Evidence Based Public Health Policy Making: Tool Support

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***Abstract* — The effective management of various health conditions depends on and requires appropriate public health policies (PHP). Such policies are important for several aspects of healthcare provision, including: (a) screening for prevention of disease; (b) early diagnosis and treatment; (c) long-term management of chronic diseases and disabilities; and (d) setting-up standards. Although it is widely recognised that the PHP life cycle (i.e., the analysis, action plan design, execution, monitoring and evaluation of public health policies) should be evidenced based, current support for it is mainly in the form of guidelines, and is not supported by data analytics and decision making tools tailored to it. In this paper, we present a novel model driven approach to PHP life cycle management and an integrated platform for realising this life cycle. Our approach is based on PHP decision making models. Such models steer the PHP decision making process by defining the data that need to be collected and the ways in which these data should be analysed in order to produce the evidence required for PHP making. Our work is part of a new research programme on public health policy making for the management of hearing loss, called EVOTION, that is funded by the European Union.**

Keywords* — *evidence-informed health policymaking; public health policy; model driven big data analytics; GDPR;

I. Introduction

According to latest WHO facts [23], around 466 million people worldwide have disabling hearing loss (HL), while unaddressed hearing loss poses an annual global cost of US$ 750 billion. Helen Keller states[1] that "Blindness separates people from things; deafness separates people from people", to witness that these people may experience lower levels of social inclusion than the blind. Numbers reassert that HL ranking is higher than diabetes and conditions causing visual impairment [8], and increasing. Such trend is noticeable and urged WHO to declare that developing a national policy for the purpose is one of the main responsibilities of the national ear and hearing health coordinator [25], while monitoring policy's implementation by using an appropriate set of indicators and tools measuring the day-today activities and achievements is a must.

In health policy domain in general, the formulation of governmental health policies could not have been an exception to the rule. In particular, the complexity and diversity of big data sources on the health sector, already highlighted several challenges to the future development of this data ecosystem and raised concerns on how governments should adhere this evolving landscape, while maintaining input confidential, private and secure [19]. According to

[13], ultimate goal of a health system is community health promotion in an equitable manner, and as such evidence is required so that policy makers be able to assess the effectiveness of a policy in question. To this we are expanding the claim (in [11]) that not only the role of evidence in health policymaking (i.e., "evidence-informed health policymaking", henceforth EIHPM) is important, but rather predominant since any aspect of a public health policy's (PHP) life cycle (i.e., the analysis, action plan design, execution, monitoring and evaluation) should be evidenced-based as well, thus be supported by data ("evidence") and less uncertainty. In the context of HL, formulating a policy to that takes into account perversion, early diagnosis, treatment and rehabilitation, detection and the avoidance of cognitive decline of HL patients and indirectly the wellbeing of all citizens, requires a holistic management of several types of data (e.g., real-time data generated hearing aids, complementary sensors, patient health record, auditory related data, lifestyle, environmental), namely objective indicators to be the core for forming EIHPM. There is already a plethora of tools supporting the analysis of big data (e.g., [28], [29]), thus evidently their applicability in HL domain – currently lacking- can be a great help for all stakeholders

The analysis of heterogeneous data to support EIHPM using big data analytics techniques can enable the investigation of whether particular health conditions have comorbidities and reveal contextual factors, social, behavioural and economic, life cycle and other factors affecting them [12]. Yet, this data heterogeneity might be considered as an obstacle for understanding, structuring and linking all this information to assess the outcome of a PHP, a rather mentally-demanding and time-consuming task, while at the same time the requirement and/or expectation is for faster decision-making processes. Inevitably we are prompted against factors such as the user-friendliness and well-understanding of policy making tools that utilise this wealth of information. We argue that the potential earnings for health organisations and governments cannot be fully exploited by analysis derived from summary reports produced outsourced or via elementary tools, but rather from the comprehensive analysis of the raw data, requiring basic analytic skills to be attained by policy makers themselves.

In parallel to such functional requirements arise, one must consider the issue of data gathering/analysis in the light of preserving the privacy of individuals. The success of the whole endeavor depends heavily on the access of health data, according to privacy frameworks in place. According to European Commission, there are still standardization problems in the healthcare sector, as data is often fragmented or generated with incompatible formats ([15], [7]), thus data sharing initiatives must provide protections for original

[1] Helen Keller > Quotes: https://www.goodreads.com/quotes/391727-blindness-separates-people-from-things-deafness-separates-people-from-people

investigators and issues related to data ownership, privacy and security [17]. Addressing this need, the EU General Data Protection Regulation (GDPR), came to harmonize privacy rules for all EU Member States [14], and to define appropriate safeguards, responsibilities and roles of data users.

Therefore, there is a need of health policies related to the hearing loss management. In the same time there is a luck of assessment techniques, providing the numerical evidential basis supporting the policy itself. That's a rationale behind our project goal, which is to develop an integrated platform supporting evidence based public health policy making related to the management of hearing loss based on the big data analysis.

In this paper, we present an e-service that supports EIHPM, based on the PHP decision making (PHPDM) models introduced in [16] and [12], as a part of the EVOTION platform [26]. This work is part of a research programme on public health policy making for the management of hearing loss, called EVOTION, that is funded by the European Union.

The main contribution of our approach is providing the novel tool to the policy makers allowing to support their policy actions by the evidences. In other words each policy action will be connected to the numerical data derived from big data analysis. This will give the strong advantage for showing that the policy corresponds with its goals and reassure decision makers that it can be successfully applied in the real case scenarios.

The rest of this paper is structured as follows. Section II describes related work. Section III provides an overview of the functionality supported, privacy by design and other GDPR related aspects. Section IV presents the implemented e-services, while Section V demonstrates its usage. Finally, Section VI presents concluding remarks and directions for future work.

II. BACKGOUND WORK: METHODS AND TOOLS SUPPORTING PUBLIC HEALTH POLICY MAKING

Effective management of HL depends on and requires appropriate PHP (24). The formation of a PHP making usually involves four main stages: (i) situational analysis; (ii) development of action plan; (iii) implementation and monitoring of programme; and (iv) programme evaluation in long/medium term [16]. To this extent, public health managers need tools that will help them on this path of analysis and assessments, and encompass high quality evidence in such decision making.

Questionnaire based assessments (e.g., EHCSAT, [2][2]), while helping determine whether a policy or program is relevant or feasible, do not taking into account heterogeneous data. In UK, [5] is a framework for evaluating adult hearing services using outcomes relevant to service users. Data and patients feedback obtained by local general practitioners and patient groups, via surveys to confirm whether aspects of services are working well. This framework introduces a fixed set of 29 performance indicators (hearing assessment, hearing aid fitting, follow up, aftercare, and core performance), created together with service descriptors with input from stakeholders, giving the latter the power to determine which of those indicators and descriptors are most useful to them (their own 'core indicators'). Still this framework does not exploit advantages of real-time big data analytics.

Another example of a questionnaire-based assessment is the CFHI Assessment Tool™ ([3]), to support EIHPM. This tool aims in guiding health organizations toward making the changes needed to become high-performing ones via measuring improvements in patient care, population health and value for money. CFHI although covers as well all stages (i)-(iv) mentioned, still implements simple guidelines to identify and incorporate evidence in health policy formulation.

To assist the assessment of ear and hearing care in developing countries, WHOs Ear and Hearing Care Situation Analysis Tool (EHCSAT), a questionnaire based tool used by ear and hearing care health professionals and policy-makers targets, gathers evidence on burden of disease, epidemiology of hearing loss, and other health status indicators forming a comprehensive description of the framework functions in context of ear and hearing care within a country [22].. EHCSAT is a questionnaire-based assessment and considered as a situation analysis tool for ear and hearing care, rather a system that allows exploration and knowledge discovery from heterogeneous data correlations.

Although these frameworks assist policy makers on directing investigations of the literature as part of public health policy decision, we argue that they suffer from many shortcomings. EHCSAT can be considered as tool to describe and assess the need for ear and hearing care services, but its static nature does not cater one of the most predominate cross-sectoral technological features, the analysis of big data. Nowadays the policy making via the effective use of big data analytics has nurtured enthusiasm for evidence-based analysis and assessments. Specialized articles for forecasting trends in economic policies (e.g., [21]), defense policies (e.g., [9]), and many other policy sectors (e.g., in the field of security a review by [1]), reemphasize the potential utility derived from such analysis. Notably, although policy making process have always owned and processed large (in terms of volume) portions of data, still the plethora currently collected from different sources provides opportunities to discover and extract knowledge in places that have never been tested or previously identified as potential source of information.

Consequently, at the level of HL, a holistic management requires tools for investigating appropriate public health policies for HL any aspect associated with treatment: prevention; early diagnosis; long-term treatment and rehabilitation; detection and prevention of cognitive decline; protection from noise; socioeconomic inclusion of HL patients, and others. Thus policy tools needed to support analysis of heterogeneous big data (e.g., HA usage, noise (TTS) episodes, audiological, physiological, cognitive, clinical and medication, personal, occupational and environmental data), correlate those and lead to knowledge extraction and evidence-based assessments. Analysis should not be limited on building knowledge upon patients' medical data. As stated in [16], in a micro-economical level, BDA usage has significant potential in generating significant health care savings, as well as broader benefits at a macroeconomics level.

[2] NCCMT Webinar: Applicability and Transferability of Evidence (A&T) Tool: https://www.youtube.com/watch?v=Fk28OMZMFlM

III. EVOTION PHPDM E-SERVICE

A. *Overal functionality*

Overall aim of the EVOTION project is to develop an integrated platform (EVOTION platform) supporting evidence based public health policy making related to the management of hearing loss [16]. To this end, the platform aims to support the acquisition, management and processing of patient medical, physiological, behavioural, hearing aid usage and cognitive activity data to support decision making.

In the heart of the EVOTION platform resides the EVOTION Data Repository (EDR). This layer provides the necessary big data storing facilities to all the EVOTION components requiring it [26], and interacts with Big Data Analytics (BDA) Engine to provide data for the execution of the analytic tasks, in the context of the decision-making process. In this respect, the Public Health Policy Decision Making (PHPDM) e-service is responsible to handle the process of PHPDM model definition (introduced in [12]) and the relative analytic definition, starting from the specification of declarative analytics using EVOTION models and the introduced Specification language, to the procedural analytics preformed and their results of which retrofit back this e-service. In brief, this e-service allows end-users (mainly policy makers and data analysts) to specify analytics tasks to be executed by the BDA Engine. As such, provides all the necessary interaction elements to support this process (i.e., interfaces to create a decision support model instances – policies and workflows - and manage the created model instances).

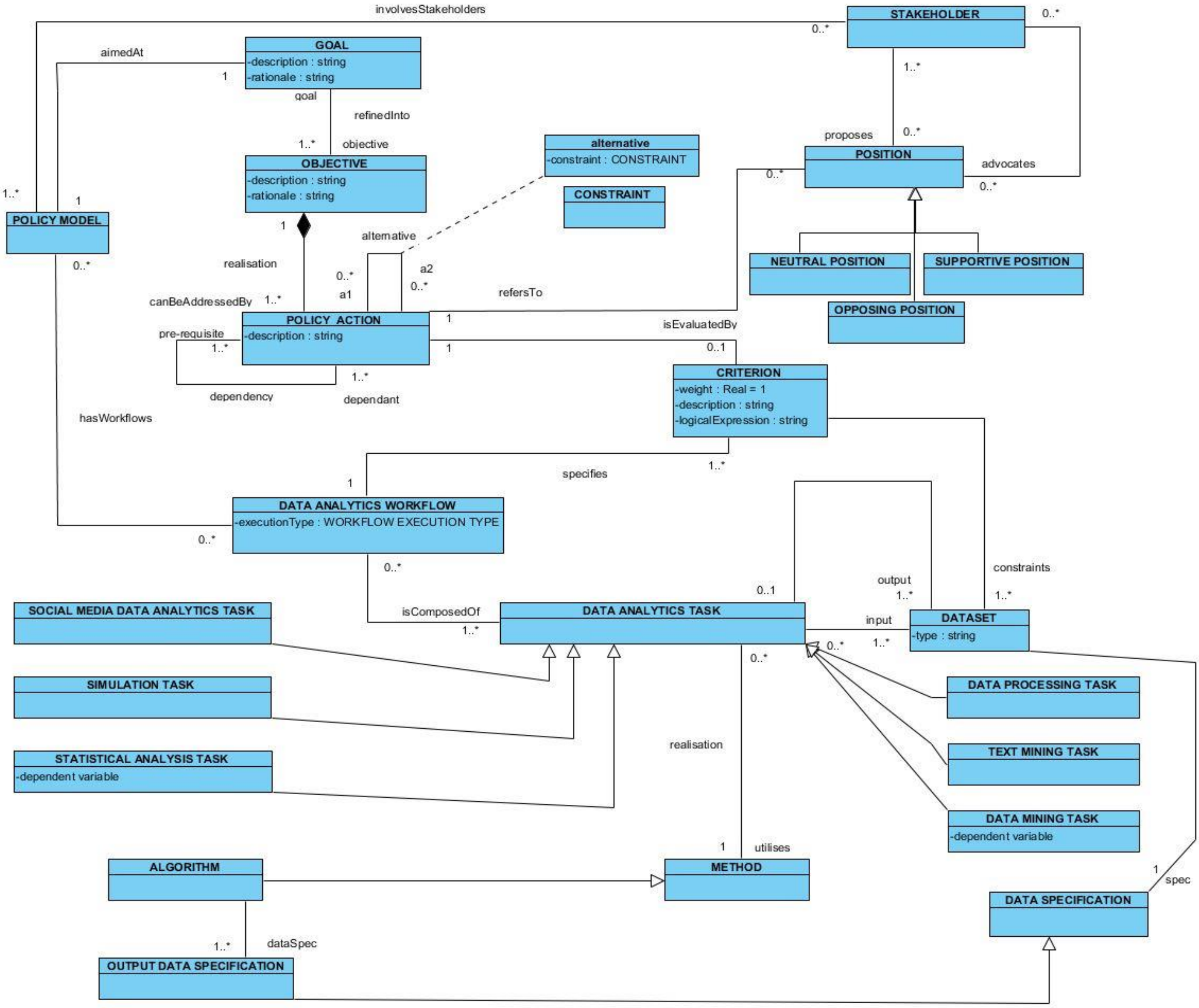

Figure 1: UML diagram: elements of an EVOTION Policy Model

B. *Functional requirements of the PHPDM e-service*

Fig. 1 shows the top-level classes and relationships of the ontology that constitutes the PHPDM language as a UML class diagram.

End-user may define: Policies: [Goal, Workflow(s)[Data Analytics Task(s): [Method, Algorithm, Input Dataset, Output Dataset], Execution Model], Objective(s)[Policy Action(s)], Execution Model].

- Each *Policy* model is aimed at one *Goal* and may have multiple data analytics workflows:

- The *Goal* has a *Description* and a *Rationale* and is refined into multiple objectives:
    - Each *Objective* has a *Description* and a *Rationale* and can be addressed by one or more policy actions:
        - A *Policy Action* can be alternative, dependent, or prerequisite to another policy action
        - Each *Policy Action* is evaluated by one Criterion. The criterion can constraint one or many datasets and specifies a data analytics workflow
- The data analytics *Workflow* is composed of one or many data analytics tasks:
    - A *Data Analytics Task* can be a social media analytics task (e.g. numerical twitter statistics), a simulation task, a statistical analysis task, a data processing task, a text mining task or a data mining task:
        - Each *Task* utilizes a *Method*, which according to the type is an operation (for data processing tasks) or an algorithm (e.g., a data mining task utilizes a data mining algorithm, a statistical analysis task utilizes a statistical analysis algorithm, a text mining task utilizes a text mining algorithm)
        - Each *Task* also has one or many *Input Datasets* and one or many *Output Datasets*
        - Each *Dataset* has a data specification
        - Finally, each *Algorithm* has a specific output data specification

Besides supporting the EVOTION Specification language itself, another influencing factor for the design of PHPDM e-service was the EDR. The EDR was constructed by integrating (big) data from multiple heterogeneous sources: (a) biosensors, (b) hearing aids, (c) a smart phone app, (d) behavioral and self-reported audiological and cognitive testing, and (e) electronic health records. From each of them quite a few variables (values) were collected [6], making the process of organizing all of these data, and presenting them in a meaningful way in the context of a data management process, a very challenging one. It is worth noticing that data analysis for the purpose of drawing conclusions differentiates from a typical data mining process [4]. In this respect, data analysis with respect to Big Data Analytics [10] defines two facets: a) the technical one that concerns the ability to derive meaningful insights by algorithmically transformed data, and b) the business one that serves as an influencer for the adaptation of processes in order to maximize the friction-free flow and throughput of data throughout an organization. We argue that the technical facet is bound to the Specification Language used, while the latter is affected by the usability, the readability, the consistency and the completeness of the results obtained and presented (i.e., overall user-friendliness of the proposed PHPDM e-service).

C. *Big data analytics engine*

BDA engine is an integral part of the EVOTION ecosystem supporting health policies decision making (Fig 2). Its main function is to analyse big volumes of data reliably stored in EDR. Such a mechanism provides factual information in numerical or graphical form to support any given health policy goal.

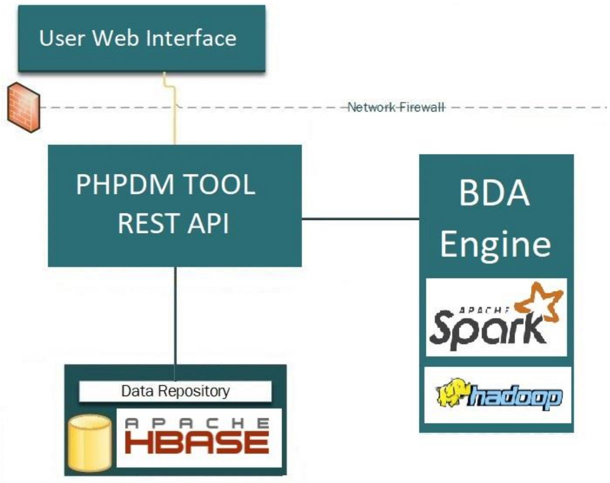

Figure 2: EVOTION ecosystem

Our analytics engine is based on the Apache Spark [27] big data processing framework. It runs on the cluster consisting of virtual machines that provide its computational power to run data analytical tasks. In order to exploit the advantage of distributed calculations, the cluster management system Hadoop YARN [18] is deployed. Such solution implements a robust mechanism to allocate the load among computational units. It worth to mention that MapReduce, usually associated with Hadoop is not a part of our big data paradigm. Instead, all tasks are processed by Spark. The choice is dictated by advantage in computational speed and disk space allocation efficiency [20]. Big data engine uses Spark MLlib to perform machine learning and graph analysis. It allows processing different dataset transformations, feature extraction and selection. This big data library provides a rich choice of classification, regression, clustering and filtering algorithms. The engine has a functional in place to process information received in real time. However, in our project we focus on offline data analysis.

In EVOTION infrastructure BDA engine plays the role of mediator between user and data. User sets up the data analytics task using web interface and executes it. The Rest API function associated with this action is called to be processed by Apache Tomcat servlet container residing at EVOTION infrastructure premises. As a result, several Spark jobs are created for a given user task. Prior to the execution, BDA engine loads the input datasets from EDR. Project data is stored in Hbase distributed database, which belongs to the Hadoop ecosystem. Such fact makes it suitable for mapping its tables as an input to the Spark jobs. EVOTION dataset is approved by several Ethics approval protocols and includes:

- Retrospective data: patients demographics, real data of HL levels, cause and duration of HL, medical history and HA usage data, Audiograms.
- Prospective data: audiological and other assessments (Montreal Cognitive Assessment, Pure Tone Audiometry, Hospital Anxiety and Depression Scale, Glasgow Hearing Aid Benefit and Health Utility Index Mark-3, HA: Hearing Aid, REM: Real Ear Measurement).

Currently, the total data-points stored in EDR during clinical study part of EVOTION [30] acquired from more than 900 patients recruited across four clinics in the UK and Greece, have reached 47 million, consisting of retrospective and prospective data. Collection of dynamic real-life HA usage data has been achieved via a mobile phone application paired to smart HAs manufactured by Oticon A/S, over a period of 12-month.

The outcome of the Spark jobs execution is combined by BDA engine and later is returned to the user web interface. Therefore, the user perspective of the task execution is simplified to a single click of a button resulting in a numerical or graphical representation of the output supporting the decision-making process.

D. User requirement analysis

One of the basic functional requirements for a PHPDM e-service that administers the creation and execution of PHPDM models supporting the formation of evidenced based public health, was the user-friendly utilization and monitoring of the actual effects of such executions. PHPDM e-service supports the generation of policies/workflows and theirs components and offers big data analytics support to aid policy makers perform policy executions according to predefined criteria. The overall success (and potential utilisation in practice) of the proposed solution offered will be ultimately influenced by the end-user (policy maker) acceptance. To accomplish this goal, the implemented functionality and overall experience offered to the end-user should be perceived as suitable in the context of the relevant everyday practice.

A user centered approach for the design and implementation of the interaction elements has been followed. The aim was to develop highly usable services, which can be easily operated by policy-makers, who might not be highly experienced in using similar applications. Thus, as the design process unfolded, the most critical aspect raised from end-users feedback was to meet expectations for KISS ("Keep it simple, stupid") characteristics.

To assess the e-service's merit in this respect, several early evaluation activities planned and carried out. These had 4 purposes: i) to identify challenges in using the e-service in real practice and ways of addressing them; ii) to increase the user-friendliness and reduce the workloads of end-users; iii) to assess whether the e-service performs in a satisfactory manner with respect to the project's objectives, iv) to ensure that end-users understand the proposed functionality and data objects and appreciate how they can boost their work.

To this purpose, an iterative design process was adopted. Several modifications of the initial design and the resulted user interface focused on several aspects of improving user experience (e.g., Fig.3, Fig.4).

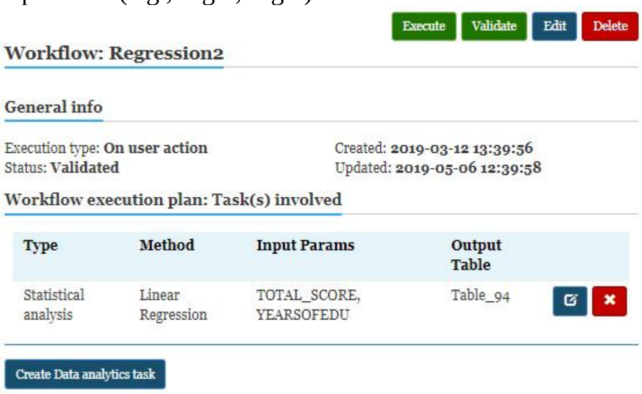

Figure 3: Workflow's info

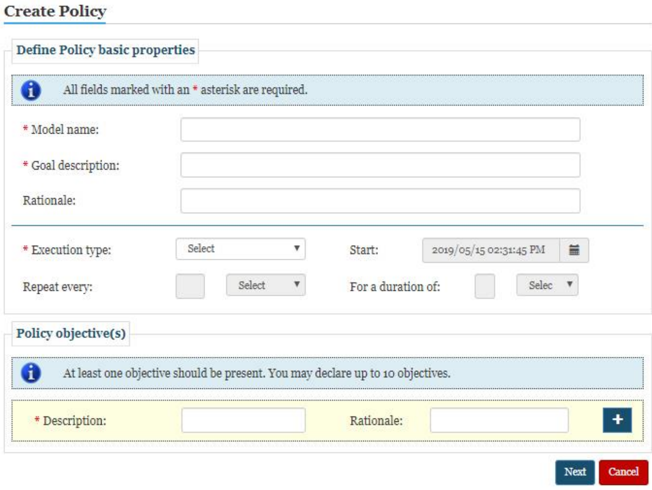

Figure 4: 1st step of policy creation wizard

E. Data repository: GDPR conformance

Real-time HA usage and other types of patients' health data are been transmitted to EDR in order to enable the analytics required for the purposes of the EVOTION project. Prior to transmitting such data, data anonymization transformations procedures applied ensure that all data and metadata references cannot make the data subject identifiable. Examples of such anonymisation procedures are:

1. IDs replacement to pseudo IDs: any real identifier generated by the proprietary Hospital System (AuditBase) or the EVOTION Hospital System (EHS) clinicians have access, prior to transmitting it to the EDR is replaced. The new pseudo identifier has no relevance to the actual identifier that it replaces and there is no way for end-users of the repository to be able to retrieve the replaced identifier by the pseudo ID that has replaced. By virtue of the identifier generation and replacement processes that it applies, EDR ensures its pseudo IDs can unambiguously distinguish the entities that they identify and maintain information about the relations that encoded by the original IDs.

2. Anonymisation of Dates: The anonymization process removes actual dates as these could potentially lead to the identification of a specific patient (e.g., in cases where the data of only one EVOTION patient have been recorded in EHS on a specific date). Actual dates are replaced by the date of the Sunday that follows it. For example, if the value of a date column in an EHS table is "19/9/2017", this date will be replaced by "24/9/2017". The later date will be used for all other records in EHS, which have an original date falling in the period from 18/9/2017 to 24/9/2017.

3. Anonymisation of Timestamps: The anonymization process removes actual timestamps as these could potentially lead to the identification of a specific patient (e.g., in cases where the data of only one EVOTION patient have been recorded in EHS on a specific date). Actual timestamps are replaced by the date of the Sunday that follows it and the custom time 12:00:00. For example, if the value of a date column in an EHS table is "19/9/2017", this date will be replaced by "24/9/2017 13:23:21". The later date will be used for all other records in EHS, which have an original date falling in the period from 18/9/2017 to 24/9/2017 12:00:00.

4. Deletion of Values: default values used in cases where personal data should be removed by the data anonymization

process (e.g., EMAIL, FIRSTNAME, LASTNAME, POSTALCODE).

These procedures accompanied by other security aspects covering the whole range of components form the EVOTION solution (such as: token-based access to RESTfull API, Role-based access control, data validation for all input elements preventing cross-site scripting attacks), as well as other at organisation level [30].

IV. NEXT STEPS

The next steps are: (a) Data cleaning: a data cleaning strategy has been in place. PHPDM e-service depends on complex real time data collected from real hearing aid users. To ensure that the PHPDMs can deliver reliable and valid outputs, it is essential that data are validated; b) Usability evaluation: user-friendly presentation of advanced analytics will enhance the PHPDMs and bring out their full potential. User acceptance of the information contained in each PHPDM is a good measure of its potential importance to the PHP makers; c) (b) Validation of the PHPDMs from the public health and technical perspectives: the validation of the outcomes of the BDA analytics from a clinical perspective will allow the BDA outcomes related to correlations between hearing loss related factors and comorbidities to be validated by the clinical partners through comparison to existing clinical studies and related causal underpinning factors that may be established from existing clinical knowledge. Moreover, the technical validation of the performance, scalability, usability, privacy, security and accuracy of the BDA enabled decision making as a public health policymaking tool, through the active involvement of the consortium's PHP makers, will validate the PHPDMs' relation to steering policy direction.

V. CONCLUSIONS

One of the most significant challenges in PHP sector is monitoring policy's implementation by applying a reliable collection of indicators measuring the day-to-day activities. In other words, public health managers need a solution to analyse and asses evidence, supporting their policy decisions.

While most existing PHP tools rely on small static datasets that can't be considered as an accurate definition of PHP data flow, the approach described in this paper mitigates those drawbacks by using big data analysis infrastructure. Unlike previous tools, it has a functionality to accumulate high quality numerical and graphical evidence supporting PHP analysis and assessment process. As the collection of data points progresses, the system generates the more and more complete representation of the information trends. As a result, PHP decisions are based on more accurate and reliable evidence. We archived this by the implementation of BDA engine. With the positive results we believe EVOTION project is able to take a PHP manager on a new, more accurate, evidence-based, level of decision making.

One of the future research directions could be further optimization of the BDA engine by tuning up Spark and Hadoop infrastructure parameters. It will speed up the execution of data analytics tasks and will decrease the load on the system itself. Another direction could be the integration of additional machine learning algorithms in order to provide more freedom to data analysts.

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