Global Health eInfrastructures (GHeI)

1. Relevance to VERDIKT call

The research on Global Health eInfrastructures (GHeI) is proposed through a cross-disciplinary (informatics, medicine, public health) international consortium comprising of researchers, users (of health information) organizations, and groups representing providers of infrastructure and information systems. Answering the call to address key challenges to society, GHeI focuses on improving health services provision through the improved access and use of health information in Norway, and internationally. Public health service provision is dependent on carefully managing resources to achieve coverage and efficient interventions, but such information is often not readily available to management due to slow, fragmented and uncoordinated health information systems.\(^1\)

GHeI responds to the problem of fragmented and uncoordinated systems, technical infrastructures and information flows, undermining efficient delivery and management of health services globally including developing countries as well as nations like Norway\(^2\). The World Health Organisation (WHO), a key user partner in this proposal, have explicitly advocated for integration of both technological and institutional systems, to facilitate horizontal and vertical, communication within and between organisations, countries and use contexts. GHeI responds to these complex integration needs by combining research and interventions to enable provision, use and application of integrated information to address health problems, such as the aim to improve timeliness of health surveillance in Norway by combining and getting faster access to information from different registries\(^3\), and to address maternal mortality in developing countries by establishing and getting access to registries. GHeI works directly with the Norwegian Government’s initiative on Millennium Development Goal 4 & 5 (Maternal and Child Health) in Tanzania and India by improving their implementation initiatives through research.

The strategies of GHeI for integrated infrastructure for global health directly address VERDIKT’s overall interdisciplinary call on communicating organisations i.e. the interaction across levels, geography, professions to provide integrated health. Globally, vertical health programmes and structures represent institutional and infrastructural barriers to integrated health service provision. GHeI will furthermore address VERDIKT’s call on seamless infrastructures as health care systems globally are inherently heterogeneous, involving a multiplicity of programs, information flows, data sets, and work practices around how data is registered, analyzed and circulated. GHeI addresses the integration of these heterogeneous systems drawing upon principles of modularity, flexible standards, gateways, developed through more than a decade of research\(^4\).

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A principal challenge to integrated care, embedded in GHeI through the consortium of partners, is the ability to integrate the whole ‘value chain’ from clinically relevant patient information as well as aggregated information (indicators) related to quality and efficiency of care delivery.

Service and technology providers, made coherent through the common goal of using Free and Open Source Software (FOSS), will collaborate with the user and research groups to design and develop GHeI, and cultivate its use. FOSS represents an effective and lightweight technological platform to establish working eInfrastructures within global health.

2. The GHeI research project

2.1 Background and status of knowledge

The African-Asian-Norwegian consortium behind GHeI builds upon but extends the Health Information Systems Program (HISP7), initiated as a NORAD project (1995-98) in South Africa. HISP supported the development of health information systems (HIS) as a component of the ANC government’s post apartheid agenda of health services reconstruction. The FOSS District Health Information Software (DHIS) was developed and used for reporting, analysis and presentation of health data8. The DHIS generates aggregated health information in the form of indicators documenting levels of quality and efficiency in the health delivery. Since then, HISP has developed into an international forerunner in HIS related research and development, being active in many African (South Africa, Nigeria, Malawi, Mozambique, Tanzania and Zanzibar, Ethiopia, and Botswana) and Asian countries (India and Vietnam)9.

Funded by the EU 6th Framework program in the BEANISH10 project, since 2005, the research and intervention has been organised around on the development of a fully open source based version of the DHIS. The modular architecture of the DHIS allows for the evolutionary development of the system, and the involvement of software teams in countries like India and Vietnam. The open source DHIS version emerging from the EU initiative has provided the basis for a strategic partnership with the WHO Open Source initiative OpenHealth, which is a standard based and extensible platform for technology and data integration. The integration of DHIS and OpenHealth using a common public health data model will enable the provision of an integrated public health information platform in which data collected through different systems can be imported and shared by multiple user groups, technologies and services to provide data querying, analysis, reporting and mapping functionalities. Through another WHO supported initiative11, the DHIS/OpenHealth application suite is currently being integrated with the electronic patient record application OpenMRS, to enable the seamless integration of statistical and


7 www.hisp.info and www.hispindia.org
10 BEANISH: Building Europe Africa Network for IST in Health. EU 6th Framework Program, 2005-08
11 Cf. the Health Metrics Network (HMN, www.healthmetricsnetwork.com)
patient based data, and a resulting framework for linking other applications, such as tuberculosis and HIV/AIDS, to support more integrated health services delivery. The figure below shows the OpenMRS integrated with the DHIS-OpenHealth suite.

The key analytic challenge addressed in GHeI is that of conceptualising – and subsequently intervening – in the fragmented (i.e. non-integrated) information systems in health care. This profound fragmentation, along geographical, professional, organizational and technological dimensions, is magnified in developing countries where donor support for particular health programs and embedded bureaucracies leads to a proliferation of non-integrated systems. Fragmentation contributes to the existing heterogeneity of health care across hierarchical levels (clinic, national, global), service types (primary health care, hospitals, and laboratories), health programs (e.g. HIV/AIDS, vaccination, tuberculosis), professional groups (e.g. nurses, physicians) and institutional actors (e.g. international donors, insurance companies).

This results in a fragmented health care service for patients as well as planners, undermining efforts of transforming health care organizations towards more collaborative, process-oriented modes of working. The urgent need for addressing this fragmentation challenge is reflected in the doubling of investments in Norway NOK 73.5 billion over a 8 year period (1990 to 1998), representing a 4.4% annual growth rate. In both research and practice, integration is positioned as the potential remedy to address the problems fragmentation produce, i.e. duplication, non-consistency, redundancy, and the

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unrealized promise of increased efficiency and quality improvements. Within the broader agenda of health reform, integration is intricately linked with notions of ‘continuity of care’, ‘shared care’ or ‘integrated care’ across boundaries of time, place and disciplines. This thinking is inscribed in policy documents of the EU and the Norwegian governments.

Our theoretical perspective on GHeI is based on framing integrated, interconnected information systems and modules as information infrastructures or eInfrastructures. This emphasises the heterogeneous and interconnected socio-technical nature of infrastructures. Research based on eInfrastructures provides insights into how to approach this challenge, especially why contemporary HIS typically fail to realize their potential. Accumulated experiences around integration, such as of web and Web 2.0, ERP (enterprise resource planning) systems and SOA (service oriented architecture) frameworks, provides useful insights in relation to GHeI, such as seeing integration beyond the narrow tunnel vision of the technical, and include the institutional, political and technical aspects that constitute its complexity. Working out a pragmatically based contingency model, the costs of integration (in terms of loss of flexibility, increase in development costs) may outweigh the benefits of integration. Singletary’s survey of practitioners’ perceptions identified downsides to integration including lock-in with vendors, costs and project risks. Empirically underpinned case studies, demonstrate in more detail the form and implications of the unintended consequences of integration, contributed to by unintended effects caused by tighter couplings of systems. Analytically, the challenge is to “strike a pragmatic balance” between uniform solutions and local idiosyncrasies. Empirically, the focus on the health district (kommune) level – sitting in between local clinics and national bodies – with the DHIS corresponds closely to the WHO’s and Health Metrics Network’s approach to “integrated data repositories”, or data warehouses. The district is the focal point for scaling (from facility to facility, and from service to service) and integrating electronic medical registries, and for linking and

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16 To illustrate, the Norwegian newspaper Dagens næringsliv run a two page story 19. Nov. 2007 on the inefficiencies costing “billions” of Norwegian crowns due to lack of integration.
17 (Norwegian Directorate for Health and Social Welfare, SHD 2004, ibid).
22 (Goodhue et al., ibid)
(Hanseth et al. 2006, ibid)
integrating local clinical data to national and global health surveillance systems. The proposed research through the concept of GHeI seeks to theoretically and practically address the challenge of how the strategies of integration can be extended across use contexts, technologies and countries.

2.2 Objectives (See grant application form.)

2.3 Approaches, hypotheses and choice of method

Our research approach is action-oriented and interpretative and characterized elsewhere as ‘networks of action’. The network of action approach is based on the principle of creating learning and innovation through multiple sites of action and use, and sharing these experiences vertically and horizontally in the network.

GHeI builds on previous and ongoing research and implementation activities within the HISP network, but seeks to add to, and extend, this body of research, by 1) establishing a key practical research site in Norway and a 2) global GHeI laboratory at the WHO head office in Geneva. The Norwegian Institute of Public Health will host the Norwegian pilot, which will aim at exploring how the efficiency and integration of Norwegian health registries may be enhanced. The WHO laboratory will enable the project to interact with other on-going global initiatives and, eventually, to influence their outcome. Pilot sites in India and Tanzania, linked with the Norwegian Governments MDG 4 & 5 initiative, will ensure a true global health perspective in that a continuum of contexts, from the least to the most developed, will become part of the research.

In GHeI, the network will comprise of three sub-networks of researchers, users of health information, and providers of health information infrastructure. The “network of action” will be empirically constructed based on the following analytic assumptions:

H0. Interventions – including innovations – in action research are neither sustainable nor viable unless they are spread to other locations (horizontally), and that learning is re-created and spread to related domains (vertically) (i.e. “networks of action”).

H1. GHeI needs to be addressed in a multi-level, multi-purpose and longitudinal manner.

H2. Effective design, development, and use of GHeI will significantly increase quality, equity, accessibility and use of existing health information, and the production of new and innovative health delivery services.

H3. Seamlessness will be achieved through better integration of health information across various dimensions of vertical health programs and services, multiple data types, technology types, uneven infrastructure contexts, and institutional and administrative commitment.

These principles will be empirically operationalized through a set of action and result oriented sub-goals and deliveries (see grant application), which will be explored across the global range of existing infrastructures through typical pilot sites; Norway and WHO.


30 Braa et al. 2004, ibid.
Geneva, (high level of infrastructure), India (mid level) and Tanzania (low level). This approach may be illustrated though the central WHO and GHeI aim to explore the concept of district based “Integrated data repository” as an approach to achieve integration and (more) seamless infrastructures. 1) A laboratory mimicking a real country context in terms of technologies and real data will be established in the WHO head quarter and mirrored to Oslo for collaborative research on its development. 2) These technologies and results are disseminated through ongoing interaction to the pilot sites in Norway, Africa and Asia. 3) In each country approaches and technologies are customised, tested, and enhanced, in close collaboration with other local actors and in interaction with other GHeI partners. 4) Through the integration of the data repository with mobile services and the OpenMRS patient database, new networks of activity, and use/production groups –and other GHeI sub-goals –are getting involved through synergies and interaction. 5) Evaluation, sharing of best practices and comparative research are carried out through web tools, by researchers moving between sites and through annual workshops –and publications. This dissemination and spreading across sites (horizontally) and across levels (vertically) constitutes the core of our “networks of action” approach.

As the laboratory is based at WHO, further dissemination of results, and the widening of the empirical research base, will be carried out through the Health Metrics Network and the Africa Health Infoway, which are aiming at implementing these approaches in a number of countries.

2.4 The project plan
GHeI is proposed over 4 years (2009-2012) (see milestones in grant application form), and organised as modular work packages supported with effective mechanisms for coordination and sharing of best practices. These modules are; setting up and coordinating a network of research consisting of groups and individuals from both technology and health domains; research into building and implementing GHeI; and research into use of GHeI.

WP 1: Project coordination and networking
A crucial part of the proposed project is to ensure coordination and communication between the developers and users of GHeI. A main task for the project management is to promote learning and research across the domains of public health and information technology. The first work package thus consist of managing the overall project and ensuring efficient running of the project, and also to arrange cross-disciplinary exchange of learning, products, and experiences. With the background in HISP/BEANISH network and the NFR GLOBVAC project, the consortium has already well established structures and routines for cross country collaboration, networking and dissemination of results. Major lesson from this 10-years period is that the project needs to be tightly managed by a devoted team and that effective communication across the network. This work package is planned according to these principles.

Establishing of electronic communication forum (Wiki), organising the project in sub-tasks/groups and work packages and the organisation of annual project workshops, are key instruments in the management of the project. Financial management and effective reporting structures are prioritised tasks.
Deliverables WP 1:
D 1.1 Detailed project plan developed, to be revised annually
D 1.2 Establishing a network of developers and users to form the Open Source Laboratory
D 1.3 Organization of annual project workshops
D 1.4 Establishing website and wiki for internal, external communication, and software repository

WP 2: Research on building, piloting and evaluating GHeI
This WP will involve and engage the “provider users” of the information infrastructure, including telecommunications, mobile, and Open Source Software. Coordination between these providers and the open standard interfacing between the technologies in use will be a major task. GHeI will establish an Open Source laboratory for seamless infrastructures in the head office WHO, Geneva, and at Ifi, Oslo. The laboratory will seek to simulate real country settings in terms of real data, data handling procedures and technologies. Research into state of the art open source approaches and technological frameworks will be carried out and new and innovative solutions will be tested out, such as for the DHIS/OpenHelath platform, its integration with OpenMRS and for the development and integration of new mobile services.

The development in the laboratory will be guided by practical implementation in Norway, India and Tanzania, where pilots will be established in the public health sector. While in Norway, a pilot will focus on national level integration efficiency enhancing of registries, managed by the Norwegian Institute of Public Health, the pilots in Tanzania and India will be incorporated within the Norwegian Millennium Goal 4 & 5 initiative. Particular products and services (such as integration of the three), and action research around each of them will provide the strategy for production and research into the experiences. Continuous communication and interaction between user and provider sub communities in relation to these pilots will be ensured. Continuous evaluation of various components and phases of the pilots will be carried out and practices of innovation will be important in order to identify value added information products and services

Deliverables WP 2:
D 2.1 Establish a laboratory including the DHIS/OpenHealth with country data and maps in Geneva shared with Oslo.
D 2.2 Develop and pilot integrated data repository (DHIS/OpenHealth)
D 2.3 Integrate and pilot DHIS/OpenHealth and OpenMRS
D 2.4 Develop pilot at the Norwegian Institute of Public Health
D 2.5 Establish pilots for practical implementation in Tanzania and India
D 2.6 Include country pilot technical teams directly in the distributed laboratory
D 2.7 Include real country specific mobile and hand held communication and services in the laboratory

WP 3: Research on use of GHeI
Crucial in this work package is promoting and evaluating use of GHeI by information-users. The global (WHO), national (such as Norway, India, Tanzania), and sub-national entities (such as in Norway), represent the key network of users. Interaction of user’s informational needs will be enabled through use of various system prototyping methodologies. Action and research in this workshop will aim at understanding systematically needs for integrated infrastructures and information, current challenges in achieving this, approaches to address them, and specifically how the new products, services and practices being produced under WP2 are being put into practice (or not), and with this providing useful feedback to the providers to improve the design of the seamless infrastructures. Strategies for linking information with health services delivery, health management and monitoring and evaluation of health interventions, health status and disease control will be developed.

**Deliverables WP 3**

D 3.1 Hold health information use workshops in the pilot sites, using the GHeI developed in WP 2

D 3.2 Analyse use patterns from clinical use perspective

D 3.3 Evaluation of impacts of information on health services delivery

D 3.4 Analysing and cross-comparing pilots

**2.5 Budget** (See grant application form)

**2.6 Project management, organisation and cooperation**

The table shows the involvement of the partners in the different work packages, where Effort shows the percentage of a full-time position spent on the project.

<table>
<thead>
<tr>
<th>Partner</th>
<th>WP 1</th>
<th>WP 2</th>
<th>WP 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>IFI/UiO, IDI/NTNU Norway</td>
<td>Project coordination and networking</td>
<td>Research on building, piloting and evaluating GHeI</td>
<td>Research on use of GHeI</td>
</tr>
<tr>
<td>NSEP, NIPH Norway</td>
<td>Coordinate overall project and network of partners</td>
<td>Coordinate research activities and dissemination, and supervise PhD and Master students. Run Open Source Laboratory in Oslo</td>
<td>Coordinate research activities and dissemination, and supervise PhD and Master students</td>
</tr>
<tr>
<td>WHO, Geneva</td>
<td>Assist in overall project coordination</td>
<td>Lead implementation of Norwegian pilot site, and disseminate results</td>
<td>Coordinate research on use of GHeI in Norway, and disseminate results</td>
</tr>
<tr>
<td>UDSM, Tanzania</td>
<td>Participate in dissemination of overall project research globally</td>
<td>Lead Open Source Laboratory in Geneva, disseminate results globally</td>
<td>Disseminate results globally Interact with other ongoing international activities</td>
</tr>
<tr>
<td>NHSRC, India</td>
<td>Coordinate related local research efforts of the NFR Globvac project</td>
<td>Coordinate pilot sites in Tanzania, and provide feedback to Open Source Laboratories</td>
<td>Facilitate research on use of GHeI in Tanzania</td>
</tr>
<tr>
<td>OpenMRS Regenstrief Institute MRC</td>
<td>Participate in planning and holding development workshops</td>
<td>Participate in seamless integration of OpenMRS and the DHIS-OpenHealth suite, through Open Source Laboratories</td>
<td>Participate in research on use of patient management systems in pilot sites</td>
</tr>
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</table>
The project team based at UiO and NTNU (J Braa, E Monteiro (also representing NSEP), S Sahay, J Sæbø, N Christoffersen, K Staring and J Sundby (CVs for all attached)) will collaborate closely with the team at the Norwegian Institute of Public Health, organised by Anne Bergh, and coordinate the overall project. The coordination of the international participation is organised through team members already actively engaged in these sub-activities; K Staring at WHO and with the OpenMRS and OpenHealth teams, S Sahay in India, and J Braa in Tanzania. Synergetic coordination with the ongoing NFR Globvac project “Integrated HIS for vaccination” is important as much of the empirical material from the HISP-network, such as feedback from implementation in a number of African and Asian countries, is coming from this project. J Braa is responsible for this coordination.

The role of the pilots in India and Tanzania is to 1) establish research components within these larger national projects, and to 2) provide direct links between two significant country projects and the GHeI laboratories in Geneva and Oslo, and thereby to provide global health research relevance to the project. These two country pilots will be coordinated by Sundararaman at NHSRC, India, and by H Kimaro, UDSM, and Tanzania. A research assistant will be hired in both countries.

3 Perspectives and compliances

3.1 Compliance with strategic documents.
On a global level, GHeI addresses key challenges identified by the WHO and Health Metrics Network in strengthening the systematic management of health information through the use of integrated information systems. This is strongly supported by the United Nations health related Millennium Development Goals (MDGs). At a national level, the Norwegian Government is firmly committed to supporting the WHO and United Nations MDGs, and has launched their MDG 4 & 5 initiative on reducing maternal and child mortality in 4 countries, including India and Tanzania. National policy documents from the Norwegian Ministry of Health has repeatedly underscored the importance of making Norwegian health infrastructure – across regions, disciplines and professions – more seamless i.e. integrated. GHeI is in line with the Norwegian Institute of Public Health’s Strategy 2008-2010 document and with the Ifi, UiO strategy. In India and Tanzania GHeI is in line with national health policy documents.

3.2. Relevance to society.
Contributing to improved health services – in Norway as well as in developing countries – is highly prioritized ambition globally (WHO, United Nations) as well as nationally in Norway as outlined above. Beyond health output, Nobel price laureate Amartya Sen argues strongly for the broader development implications following from improved health in developing countries; improved health accordingly contribute also more

32 Health Metrics Network Technical Framework (www.healthmetrics.org)
34 See SHD (2004) for latest in a series of policy documents all underscoring the importance of ‘integrated care’.
35 (http://www.fhi.no/dav/ec8228cb4e.pdf)
broadly to economic development. The spill-over effect from health to other sectors generating economic value and knowledge build-up is similarly identified in recent perspectives on economic development\(^37\).

### 3.3 Environmental aspects
N/A.

### 3.4. Ethical aspects.
The project is working closely with WHO and involved Ministries of Health in the implementation countries and will follow closely their instructions on ethical issues.

### 3.5. Gender equity and gender perspectives
**The focus on the** Norwegian Governments MDG 4 & 5 initiative (reducing maternal and child mortality) is directly linked to gender equity. Also in Norway and other developed countries’, the improvement of public health objectives of GHel are linked to gender equity as women and children are key beneficiaries of public health services. A key target of the project is to support WHO in their efforts to achieve the MDGs, a major component of which is to improve vaccination and health services for women and children in marginalised areas and communities, in the excluded countries of the world. Gender equality is the key issue in this target, and collecting gender specific information is one of the challenges to be addressed by the project. From the project management point of view, we will ensure that at least 40% of researchers and PhD students engaged by the project are women.

### 4. Communication with users and utilisation of results

#### 4.1 Communication with users
**The research** results will be communicated to the Norwegian user audience through the Norwegian Institute of Public Health’s extensive network of practitioners and user organisations. Through WHO and the Health Metrics Network research results will be communicated globally through documentation and workshops, practical applications, and implementation projects. Results will also be communicated through the Indian and Tanzanian Ministries of Health through practical improvements. Ultimately it is the common citizen who will benefit from the improved health services. The project will follow a participatory action approach and cooperation and communication with users is an integral part of the research approach.

#### 4.2 Dissemination plan
In addition to the research outputs (see grant application form), the project will aim at wide dissemination to the research community, including journals and conferences.

Further, the production of products and services which will strengthen the capacity of health services, and also provide firms with more innovative business opportunities, will be developed and made available. Software and other products of the project are all free and open source. Among the channels to be used for dissemination are those of GAVI, Health Metric Network and WHO, as well as the HISP web portal ([www.hisp.info](http://www.hisp.info)), which contains downloadable open source software as well as auxiliary documents.

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