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Impact Evaluation of an Emerging European Health Project – the MIDAS Model

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Abstract

Background: This paper describes the impact evaluation of a large big data platform initiative that is being undertaken in order to increase the probability of its success. The initiative, MIDAS (Meaningful Integration of Data Analytics and Services), is a European health-based Horizon 2020 project comprising a consortium of members from various universities, research institutions, and government agencies. **Objectives:** The purpose of the paper is to present a pioneering platform that will support healthcare policymakers in their decision-making by enabling greater and more efficient use of their data. The goal is to present and evaluate the results of the MIDAS project across four countries. **Methods/Approach:** The literature is replete with examples of worthwhile technology projects that have failed due to user resistance. In order to avoid such failure, and ensure the success of the final MIDAS platform, a detailed impact evaluation is being undertaken at timed periods of development. **Results:** This paper describes the impact evaluation process, outlining the use of Q-methodology and the development of a 36-item concourse using the HTMLQ system for that purpose. **Conclusions:** This research contributes to the overall understanding of how impact evaluation can be undertaken at timed periods during the development of an innovative technology for organisational purposes.

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Introduction

ICT projects face challenges that are specific to the unique attributes and novelty of the technology that is being developed, as well as the characteristics of the environment in which the technology is introduced. This is particularly evident in the healthcare context. As Abouzahra (2011, p.46) states: "IT projects in the healthcare sector have many differentiating characteristics over other types of projects. These characteristics arise from the sensitive nature of the healthcare environment as well as the diversity in user groups and IT systems usually installed in hospitals".

The paper focuses on one such technology development project. Firstly, the factors that can influence resistance to and failure of IT projects are described. It then describes a specific big data health platform, MIDAS, which is being developed for introduction across five countries and the factors that have the potential to influence its success. The impact evaluation methodology that is currently being employed to increase its adoption – a Logic Model framework, participant interviews, and Q Sort Analysis Methodology - is described in detail and this is accompanied by a brief description of the technical issues that must be considered in order to ensure success. Since the data is not yet available, the paper focuses on outlining the process that is being followed, which will serve as a useful template for other researchers interested in conducting technology impact evaluations.

Failure of Large Research Projects

Despite advances in technology and medical science, modern health-based projects are open to systemic failure due to many factors. These include I.T. developer's lack of awareness regarding end-user needs, poor communication amongst all parties concerned and inappropriate or inadequate tests of the emerging system. Other issues may be external (e.g. political and legal) such as sharing of patient data and issues surrounding consent.

For projects to be successful, lessons must be learned from the past with regard to previous technologically driven healthcare projects. The reasons for the failures of many large IT projects in the healthcare sector are complex and can be influenced by internal or external factors. Internal factors relate to issues within the university or department from which team members working on the project interact. Such issues can relate to disagreements within these project groups regarding decision making over priorities, resourcing or strategic planning. External factors can be linked to political or legal issues outside of these project sub-groups but, being inextricably linked to them, can heavily influence the final project outcome. Research by Lu et al. (2010) suggests that internal factors in project failure involve variables strongly related to project management processes and project team dynamics. They posit that such internal issues are responsible for and are far more influential in project failure than external issues. In healthcare projects, such issues may be political or legal such as sharing of patient data and issues surrounding consent. Key factors include poor communication or misunderstanding between developers and end-users of the system. In certain cases, users may become confused between their *wants* and actual *needs* and their grasp of data analysis techniques may lack the sophistication required to enable the best use of the available data. Regarding project implementation, objectives may be impractical or unrealistic and, therefore, either difficult or impossible to achieve, particularly given strict time and financial constraints. Once the system is implemented there may follow inappropriate or inadequate testing of the emerging system.

In particular, inappropriate testing could take the form of irrelevant or insufficient test data. Technical development and end-user requirements may differ based on poor communication between developers and users. Pinto and Mandel (1990) consider the main factors of project failure to include an incomplete or inaccurate vision of project objectives, a failure to correctly identify and include the involvement of stakeholders, and communication and risk management issues. Such factors can have a cascade effect that changes to the project may increase, customers are dissatisfied with outcomes, the quality of deliverables is poor, and it may cause poor morale amongst developers. Furthermore, extended schedules inevitably lead to increased project costs.

Due to the multiplicity of such factors and differing stakeholder pressures and contexts, there is greater recognition of the importance of evaluating impact as a health system project evolves. These evaluations must take into consideration the resulting impact(s) identified in that evaluation and not merely provide a review or account of what happened. Stakeholders, shareholders and those funding large-scale projects need to see measures of program effectiveness as well as progress (O'Neill, 1998). On the other hand, an evaluation process is likely to be more successful if it considers the impact of programs and not merely the results from those programs. Impact represents results or accomplishments at a higher level. Therefore, impact refers to the implications of a given output, program, or project beyond the immediate intended outcomes. In particular, there is an emphasis on the broader long-term effects beyond the project itself. In effect, the ramifications of impacts resulting from this project will extend to society and influence decisions in health-based policymaking, sharing of health data and governance best practice.

Background

The MIDAS Project

Healthcare systems (Kruse et al., 2016) store patient data on large database systems where the data is heterogeneous and siloed. However, sharing of patient data at regional, national and cross-national level is increasingly needed to support integrated care, and provides an opportunity to better understand, prevent and predict potential health and healthcare problems. Furthermore, it is believed that the availability of such data will help to reduce costs to healthcare providers. Many healthcare systems worldwide (Hicks, 2017) are adopting an "outcomes-based healthcare" approach. Using data from a variety of sources, healthcare providers have the potential to identify which treatment works best for individual cases and at a demographic level. Such healthcare systems aim to help policymakers within the medical field and at the government level to improve the quality of patient health care.

The Meaningful Integration of Data, Analytics, and Services (MIDAS) research project is a European-centered healthcare initiative. Its main purpose is to optimize the use of current healthcare data to better inform public policy and improve healthcare and social well-being outcomes across Europe via a unified big data platform. It intends to achieve this by integrating patient data from various European health authorities where individual data will be collated and analyzed using various bespoke applications, modeling and visualization tools. Data will also be gathered via social media. The data will be analyzed on the MIDAS platform. It is expected that this pioneering healthcare platform will enable and provide tools for end-users, in particular policymakers, to benchmark, simulate and predict outcomes that will influence future healthcare policy decisions at both regional, national and European levels. There are four use cases involved in this project, based in Northern Ireland, the Republic of Ireland, Finland and the Basque Country. Currently, European healthcare systems generate considerable data on a day-to-day basis. Such data includes patient prescriptions, patient care, hospital discharge records, waiting lists, data on blood-sugar levels, cardiac-related issues, etc. However, the data is localized, and external access is difficult, thus limiting our understanding of health-based issues. This technology platform will not only provide critical insights into the health of different populations but will enable policymakers to design and develop evidence-based preventative strategies that will address health and social care challenges at a wider level than is currently possible. Data analysis will enable policymakers to explore health trends, identify correlations and patterns amongst the

general population and test various theories (e.g. diet patterns and obesity amongst particular regions according to age group and gender).

Overall, the MIDAS system is expected to be user-friendly and provide access to data analytics and visualization tools without the need for data-science expertise. It is also anticipated that there will also be a focus on simple, routine analytics with an element of prediction. A current problem with data systems is the lack of available analytics and tools for data mining. It is believed that the MIDAS tool will highlight gaps in the system and facilitate data system linkage to answer additional research questions and enable analytics and work that previously wasn't possible. At its core level, the MIDAS platform will utilize Analytics Engines XDP which operates on three core principles: (i) it facilitates access to the data from a singular location without the need for replication; (ii) the data is analyzed once and the process of analysis can be reused as the data is updated; (iii) data sharing and analysis is feasible through repeatable processes (Analytics Engines, n.d.). The developed system will not allow users to study single patient data. Instead, it will allow cohort level analysis to support health-based decision making (as policies are applied to populations and not individuals). The MIDAS technical teams will install this form of data analytics in the four European healthcare systems for data integration, analytics, and visualization. However, stakeholder understanding of analytics and other core technical issues is paramount to successful outcomes. Good data mining techniques and optimum use of decision-support systems are dependent on individual competence in using the technology presented. One key technical challenge is in making the system a very useable platform for end-users not highly experienced in data analysis techniques. This issue has to be balanced against a need to ensure that the system produces health-based reports that are easy to generate but provide an output that is meaningful and accurate. The system will also support time-series analysis and projection analysis to provide accurate forecasting of potential health issues based on the health data available at regional, national and cross-border level.

An expected outcome from the MIDAS system will be the use of predictive modeling as an analytical tool, which, in turn, will help to prevent rather than treat certain conditions. This will also influence future health-education projects. It is hoped to connect existing datasets and reduce fragmentation in order that the true value of combined datasets can be unlocked.

MIDAS Stakeholders & the Consortium

The principal stakeholders involved in the MIDAS project were chosen from various fields of expertise to provide the best possible outcome. The stakeholders involved in the Midas project are comprised of a consortium of specialists from two main areas: 1) Technical partners; i.e. academic research institutions. 2) The policy board; i.e. end-user organizations – policy advisors, data gatekeepers and health-care providers.

Overall, there are fifteen participating organizations from six European countries and one group from the United States of America. The list of stakeholders involved in the project is as follows: University of Ulster; Dublin City University; KUL (Belgium); Vicomtech; University of Oulu; Analytics Engines Ltd; Quintelligence; Regional Business Services Organisation; Dept. of Health (Public Health England); Basque Foundation for Health Innovation & Research; Teknologian Tutkimuskeskus (VTT); South Eastern Health & Social Care Trust (NHS); IBM Ireland Ltd; Arizona State University; Terveyden ja hyvinvoinnin laitos;

Methodology for impact evaluation of a novel technology

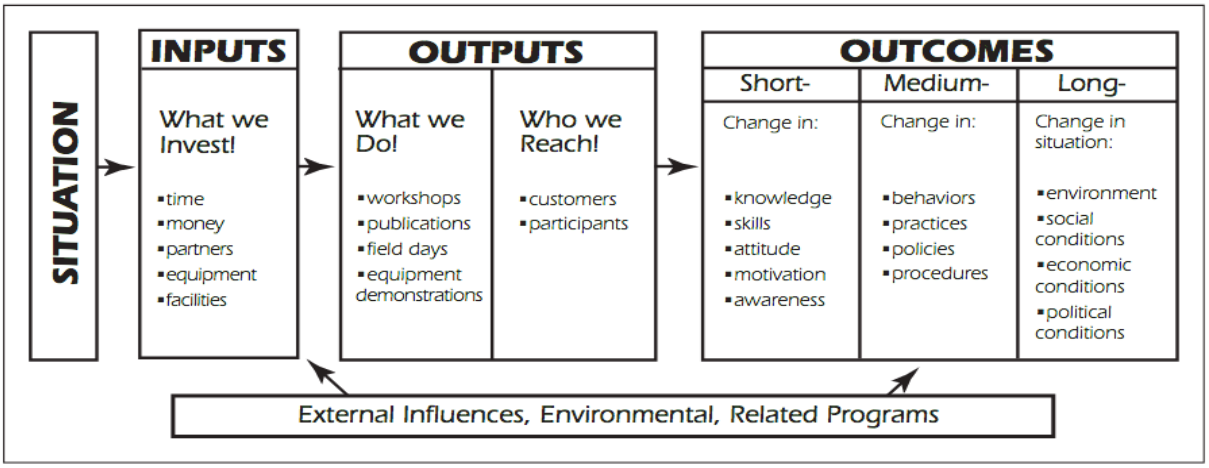
As discussed in the previous section, many large-scale health system projects fail due to a variety of internal and external issues. In order to ensure a successful outcome for the MIDAS project, it was decided to undertake a thorough and in-depth evaluation and impact assessment methodology. The initial evaluation was designed as a multi-pronged approach through the application of a logic model framework, longitudinal semi-structured interviews with stakeholders and developers, and the use of Q-Methodology to assess both impact and evaluation.

Logic Model Framework

A logic model (Kellogg Foundation, 2004) was developed during the early stages of the project in conjunction with stakeholders to identify anticipated outcomes, outputs, and impacts throughout the life cycle of the project. Logic models are a standard tool used to design and carry out evaluations. The model should guide the program, illuminating the sequence of activities and clarifying how these will result in the required outcomes. The basic components of a logic model are shown in Figure 1 and highlight the connection between the determined activities and desired results as part of an evaluation plan.

Figure 1

Diagram showing how evaluation plan is guided by the Logic Model

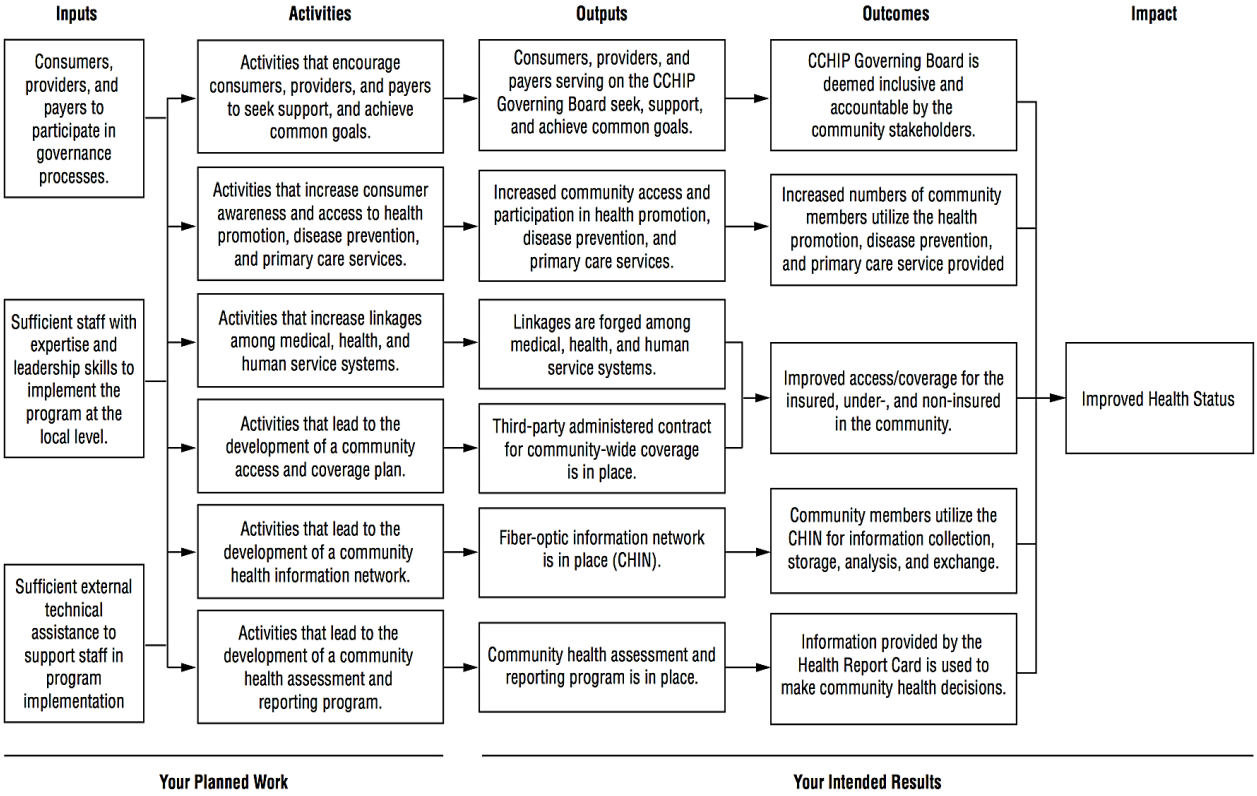


Source: McCawley, P.F., 2001, p.1.

The diagram below highlights the effectiveness of a logic model approach to the development of a health-based program and shows how the various components of the model are linked in the evaluation process; i.e. the project outcomes (both short- and long-term) with program activities/processes, as well as the theoretical assumptions associated with the program. Stages 1 and 2 (Inputs and Activities) relate to planned work; stages 3 to 5 (Outputs, Outcomes, and Impact) relate to intended results.

The Kellogg Foundation (2004) describes the logic model as 'a systematic and visual way to present and share your understanding of the relationships among the resources you have to operate your program, the activities you plan, and the changes or results you hope to achieve' (p.1). At its most basic level, a logic model is a tool used in the planning, evaluation and systematic development of a project.

Figure 2.
Example of an Outcome Approach Logic Model in a health-based program.



Source: WK Kellogg Foundation, Logic Model Development Guide, 2004, p12.

Interviews & Participant Sample

A key element of the interview process was to gain insight into what constituted end-user needs and expectations in relation to the MIDAS platform. The interviews also sought to elicit developers' understanding of those needs and expectations. Due to the expansive nature of this European-based project, interviews were conducted online. Interview templates were created in advance of the interviews and submitted to interviewees in advance of the interviews. This enabled the interviewers' sufficient time to reflect on responses to the questions and, in the case of interviewees whose primary language was not English, it enabled them to question wording and structure their responses to the questions in a more appropriate manner. The questions presented to the interviewees related to the end-users understanding of the developing system, their concerns and their perceived needs/requirements of the system. Four countries were selected for these interviews and, in each case, the questions remained the same. This ensured consistency and provided an opportunity to identify differences and similarities in the interview responses.

Data was collected in the first round of interviews through longitudinal semi-structured interviews. These were transcribed and coded using the Framework Approach (Richie and Lewis 2003). Recurring interviews with the same interviewees (stakeholders and developers involved in the project) helped ensure that there was a mutual understanding between I.T. developers and those who would be using the system at key stages of the project and any inconsistencies could be eliminated. In all, interviews will be conducted four times at key points throughout the lifetime of the project. The four European health institutions used in the case studies were Finland, the Basque region, Northern Ireland and the Irish Republic. Each country

had a different health-based focus: Republic of Ireland (A "Healthy Ireland" framework with the focus on diabetes); Northern Ireland (Children in Care); Finland (Preventive Mental Health and Substance Abuse of Young People); Basque Region (child obesity and prevention policy). The objective was that a minimum of two stakeholders per region would be interviewed, (one technical person, and one policymaker. Each interview was recorded and transcribed. Following transcription, the interviews were sent to the interviewees to confirm the accuracy and to enable additional information to be provided that may not have been mentioned during the recorded interview. The interviews were then coded. A report was generated based on the key findings and themes that had emerged from the coded material for developers and members of the MIDAS consortium to consider.

Coding

The transcript coding was based on the framework approach to qualitative data analysis (Ritchie, Spencer & O'Connor, 2003), (Smith & Firth, 2011), and was guided by the logic model. Interview transcripts were subject to independent double coding to verify their content. The initial coding process involved a preliminary review of the transcripts, highlighting relevant phrases and noting possible codes. These codes were compared with the logic model codes to identify common, new and novel themes relating to outcomes and impacts of the MIDAS platform-tools development. Post-interview analysis of the data involved the identification of initial themes and categories. This was based on the developed logic model and was followed with the development of a coding matrix. Data and keywords were assigned to the various themes and categories in the coding matrix. Statements made during the interview process, which were considered to be of key significance were summarised using the interviewee's own words. These coded summaries (or 'in-vivo' codes) are advocated in the framework approach as a means of staying 'true' to the data (Ritchie and Lewis 2003). As the cycle of interviews is undertaken, the coding index is constantly refined and developed as new insights emerge. Therefore, the original themes and categories are further refined and any 'outliers' in the originally captured data are removed. Consequently, associations between themes became more apparent and recurring key health-based issues began to emerge.

Q-Sort Methodology

To further strengthen the original data analysis undertaken, Q-Sort analysis was undertaken. Q Methodology (or Q-Sort analysis) take a subjective approach to data analysis and is a combination of both qualitative and quantitative research methods. It is principally used in the fields of psychology and the social sciences and it is particularly effective in identifying attitudes, perceptions, feelings, and values. Developed by William Stephenson (a psychologist) in the 1930s (McKeown and Thomas, 1988), it is used in research settings where individual perspectives on a topic can be analyzed for consistency or deviation over time. Essentially, Q Methodology derives from factor analysis. However, whilst standard factor analysis uses the "R method" to find a correlation between variables from a data sample, Q is used to identify correlations between subjects from a sample of variables. It does this using ranking. The statements used in the Q sample are derived from and represent a "concourse" which is the set or sum of statements pertaining to the topic being investigated. These statements relate to those used in interviewing the various developers and shareholders in the interview cycle. This research method will also help to identify if and how the interviewee's rankings change over time based on

individual attitudes and beliefs. In-depth follow-up interviews will involve gathering information based on the responses provided during the Q-sort or ranking of variables.

Conclusion

This paper has outlined the procedures that can be employed to undertake an impact evaluation of a novel technology as it proceeds through development. The purpose of such an iterative evaluation is to increase its successful adoption by the end-user group. This is particularly important in the context of the high failure rates associated with novel technology introduction, particularly in an organizational context. The procedures outlined in this paper include the use of a Logic Model, the Framework Approach and Q- Methodology in the context of a large-scale cross-national big data platform. The paper points to the value of such an evaluation approach and its potential to increase the successful adoption of the final technical platform. One limitation of this paper relates to the fact that it is research in progress and therefore it is not possible to include results of the analysis at this point. However, as the purpose of the paper is to outline the procedures involved in undertaking an impact evaluation in a technology healthcare context, the absence of results does not reduce that contribution.

Healthcare ICT projects are intrinsically complex, and without careful planning and implementation, they are likely to fail. Beyond the technical issues and stakeholder requirements involved, there are legal and political issues to be considered. Development of the MIDAS project has been and continues to be, an ongoing process of evaluating outcomes and identifying potential impacts to reduce the possibility of critical issues emerging. Applying a systematic and rigorous approach to each stage of the developmental process will help to ensure the project's success using proven research methods. Project success is further supported through regular communication between technical developers and the stakeholders or end-users of the system. It is expected that the final system will enable better data mining techniques with new tools developed specifically for patient data analysis and decision-making by policymakers.

The paper also demonstrates the effectiveness of a logic model and Q Method approach in evaluating impact, thereby increasing the alignment of the technical system and its functionality with the requirements of the end-user, which will increase the potential adoption of the system. The impact evaluation framework described in this paper will provide a useful rationale and template for other researchers who are considering incorporating such analysis into their project development in order to increase the successful adoption of new technology.

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