstruct diabetes care into seven dimensions, one of them with two subdimensions. These dimensions emerged from our pilot studies as well as the literature reviewed to date. Specifically, these include (a) stakeholders in the care, (b) medium of care, (c) semiotics of care, (d) continuity of care, (e) function of care, (f) diabetes type, and (g) value of care. The semiotics of care has two subdimensions—semiotic phase and semiotic process. The underlying argument is that the stakeholders use the media-based semiotics to assure the continuity of the various functions of diabetes care to manage the value of care. This argument can be expressed as:

Value = f (Stakeholder, Medium, Semiotics (Phase, Process), Continuity, Function, Diabetes)

The stakeholders in diabetes care are many—both a cause and a consequence of the complexity of diabetes care. They are enumerated as a two-level taxonomy under the Stakeholder dimension (column) in Fig. 6.3. (Notes: We will capitalize the words that refer to the dimensions and elements in the ontology, except in narrative descriptions of full or partial components. The dimensions and elements of

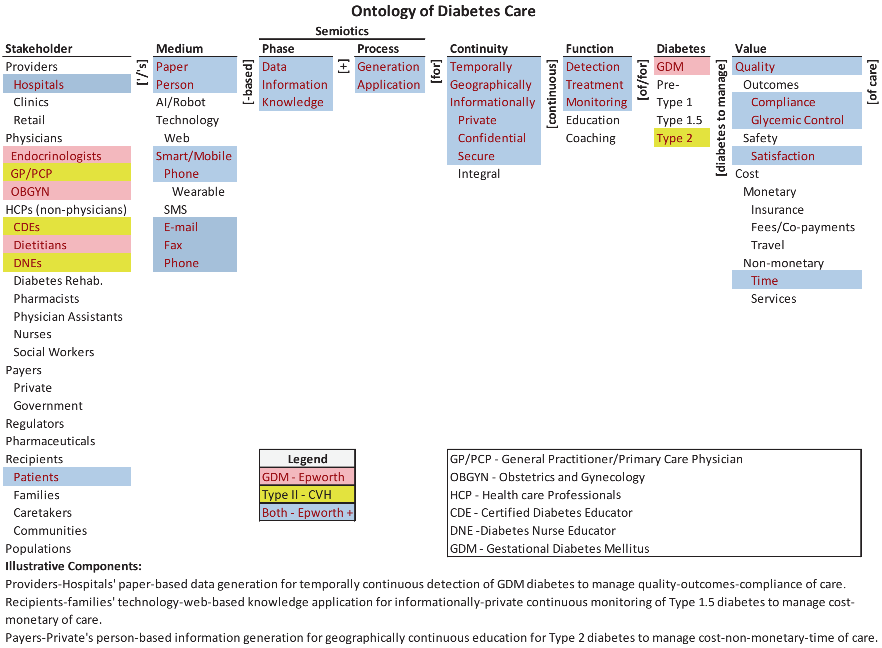

Fig. 6.3 Mapping of case study data to ontology

the ontology are defined in greater detail in the glossary in the Appendix.) The stakeholder can be expressed as:

Stakeholder ⊂ (Providers, Physicians, Healthcare Professionals, Payers, Regulators, Pharmaceuticals, Recipients)
Providers ⊂ (Hospitals, Clinics, Retail)
Physicians ⊂ (Endocrinologists, General Practitioners/Primary Care Physicians, Obstetricians/Gynecologists)
Healthcare Professionals (non-physicians) ⊂ (Certified Diabetes Educators, Dietitians, Diabetes Nurse Educators, Diabetes Rehabilitation Specialists, Pharmacists, Physician Assistants, Nurses, Social Workers)
Payers ⊂ (Private, Government)
Recipients ⊂ (Patients, Families, Caretakers, Communities, Populations)

Part of the complexity of diabetes care is, in addition to the individual interventions of the stakeholders, one has to include the many interactions among them. The Stakeholder dimension helps identify the stakeholders in a specific context; a Stakeholder x Stakeholder table can help map the interactions among them systematically.

The media employed in diabetes care are shown in the Medium dimension of the ontology. It includes both the traditional and emerging media. The emergence of new media, their capabilities, and the interaction of the new and traditional media in innovative ways can help transform diabetes care. To unleash their power to transform, it is necessary to understand the stakeholders' use of the media and its effects on semiotics (discussed next) systemically and systematically. The ontology can help do so. The Medium is a three-level taxonomy which can be expressed as follows:

Medium ⊂ (Paper, Person, AI/Robot, Technology)
Technology ⊂ (Web, Smart/Mobile, SMS, E-mail, Fax, Phone)
Smart/Mobile ⊂ (Phone, Wearable)

Semiotics is the core engine of the logical and translational work of diabetes care. The logical work is performed through the iterations of Data-Information-Knowledge in the Phase subdimension of the ontology. The translation work is performed through the iterations of Generation-Application labeled the Process subdimension. Thus, Semiotics consists of the six combinations of Data-Generation, Information-Generation, Knowledge-Generation, Data-Application, Information-Application, and Knowledge-Application. The stakeholders, individually and interactively, may use the media, individually and in combination, to perform these six semiotic functions. Thus:

Semiotics = (Phase, Process)
Phase ⊂ (Data, Information, Knowledge)
Process ⊂ (Generation, Application)

Continuity is a critical dimension of diabetes care. Diminution of continuity can diminish the value of care significantly. The emergence of new media has made it easier, efficient, and effective for the stakeholders to maintain the continuity of care through collaboration and coordination. While continuity is commonly perceived a temporal continuity, geographical and informational continuity are equally important in assuring the value of diabetes care. A recipient should be able to obtain timely care, irrespective of location, based on the same information. It is also necessary for information continuity that it be private, confidential, secure, and correct. Thus:

Continuity ⊂ (Temporally, Geographically, Informationally)
Informationally ⊂ (Private, Confidential, Secure, Integral)

There are five basic functions of diabetes care—detection, treatment, monitoring, education, and coaching. They are in roughly ordinal—each following the other—and iterative. From education one may move back to treatment and then monitoring, etc. Different stakeholders using a portfolio of media may be involved in performing these functions. The semiotics of these functions too is connected but separate. The semiotics of treatment is related to but different from that for education, for example. Yet, it is necessary to maintain the temporal, geographical, and informational continuity in performing these functions. Thus:

Function ⊂ (Detection, Treatment, Monitoring, Education, Coaching)

There are different types of diabetes each of which requires a different type of care. The five types considered are gestational diabetes mellitus, prediabetes, type 1 diabetes, type 1.5 diabetes, and type 2 diabetes. The functions, continuity, semiotics, media, and stakeholders may be different for each. Thus:

Diabetes $\subset$ (GDM, Pre-, Type 1, Type 1.5, Type 2)

The values sought from diabetes care are the improvement in the quality and cost of care. The Value can be expressed as a three-level taxonomy. Quality may be in terms of its outcomes, safety, and satisfaction with it. The outcomes can be further in terms of compliance with care and glycemic control. The cost may be monetary or nonmonetary. Monetary costs may be insurance costs, fees/co-payments, and travel costs. The nonmonetary costs may be of time and for services. The value profile may vary by the type of diabetes, function of care, continuity of care, semiotics of care, media used for care, and the stakeholders. Further, the Quality elements may affect cost and vice versa. One can map the interaction among the value elements using a Value × Value table. Thus:

Value $\subset$ (Quality, Cost)
Quality $\subset$ (Outcomes, Safety, Satisfaction)
Outcomes $\subset$ (Compliance, Glycemic Control)
Cost $\subset$ (Monetary, Nonmonetary)
Monetary $\subset$ (Insurance, Fees/Co-payments, Travel)
Nonmonetary $\subset$ (Time, Services)

6.4.2 Interactions Among Dimensions of Diabetes Care

There are seven dimension of diabetes care in the ontology. We have discussed each dimension in the context of the others in the above. One may also systematically analyze the interaction between each of the 21 pairs of dimensions to obtain the following insights:

Stakeholder × Medium—Use of media by stakeholders in diabetes care
Stakeholder × Semiotics—Semiotics of diabetes care by different stakeholders
Stakeholder × Continuity—Role of stakeholders in different aspects of continuity of diabetes care
Stakeholder × Function—Role of stakeholders in different functions of diabetes care
Stakeholder × Diabetes—Role of stakeholders in different types of diabetes care
Stakeholder × Value—Role of stakeholders in delivering different types of value in diabetes care
Medium × Semiotics—Semiotics of media in diabetes care
Medium × Continuity—Role of media in different aspects of continuity of diabetes care
Medium × Function—Role of media in different functions of diabetes care
Medium × Diabetes—Role of media in different types of diabetes care

Medium × Value—Role of media in delivering different types of value in diabetes care
Semiotics × Continuity—Semiotics of different aspects of continuity of diabetes care
Semiotics × Function—Semiotics of different functions of diabetes care
Semiotics × Diabetes—Semiotics of different types of diabetes care
Semiotics × Value—Semiotics of delivering different types of value in diabetes care
Continuity × Function—Continuity of different functions of diabetes care
Continuity × Diabetes—Continuity of different types of diabetes care
Continuity × Value—Value of continuity in diabetes care
Function × Diabetes—Role of functions in different types of diabetes care
Function × Value—Value of functions in diabetes care
Diabetes × Value—Value of care of different types of diabetes

6.4.3 Components of Diabetes Care

The arrangement of the dimensions of the ontology left to right with adjacent punctuations/words/phrases makes it convenient to concatenate all the logical components of diabetes care in natural English. Each component consists of an element from each dimension together with the adjacent punctuation/words/phrases. Three illustrative components are shown at the bottom of Fig. 6.1 and reproduced below.

1. Providers-hospitals' paper-based data generation for temporally continuous detection of GDM diabetes to manage quality-outcomes-compliance of care.
2. Recipients-families' technology-web-based knowledge application for informationally private continuous monitoring of type 1.5 diabetes to manage cost-monetary of care.
3. Payers-private's person-based information generation for geographically continuous education for type 2 diabetes to manage cost-nonmonetary-time of care.

There are 23 × 10 × 3 × 2 × 6 × 5 × 5 × 9 = 1,863,000 potential components of diabetes care encapsulated in the ontology. It would be laborious and voluminous to enumerate all of them. The ontology provides a convenient and concise "big picture" of the diabetes care in a limited space. It helps visualize its combinatorial complexity. A component may be instantiated in many different aspects of the diabetes care. Consider the first illustrative component above. An instance of it can be a hospital's paper-based system to collect GDM compliance data. An instance of the second can be a patient's family's online search and study to minimize the monetary cost of type 1.5 diabetes care. Last, an instance of the third can be a regional education program instituted by an insurer to save time spent on type 2 diabetes care.

Some components of diabetes care may be instantiated frequently, some infrequently, and some not at all in a system. The frequently instantiated components will constitute the dominant themes, the infrequently instantiated ones the less-dominant themes, and the un-instantiated one the non-dominant themes or potential gaps in diabetes care. The frequency of instantiation of a component may not necessarily indicate its importance, centrality, criticality, or other priority. A dominant theme may simply be a product of convenience or a “herd effect”; a less-dominant theme may be a product of inexperience or oversight; and a gap may in fact have been overlooked or infeasible.

In summary, the ontology can be used to study the anatomy of diabetes care systemically and systematically. It can be used to study both the research on and the practice of diabetes care. Mapping the growing research corpus on the topic will highlight its areas of emphasis, lack of emphasis, and oversights. Mapping its practice will highlight the priority of different elements and components in practice. The insights from such mappings can be used to develop a roadmap for future research and practice.

Returning briefly to our pilot studies, the presented ontology or universal framework of diabetes care supports both the GDM trial conducted in Australia and the type 2 study conducted in Canada. The relevant paths are highlighted in Fig. 6.3, respectively. This serves to illustrate the benefits of the proposed ontology. Our future work will focus on validating the ontology. What Fig. 6.3 clearly highlights is that the studies only serve to capture part of the picture of all elements that impact diabetes care (the shaded parts respectively red and yellow). Indeed we can see that the studies do have overlap, i.e., indicated by the blue shaded cells; however, this figure also has many unshaded cells which are the parts not captured by the studies but captured by our ontology. Diabetes is a global phenomenon, and many multiplicity of factors need to be considered in order to provide the full benefits of the pervasive mobile solution. If these factors are not recognized and modeled, it is likely they will not be addressed. The proffered ontology thus serves to capture all these factors.

6.5 Conclusion

The DiaMonD study is a longitudinal multi-country study that supports a pervasive mobile technology solution, which, while not exorbitantly expensive, has the potential to facilitate the superior monitoring and management of diabetes suffers. The proposed solution enables patient empowerment by way of enhancing self-management. This is not only a noted desirable objective because it allows patients to become more like partners with their clinicians in the management of their own health care (Opie 1998; Radin 2006; Lacroix 1998) but also to date yet to be achieved in an optimal or satisfactory fashion (Colagiuri et al. 1998). Further, by enhancing the traditional clinical-patient interactions (Mirza et al. 2008; Gururajan and Murugesan 2005), the solution should provide better data management and effective and efficient clinical care focus.

Our results to date have served to provide directional data to support the benefits of using a pervasive technology solution to facilities superior care delivery. More importantly, however, our results underscored the need for an organizing framework to facilitate the maximizing of benefits to patients suffering from diabetes. We have addressed this by presenting an ontology for diabetes care which has been developed by combining our results to date with our findings from analyzing the extant literature. Three illustrative components of diabetes care were derived from the ontology. Our method of constructing an ontology is explained by Ramaprasad and Syn (2014) and Ramaprasad and Syn (2015). It was iterative among the authors of the paper (a physician, a healthcare executive, and two information systems professors—all involved in diabetes care and/or healthcare research). The challenge was to construct an ontology which is logical, parsimonious, and complete. It had to be logical in the deconstruction of the domain, parsimonious yet complete in the representation of the domain. It had to be a closed description of the diabetes care domain. We should note that the ontology presented is one of many possible ontologies of the mHealth domain.

Current debate on healthcare delivery in the United States and globally is focusing on delivering value and being patient centered. The proffered pervasive mobile solution promises to deliver on both these, and our directional data to date support this position. However, if we are to understand the complex context of diabetes, we need an organizing framework so that we can systematically evaluate value and patient-centered aspects. To address this we present the ontology of diabetes care. A complex domain like diabetes care can be studied from many points of view, each with its own ontology. It is a “wicked” (Churchman 1967) problem with many potential formulations. Our future research will serve to unpack these perspectives in detail. We contend this is essential if we are to understand the true influences, barriers, and facilitators to effecting superior diabetes care. In so doing we will also be able to address critical issues regarding value-based health care, quality outcomes, patient centeredness, and access, all critical considerations in today’s healthcare delivery landscape. Indeed diabetes is a pressing issue in global health care, and it is necessary to understand the full and far-reaching aspects of this domain, so we can design and develop solutions to address this problem. The presented ontology promises to assist in this pursuit. We close by noting the benefits for using ontology to assist mapping problem domains in healthcare contexts.

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References

AIHW. (2007). *National indicators for monitoring diabetes: Report of the Diabetes Indicators Review Subcommittee of the National Diabetes Data Working Group*, *Diabetes series 2007*. Canberra, ACT: The Australian Institute of Health and Welfare.

AIHW. (2008). *Australian facts 2008*. Canberra: Australian Institute of Health and Welfare.

AQUA. (2013). *Bundesauswertung zum Erfassungsjahr*. National evaluation report. http://www.sqg.de/sqg/upload/CONTENT/Qualitaetsberichte/2013/AQUA-Qualitaetsreport-2013.pdf.

Balas, E. A., et al. (2004). Computerized knowledge management in diabetes care. *Medical Care, 42*, 610–621.

Bodenheimer, T., et al. (2002). Patient self-management of chronic disease in primary care. *JAMA, 288*(19), 2469–2475.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.

Britt, H., et al. (2009). *General practice activity in Australia 2008-09*. Australian Institute of Health and Welfare, and University of Sydney.

Catanzariti, L., Faulks, K., & Waters, A.-M. (2007). *National diabetes register: A statistical profile 1999-2005*. Australian Institute of Health and Welfare.

Centers for Disease Control and Prevention. (2014). *National diabetes statistics report: Estimates of diabetes and its burden in the United States, 2014*. Atlanta, GA: US Department of Health and Human Services.

Chau, S., & Turner, P. (2007). Utilisation of mobile handheld devices for care management at an Australian aged care facility. *Electronic Commerce Research and Applications, 5*(4), 305–312.

Chittleborough, C. R., et al. (2007). The increasing prevalence of diabetes in South Australia: The relationship with population ageing and obesity. *Public Health, 121*(2), 92–99.

Churchman, C. W. (1967). Wicked problems. *Management Science, 14*(4), B-141–B-142.

Cimino, J. J. (2006). In defense of the Desiderata. *Journal of Biomedical Informatics, 39*(3), 299–306.

Colagiuri, S., Colagiuri, R., & Ward, J. (1998). *National diabetes strategy and implementation plan* (pp. 1–281). Canberra, ACT: Diabetes Australia.

Colagiuri, S., et al. (2002). DiabCost Australia-assessing the burden of type 2 diabetes in Australia. In *Diabetologia*. New York: Springer.

Crowther, C. A., et al. (2005a). Effect of treatment of gestational diabetes mellitus on pregnancy outcomes. *New England Journal of Medicine, 352*(24), 2477–2486.

Crowther, C., et al. (2005b). Australian carbohydrate intolerance study in pregnant women (ACHOIS) trial group effect of treatment of gestational diabetes mellitus on pregnancy outcomes. *The New England Journal of Medicine, 352*(24), 2477–2486.

Degusta, M. (2012, October). *Smartphones spreading faster than any other technology*. Available from http://www.technologyreview.com/news/427787/are-smart-phones-spreading-faster-than-any/

DeSisto, C. L., Kim, S. Y., & Sharma, A. J. (2014). Prevalence estimates of gestational diabetes mellitus in the United States, pregnancy risk assessment monitoring system (PRAMS), 2007-2010. *Preventing Chronic Disease, 11*, E104.

Diabetes Australia. (2016). *Diabetes in Australia*. April 11, 2016. Available from https://www.diabetesaustralia.com.au/diabetes-in-australia

Downer, S. R., et al. (2006). SMS text messaging improves outpatient attendance. *Australian Health Review, 30*(3), 389–396.

Geisler, E., & Wickramasinghe, N. (2005). The role and use of wireless technology in the management and monitoring of chronic diseases. DC. http://www.businessofgovernment.org/report/role-and-use-wireless-technology-management-and-monitoring-chronic-diseases.

Goldberg, S. (2002a). HTA quality assurance component summary. Internal INET documentation.

Goldberg, S. (2002b). *Building the evidence for a standardized mobile internet (wireless) environment in Ontario, Canada*. January Update, Internal INET Documentation.

Goldberg, S. (2002c). *HTA presentation rendering component summary*. Internal INET documentation.

Goldberg, S. (2002d). *HTA presentational selection and aggregation component summary*. Internal documentation.

Goldberg, S. (2002e). *Wireless POC device component summary*. Internal INET documentation.

Gururajan, R., & Murugesan, S. (2005). Wireless solutions developed for the Australian healthcare: A review. In *International Conference on Mobile Business, 2005. ICMB 2005*. IEEE.

Help4Diabetes. (2012 [cited 2012 September 2012]). *Diabetes: Aa-worldwideepidemic*. Available from http://www.hope4diabetes.info/general-information/diabetes-a-worldwide-epidemic.html

Hoffman, L., et al. (1998). Gestational diabetes mellitus-management guidelines—The Australasian Diabetes in Pregnancy Society. *Medical Journal of Australia, 169*(2), 93–97.

ICIC. (2008). Improving chronic illness care: The chronic care model. http://www.ic-ic.org/2008/SpecialSession.htm.

International Diabetes Federation. (2015). *IDF diabetes* (7th ed.). Brussels: International Diabetes Federation.

Kim, C., Berger, D. K., & Chamany, S. (2007). Recurrence of gestational diabetes mellitus a systematic review. *Diabetes Care, 30*(5), 1314–1319.

Kleinwechter, H., et al. (2011). Gestationsdiabetes mellitus (GDM). Evidenzbasierte Leitlinie zu Diagnostik, Therapie u. Nachsorge der Deutschen Diabetes-Gesellschaft (DDG) und der Deutschen Gesellschaft für Gynäkologie und Geburtshilfe (DGGG) (www.deutsche-diabetes-gesellschaft.de).

Knuiman, M. W., Welborn, T. A., & Bartholomew, H. C. (1996). Self-reported health and use of health services: a comparison of diabetic and nondiabetic persons from a national sample. *Australian and New Zealand Journal of Public Health, 20*(3), 241–247.

Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing*. Los Angeles: Sage.

Lacroix, A. (1998). International concerted action on collaboration in telemedicine: G8 sub-project 4. *Studies in Health Technology and Informatics, 64*, 12–19.

Metzger, B. E., et al. (2008). Hyperglycemia and adverse pregnancy outcomes. *The New England Journal of Medicine, 358*(19), 1991–2002.

Mirza, F., Norris, T., & Stockdale, R. (2008). Mobile technologies and the holistic management of chronic diseases. *Health Informatics Journal, 14*(4), 309–321.

Mullins, C., Abdulhalim, A. M., & Lavallee, D. C. (2012). Continuous patient engagement in comparative effectiveness research. *JAMA, 307*(15), 1587–1588.

Opie, A. (1998). "Nobody's asked me for my view": Users' empowerment by multidisciplinary health teams. *Qualitative Health Research, 8*(2), 188–206.

Poulton, B. C. (1999). User involvement in identifying health needs and shaping and evaluating services: is it being realised? *Journal of Advanced Nursing, 30*(6), 1289–1296.

Rachlis, M. (2006). *Key to sustainable healthcare system*. Retrieved June, 2006. Vol. 21. p. 2008.

Radin, P. (2006). "To me, it's my life": Medical communication, trust, and activism in cyberspace. *Social Science & Medicine, 62*(3), 591–601.

Ramaprasad, A., & Syn, T. (2014). Design thinking and evaluation using an ontology. In M. Helfert, B. Donnellan, & J. Kenneally (Eds.), *Design science: Perspectives from Europe* (pp. 63–74). Cham: Springer International Publishing.

Ramaprasad, A., & Syn, T. (2015). Ontological meta-analysis and synthesis. *Communications of the Association for Information Systems, 37*, 138–153.

Rasmussen, B., Wellard, S., & Nankervis, A. (2001). Consumer issues in navigating health care services for type I diabetes. *Journal of Clinical Nursing, 10*(5), 628–634.

Reach, G., et al. (2005). Adjusting insulin doses: From knowledge to decision. *Patient Education and Counseling, 56*(1), 98–103.

Rudi, R., & Celler, B. G. (2006). Design and implementation of expert-telemedicine system for diabetes management at home. In International Conference on Biomedical and Pharmaceutical Engineering, 2006. ICBPE 2006. IEEE.

Rumbold, A. R., & Crowther, C. A. (2001). Guideline use for gestational diabetes mellitus and current screening, diagnostic and management practices in Australian hospitals. *Australian and New Zealand Journal of Obstetrics and Gynaecology, 41*(1), 86–90.

Russell, L. B., Suh, D.-C., & Safford, M. (2005). Time requirements for diabetes self-management: Too much for many. *The Journal of Family Practice, 54*(1), 52–56.

Templeton, M., & Pieris-Caldwell, I. (2008). *Gestational diabetes mellitus in Australia, 2005-06*. Canberra, ACT: Australian Institute of Health and Welfare.

Van Eyk, H., & Baum, F. (2002). Learning about interagency collaboration: Trialling collaborative projects between hospitals and community health services. *Health & Social Care in the Community, 10*(4), 262–269.

Vredenburg, K., et al. (2002). A survey of user-centered design practice. In *Proceedings of the SIGCHI Conference on Human factors in Computing Systems*. ACM.

Wellard, S. J., Rennie, S., & King, R. (2008). Perceptions of people with type 2 diabetes about self-management and the efficacy of community based services. *Contemporary Nurse, 29*(2), 218–226.

Wickramasinghe, N., & Goldberg, S. (2003). The wireless panacea for healthcare. In *Proceedings of 36th Hawaii International Conference on System Sciences, Hawaii*.

Wickramasinghe, N., & Goldberg, S. (2004). How M= EC^2 in healthcare. *International Journal of Mobile Communications, 2*(2), 140–156.

Wickramasinghe, N., & Goldberg, S. (2007). Adaptive mapping to realisation methodology to facilitate mobile initiatives in healthcare. *International Journal of Mobile Communications, 5*(3), 300–318.

Wickramasinghe, N., et al. (2013). A transaction cost assessment of a pervasive technology solution for gestational diabetes. In *Healthcare information technology innovation and sustainability: Frontiers and adoption: Frontiers and adoption* (p. 109). Hershey, PA: IGI Global.

Wild, S., et al. (2004). Global prevalence of diabetes estimates for the year 2000 and projections for 2030. *Diabetes Care, 27*(5), 1047–1053.

Wolever, R. Q., et al. (2013). A systematic review of the literature on health and wellness coaching: Defining a key behavioral intervention in healthcare. *Global Advances in Health and Medicine, 2*(4), 38–57.

Zgibor, J. C., & Songer, T. J. (2001). External barriers to diabetes care: Addressing personal and health systems issues. *Diabetes Spectrum, 14*(1), 23.

Zhang, F., et al. (2011). Increasing prevalence of gestational diabetes mellitus in Chinese women from 1999 to 2008. *Diabetic Medicine, 28*(6), 652–657.