Vision: Developing Collaborative Model-Driven Apps for Personalised Care Plans

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ABSTRACT

We present a proposal for designing collaborative, human-centred care plans to improve the quality of life for people living with disabilities and/or chronic diseases. This position paper proposes the design of a novel set of domain-specific visual languages and collaborative tools to allow end-users to easily specify their requirements and communicate with domain experts and clinicians to design and develop personalised care plan-supporting mobile apps. The visual languages will have the capacity for "Modeling the human aspects of stakeholders and end-users of the software, such as age, gender, personality, emotions, disability and preferences". Expected outcomes include an eHealth solution providing an improved capability for individuals to design and manage their own care plans. Benefits include enabling marginalised and vulnerable people to more easily communicate with practitioners, receive community support and be actively involved in their care planning.

CCS CONCEPTS

• **Software and its engineering → Collaboration in software development**; **Integrated and visual development environments**.

KEYWORDS

care planning, domain-specific visual languages, model-driven engineering, human-centred

ACM Reference Format:
Hourieh Khalajzadeh, John Grundy, and Jennifer McIntosh. 2022. Vision: Developing Collaborative Model-Driven Apps for Personalised Care Plans. In *ACM/IEEE 25th International Conference on Model Driven Engineering Languages and Systems (MODELS '22 Companion), October 23–28, 2022, Montreal, QC, Canada.* ACM, New York, NY, USA, 5 pages. https://doi.org/10.1145/3550356.3559100

1 INTRODUCTION

Chronic health conditions are becoming more prevalent as the population ages, and require complex health management. As well as this, advances in the early-detection and treatment of a range of medical conditions such as cancer, have led to a growing number of people living with chronic illness, disabilities, and ongoing special care needs after treatment. More recently, the COVID-19 pandemic has led to many people with long COVID, a chronic form of COVID requiring complex management [24]. Other areas including organ transplantation bring an increased prevalence of associated long-term morbidity which need to be monitored and managed expediently, to maximise patient quality of life [18].

Chronic disease management relies on care plans to help clinicians, patients and carers manage chronic illness. A care plan outlines a person's health care needs, associated service providers, care management arrangements, future reassessment needs, as well as their goals and preferences, and involves the person (target end-user), carer or family members, and clinicians or educators (stakeholders) [2]. Care plans need to be individualised and adaptable, given the complex needs of long term mental, physical and social care and support for each person. An effective care plan by definition should be a collaborative effort between various stakeholders, and to develop a user-centred care plan, having the end-user involved in its design is key. Most existing care plans provide static, document-based, one-way care plans. Hence, they offer a one-size-fits-all approach that is not necessarily as effective as a complex individualised care plan [5]. There is a critical need to leverage collaborative platforms, using technology such as mobile apps, to facilitate communication and to develop tailored care plans [7]. This will provide an opportunity to allow vulnerable people to connect with domain experts, healthcare clinicians and carers, and to access the necessary resources and long-term planning information.

Many apps are being developed to solve human issues of this kind, designed by software developers, but often without taking users' preferences, and human-centric aspects into account. Healthcare apps bring additional complexity as clinical communication involves an exchange of information important for the patient's care between treating clinicians, patients, families and carers [23]; often using language that might be unfamiliar to lay people including medical and technical terminology. Despite its importance, effective communication can be difficult with many people involved, an extended period of health management, use of unfamiliar medical terms, language and cultural barriers, and lack of data sharing across providers. Communication dissonance and inadequate documentation can potentially have serious consequences [23].

This paper presents a novel vision for modelling and generating collaborative mobile applications to help individuals experiencing serious health challenges to design and manage their own care plans, ultimately to improve their quality of life. Designing accurate and effective care plans – tailored for users with diverse characteristics including physical and mental disabilities – requires effective communication with, and involvement of, the end-user

MODELS '22 Companion, October 23–28, 2022, Montreal, QC, Canada

ACM ISBN 978-1-4503-9467-3/22/10…$15.00
https://doi.org/10.1145/3550356.3559100

in designing their own individualised care plan. We propose to design a set of new Domain Specific Visual Languages (DSVLs) for end-users to be able to effectively communicate their specific needs and preferences, with their caregivers, clinicians and any associated allied health professionals. To achieve this, the following objectives need to be achieved:

- Develop a new set of design principles for DSVLs for the care planning domain, and design and evaluate them based on real end-users' requirements from various domains.
- Incorporate human-centric issues such as age, gender, culture, physical and mental impairments, and emotional effects of the notations into the design of the DSVLs.
- Develop an interactive recommender for the clinicians and end-users to use the DSVLs to specify their requirements.
- Generate and deploy individual care plan apps for a variety of domains, using end-user specified requirements through Model-Driven Engineering (MDE).

There are many potential applications for this technology, e.g. healthcare sector (e.g., as more people are surviving cancer, it is being redefined as a chronic disease [21]); post-pandemic care planning (COVID-19 can lead to a long-term syndrome and engaging appropriate care through new technologies is critical [8]); education sector (develop disability learning plans for students with special needs to replace with the existing document based plans [9]).

2 MOTIVATING EXAMPLE: CANCER CARE PLANNING

After cancer treatment, people enter a 'survivorship' phase where they no longer have active disease but might have cancer related and/or treatment related problems. To manage post treatment symptoms, patients are often given a survivorship care plan (SCP). The Australian Cancer Survivorship Centre (ACSC) [6] recommend SCPs to manage health concernsincrease adherence to medical surveillance, and improve communication with healthcare providers. Multi-disciplinary teams, iterative development, patient needs' assessment, and transitional planning are key features of integrated SCPs [16]. In 2005, the National Research Council (NRC) recommended SCPs for cancer survivors after completing primary treatment/s [25]. In 2016, Nekhlyudov [22] reflected on the progress made since the NRC report was published and claimed that despite some progress, there are still many gaps [22].

This paper envisages producing a user-centred approach to allow patients to be involved in their active and post-treatment care planning including the immediate post treatment phase and long term survivorship [10] as shown in Figure 1. There are a variety of activities and potential items to be included in a care plan, that makes it very complicated and mean a user-centred approach should be very effective at identifying important features. Examples of some features to incorporate in a customised cancer care plan include: 1. (if including the treatment phase) Treatment phase: treatment appointment management e.g. radiology (cancellations and delays), specialist appointments (scans, treatment, GP check in, allied health care), exercise reminders, nutritional advice, clinical support from nurses (radiology nurses, breast care nurses), support group connections (e.g. BreaCan, a breast cancer support network), entertainment for the treatment waiting room, car parking; and 2. Survivorship phase: 2a. Immediate post treatment phase: connecting with post-treatment care e.g. delayed side effects, post management mental health care, 'getting back to health programs'; and 2b. long term Survivorship phase: GP/specialist appointment reminders, surveillance appointments (e.g. PET scans, mammograms), mental health, carers' and health services' contacts, peer support groups.

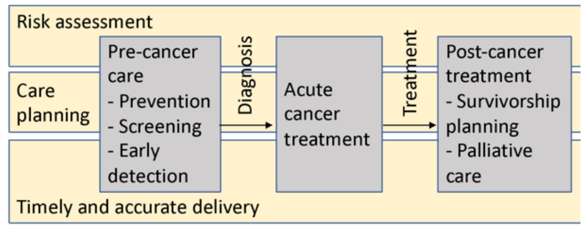

Figure 1: Cancer treatment phases [10]

3 RELATED WORK

DSVLs are visual modelling languages where the models and notations are customised for a particular domain [4], as opposed to general-purpose modelling languages, such as the Unified Modelling Language (UML). A DSVL sacrifices generality of the underlying model and notations for the ability to only model constructs in the target domain using visual elements and metaphors specific to the target domain. The advantage is a set of higher level, domain-oriented modelling and notational constructs optimised for target domain users, achieving better user experience, reducing time and cost, and improving quality of the solution. Examples of DSVLs include: Enterprise Modelling Language (EML) [19], Statistical Design Language (SDL) [17]; and the BiDaML suite of DSVLs for data analytics' applications [14]. Several visual language design principles can be used to guide notational design and evaluation, e.g. Cognitive Dimensions of Notations [11] and Physics of Notations (PoN) [20]. However, design of DSVLs, as an essential step towards human-centred design, is an under-researched area with only limited principles, guidelines and tools to guide their design.

Many DSVLs utilise MDE to synthesise code, scripts, configurations and other artefacts, in order to realise software applications based on the solution modelled with the DSVL [27]. MDE provides an approach to generate software systems from high-level abstract models, rather than from low-level programming languages. The idea is to use high-level models to describe the elements of an application and then to successively transform the models to low-level configurations, scripts and/or code. For example, EML generates configuration scripts to orchestrate web services, SDL generates R scripts to realise statistical analysis techniques, and BiDaML generates python scripts and documentation to design data analytics solutions. There have been several works in developing apps for carers of various types [13, 26], however, this project aims to develop apps for the patients with the helps of carers and practitioners using a model-based approach. DSVLs and MDE-based approaches have neither been employed to design human-centric notations, nor individualised care plans. No research has been conducted to date on determining how care planning can be modelled, and the requirements can be specified for a variety of different applications using DSVL-based approaches.

4 METHODOLOGY

DSVLs provide customised visual modelling languages and notations for a particular problem domain and enable end-users to create and tailor software and apps without having knowledge or background in programming or software engineering (SE). Care planning-specific DSVLs will provide a common language for requirement specification and modelling of the end-user's needs. Human-centric aspects need to be incorporated in the DSVLs in order to design the care plans based on not only the domain, but also the end-users' age, gender, physical and mental impairments, preferences, culture, and language. The end-users and their caregivers, family and friends will collaboratively work with health practitioners such as GPs, nurses, specialists, and allied health professionals to design their own care plans. They will be able to choose the key features they want to include in the specific care plan. Figure 2 shows a preliminary meta-model of our care planning problem. This will be extended and used for creating the DSVLs.

The proposed DSVL suite will be equipped with a recommender that uses machine learning (ML) methods to learn from the user's behaviours and preferences to guide them through using the DSVLs for effective communications. The recommender tool will be a web-based collaborative tool where users (i.e. end-users and stakeholders) can work on the visual notations and diagrams simultaneously. It will also be enabled with hearing, visual and voice-to-text based tools, for users who are visually impaired, computer illiterate or hearing impaired. Usability tests need to be run with real end-users and clinicians. Finally, a tailored care plan support app for each end-user will be generated using the MDE approaches. MDE approaches will be used to convert the visual based elements, designed based on the end-user's characteristics and individual features, into individualised care plans as mobile apps.

4.1 New Methodologies and Technologies

The key technological significance of this proposal lies in the development of novel tools and technologies that will enable diverse end-users to manage their own health and stay connected and looked after, but remain in control of their health / chronic disease management. This will extend and broaden the applicability of DSVLs and MDE-approaches to a completely new domain of care planning. Using these new technologies, a comprehensive range of integrated human-centred platforms will be developed and evaluated for the benefit of vulnerable individuals with special needs. Methodologies will be unique in that they will cater for a range of users who are culturally, physically, and cognitively diverse. Novel collaborative recommender tools based on MDE will be developed to generate low-level, highly scalable care plans from abstract specifications, integrating the required reusable care planning tools, software and services to much better satisfy clinicians' and end-users' needs [1]. We aim to overcome the existing barriers through:

- Bringing together the fields of MDE, app development and chronic care planning
- Using DSVLs to specify individualised care plan app features and enabling end-users' engagement via a high-level, controlled environment, instead of sharing a pre-filled one-way care plan not specific to the user
- Involving domain experts, clinicians, caregivers, and end users in the design and management of their own care plan by the use of DSVLs, and MDE-based development
- Co-designing novel visual metaphors specific to the experts' target domains, providing an efficient, effective, user-friendly and familiar solution
- Developing novel collaborative recommender tools to guide users through using the platform
- Incorporating human-centric software development approaches to enable users who are culturally, physically, and mentally diverse to better manage their own health
- Generating ready to use individualised care plan mobile apps specific to the diverse group of the target end-users' requirements, usages and settings with using MDE

A high-level overview of our approach to supporting the end-user deployment of care plans for the cancer case study example is shown in Figure 3. In this approach: (1) clinicians and end-users provide the required information and decide on the features (e.g. appointment and medication reminder, connect to cancer survivors and family/friend catch-ups, planning, entertainment, hearing/visualisation plugins) using DSVLs and a recommender collaborative tool; (2) an app for the patient and a web-based interface for the clinicians are automatically generated using users' input through MDE approaches; and (3) users use the app and update its features if required, and these steps are iteratively repeated.

5 PROJECT APPROACH

We describe the key steps we are using to achieve the objectives of this research. These include (1) developing a novel set of care plan modelling DSVLs; (2) collaborative recommender tool supporting co-creation by developers and end users; (3) mobile app generator to embody personalised care plans; (4) and evaluation with various real-world examples.

5.1 Domain-Specific Visual Languages

Through close engagement with end-users, a novel set of DSVLs specific to care planning in different domains needs to be developed. Focus groups from diverse groups (e.g. age, gender, culture) of target end-users and domain experts need to be recruited, to conduct usability tests throughout the project by running workshops, user studies and cognitive walkthroughs. Surveys and interviews with end-users, practitioners, and domain experts can be used to collect individual's requirements. We are working to design a set of diagrams to capture details from a high level of abstraction to a low technical level. To evaluate the usability and accessibility of the languages, PoN evaluations [20] can be extended and operationalised.

Human-centric principles for the design and evaluation of Mobile App Care Plan DSVLs. A set of design guidelines are being constructed for developing human-centric care plan specific visual languages. Design principles need to include identifying visual metaphors suitable to describe key aspects of care planning applications for different domains, such as (in the cancer care example) scheduling radiology and specialist appointments.

Co-design DSVLs for care planning in different domains. Appropriate visual metaphors are being identified to map each key aspect of the care plan to the required features of the end user specific

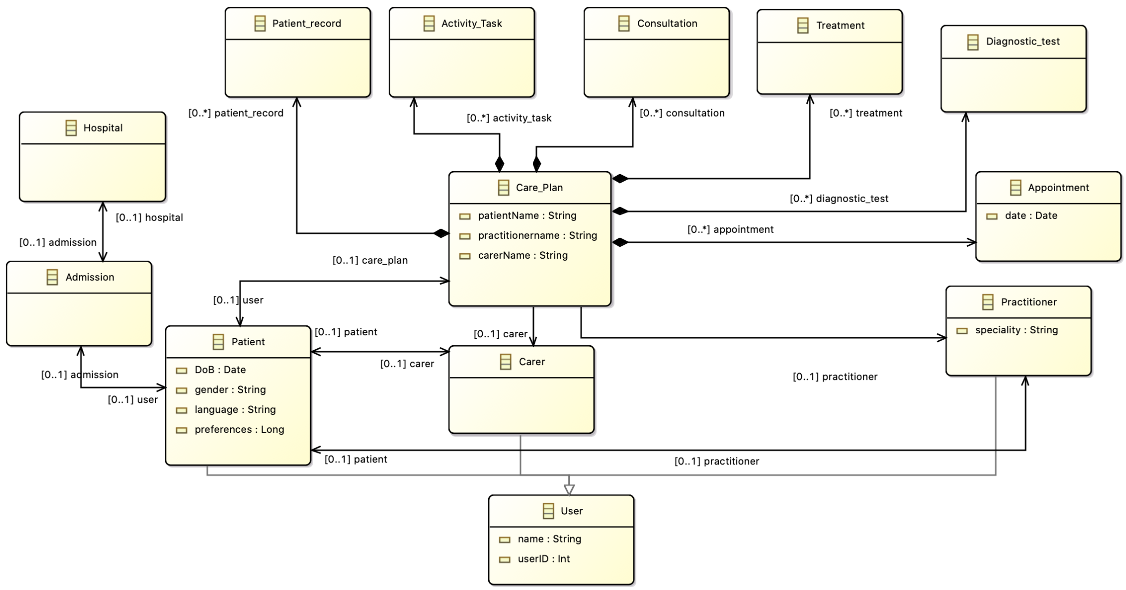

Figure 2: An overview of the care planning meta-model

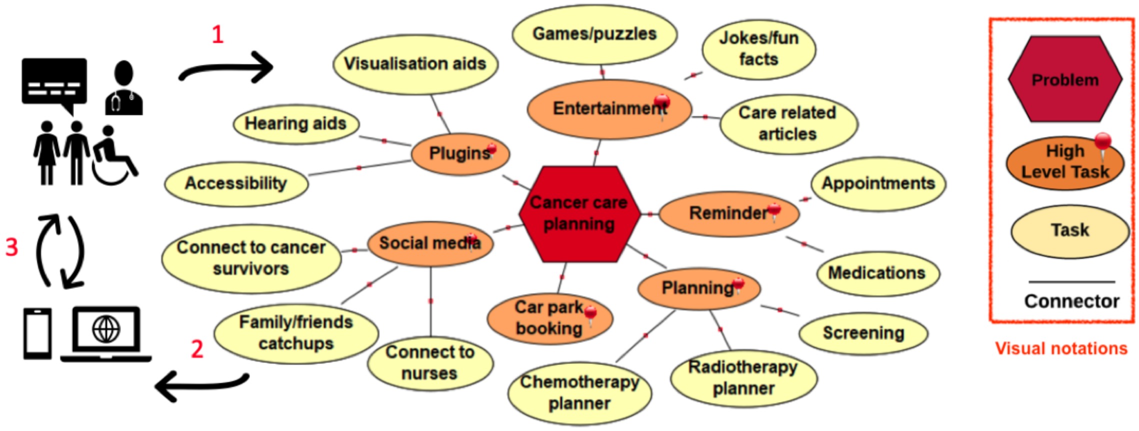

Figure 3: The collaborative care plan structure and sample features for the cancer care planning example

to the domain of focus. We are using these to co-design a set of new DSVLs to enable collaboration and requirements specification, and to capture different human-centric aspects such as age, gender, culture, languages, and physical and mental impairments [12].

Evaluate and improve DSVLs. Clinicians and end-users must be involved throughout the entire lifecycle of the software development, from requirements engineering and design to the development of the languages. Usability tests need to be conducted with end-users to evaluate the models [28]. The languages should be designed in a way that different users can choose one of multiple views of the diagrams based on their needs and preferences.

5.2 Collaborative Recommender Tool

We are developing a collaborative web-based modelling framework equipped with a recommender tool to assist developers and end users to use our mobile app care plan modelling DSVLs to co-create apps. Recommender tools recommend items of interest to a user based on their behaviour [15]. Recommender systems can surface results based on data passively collected from the user. The modelling tool should be equipped with a recommender to assist and enable the users to learn how to use the visual languages developed in the previous task. It then acts as a modelling assistant enabled with plugins to help users who cannot use computers, or users with visual or hearing impairments, to be able to use the tool to specify and design their care plans.

Web-based collaborative tool that allows simultaneous changes. A collaborative web-based tool enables different stakeholders from different locations to interactively communicate through the diagrams at the same time and store the data on the cloud. We are developing collaborative web-based visualisation tools, specifically designed for creating and modelling care plans for different fields.

Recommender tool by incorporating ML methods. Our recommender tool incorporates ML methods to learn from the users' behaviours and habits over time and suggest modelling patterns based on their specific characteristics.

Accessibility related plugins for visually or hearing impaired and computer illiterate users. The visual elements developed in previous steps are designed following design principles that cover all users, including those who are colour-blind. In addition to using best practices in respect to accessibility e.g. Web Content Accessibility Guidelines (WCAG), plugins need to be provided for users to be able to access the tool using alternative, accessible options.

5.3 Automatic Care Plan App Generator

An MDE approach is employed to generate care plan supporting mobile apps for the end-users and caregivers. The generated app is tailored toward the end-user's preferences specified in the previous steps. MDE approaches are applied to automatically generate mobile applications from the models.

Generate reports and documentation from the models. A set of reports and documentation are generated in different formats so that the users can easily share them with others who do not collaborate with them via the tools.

Generate apps from the models. MDE is employed to generate apps from the models, specific to the users' specified features [3].

5.4 Evaluation on Real World Exemplars

We will evaluate our approach using a variety of real-world exemplars. These include cancer care planning, and care plans for people living with chronic diseases, disabilities, organ transplantation, and so on. We aim to work closely with eHealth technology providers, as well as software developers and stakeholders, to obtain their feedback on the developed DSVL and visualisation designs, prototype tools, and the overall usefulness of the approach.

6 CONCLUSION

We have proposed a vision for a collaborative, human-centred mobile application care planning development platform using DSVLs and MDE. Using a novel set of DSVLs and collaborative tools, end-users living with chronic conditions can specify their requirements and communicate with domain experts and clinicians to co-design and generate personalised care plan mobile apps for a better quality of life. The proposed DSVLs will be designed in a way that can capture different human-centric aspects such as age, gender, culture, languages, and physical and mental impairments.

ACKNOWLEDGMENTS

Support for this research from ARC Laureate Program FL190100035 is gratefully acknowledged.

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