# Digilego: A Standardized Analytics-Driven Consumer-Oriented Connected Health Framework

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**Abstract.** Connected health solutions provide novel pathways to provide integrated and affordable care. Emerging research suggests these connected tools can result improved health outcomes and sustainable self-health management. However, current health technology frameworks limit flexibility, engagement, and reusability of underlying connected health components. The objective of this paper is to develop a data-driven consumer engagement framework, which we call Digilego, to facilitate development of connected health solutions that are targeted, modular, extensible, and engaging. The major components include social media analysis, patient engagement features, and behavioral intervention technologies. We propose implementation of these Digilego components using FHIR specification such that the resulting technology is compliant to industry standards. We apply and evaluate the proposed framework to characterize four individual building blocks (DigiMe, DigiSocial, DigiConnect, DigiEHR) for a connected health solution that is responsive to cancer survivor needs. Results indicate that the framework (a) allows identification of survivor needs (e.g. social integration, treatment side effects) through semi-automated social media analysis, (b) facilitates infusion of engagement elements (e.g. smart health trackers, integrated electronic health records), and (c) integrates behavior change constructs into the design architecture of survivorship applications (e.g. goal setting, emotional coping). End user evaluation with 16 cancer survivors indicated general user acceptance and enthusiasm to adopt the solution for self-care management. Implications for design of patient-engaging chronic disease management solutions are discussed.

**Keywords:** Connected health · Consumer informatics · Chronic disease

## 1 Introduction

Connected health ecosystems have revolutionized care delivery and patient engagement in chronic disease management [1]. Several consumer-facing health technologies, such as physical activity trackers, health journals, social logs, have become indispensable components of care coordination playing a crucial role in health and wellness infrastructure. Managing the appropriate integration of these new era consumer-driven data-intensive artifacts into traditional health care ecosystem is vital to exploit the positive effects of connected health, while simultaneously addressing data quality


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issues and vulnerability threats. Further, such integration should be flexible and adaptive to consumers' personal preferences and privacy concerns. Although, there are several technology development frameworks in health care that focus on infusing health technologies with theoretical constructs, behavior change techniques, usability features, and device automation [2, 3], the majority of existing frameworks do not address the issue of care management in connected health ecosystem from a health consumer's perspective. The risk of a data deluge from these heterogeneous, siloed, distributed technology components can result in a chaotic health data repository. This resulting complexity can overwhelm a general health consumer and result in suboptimal knowledge management and self-health management. Given the complexity of decision making associated with chronic care management, the new technology revolution facilitated by connected health should ease the burden of personal health management. To address these challenges, we present a novel framework, *Digilego*, for the development of consumer-facing connected health applications that effectively integrates personal demographics, clinical data from electronic health records, and personal health data from wearables and home-based monitoring systems, while accounting for consumers' personal preferences in care management. The *Digilego* framework integrates the Social Media Analysis (SMA) [4, 5], Patient Engagement Framework (PEF) [6], Behavioral Intervention Technology (BIT) model [7], and Fast Healthcare Interoperability Resources (FHIR) Specification [8, 9], a standard for exchanging healthcare information electronically. Research shows the use of SMA effective in the design of targeted health applications that are consumer-centered focus, specifically for the purpose of self-monitoring and behavior change in chronic disease management [4]. SMA facilitates capture of culturally sensitive expressions of consumers' information needs in social platforms at scale [4]. Subsequently, PEF acts as a bridging tool to identify opportunities that can help translate the knowledge abstracted within a disease domain to engagement elements of a consumer-centered application. The BIT model allows instantiation of individual *digilego* blocks as technological constituents of the intended connected health solution. Finally, the FHIR specification facilitates implementation of the *digilego* in a web-based user interactive form. In the next sections of the paper, we describe the framework components along with illustrative examples demonstrating its application to the domain of cancer survivorship. Specifically, we focus on facilitating the development of a connected health solution for cancer survivorship, an important chronic health condition [10] through the *digilego* blocks.

## 2 Methods

Figure 1 provides a high-level overview of our proposed *Digilego* framework, which facilitates the development and integration of individual *digilego* building blocks to form a consumer-facing connected health solution. The four main components are (1) content-inclusive social network analysis, (2) engagement elements of *digilego* blocks, (3) feature development using the BIT model, and (4) implementation of standard-compliant software features using FHIR specification.

### 2.1 Digilego Development Framework

***Social Media Analysis:*** As part of our needs analysis for Digilego framework, we analyzed 24,723 publicly available deidentified peer interactions in an online community devoted to cancer survivors. We conducted qualitative analysis of 1000 messages selected at random using a random number generator to gain insights into survivors' sociobehavioral and information needs. The analysis also helped us identify communication topics related to care management of a cancer survivor. We assigned each message to one or more communication topic ranging from treatment discussions to insurance management and medical wills. These qualitative codes were scaled up to the entire dataset by using random indexing approaches found in Semantic Vectors package [11]. The resulting vectors were used as features of machine learning classifiers within Weka [12], an open source text analysis software. Multiple classifiers (Nearest neighbor, J48, Random forest, Naïve Bayes, Support Vector Machine) were compared and we have chosen the best performing classifier based on accuracy metrics (F-measure). The resulting fully annotated dataset was then used to conceptualize individual Digilego blocks.

***Digilego Engagement Elements:*** PEF has been developed by Healthcare Information and Management Systems Society (HIMSS) through cumulative layering of five phases- "inform me," "engage me," "empower me," "partner with me," and "support my e-community." A total of nine features have been specified at the highest engagement level, including 'information and way-finding', 'e-tools', 'forms', 'patient-specific education', 'patient access and use', 'patient-generated data', 'interoperable records', 'collaborative care and community support' [6]. This framework has been used in our study to define the functionality of individual Digilego blocks that form our proposed connected health solution to facilitate self-management, goal setting and reinforcement, peer support, and patient-provider communication. A mapping process was conducted to identify the engagement features which were used to operationalize the insights from SMA in prior step. The lessons learned in the previous step allowed us to understand the characteristics of the information that should be delivered to the survivor through PEF features. We also specified the level of intended survivor engagement to characterize granularity and complexity of the system features.

***Digilego Development:*** We used BIT model to conceptualize digilego blocks (reusable analytics-driven connected health components) to delineate the operational aims, identify behavior change strategies (where applicable), define user interactions, and outline technical aspects for real-time implementation. The BIT model provides a framework for articulating the relationship between intervention aims, elements, characteristics, and workflow [7]. The BIT model was originally proposed to develop behavioral interventions, however, all digilego blocks did not have a behavioral component associated with them (e.g. DigiEHR, DigiMe). For the non-behavioral ones, we still used BIT model to ensure workflow alignment and smoother interfacing among digilego blocks.

***Digilego Software Implementation:*** We developed HTML prototype of implementation of the digilego. The HTML prototype is a responsive design that can scale based on the digilego specific to the user. The prototype was powered by Fast Healthcare Interoperable Resources (FHIR®) compliant server-side app [8]. We used Model View Control (MVC) approach to design the web app. The view comprises of the digilego groups under four domains – Profile (DigiMe), Clinical data (DigiEHR), Sensor and personal health device integration (DigiConnect), and Social engagement (DigiSocial). The controllers were HTTP requests using FHIR specifications to manipulate the data and the view. Specifically for DigiMe and Digi EHR, we used resources that are specified under HL7 FHIR DSTU 2 (version 1.0.2) in alignment with implementation of commercial EHR vendors in the United States. For DigiConnect and DigiSocial that did not have existing FHIR resources, we used data model based on schema.org, compliant with FHIR extensions.

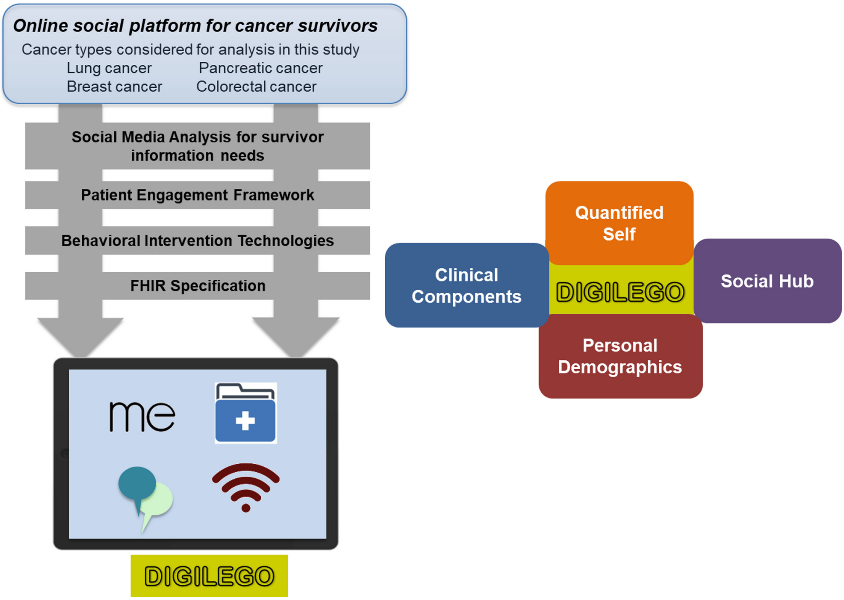


**Fig. 1.** Proposed development framework for cancer survivor digilego

## 2.2 Digilego Evaluation

Having developed four Digilego blocks in the context of cancer survivorship, we conducted a preliminary evaluation of user perceptions of the technology and underlying framework. Two focus group sessions were conducted with 16 cancer survivors. The focus group participants were shown a web-based mobile-responsive prototype and were asked open-ended questions to understand the levels of technology acceptance, system usability, and perceived usefulness of the proposed design methodology and Digilego environment.

In the next sections, we describe the application of Digilego framework to develop a connected health solution for cancer survivorship using illustrative examples. Such compartmentalized design architecture allowed us to facilitate customization, harness analytics-mediated knowledge, integrate engagement tactics, and adopt theory-driven techniques that ultimately result in targeted engagement of cancer survivors throughout the cancer care continuum.

## 3 Results and Discussion

### 3.1 Application of Digilego Framework to Cancer Survivorship Domain

***Social Media Analysis:*** Initial qualitative analysis revealed 15 communication topics, which are distributed in the study dataset as follows.

(a) 39% of the messages were related to (a) care management and coordination: treatment plan discussions (complications, recovery time), medication questions, and request for guidelines to structure upcoming physician appointments,
(b) 36% of the messages were related to social integration, emotional support, positive mindfulness, and support groups,
(c) 18% of the messages were related to healthy living, remission prevention, and late effects of cancer treatment,
(d) 4% of the questions were related to monetary topics (fundraising, insurance limits, exclusions), feedback on care providers and treatment centers, and
(e) the remaining 3% of the messages were related to medical wills and hospice care.

The automated text analysis methods revealed that Random forest classifier resulted in the optimal F-measure of 0.66. The following automated analysis resulted in a completely annotated dataset. Figure 2 shows the distribution of the communication topics in the entire corpus.

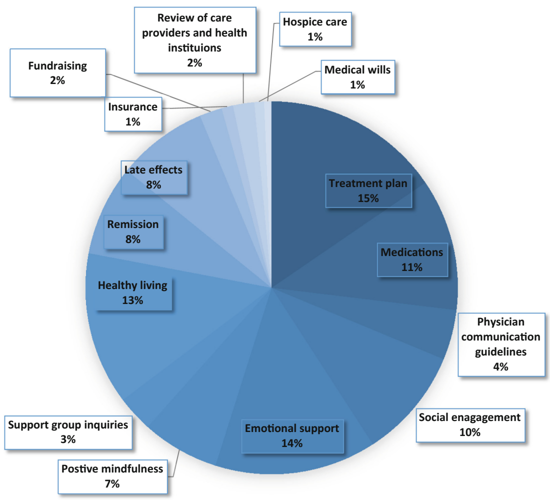


**Fig. 2.** Distribution of the communication topics in cancer survivorship dataset

***Digilego Development, Optimization, and Implementation:*** Four distinct digilego blocks (see Table 1) were conceived and prototyped. Each of the blocks are further segmented to meet the granular information needs that have manifested in the social media interactions. These Digilego blocks are responsive to 12 of the 15 social media topics extracted using automated text analysis methods described in the earlier sections of the paper. For instance, around 13% of the messages focused on adoption of cancer prevention behaviors (e.g. smoking cessation, physical activity, stress management). The Digiconnect and DigiSocial modules are designed considering these interactions.

**Table 1.** Cancer Survivorship Digilego components and related social media topics

| Digilego | Digilego | Social media topics |
|---|---|---|
| **DigiMe**<br>Allows management of administrative and personal information pertinent to cancer survivorship |  | Insurance<br>Personal summary<br>Caregiver profile<br>Agenda for physician appointments<br>Surveys and review submissions |
| **DigiSocial**<br>Connects survivors with peers, care providers while also enabling journal writing of their efforts to stay healthy |  | Physician communication<br>Social engagement<br>Emotional support<br>Positive mindfulness<br>Support group inquiries |
| **DigiEHR**<br>Provides a recent copy of survivor health information from physician's EHR as related to the stage of cancer survivorship |  | Treatment summary<br>Recent labs<br>Phsycian communication |
| **DigiConnect**<br>A snapshot of objective sensor measurements from personal health devices |  | Healthy living<br>Physician communication<br>Positive mindfulness |

The engagement elements identified using the PEF framework for feature selection of Digilego blocks are provided in Table 2. For example, the DigiEHR module is fitted with Empower (Level III) Integrated form: EHR. Similarly, DigiConnect employs Engage (Level II) e-Tools through behavioral trackers and external sensors. For the purpose of our case study on cancer survivorship, Digilego functionalities and inter-relations are modeled as behavioral intervention technologies by defining the overarching operational intention, which is to promote self-management of cancer care and survivorship through adaptive means, as survivor needs change with the stage of cancer continuum. Examples of the sub-goals (see Fig. 3) for each component include increasing positive health behaviors, informing survivors of the late effects of cancer treatment, and promoting adherence to follow-up care regimen. While the operational intention for each *digilego* is unique depending on the content specialty, the usage intention is same across all components where the aim is to engage survivors in self-management of their health. Henceforth, social media features that connects survivor to care providers and peers, and personalization features (age-specific, cancer-specific, stage-specific educational material) have been integrated to the design framework of *digilego* to promote user engagement. Furthermore, DigiSocial and DigiConnect operationalize multiple theoretical constructs that range feedback and self-monitoring via e-health tools such as health behavioral trackers, social support, observational learning [7]. Mapping these strategies to digilego elements is straight-forward, given the clear formulization of the intentions of each component and strategy using BIT model. Further, the instantiation criteria for each of the digilego are defined in terms of the interaction features and workflow. Notifications, logs, information delivery are the most used interaction elements. For example, notifications and logs are assigned to “DigiMe” for review submissions, agenda generation, and survey responses. Similarly, messaging elements and visualizations are used for Digi Social and DigiConnect respectively to provide users with (a) communication tools to interact with peer and care providers, and (b) consolidated feedback to users on their healthy living indicators. Event-based and time-based workflow criteria are used to derive personalization effects. For instance, consider a transition in the cancer care continuum from diagnosis to treatment, education materials related to the treatment type (e.g. chemotherapy, mastectormy) are delivered depending on cancer stage and cancer type. Similarly, time-based workflow is defined for “DigiMe” and “DigiConnect”, where customizations will come to effect depending on time interval since last survey response and goal setting. Figure 3 shows the prototypes for the four Digilego and their underlying information components. These prototypes are FHIR-compliant, extensible, and truly connected from a health consumer’s perspective. The four Digilego components integrate clinical, personal, administrative and social facets of survivor care management. The interface supports interactions such as view, edit, search, write, etc., depending on the digilego. The DigiEHR and DigiConnect are read-only interactions, and enable related entries in DigiSocial or DigiMe. For instance, a survivor can navigate from DigiEHR to DigiConnect to resolve medication-related questions by intetracting with peers and care providers.

**Table 2.** Cancer survivorship Digilego and engagement elements

| Engagement phase | Features | Related Digilego |
|---|---|---|
| Engage (Level II)<br>• Behavioral trackers<br>• Physiological sensors<br>• Survivor profile<br>• Insurance information<br>• View components of electronic health record | e-Tools<br>Interactive tools<br>Patient access: records | DigiConnect<br>DigiMe<br>DigiEHR |
| Empower (Level III)<br>• Care experience surveys<br>• Self-management diaries | Patient-generated health data | DigiMe<br>DigiSocial |
| Partner with me (Level IV)<br>• Home monitoring<br>• Condition-specific self-management tools | Patient-generated data<br>Patient-specific education | DigiConnect<br>DigiSocial |
| Support my e-community<br>• Online support forums | Community support | DigiSocial |

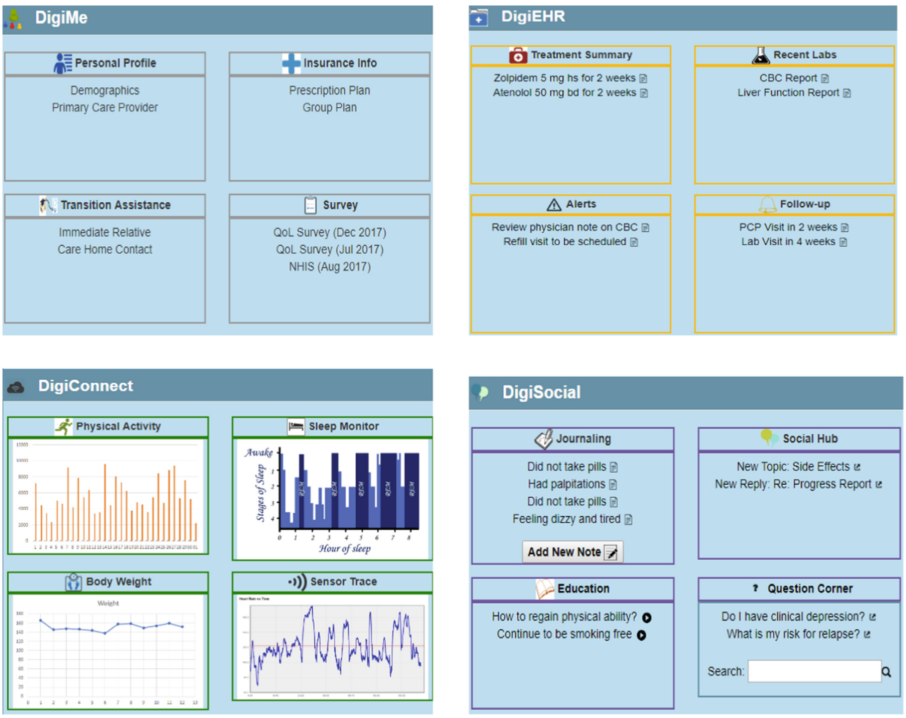


**Fig. 3.** FHIR-compliant cancer survivorship Digilego prototypes

### 3.2 Preliminary Evaluation of Cancer Survivorship Digilego

All participants expressed confidence giving in the proposed design methodology giving it a rating of '5', indicating they strongly believe the proposed system will improve the quality of my cancer care management. 75% of the participants indicated that use of social media analysis in the development process increased their belief in the system's ability to assist them in care management and specifically mentioned it played a role in their acceptance of the proposed technology platform. 87.5% of the participants voted favorably for all the four Digilego bloacks, while the remaining 12.5% felt communication with care provider team and caregivers (family) warrants two separate Digilego blocks. 100% of the participants preferred a mobile platform to a web-based system. Overall, the design philosophy of Digilego that allows cancer survivors to tailor the features of their care assistant technology is favorable received.

In summary, a cluster of connected health components have been conceived, defined, characterized, prototyped using Digilego, an integrative multifaceted standard-compliant framework. Initial evaluation indicated high rates of user acceptance of the prosed development framework.

## 4 Limitations and Future Steps

Our study incorporated design elements from user perspective alone. Future work should focus on expert advisory board to ensure coverage of information needs that are not captures through social media analysis. The automated text analysis methods can be refined to include background corpus and sophisticated machine learning algorithms and distributional representations to improve accuracy of automated classification system [13]. Future work should integrate ontology models [14] with social media analytics to ensure inclusion of knowledge from existing literature into Digilego architecture. Some digilego blocks may not have existing FHIR resources, and custom FHIR compliant extensions/schemas should be generated and validated. The evaluation is limited to user perceptions of system utility. Further studies should investigate usability, performance, and effectiveness of Digilegos in care management. Finally, the four Digilego components form a preliminary proof–of-concept and do not offer full coverage of chronic disease domains such as cancer. Future research should focus on the development of a Digilego bank for a given disease profile from which a health consumer can build a customized connected health tool for self-health management.

## 5 Conclusion

Connected health solutions are becoming increasingly popular in healthcare. However, the current ecosystem lacks design methodologies that are theory-driven, standard-compliant while considering health consumer preference during the design and field implementation stages. This paper presents an approach that aims at the development of integrated consumer-facing connected health solutions. Chronic diseases (e.g. cancer, diabetes) are lifelong endeavor for patients, their families, and caregivers. The Digilego framework is a foundational step that will help influence the development of connected health applications with reusable and customizable components as per the needs of the health consumers.

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