VPH-Share: Embodying a Patient Avatar for Computational Workflows

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Introduction – The Virtual Physiological Human (VPH) initiative began in 2005 primarily as a research initiative and since its inception, its focus according to the STEP Roadmap [1] has been the "creation of a framework of methods and technologies that, once established, will make it possible to investigate the human body as a whole". The current evolutionary approach of integrating heterogeneous data, information and knowledge within the VPH is a radical approach that is envisaged to yield applications to specific clinical targets, but requires novel and innovative ICT and scientific approaches far beyond what the VPH has today.

In this light, the multitude of research projects and the availability of free biomedical data, tools and services, across the length and breadth of the VPH community, could conceivably converge toward a common reference system for human biomedical data, information and knowledge, namely a Patient Avatar.

Within the context of the VPH, the Patient Avatar equates to a large catalogue of every item of data, information and knowledge on a patient or a collection of patients that can be shared securely, to allow it to be searched, browsed, interactively explored, for a broad range of reasons, including leisure, education, healthcare, etc. In particular, with respect to scientific workflows, the possibility to find, retrieve, and reuse all of the data, information and knowledge that is available on patients and their physiological attributes could truly revolutionise the field, increasing exponentially the potential uses of VPH technology.

Methods – VPH-Share has chosen to exemplify the patient avatar concept by using four flagship workflows. Each of the four 'flagship' workflows simplifies the complex chain of events associated with normal and abnormal functioning of a physiological process within a human being or a population. This functional simplification is embodied as a mathematical or computational model that describes the sequence of events with certain assumptions. A modeller uses these assumptions and parameterises the model, ultimately creating a generic description (model) that can help answer the research question of interest.

Generic models may be transformed to represent a specific subject (patient) using parameters derived from clinical or statistical measurements. Such introductions of computational modelling techniques may not only provide us insights into the progression of a disease, but also help predict the response to altered physiological conditions, supporting diagnostic and prognostic therapy planning.

The potential integration of clinical, genetic, epidemiological, demographic and biological information with support from advanced computational and image processing techniques is of particular interest to all four workflows. In fact, all four workflows have already attempted to integrate the clinical and workflow relevant information into their own respective pipeline internally. The Patient Avatar is an attempt to expose commonalities and specificities into a global representation of a patient to help integrate and augment the data items with scattered external data, and allow workflows and other VPH projects interoperate with each other.

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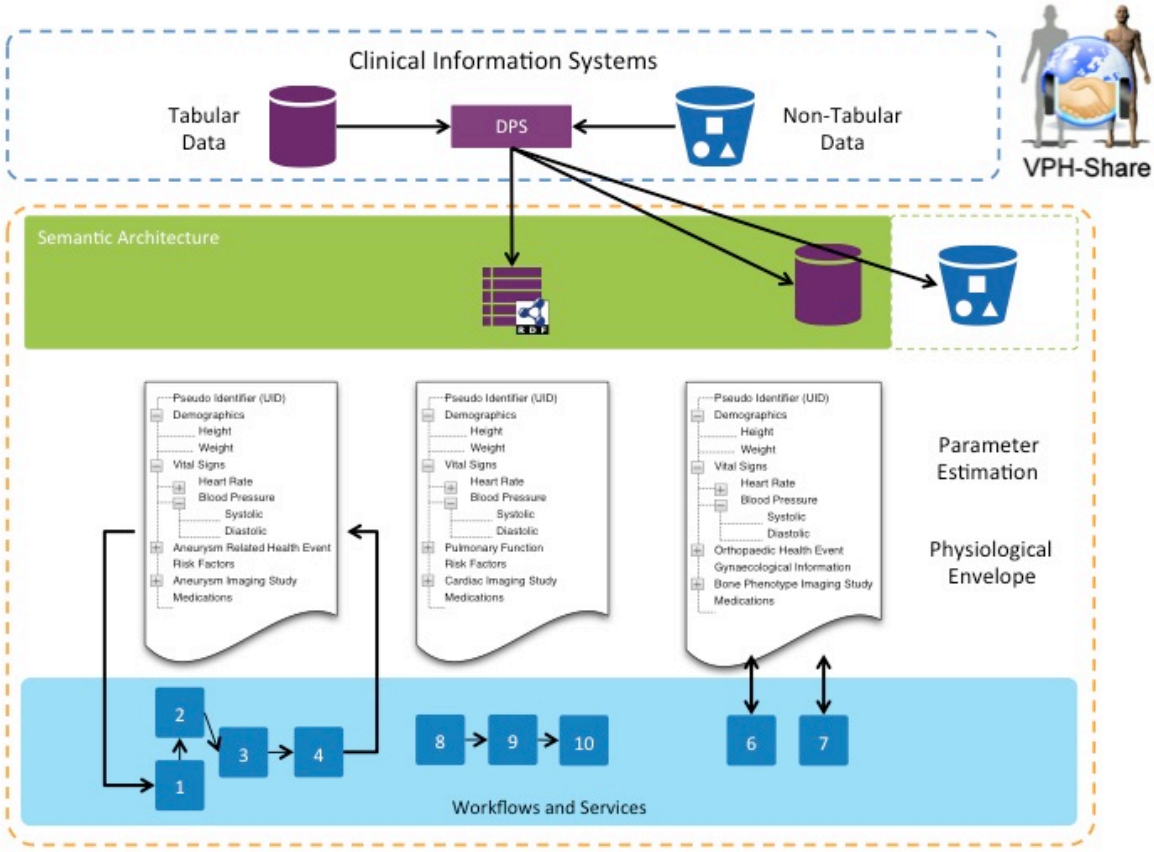

Figure 1: Patient Avatar Clinical Data Integration and Computational Workflows

Progress – A key strategy to the successful creation of a useful Patient Avatar is to employ an Avatar Design Methodology. The design methodology details the essential steps to be performed by each healthcare organisation and/or research unit to identify the key information process flows and relevant data items. It is essentially a protocol that permits patient avatar compliance across multiple organisations and institutions. The design methodology that has already been instituted within VPH-Share see Figure 1, and is detailed below:

1. Document the information process flows for the domain to be modelled identifying the key information sources such as data formats, paper documents, electronic documents and medical devices.
2. Determine all clinical items in the domain to be modelled based on the key information sources identified in the process flow analysis.
3. Merge related individual clinical items to single archetype clinical concepts.
4. Where possible, map the derived clinical concepts to existing archetypes.
5. Data model the clinical concepts identified and re-model them to eliminate duplication of items.
6. Model new archetypes for clinical concepts that cannot be mapped to existing archetypes.
7. Create templates to group and constrain related archetypes that represent the contents of locally used forms or data documents.
8. Document archetype design patterns for reoccurring scenarios or design issues that have arisen during archetype design.
9. Publish newly created archetypes to the VPH and openEHR archetype knowledgebase for validation and feedback from archetype design experts. Allow others to share the knowledge that you have created. Incorporate this design feedback into archetype design patterns and document where appropriate.

These steps entail a detailed and intimate look at the information process flows within a domain. The four 'flagship' workflows serve as the key domains providing a practical framework with which to create a Patient Avatar, which itself reuses EHR standards such as openEHR [2] and CEN13606 [3].

Conclusion – A collaborative and domain-expert-led approach to creating consolidated clinical and research information, such as the one presented in this document, is likely to provide numerous benefits:

- Shared clinical content combined with specialised domain-expert knowledge that is ratified and vetted through an evolutionary process is bound to produce improved data quality to all the stakeholders.
- Commonly agreed specifications for data storage and transmission will improve data liquidity and accessibility to allow the data to be used and reused in multiple contexts and modalities.
- Improve transparency of data held within multiple healthcare silos for the clinicians and patients.
- Use and re-use of existing concepts and archetypes will increase efficiency and help accelerate the transition process.
- Provides detailed and standardised provenance, governance and compliance to all the stakeholders.
- Allows clinicians get back to treating patients, researchers to undertake breakthrough research and software developers to develop applications around a common specification.
- Common specifications ratified by clinical and domain-experts ensures that the data is safe and 'fit-for-purpose'

Undoubtedly such integration and knowledge sharing will significantly improve use of gathered data, but many organisations in global health exist to address a single disease or work in a specific sector. There is a real need for mechanisms allowing research organisations, governments, and universities to collaborate outside their usual remit and locations, to maximise the impact of data and available resources, to inform the Patient Avatar and workflows.

We believe the Patient Avatar is a strategy that allows sparse, disperse and inconsistent data to be integrated and shared across the VPH via secured access services. It allows users to use a shared global reference scheme to tailor their applications around and hence helps to interoperate with other applications and data.

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