THE GLOBAL KNOWLEDGE COMMONS FOR INNOVATIONS IN HEALTH: a global repository and knowledge sharing platform
The Innovation Working Group (IWG)
The Innovation Working Group (IWG) was convened by the United Nations Secretary-General in 2010 to use cost-effective innovation in accelerating progress towards achievement of the health-related Millennium Development Goals (MDGs). Supporting the Global Strategy for Women’s and Children’s Health, the IWG is the global hub for innovation in the Secretary-General’s Every Woman Every Child initiative.

At the time of creation of the IWG Task Force, the IWG was co-chaired by Tore Godal, Special Adviser on Global Health to the Norwegian Ministry of foreign Affairs, and Allan Pamba, Vice President Pharmaceuticals, East Africa and Government Affairs, Africa, at Glaxo Smith Kline Beecham (GSK). Tore Godal has since handed over to Peter Singer, Chief Executive Officer of Grand Challenges Canada and Director at the Sandra Rotman Centre, University Health Network and University of Toronto, as co-chair of the IWG. The project manager is Haitham El-noush at the Norwegian Agency for Development Cooperation (Norad), and the secretariat is housed at the Partnership for Maternal, Newborn & Child Health (PMNCH) at the World Health Organization (WHO).

The IWG supports the initiation and scaling-up of innovations – whether technological, social, financial, policy or business-related. The IWG also supports and leads collaborative efforts among stakeholders in mHealth (i.e. mobile health, or health services supported by mobile communications technology).

The IWG consists of a broad network of interested parties with a small secretariat, working through partner organizations. It comprises members of governmental, intergovernmental and nongovernmental organizations, as well as the private sector (both for-profit and not-for-profit), with all on an equal footing.
IWG Task Force on the Global Knowledge Commons for Innovation in Health: a global repository knowledge-sharing platform

In 2014, IWG created this Task Force to draw up an agreed set of guidelines to be followed by repositories of information and knowledge relevant to innovation in health.¹

The International Society for Telemedicine and eHealth (ISfTeH)

The International Society for Telemedicine and eHealth serves as custodian organization of the small grant provided to the Task Force for the preparation of the report.

¹ For more information on the IWG, see: www.everywomaneverychild.org/networks/innovation-working-group (accessed 14 September 2015).
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The PMNCH provided teleconferencing facilities to the Task Force, thus enabling live discussions among Task Force members. This service is gratefully acknowledged.

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The Task Force is grateful for the work done on the WHO International Clinical Trials Registry Platform (ICTRP) for the content of the guidelines, which required only slight adaptation to suit the purposes of the Global Knowledge Commons (GKC). Similarly, the Health on the Net (HON) Foundation’s work on a code of ethics for websites presenting health-related information was leveraged to support the web functions of the registries in the proposed GKC network. These two sets of guidelines greatly facilitated the work of the Task Force. Instead of developing an entirely new set of guidelines, it made sense – one might even say it was imperative – to leverage existing work of a similar kind that was based on a common ethos of integrity of data and comprehensiveness of information to be managed by the registries.

Finally, the printing and dissemination of this report would not have been possible without the support of Norad and its health department who provided a small grant to the International Society for Telemedicine and eHealth (ISfTeH) for the production of this report. We are thus also indebted to the ISfTeH for their institutional support to this work.
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Executive summary

Chapter 1: Rationale for the Global Knowledge Commons for innovations in m-eHealth

The key challenge facing m-eHealth is that of converting our collective knowledge into a global public good, that is accessible to all, thus enabling each m-eHealth actor to benefit from what others know. A Global Knowledge Commons (GKC) for innovation in health or simply “the Commons”, would be composed of three main constituents:

1. A database of projects, products and services;
2. A “Who is who in eHealth” – individual experts and institutions; and
3. Reusable m-eHealth knowledge objects, in various formats, such as articles, presentations, videos, etc.

The Commons would leverage existing repositories of the m-eHealth space, and lead to five significant beneficial outcomes: 1) eHealth intelligence at-a-glance through dash-boards by geography, application area and thematic area; 2) Clearinghouse for IP on eHealth issues; 3) Development of new knowledge as well as the reinforcement of partnerships; 4) More effective and efficient use of eHealth resources through better use and re-use of eHealth experience; 5) Availability of instruments for transforming the knowledge from the Commons into new products and services through creation of product development partnerships (PDPs) and incubator systems for m-eHealth innovation.

Chapter 2: Guidelines for Registries of the GKC

The guidelines are adapted from the WHO International Clinical Trial Registry Platform (ICTRP) and focus on nine criteria, indispensable to proper organization of registries in the GKC network. These are: i) authoritativeness and accuracy of the information; ii) privacy and confidentiality of personal data; iii)
appropriateness and updating of the content; iv) Quality and validity of the data; v) Accessibility of the contents to users; vi) Unambiguous identification of the records to avoid multiple records of the same item; vii) Technical capacity to function according to the recommendations of the GKC; viii) Administration and governance to ensure legitimacy of the registry; and ix) the GKC initiative registration data set which defines the minimum amount of initiative information that must appear in a register in order for it to be considered fully registered.

Each criterion is inspired by a guiding principle, and together they ensure that the data collected meet the standards of the GKC for innovations in m-eHealth.

Chapter 3: Guidelines for repositories and web platforms of the Commons

These guidelines are excerpted, with adaptations, from the HON Code of Conduct for medical and health websites. The same guidelines on: 1) authoritativeness, and 2) complementarity of the information, apply to repositories and websites as they do to registries (see sections 2.1 and 2.2). The remaining six criteria cover: 1) Privacy and confidentiality of data; 2) Attribution of information to sources; 3) Justifiability of any claims made about benefit or performance; 4) Transparency and willingness to share more information as requested; 5) Financial disclosure of funding sources; and 6) Policy on advertising of the repository or website. The underlying principle in each case is cited.

Chapter 4: Recommendations

Vision: The vision of the GKC platform is to provide a unified, simple and yet powerful portal, where data are syndicated from various valuable sources, providing access to global knowledge.
Adoption and adherence to the guidelines: The guidelines should be widely adopted and adhered to, because they underpin the power of the GKC.

Support further development of the GKC: Development of the GKC network, along the lines proposed in this report, should be supported by all stakeholder groups.

Collaboration with the wider community: Future work should focus on user organizations and identification of other partners. Benefits to knowledge management would also derive from efficiency improvements among donors and partners.

Roadmap to the Commons: The Commons should be built in phases, leveraging the work done by various organizations outlined in Chapter 1.

Options for long-term sustainability the GKC: Various options should be considered for financial sustainability of the Commons – e.g. open access and fees structures.

Models for collaboration: The Commons should include information and knowledge objects covered by intellectual property rights and seek to attract the private sector for-profit players, as well.

Governance of the Commons: A structure for proper governance of the GKC should be studied, adopted and implemented.

Updating the GKC: The GKC should have built-in mechanisms for discovery of new sources and updating of its nodes, as well as the contents of the repositories.

The GKC technical platform: The GKC technical platform should provide a single access point to the most comprehensive available information, knowledge, experience and people, across multiple existing systems. The platform should be an integrated, go-to portal for key organizations in the m-eHealth space, to collaborate with one another and find critical and up-to-date information.
It should be extendable, with the ability to “plug in” additional systems and syndicate knowledge from the most relevant industry sources, while providing a legitimate, neutral environment for knowledge-sharing and collaboration. The GKC platform should provide an extendable taxonomy to allow users to configure appropriate sets of metadata and taxonomy, with no additional software development required to create and manage the data.

**Conclusion**

Three key factors distinguish the GKC from previous attempts at sharing information and knowledge through a common platform: a) A focus on integration and collaboration around knowledge, not on the creation of new tools; b) There will be no need for users to switch from the tools they currently use; c) The backing of the IWG, and the composition of Task Force auger well for the future success of the Global Knowledge Commons.
Explanation of terms

Many terms are used to describe the deployment of information and communication technology (ICT) to improve health – mHealth, eHealth, digital health, wireless health, iHealth, etc. It is, therefore, of crucial importance to begin by defining various terms which cover the broad scope of the use of ICT in the health sector.²

**Telemedicine:** The delivery of health care services, where distance is a critical factor, by health-care professionals using ICTs for the exchange of valid information for diagnosis, treatment and prevention of diseases and injuries, research and evaluation, and for the continuing education of health-care providers, all in the interest of advancing the health of individuals and their communities.³

An example of this is when clinicians obtain second opinions about patients or consult specialists at remote locations about a case by telephone, email or through the Internet.

**Telehealth:** The use of electronic ICTs to support long-distance clinical health care, patient and professional health-related education, public health and health administration.⁴ Telehealth is therefore broader than telemedicine in that the former also includes public health interventions.

When health professionals use information and communication tools to interact with other health professionals or with the public in order to support public health interventions, they are engaged in telehealth activities.

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**eHealth:** A systematic review of published materials carried out in 2005 identified 51 unique definitions for eHealth. They ranged from broad and all-embracing statements to concise descriptions; for example:

- “eHealth is the use of information and communication technologies (ICT) for health”.
- “eHealth is an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology”.

For the purposes of this report, the term eHealth is used as defined by WHO above – i.e. the use of ICT for health.

Examples of eHealth are: the development, maintenance and use of electronic medical records, use of the Internet for health purposes, or employment of decision support tools for diagnosis and/or case management.

**mHealth:** The term mHealth is a contraction of “mobile eHealth”. It broadly encompasses health-related uses of mobile telecommunication and multimedia technologies within health service delivery and public health systems. It is therefore eHealth with the further requirement that the dominant technology platform is a hand-held device, such as a mobile phone (cell phone).

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or PDA (personal digital assistant) or more recent devices such as smart phones and tablet computers. The most common examples of mHealth, for the purposes of this assessment, are the use of mobile phones for: a) data collection and transfer directly into databases; b) professional communications between health workers; and c) consultation of websites with smart phones and tablet computers.

If any of the above activities, cited as examples, are carried out with the use of mobile devices, then the activities are considered to be mHealth.

**Digital health:** A term which denotes the convergence of the digital revolution with genetics and health. The term is also used in some cases as a synonym for eHealth and mHealth.

**iHealth:** This term is a shortened form of “Internet Health”. The term is used primarily in relation to support for the health and wellness of the individual through mHealth Apps.

**m-eHealth:** This term is used as an abbreviation for mHealth and eHealth.

In 2005 the WHO Global Observatory for eHealth adopted an operational definition to cover all of the terms above – namely, ICT for health. This report focuses on the most popular of these enablers for health: mHealth and eHealth, which we refer to as m-eHealth (*pronounced “me health”). “The appellation has a certain ring to it, as it conjures up images of personalised health – the holy grail of health care now being ‘patient-centred health’, with health care organizations aspiring to become ‘patient centric’ and provider groups striving to be ‘accountable care organisations’.”

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Chapter 1: Rationale for the Global Knowledge Commons for innovation in health: a global repository and knowledge-sharing platform

1.1 Background: Global Knowledge Commons for m-eHealth – the key to unlocking the potential of m-eHealth

Six eHealth grand challenges have been identified and need to be addressed as a group in order to derive the most benefit from the great potential of m-eHealth. As described briefly in a special theme issue of the WHO Bulletin published in May 2012, they are:  

i. Creating a Knowledge Commons for eHealth – a widely-available repository of knowledge and information on eHealth that is global in scope, and which will allow users to create once and use many times;

ii. Going to scale with eHealth interventions that are commensurate with the size of the problems, and this, clearly, based on evidence of the effectiveness of such interventions;

iii. Creating integrated eHealth systems that resolve perennial issues of siloed systems and lack of interoperability;

iv. Transforming health workers into ePractitioners, thus developing the individual and institutional capacity to use eHealth tools and services;

v. Developing ICT for health by viewing health as a production function and investigating where ICT can support such production, not just through care but also through other influence pathways to health, for example, the social determinants of health; and

vi. Building ICT for the health system of the future by anticipating future needs of the health system, so as to bridge the perpetual lag created when today’s interventions are in response to yesterday’s challenges and will not take effect until tomorrow.

Although it is imperative to leverage the interrelationships between them, in that all eight of the health-related Millennium Development Goals (MDGs) are mutually supportive, the key grand challenge is that of converting our collective knowledge into a global public good that is accessible to all. The paradigm would enable each actor in the m-eHealth network to benefit from what others know. A motto for this effort might be “Working in collaboration with a view to:

- helping us to know what we need to know;
- ensuring that we all know what others know; and
- making what we know contribute effectively to improving health.”

Knowledge is, therefore, the key to unlocking m-eHealth potential. Knowledge of who is doing what where in the m-eHealth space, and how well it is working, is crucial for optimizing the use of resources, which are currently spent on duplicating work that has already been done elsewhere but remains unknown to others.

Such knowledge would necessarily include evidence on m-eHealth. Al Shorbaji & Geissbuhler argue that programme evaluators need to generate evidence of the benefits of eHealth, while Gernert-Pijnen et al believe that eHealth development should be holistic, evidence-based and people-centred. To use an analogy from

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particle physics, evidence is the “Higgs boson” of m-eHealth. We know it is out there. The theories say it has to exist – witness the large amounts of money spent so far and expected to be spent annually. The Global Knowledge Commons for m-eHealth could thus serve as a large Hadron collider which will help us to finally find the m-eHealth Higgs boson.

This report sometimes refers to the Global Knowledge Commons for innovation in health by its initials GKC or simply as “the Commons”.

The three major components of the Commons are:

1. A database of projects, products and services – with descriptions in a standardized format that is conducive to indexing and classification, and amenable to electronic searching;
2. A “Who is who in eHealth” – individual experts and institutions (building on the ISfTeH current database of more than 22000 individuals and institutions); and
3. Reusable knowledge resources – m-eHealth evidence and knowledge objects, in various formats, such as articles, presentations, videos, etc.

Elements of the Commons exist in several places. Although some of the initiatives cited here no longer exist, they are mentioned for completeness, particularly as their successor activities are relevant to knowledge sharing in the m-eHealth space.

*Health Ingenuity Exchange*

The Health Ingenuity Exchange (HingX) states: “Whether by a keyword search, a filtered inquiry, or a general browse of the many resources, HingX users will find useful, relevant information and people that they are looking for. In addition to its social Community features, HingX can be used to acquire valuable policy reviews, software architecture, and extensive reports on Health information technology (IT). Users will find that making
connections, finding valuable material, and navigating Hingx is easy and achievable.3

The resources currently available include 1238 health IT resources, 299 members and 40 user communities.15

**mHealth Tracker**

With over 6.8 billion mobile telephone subscriptions, and extensive geographical and population coverage (sometimes above 90%), mobile phones are the technology of choice for appropriately designed health interventions. The GSM Association (GSMA) mHealth Tracker is a platform which “collates mobile health products and services around the globe. It tracks solutions in both planning phase and those which have been commercially deployed. Use the map to discover the number of products and services per country and to learn more about each example. Filter your search to view the results by organization, organization type and country.”16

**Impact pathways and its successor**

The GSMA also operated a logical framework, called Impact Pathway, for measuring inputs, outputs and outcomes against stated activities or occurrences. The system was based on a theory of change, and demonstrated “how access to mobile services for development can bring about short, medium, and long term change that improves lives”.17

**Health Unbound and its successor**

Conceived at the 2008 mHealth week of the Rockefeller Foundation – a sponsored eHealth summer series in Bellagio, Italy – Health Unbound (HUB) was an interactive network and online knowledge resource centre for the mHealth community, operated by the mHealth

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17 See: [https://mobiledevelopmentintelligence.com/impact_pathways](https://mobiledevelopmentintelligence.com/impact_pathways)
HUB enabled “the mHealth community to exchange ideas, share projects and outcomes, and build connections among the dynamic mHealth community.” The system brought together individuals from all disciplines of the mHealth community, from developers to doctors, to generate collective solutions and inspired new innovations that would transform health with technology. HUB offered “a database of resources, curated topic collections, and an open mHealth community to connect with to promote collaboration efforts and share lessons learned”.

HUB was a network of networks, not unlike the World eHealth Collaborative Action Network (WECAN) advocated at another of the Bellagio summer series on eHealth “to bring together diverse stakeholders, ideas, and activities — a network to foster discussion and collaboration, providing the foundation for the meaningful use of technology in health.”

Global Observatory for eHealth

The surveys and reports of the WHO Global Observatory for eHealth have been cited above. However, the WHO Global Observatory can do much more than collect and publish information on various aspects of eHealth. The broader vision is that of a Knowledge Commons – a networked observatory, a network of networks, with National Observatory Groups (NOGs) – themselves composed of networks, collecting and using the information they need for their own purposes, while allowing authorized authenticated access to their data. See attributes of the observatory of the future – frequency and granularity (import from report to WHO)

The WHO Global Observatory has also just published a directory of eHealth policies which “includes documents that outline the vision, goals, and approaches for the use of ICT for health at a national level. It also includes meta-data about each of these documents, a

18 The mHealth Alliance ceased to exist in the later half of 2014. Even so, the HUB initiative continues.

19 See the HUB website http://www.healthunbound.org/
brief summary of the content, and a link to the full text document in the original language of publication. For those documents not available in English, translations of executive summaries will be underway soon and made available online.”

**ISfTeH – Med-e-Tel knowledge resources**

The road to the Commons will build on the work the International Society for Telemedicine and eHealth (ISfTeH), which currently manages a database of 20,000 records of individuals and institutions, and a knowledge repository of papers and presentations from Med-e-Tel, the fixed event of the Society held in Luxembourg in April each year. The ISfTeH has national member associations in 45 countries and institutional members in another 31 countries. The national member society for France is currently developing a national repository, with funding from the French government.

**European Commission websites on eHealth**

As repositories with an emphasis on Europe, the European Commission websites on eHealth provide: reports on policy-making activities at the level of the European Union; information on research and innovation projects, as well as supporting actions; development frameworks; and links to trustworthy sources of information and data on health-related issues and activities at European, national and international levels.

The above are but a few examples of the repositories in existence. They underscore the fact that the potential for innovation in m-eHealth to improve health is increasingly undisputed. However, there is a dire need to share innovations more widely and replicate those that have proven successful. In the absence of a global mechanism for sharing of information and knowledge, much effort is unknowingly invested in reinventing the wheel, in the form

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of proofs of concept and pilot projects. A networked repository of intelligence will provide not only a dashboard by geography, thematic area and actors, but will avoid duplication and lead to better use and re-use of m-eHealth experience. The Commons will also facilitate the development of new knowledge, as well as the reinforcement of partnerships.

With the above building blocks in place, what remains is the organizational task of brokering agreements among the stewards of these platforms and orchestrating structured links between the repositories. Additional categories of resources that could be collected and shared, as well as constituting the subject of communities of practice, are those which address the barriers identified in a 2012 study of eHealth challenges in Europe by Moen et al – such as business models, legal frameworks, stakeholder engagement and education, how to link research and implementation, governmental priorities, and traceable benefits.22

1.2 An authoritative source of m-eHealth information

The effort of organizing the repositories of information cited above, along with many others still to be identified, as nodes of a network of networks is in line with recent developments concerning the .health (dot health) top-level domain (TLD) on the Internet. The Internet Corporation on Assigned Names and Numbers (ICCAN) is in the process of reviewing applications for management of the .health TLD. Such a TLD, if properly managed, could be a seal of approval for the quality and appropriateness of information available on sites in the TLD. This would make such sites play the role of a trusted source of information for the public and their health. However, there are concerns because appropriate mechanisms and safeguards for consumer protection and the public interest in general are not yet in place. The resolution on eHealth standardization and interoperability, passed by the 66th session of the World Health

Assembly in May 2013 (Resolution WHA66.24) attests to this and urges all 194 member countries of WHO, inter alia,

“to consider ways for ministries of health and public health authorities to work with their national representatives on the ICANN Governmental Advisory Committee in order to coordinate national positions towards the delegation, governance and operation of health-related global top-level domain names in all languages, including ‘.health’, in the interest of public health; ...”

1.3 Methodology

The methodology adopted by the Task Force for this study consisted of three main areas of activity, namely:

1. Background research by members of the Task Force
2. Calls to share information and review
3. Preparation of the draft
4. Review of the report.

For this purpose a collaborative workspace was set up to share documents and to facilitate joint editing and revision of drafts.

1.4 Structures of the Global Knowledge Commons

To promote better understanding of the concepts involved in the GKC, we provide the following outline of the components of the Commons.

*Global Knowledge Commons for m-eHealth (GKC)* – the totality of elements which serve the purposes of the Commons.

*Global Knowledge Commons Initiatives Platform (GKCIP)* – a technical platform for enabling interconnections among the sources of information and the users of the information.

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Global Knowledge Commons Repository (GKCR) – a repository of information and knowledge adhering to the guidelines of, and linked to, the GKC platform. It is also an institution that hosts m-eHealth information and knowledge objects.

Global Knowledge Commons Repository Network (GKCRNet) – the interconnecting set of repositories. Each registry is a node of the GKCRNet.

Global Knowledge Commons Repository (GKCR) –

Global Knowledge Commons Registry (GKCRReg) – an institution which maintains an up-to-date log of m-eHealth entities (initiatives and associated individuals and institutions) in line with the three major components of the GKC cited in section 1.1. Thus, while every registry can serve as a repository (of information from its records), a repository may not qualify as a registry according to the guidelines described in Chapter 2.

Global Knowledge Commons Registry Network (GKCRRegNet) – the interconnecting set of registries. Each registry is a node of the GKCRRegNet.

1.5 Expected outcomes

To realize the full benefits from m-eHealth, countries must advance from individual pilot projects to fully scaled-up and coordinated programmes, in telemedicine, eLearning, electronic health records, health promotion, etc. This requires a vision, and a roadmap – usually embodied in a national eHealth strategy. Hence, due emphasis and importance must be given to the development of national eHealth strategies and roadmaps. This essential step can itself derive great benefit from shared experiences.

The GKC will lead to a number of significant beneficial outcomes, such as:
1) m-eHealth intelligence at-a-glance through dashboards by geography, application area and thematic area;

2) A clearinghouse for intellectual property (IP) on m-eHealth issues;

3) Development of new knowledge as well as the reinforcement of partnerships;

4) More effective and efficient use of m-eHealth resources through better use and re-use of eHealth experience;

5) Availability of instruments for transforming the knowledge from the GKC into new products and services through the creation, by others, of product development partnerships and incubator systems for m-eHealth technology.

For project operators, there would be greater visibility of their projects in a global repository, and for managers of repositories there would be exposure of their resources to a worldwide audience.
Chapter 2: Recommended guidelines for registries of the Commons

- Adapted from the WHO International Clinical Trial Registry Platform (ICTRP) and the Health on the net Foundation Code –

Registries in the Global Knowledge Commons Network must meet certain criteria so as to ensure that the data collected meet the standards of the GKC for innovations in m-eHealth. These criteria can be categorized into nine main areas, as described below.

2.1 Authoritative – Information should be accurate and authoritative

All information contained in the records of the repositories of the GKC should be accurate. The source of the information should be identified so that users can judge how authoritative the information is.

Guiding principle 1 – Information must be authoritative

Information presented in a GKC registry must be attributed to a source, with sufficient information provided about the source to enable users to assess for themselves the authoritativeness of the information.

This may be done for each item or on an “Advisory Board” or “Editorial Board” page.

The qualifications of the information provider (author, webmaster or editor) must be clearly stated.

Note: All acronyms relating to degrees or affiliations must be explained. They can be identified on a separate page entitled “Information page”.

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2.2 Complementarity and purpose – The mission and purpose must be clearly stated

In cases where medical information is recorded, it should be clearly stated that the information is designed to support, and not replace, the relationship that exists between a platform user and his/her physician.

**Guiding principle 2 – Purpose of the platform**

A statement clearly declaring that the information in the repository is not intended to replace the advice of a health professional must be provided.

A brief description of the registry’s mission, purpose and intended audience is necessary.

Furthermore, a brief description of the institutional owner of the registry, its mission and its purpose is also necessary.

The registry must reflect its engagement to respect this principle in its editorial content. A statement such as “Any medical information provided on [repository name] is designed to complement, and not replace, the relationship between a patient and his/her physician” may be used for this purpose.

2.3 Content

Registries in the GKC registry network will:

- accept prospective registration of interventions trials submitted by responsible registrants;
- be open to all prospective registrants (either internationally or within one or more specific countries);
- be able to collect and publicly display the GKC initiative registration data set;
- endeavour to keep registered information up-to-date;
- never remove a project once it has been registered.
2.4 Quality and validity

Registries in the GKC registry network will:

• have a mechanism in place to ensure the validity of the registered data;

• maintain a publicly accessible audit trail so that changes to the GKC initiative registration data set can be tracked for individual initiatives;

• participate in the development of GKC best practice guidelines for initiative registries.

Data validity can be ensured by having processes in place to maximize the possibility that the data registered are complete and accurate. These processes should be documented as standard operating procedures and should include processes to ensure that:

• the person registering the initiative exists and is the appropriate responsible registrant;

• the initiative exists;

• the data submitted are complete.

It is the responsibility of the responsible registrant to make sure that data provided to the registry are complete and accurate.

2.5 Accessibility

Primary registries in the GKC registry network will:

• ensure that the GKC initiative registration data set for all registered initiatives will be:
  – accessible to the public at no charge
  – electronically searchable
  – made available to the GKC initiatives platform in English;
allow registrants to submit a project for registration at any
time of day on any day of the week (24 hours a day, seven
days a week);

allow the register to be searched at any time of day on any
day of the week (24 hours a day, seven days a week).

It is desirable that registries in the GKC registry network also make
the GKC initiative registration data set available in the language(s)
of the country or countries served by the registry.

2.6 Unambiguous identification

Registries in the GKC registry network will:

- have in place processes to prevent the registration of a
  single project more than once on their database;
- facilitate the retrospective linking (or bridging) on the GKC
  search portal of a single initiative registered with more than one
  registry by entering secondary identifiers. This includes the
  universal initiative number (UIN), and the unique identifiers
  allocated by other registries in the GKC registry network

It is desirable that registries in the GKC registry network, as part
of the registration process, search the GKC search portal and at-
tempt to determine whether the project has already been regis-
tered by another registry.

2.7 Technical capacity

Registries in the GKC registry network will:

- submit the GKC initiative registration data set for all
  records on their registry, in English;
- have access to a database that is used to store and manage
  the submitted data (registries are not required to develop
  their own database); See the Data Providers section for
  more information
• be able to demonstrate that they have access to adequate information technology support;
• have adequate security and other provisions against data corruption and loss.

2.8 Administration and governance

Registries in the GKC registry network will:

• have at least a local remit, and the support of government within the country (or region), to act as the GKC registry for that country (or region); (*)
• provide a letter of support from the Ministry of Health or other relevant national or regional agency;
• publicly disclose ownership, governance structure and status (for-profit/not-for-profit);
• be managed by a not-for-profit agency.

Should a registry cease to function the registry agrees that at least the GKC initiative registration data set (original and updated) for all initiative records will be transferred to another registry in the GKC registry network.

It is desirable that registries in the GKC registry network have a strategy in place to address the medium- to long-term sustainability of the registry.

2.9 Global Knowledge Commons initiative registration data set

This refers to the minimum amount of initiative information that must appear in a register in order for a given initiative to be considered fully registered. There are currently 20 items in the GKC initiative registration data set. It is sometimes referred to as the PRDS.
• **Primary registry and initiative identifying number**
  Name of primary registry, and the unique ID number assigned by the primary registry to this initiative.

• **Date of registration in a GKC registry**
  Date when initiative was officially registered in the primary registry.

• **Secondary identifying numbers**
  These are any identifiers that are additional to the initiative identifying number allocated by the registry. These include:
  
  – the universal initiative number (UIN);
  
  – identifiers assigned by the sponsor (record sponsor name and sponsor-issued initiative number);
  
  – other initiative registration numbers issued by other registries in the GKC registry network;
  
  – identifiers issued by funding bodies, collaborative research groups, regulatory authorities, ethics committees, institutional review boards, etc.

  All secondary identifiers will consist of two elements: an identifier for the issuing authority (e.g. WHOGOE, HINGEX, CHMR, etc.) plus a number.

  There is no limit to the number of secondary identifiers that can be provided.

• **Source(s) of monetary or material support**
  Major source(s) of monetary or material support for the initiative (e.g. funding agency, foundation, company, institution).

• **Primary sponsor**
  The individual, organization, group or other legal entity which takes responsibility for initiating, managing and/
or financing a study. The primary sponsor is responsible for ensuring that the initiative is properly registered. The primary sponsor may or may not be the main funder.

- **Secondary sponsor(s)**
Additional individuals, organizations or other legal persons, if any, that have agreed with the primary sponsor to take on responsibilities of sponsorship.

A secondary sponsor may have agreed to:

- take on all the responsibilities of sponsorship jointly with the primary sponsor; or
- form a group with the primary sponsor in which the responsibilities of sponsorship are allocated among the members of the group; or
- act as the primary sponsor’s legal representative in relation to some or all of the initiative sites.

- **Contact for public queries**
Email address, telephone number and postal address of the contact who will respond to general queries, including information about current recruitment status.

- **Contact for scientific queries**
Responsibility for scientific leadership must be clearly assigned to a named principal investigator. The principal investigator may delegate responsibility for dealing with scientific enquiries to a scientific contact for the initiative. This scientific contact will be listed in addition to the principal investigator.

The contact for scientific queries must therefore include:

- the name and title, email address, telephone number, postal address and affiliation of the principal investigator; and
the email address, telephone number, postal address and affiliation of the contact for scientific queries on the initiative (if applicable). The details for the scientific contact may be generic (i.e. there does not need to be a named individual but a generic email address can be used for research team members qualified to answer scientific queries).

- **Public title**
  This title is intended for the lay public and should be in easily understood language.

- **Scientific title**
  The scientific title of the study should be as it appears in the proposal submitted for funding. Include the initiative acronym if available.

- **Countries of recruitment**
  The countries from which beneficiaries will be, are intended to be, or have been recruited at the time of registration.

- **Health condition(s) or problem(s) studied or area of innovation**
  Primary health condition(s) or problem(s) studied (e.g. depression, breast cancer, medication error).
  If the initiative is conducted in healthy human volunteers belonging to the target population of the intervention (e.g. preventive or screening interventions), enter the particular health condition(s) or problem(s) being prevented.

- **Intervention(s)**
  For each arm of the initiative, record a brief intervention name plus an intervention description.
  Intervention name: Provide a brief descriptive name for interventions.
**Intervention description**: This must be sufficiently detailed for it to be possible to distinguish between the arms of a study and/or between similar interventions.

If the intervention consists of several separate treatments, list them all in one line separated by commas (e.g. "low-fat diet, exercise").

For controlled trials, the identity of the control arm should be clear. The control intervention(s) is/are the interventions against which the study intervention is evaluated (e.g. placebo, no treatment, active control). If an active control is used, be sure to enter in the name(s) of that intervention, or enter “placebo” or “no treatment” as applicable. For each intervention, describe other intervention details as applicable (dose, duration, mode of administration, etc).

- **Key inclusion and exclusion criteria**

Inclusion and exclusion criteria apply to participant selection, including age and sex. Other selection criteria may relate to clinical diagnosis and comorbid conditions; exclusion criteria are often used to ensure patient safety.

- **Study typ**

The initiative type consists of:

- type of study (interventional or observational);
- initiative design, including:
  - method of allocation (randomized/non-randomized)
  - masking (is masking used and, if so, who is masked?)
  - assignment (single arm, parallel, crossover or factorial)
  - purpose;
phase (if applicable).

For randomized trials, the allocation concealment mechanism and sequence generation will be documented.

- **Date of first enrolment**
  The anticipated or actual date of enrolment of the first participant.

- **Target sample size**
  The total number of participants that this initiative plans to enrol.

- **Recruitment status**
  Recruitment status of this initiative:
  - Pending: participants are not yet being recruited or enrolled at any site.
  - Recruiting: participants are currently being recruited and enrolled.
  - Suspended: there is a temporary halt in recruitment and enrolment.
  - Complete: participants are no longer being recruited or enrolled.
  - Other.

- **Primary outcome(s)**
  Outcomes are events, variables or experiences that are measured because it is believed that they may be influenced by the intervention.
  
  The primary outcome should be the outcome used in sample size calculations, or the main outcome(s) used to determine the effects of the intervention(s). Most trials should have only one primary outcome.

  For each primary outcome, provide:
the name of the outcome (do not use abbreviations);
the metric or method of measurement used (be as specific as possible);
the time point(s) of primary interest.

Example:
Outcome name: depression.
Metric/method of measurement: to be determined (see RHR mHealth methods).
Time point: 18 weeks following end of treatment.

• **Key secondary outcomes**

Secondary outcomes are outcomes which are of secondary interest or that are measured at time points of secondary interest. A secondary outcome may involve the same event, variable or experience as the primary outcome, but is measured at time points other than those of primary interest.

As for primary outcomes, for each secondary outcome provide:

– the name of the outcome (do not use abbreviations);
– the metric or method of measurement used (be as specific as possible);
– the time point(s) of interest.
Chapter 3: Recommended guidelines for repositories web and platforms of the Commons

(Excerpted from the HON Code of Conduct for medical and health websites – www.healthonthenet.org)

Guiding principles

The same guidelines on: 1) authoritativeness, and 2) complementarity of the information, apply to repositories and websites as they do to registries (see sections 2.1 and 2.2). They are reproduced here, with appropriate modifications, for completeness as not every repository or website of the GKC is also a registry.

3.1 Authoritative – Information should be accurate and authoritative

All information contained in the records of the repositories of the GKC should be accurate. The source of the information should be identified, so that users can judge how authoritative the information is.

Guiding principle 1 – Information must be authoritative

Information presented on GKC websites must be attributed to a source, with sufficient information provided about the source to enable users to assess for themselves the authoritativeness of the information.

This may be done for each item or on an “Advisory Board” or “Editorial Board” page.

The qualifications of the information provider (author, webmaster or editor) must be clearly stated.

Note: All acronyms relating to degrees or affiliations must be explained. They can be identified on a separate page entitled “Information page”.

The Global Knowledge Commons for m-eHealth
**Collaborative platforms**

It must be clearly stated whether a platform is moderated or not. The qualifications/credentials of the moderator(s) must also be clearly stated. The names of the moderators are not mandatory. Moderators may use pseudonyms. The frequency with which the moderator function is carried out on the platform must be given.

It must be clearly stated that platform users and moderators must behave at all times with respect and honesty.

It must be clearly explained that the moderators may intervene and that platform users may be banned. It must also be stated whether platform users are warned or notified before being banned.

**3.2 Complementarity**

In cases where medical information is recorded, it should be clearly stated that the information is designed to support, and not replace, the relationship that exists between a platform user and his/her physician.

**Guiding principle 2 – Purpose of the platform**

A statement clearly declaring that the information in the repository is not intended to replace the advice of a health professional must be provided.

A brief description of the repository’s mission, purpose and intended audience is necessary.

Furthermore, a brief description of the institutional owner of the repository, its mission and its purpose is also necessary.

The repository must reflect its engagement to respect this principle in its editorial content. A statement such as “Any medical information provided on [repository name] is designed to complement, and not replace, the relationship between a patient and his/her physician” may be used for this purpose.
3.3 Privacy and confidentiality – Cite the source(s) of published information, date medical and health pages

The privacy and confidentiality of personal data submitted to the platform by the visitor must be strictly respected.

Confidentiality of data relating to individual users of the GKC repository, including their identity, must be respected by repository. Repository owners undertake to honour or exceed the legal requirements of health data privacy that apply in the jurisdiction and state where the repository and mirror repositories are located.

Guiding principle 3 – Confidentiality
The repository must describe its privacy policy regarding how it treats confidential, private or semi-private information such as email addresses and the content of emails received from or sent to its users.

The repository must inform its visitors whether their data will be recorded in the repository’s own database, who can access this database (others, repository only), whether this information is used for the repository’s own statistics (anonymized or not), or if these statistics are used by third parties. The repository must also declare if it uses cookies in its interaction with users.

Collaborative platforms
The platform must have a privacy policy which should underscore the fact that everyone can read a post and use its content. It must be clearly stated whether or not the platform user has the possibility to modify or erase his/her posts.

3.4 Attribution
The source(s) of published information should be cited, and medical and health pages should be dated.

Where appropriate, information should be supported by clear references to source data and, where possible, there should be specific HTML links to that data. The date when an item was last modified should be clearly displayed (e.g. at the bottom of a web page).
Guiding principle 4 – Information must be documented: referenced and dated

All medical content (page or article) has to have a specific date of creation and a last modification date.

Date of last modification must also be included on every page, and should provide ethical and legal information, author(s), mission, and the intended audience.

All sources of the medical content must be given. The platform must clearly indicate the recognized scientific or official sources of health information quoted in its articles. If the source is a website, book, article database or any other support, it should be specified. References should lead to the article mentioned. The platform should provide a precise link to the source whenever possible, and the references should have a direct relationship to the content for which they are given.

It is recommended that, at the bottom of a health or medical web article, scientific references should be provided in the following format:

Journal articles
Author1, Author2, Author3 Title Name of the journal. year-references - page number.

Conference proceedings or books
Author1, Author2, Author3 Title Name of the conference or book name - year - page number using http://www.webcitation.org/

Note: The date of last update of the entire website or the copyright date only are not sufficient to comply with this principle. The “last update” date should not be set to automatically display the current date.

Depending on the platform and its content, a bibliography may be provided instead of a specific source for each medical article or page. This bibliography should clearly indicate the medical subject for which each reference is provided.
**Key points:**

- Cite the source of the information.
- State the basis (scientific or other literature) on which the information is founded.
- When appropriate, include a bibliography and, when possible, give hypertext links.
- Ensure that the date of last modification is shown on each medical and health page.
- Give the date of last modification on pages containing the privacy policy and legal information.
- Give the date of last modification on the pages describing the author(s), the mission and the audience of the platform.

**Collaborative websites**

A statement requesting platform users to provide references (e.g. links) to the health/medical information they give, when this is not based on personal experience, must be provided.

Personal experience is any experience that the person or a close collaborator has undergone himself/herself. All posts must be automatically dated.

**3.5 Transparency – Repository should back up claims relating to benefits and performance**

The repository must back up claims relating to benefits and performance. Any claims relating to the benefits/performance of a specific intervention, product or service should be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

**Guiding principle 5 – Justification of claims**

All information about the benefits or performance of an intervention, product or service is considered a claim. All claims should be backed up with scientific evidence (reputable journals, authoritative reports, etc.).
All brand names should be identified (e.g. with ®).

Unless a platform is clearly stated to be the commercial platform of a particular product, it must include alternative solutions or products (including generics).

**Collaborative platforms**

It should be stipulated that all users of the platform should undertake to disseminate only information that is true and correct in light of their knowledge.

### 3.6 Transparency

The designers of the repository and its associated platform should seek to provide information in the clearest possible manner, as well as contact addresses for users who need further information or support. The platform manager will display his/her email address clearly throughout the platform.

**Guiding principle 6 – Website contact details**

The platform must be operational and the information must be accessible and clearly presented.

There must be a way to contact the manager, such as a working email address or contact form, for users who would like to have more details or support. This contact must be easy to access from anywhere on the site.

The platform must endeavour to give individual and prompt responses to any user’s inquiries.

Note: In order to avoid spam or misuse, contact email address can be encrypted.

**Collaborative websites**

A specific contact form or an email address should be accessible for web 2.0 platform users in order to contact the editor or the moderators of the forum.
The platform rules must be easily accessible from the platform’s homepage.

3.7 Financial disclosure – Identify funding sources

Support for the GKC repository and associated platform should be clearly identified, including the identity of commercial and noncommercial organizations that have contributed funding, services or material to the repository.

**Guiding principle 7 – Disclosure of funding sources**

The platform must include a statement declaring its sources of funding. This is required for all GKC platforms.

All funding must be declared: government agency, private companies, donations, etc.

The platform should also declare all conflicts of interest.

**Collaborative websites**

It must be clearly stated if the moderators are volunteers or not.

3.8 Advertising – Clearly distinguish advertising from editorial content

If advertising is a source of funding for the registry and its associated platform, this should be clearly stated. A brief description of the advertising policy adopted by the repository owners should be displayed on the platform. Advertising and other promotional material should be presented to users in a manner and context that facilitates differentiation between it and the original material created by the institution operating the repository.

**Guiding principle 8 – Advertising policy**

**Editorial policy**

Conflicts of interest and external influences that could affect the objectivity of the editorial content should be clearly stated in the disclaimer.
Advertising policy

All platforms with paid banners should display an advertising policy. This policy must explain how the site distinguishes between editorial and advertising content, and which advertisements are accepted. Any conflict of interest should be explained.

Any non-paid banner or “friendly” link should also be distinguished from editorial content by a label such as “banner” or “friendly banner”. A policy should be provided to explain to users that these banners are not advertisements but have been provided for further reference or other purposes.

If the site does not display advertisements, a clear statement should indicate that the site does not host or receive funding from advertising or from the display of commercial content.

All advertisements and any promotional, commercial or other information in the form of articles, or display advertisements (banners or logos), should be clearly indicated and easily identifiable as such, and should be separated and distinguished from the editorial content. All advertising (including pop-up windows and banners) should be identified with the word “Advertising” or similar etiquette that clearly identifies the sponsor.

If banners are served from a free web hosting service or “banner exchange”, the platform manager must clearly state that the advertising banners are from the free web host and are not endorsed by the platform editor.

Note

Hosting of advertising is the responsibility of the editor. Platforms that display advertisements for pornographic websites (even if not under their direct control, such as with “banner exchange” services) will be removed from the GKC network of repositories.

Collaborative websites

A policy should be adopted regarding whether or not the users of the platform have the right to publish advertisements in the form of content, banner or links etc.
Chapter 4: Recommendations and long-term considerations for the Global Knowledge Commons

Recommendation 1 – Vision of the Global Knowledge Commons

In the current eHealth landscape, there are many websites within the community that serve as sources of information. Some of those sources are well structured in the form of registries while others provide materials in a more elementary format. Valuable information can also be sourced from social networks and discussion forums. This variance in presentation of information is further complicated by a variety of authoring methods, where some data sources are highly curated and others are the result of user experience and present the perspectives of these users on specific issues. Nevertheless, usability and applicability of knowledge cannot be clearly validated on the basis of presentation format or the author of the particular content. With that in mind, the GKC platform should be built with the view that the method of providing information should not impact accessibility to knowledge. The vision of the GKC platform is therefore to provide a unified, simple and yet powerful portal where data are syndicated from various valuable sources, providing access to global knowledge.

Recommendation 2 – Adoption and adherence to the guidelines

The power of the GKC to facilitate the sharing of knowledge derives from the guidelines underpinning the information and knowledge in the repositories that form part of the network. The guidelines should therefore be widely adopted and adhered to.
Recommendation 3 – Support further development of the Global Knowledge Commons

Promoters of registries and repositories, as well as funders of and donors to m-eHealth initiatives, should support the development of the GKC network along the lines proposed in this report.

Recommendation 4 – Collaboration with the wider community

To promote adoption of the guidelines and build partnerships for the Commons, future work should focus on user organizations and identification of other partners. Activities might include:

a) preparation of a white paper;
b) publication and targeted dissemination to identified repositories for comment;
c) periodic updates of these guidelines, with launches at strategic global events such as the Mobile World Congress.

User categories would include governments, development and implementation partners, researchers and NGOs. Benefits to knowledge management would derive not only from information-sharing but also from efficiency improvements among donors and partners by facilitating the due diligence that must be carried out before funding projects.

Recommendation 5 – Roadmap to the Commons

The Commons should be built in phases, leveraging the work done by various organizations, as outlined in Chapter 1. As an example, the International Society for Telemedicine and eHealth (ISfTeH) currently manages a database of 22,000 records of individuals and institutions, and a knowledge repository of papers and presentations from Med-e-Tel held over the last 12 years.
Recommendation 6 – Options for long-term sustainability the Global Knowledge Commons

Considerations for long-term financial sustainability of the Commons should include the following options:

a) subscription for users of the Commons;
b) free registration and usage with advertising by sponsors;
c) a combination of the two based on criteria such as country development index, per capita GDP, etc.

Recommendation 7 – Models for collaboration

The Commons should not be limited to material that is in the public domain, but should embrace models for sharing information and also knowledge objects covered by intellectual property rights. The Commons should, therefore, also seek to attract the private sector for-profit players.

Recommendation 8 – Governance of the Global Knowledge Commons

The structure for proper governance of the GKC should be studied, and adopted, with provisions made for transitional measures to be put in place for moving the initiative from where it is today to a permanent structure.

Recommendation 9 – Updating the Global Knowledge Commons

The GKC should not be a static source of information and knowledge, but should have built-in mechanisms for discovery of new sources and updating of its nodes, as well as the contents of the repositories.

Recommendation 10 – The GKC technical platform

The GKC platform should provide a collaborative environment with a single point of access to the most comprehensive available
information, knowledge, experience and people across multiple existing systems (Fig. 1). The platform should be an integrated, go-to portal for key organizations in the m-eHealth space, to collaborate with one another and find critical and up-to-date information (Fig. 2). The platform should be extendable, with the ability to “plug in” additional systems and syndicate knowledge from the most relevant industry sources (Fig. 3).

It should also provide a legitimate, neutral environment for knowledge-sharing and collaboration (Fig. 4).

Finally, the GKC should provide an extendable taxonomy to allow users to configure appropriate sets of metadata and taxonomy. No software development would be required to create and manage data.
What is Global Knowledge Commons?

Federated, cloud-based Knowledge Management Platform designed to integrate and extend existing systems and knowledge repositories.

Fig. 2

Global Knowledge Commons Platform Architecture

Knowledge Commons Presentation Layer

Knowledge Commons Business Logic Layer

Existing Knowledge Management Systems / Repositories

Fig. 3
Conclusion

The idea of sharing information and knowledge through a common platform is not new. However, three key elements distinguish the GKC from other similar efforts and should result in its success. These are:

a) The focus of the GKC is on integration and collaboration around knowledge, not on the creation of new tools.

b) There will be no need for users to switch from the tools they currently use. They will continue to use the tools which with they are familiar. Adherence of their host repositories to the guidelines, coupled with the technical functionalities of the proposed GKC platform, will ensure this.

c) The backing of the IWG, and particularly the fact that the members of the Task Force are promoters of the major repositories of information and knowledge in the m-eHealth space, are strong drivers for widespread adoption, and hence the future success, of the Global Knowledge Commons.
Annexes

Annex 1: Concept Note − Global Knowledge Commons for Innovation in Health: a global repository and knowledge sharing platform

It is recommended that a task force be created within the IWG to address the issue of information and knowledge sharing on a global scale.

Purpose

The purpose of the task force will be to agree on guidelines to be followed by repositories of information and knowledge relevant to innovation in health.

Rationale

The potential for innovations, particularly in m-eHealth, to improve health is increasingly undisputed. However, there is a dire need for innovations that have proved successful to be shared more widely and replicated. In the absence of a global mechanism for such sharing of information and knowledge, much effort is unknowingly invested in reinventing the wheel, in the form of proofs of concept and pilot projects.

A networked repository of intelligence, which we call the “m-eHealth Knowledge Commons” will provide not only a dashboard by geography, thematic area and actors, but will also avoid duplication, and lead to better use and re-use of m-eHealth experience. Furthermore, the Commons will facilitate the development of new knowledge as well as the reinforcement of partnerships.

Scope

The initial focus will be on m-eHealth. As the boundaries of m-eHealth are quite fluid, this will naturally extend to other
innovations beyond m-eHealth; hence the Commons will cover innovation in health in general. Moreover, the outcomes of the m-eHealth focus on repositories will benefit and inform other innovations encountering the same challenge.

The Commons will document information and knowledge in a format that makes them retrievable through a network of structured repository nodes, based on existing repositories. Particular emphasis will be placed on the user’s perspective in developing the Commons.

The task force will strike a balance between wider inclusion of many sources of information, and the challenge of managing the process to a rapid conclusion – agreement of guidelines for all repositories to follow. The nodes of the Commons will grow organically as nodes that agree to the guidelines join the network.

**Records**

The three major components of the m-eHealth Knowledge Commons are:

a) a database of projects, products and services – with descriptions in a standardized format that is conducive to indexing and classification, and amenable to electronic searching;

b) a “Who is who in eHealth” – listing individual experts and institutions; and

c) a knowledge resources repository – reusable m-eHealth knowledge objects, in various formats such as articles, presentations, videos, etc.
Task force members

<table>
<thead>
<tr>
<th>Institution</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Center for Health Market Innovations (CHMI)</td>
<td>1. Christina Synowiec</td>
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<tr>
<td>European Commission</td>
<td>2. Peteris Zilgalvis</td>
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<td>GSM Association (GSMA)</td>
<td>3. Craig Friderichs</td>
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<tr>
<td>Harvard School of Public Health</td>
<td>4. Marc Mitchel</td>
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<tr>
<td>Health Ingenuity Exchange (HingX)</td>
<td>5. Ann Green</td>
</tr>
<tr>
<td>International Society for Telemedicine and eHealth (ISfTeH)</td>
<td>6. Yunkap Kwankam</td>
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<tr>
<td>International Telecommunications Union (ITU)</td>
<td>7. Hani Eskandar</td>
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<tr>
<td>Kaiser Permanente</td>
<td>8. Jaime Ferguson</td>
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<td>mHelp</td>
<td>9. Patty Mechael</td>
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<td>USAID</td>
<td>10. Adam Slote</td>
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<tr>
<td>WHO</td>
<td>11. Misha Kay</td>
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<tr>
<td>WHO</td>
<td>12. Garrett Mehl</td>
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Co-Chairs: Yunkap Kwankam and Marc Mitchel.

Technical options

Two main technical options for sharing and exchange of records are:

1. Tagging – metadata on projects described in varying formats
   • agreed common taxonomy, structure and user interface for such tagging;
   • applicable to both old and new records (it is also easier to retroactively tag old records).

2. Use of a common framework to describe records in repositories
• agree common taxonomy, structure and user interface;
• applicable to new records, with a significant effort required to restructure old records).

These technical issues are part of the work to be addressed by the task force. Efforts could build on the work done in describing mHealth projects for RMNCH by Labrique et al.

**Roadmap to the Commons**

The Commons will build on the work already done by organizations and institutions such as those listed below:

1. WHO Global Observatory for eHealth ([www.who.int/goe](http://www.who.int/goe))
2. mHealth Alliance’s Health UnBound
3. Health Ingenuity eXchange ([www.hingx.org](http://www.hingx.org))
4. GSMA mHealth Tracker
5. ISfTeH’s Med-e-Tel knowledge repository ([www.medetel.lu](http://www.medetel.lu))
8. Grand Challenges Canada ([www.grandchallenges.ca](http://www.grandchallenges.ca))
10. International Telecommunications Union WSIS stock-taking database ([http://groups.itu.int/stocktaking/Database/SearchDatabase.aspx](http://groups.itu.int/stocktaking/Database/SearchDatabase.aspx))
11. International Society for Telemedicine & eHealth database of 20,000 eHealth specialists and institutions ([www.isfteh.org](http://www.isfteh.org))
Additional sources (sites that list mHealth projects and research)

1. https://www.mhealthevidence.org/
2. pubmed
Annex 2: Overview of key existing repositories

1. WHO Global Observatory for eHealth - [www.who.int/goe](http://www.who.int/goe)
a. What is it?
   i. An information portal, with a core goal to provide Member States with strategic information and guidance on effective practices and standards in eHealth
b. Important data elements include:
   i. Country
   ii. Policy
   iii. Language
c. Materials for the GKC library:
   i. Global survey questionnaire and survey results
   ii. Country profiles, survey summary data
   iii. Published reports and articles
   iv. eHealth policies for all member countries

a. What is it?
   i. A free cloud-based knowledge management and community collaboration platform for the health ICT community
   ii. Used by 20 000 people from 180 countries
b. Components:
   i. Content cloud
   ii. Team coordination
   iii. Knowledge exchange
   iv. Community collaboration
c. Core features:
   i. Global registry with configurable ontology
   ii. Repository
   iii. Social networking
   iv. Project management tools
   v. Custom private/public collaboration clouds

d. Materials for the GKC library:
   i. 1665 reusable resources
   ii. 150 projects
   iii. 77 groups (organizations)
   iv. 836 members with configurable profiles

3. **GSMA mHealth Tracker**

a. What is it?
   i. The GSMA mHealth Tracker is a customized tool which collates mobile health products and services around the globe. It tracks solutions in the planning phase as well as those which have been commercially deployed

b. Core features:
   i. Interactive map
   ii. Ability to search by country, organization, type, category and status

c. Materials for the GKC library:
   i. 1157 deployments (projects) populated by mHealth services
   ii. Alphabetically ordered list of organizations and their respective country of origin
iii. Information regarding organization function, status, launch year, health-sector role, category, target population, business model, device consideration, technology class

4. **ISfTeH - International Society for Telemedicine & eHealth** - [www.isfteh.org](http://www.isfteh.org) and [http://www.medetel.eu](http://www.medetel.eu)

   a. What is it?

      i. An organization with a mission statement to facilitate the international dissemination of knowledge and experience in telemedicine and eHealth, and providing access to recognized experts in the field worldwide

      ii. The ISfTeH working groups offer ISfTeH members an opportunity to network, discuss and exchange information on specific topics

   b. Core features:

      i. The ISfTeH working groups offer ISfTeH members an opportunity to network, discuss and exchange information on specific topics

   c. Materials for the GKC library:

      i. 14 working groups (projects)

      ii. Members comprise national, corporate, institutional and associate groups. Each is listed by country of origin

      iii. Knowledge resources, such as conference presentations, HealthTech Wire newsfeeds, calendar of events, member announcements

   a. What is it?
      i. An aggregated portal that serves as a trustworthy gateway to a wide range of information and data on health-related issues and activities at European, national and international levels
      
      ii. The content is produced by the European Commission, the Member States of the EU and the European Economic Area (EEA), plus EU candidate countries; by international organisations, and by pan-European non-governmental organizations in the area of public health

   b. Materials for the GKC library
      i. Projects: 9 Project listings with links to further information
      ii. Within portal - 5 listed NGOs, 3 listed international organizations
      iii. 13 key documents
      iv. 11 press publications

6. **Center for Health Market Innovation**

   a. What is it?
      i. CHMI’s digital platform provides a way for people to learn about and connect with programmes striving to improve the health of the world’s poor
b. Core features:
   i. Interactive map, downloadable data and ability to edit programme information online. Fixed set of fields
   ii. Not only for eHealth
   iii. Ability to search for content using various fields, such as countries and health focus
   iv. Mix of curated data and data contributed by users

c. Materials for the GKC library:
   i. Projects: 463 programmes for health ICT
   ii. Additional projects that span beyond health ICT
   iii. Each project has listed parent organizations (usually multiple per project)
   iv. Document library: 10 documents on health ICT, more on other aspects of public health
   v. 31 blog posts
   vi. Data visualizations for programme funding, programme focus

7. **Grand Challenges Canada** - [www.grandchallenges.ca](http://www.grandchallenges.ca)
   a. What is it?
      i. Grand Challenges Canada is dedicated to supporting Bold Ideas with Big Impact® in global health. It is funded by the Government of Canada and supports fund innovators in low- and middle-income countries and Canada
b. Core features:
   i. Ability to browse projects and innovators
   ii. Proposal development resources, polices and publications
   iii. Not only for eHealth

c. Materials for the GKC library:
   i. 79 projects for health ICT
   ii. Community: Government of Canada
   iii. Proposal development resources
   iv. Policy documents

   a. What is it?
      i. The eHSCG is a platform to promote stronger coordination among the key players in all technical areas of e-health standardization

b. Core features
   i. Set of curated materials for member organizations

c. Materials for the GKC library:
   i. List of organizations
   ii. Standards lists in PDF format

9. WSIS Stocktaking - [http://groups.itu.int/stocktaking/Database/SearchDatabase.aspx](http://groups.itu.int/stocktaking/Database/SearchDatabase.aspx)
   a. What is it?
i. A register of activities carried out by governments, international organizations, the private sector, civil society and other entities

ii. **Not only on eHealth**

b. **Core features:**
   i. **Project-centric view**

c. **Materials for the GKC library:**
   i. **12 projects related to eHealth**
   ii. **Over 630 projects related to health**
   iii. **Organizations, with country of origin and World Summit materials**

10. **WIPO** - [www.wipo.int](http://www.wipo.int)
   a. **What is it?**
      i. The global forum for intellectual property services, policy, information and cooperation
   b. **Core features:**
      i. File, manage or search patents, trademarks, designs and appellations of origin.
   c. **Materials for the GKC library:**
      i. Links to documents, country profiles, case studies, etc.
      ii. Publications on eHealth

11. **USAID mHealth Evidence** - [mhealthevidence.org](http://mhealthevidence.org)
   a. **What is it?**
      i. The portal was designed to bring together the world’s literature on mHealth effectiveness, cost-effectiveness and programme efficiency
b. Core features:
   i. Library of curated content.
   ii. Ability for users to submit materials for review
   iii. List of taxonomy fields available

c. Materials for the GKC library:
   i. Currently indexing almost 6000 global evidence sources
   ii. K4Health provides additional information, such as toolkits, events, resources and blogs


a. What is it?
   i. The portal comprises more than 24 million citations for biomedical literature from MEDLINE, life science journals and online books. Citations may include links to full-text content from PubMed Central and publisher websites

b. Core features:
   i. Free text search through library of articles. Not all articles are publicly available

c. Materials for the GKC library:
   i. Over 1000 articles on health ICT


a. What is it?
The objective of the compendium series of innovative medical devices, assistive devices and eHealth solutions is to provide a neutral platform for technologies which are likely to be suitable for use in less resourced settings.

b. Core features:
   i. Validated WHO content
   ii. Country data

c. Materials for the GKC library:
   i. List of medical devices for eHealth
   ii. Description of programmes


   a. What is it?
      i. Provides the portal for general health care-related blogs

   b. Materials for the GKC library:
      i. Some blogs on mobile health


   a. What is it?
      i. Event portal for the eHealth community. Knowledge resource section provides references of the presentations that have been made at Med-e-Tel throughout the past years

   b. Core features:
      i. The information is available sorted per year, topic and country, and also includes
a list of evidence-based telemedicine/telehealth experiences

c. Materials for the GKC library:
   i. Presentations from prior events

   a. What is it?
      i. A collection of information targeted at providers & professionals, patients & families, and policy researchers and implementers.
   b. Core features:
      i. Information for providers and professionals has a wide selection of validated and curated resources
   c. Materials for the GKC library:
      i. Several research projects and programmes
      ii. Guides, case studies, EHR implementation resources
      iii. Information for policy researchers and implementers

   a. What is it?
      i. HIMSS is a cause-based, global enterprise producing health IT thought leadership, education, events, market research and media services around the world
   b. Core features:
      i. Library of curated resources, industry research papers, podcasts
c. Materials for the GKC library:
   i. Resource library, searchable by topic and sub-topic
   ii. Newsletters
   iii. Membership network for global health ICT professionals

18. Institute Of Medicine - www.iom.edu
   a. What is it?
      i. The Institute of Medicine (IOM) is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision-makers and the public
   b. Core features:
      i. More than 2000 individuals work on the studies that IOM undertakes. A collection of 540 Consensus and 356 workshop summaries
   c. Materials for the GKC library:
      i. 2000 contributing individuals
      ii. Over 900 reports

19. mRegistry - http://www.mregistry.org/
   a. What is it?
      i. A global repository of mHealth implementations
   b. Core features:
      i. mRegistry.org provides a way for projects to submit descriptions of their mHealth approaches to the central mHealth
Registry, from where a unique ID will be issued. This unique ID will be linked by a variety of partner organizations as a unique reference to the specific mHealth implementation

c. Materials for the GKC library:

i. List of projects and associated documents
Annex 3: GKC for m-eHealth – Registry Profile Questionnaire

General information

- Address:
  Registry URL:
- Registration URL:
- Email:

Content

1. Does the registry accept prospective registration of m-eHealth initiatives submitted by responsible registrants?

2. Is the registry open to all prospective registrants, either internationally, or within one or more specific countries?
   - 2.1. From which countries will the registry accept projects for registration?
   - 2.2. If the registry is not open to ALL registrants (that is, it accepts projects only from a particular sponsor, health care condition (e.g. cancer), intervention, etc.) please specify which projects the registry is open to.

3. Is the registry able to collect and publicly display the GKC initiative registration data set?

4. Does the registry endeavour to keep registered information up-to-date?
   - 4.1. Does the registry have a reminder system to facilitate the submission of updated information by the responsible registrant?
   - 4.2. Does the registry highlight or flag records that are not current (have not been updated in more than 12 months) so users are aware that
information contained in such records may not be current?

• 5. Does the registry always keep the record of an initiative once it has been registered?

Quality and validity

• 6. Does the registry have a mechanism in place to ensure the validity of the registered data?

  o 6.1. Does the registry contact responsible registrants when one or more items in the GKC initiative registration data set are incomplete or potentially inaccurate?

  o 6.2. Does the registry have documented standard operating procedures (SOPs)?

  o 6.3. Are there mechanisms in place to ensure compliance with these SOPs (e.g. staff training)?

  o 6.4. Please briefly describe these compliance mechanisms.

• 7. Does the registry maintain a publicly accessible audit trail so changes made to the GKC initiative registration data set for an individual initiative can be tracked?

• 8. It is desirable that registries participate in the further development of the International Standards for GKC Initiative Registries. Does the registry agree to participate in the development of these standards?

Accessibility

• 9. Is the GKC initiative registration data set accessible to the public at no charge?

• 10. Is the GKC initiative registration data set electronically searchable?
11. Is the GKC initiative registration data set available in English?

12. Can registrants submit an initiative for registration at any time of day on any day of the week (24 hours a day, seven days a week)?

13. Can the register be searched at any time of day on any day of the week (24 hours a day, seven days a week)?

14. It is desirable that the GKC initiative registration data set be available in the language(s) of the countries served by the registry. Please indicate the languages in which the registered information is displayed.

   14.1. If initiatives are registered in more than one language, does the registry check the quality of translation?

15. What quality control measures does the registry have in place to make sure that all items in the GKC initiative registration data set are as complete and accurate as possible?

Unambiguous identification

16. Does the registry have processes in place to prevent the registration of a single trial more than once on their register?

   16.1. Briefly describe these processes.

17. Does the registry agree to facilitate the retrospective linking (or bridging) on the GKC search portal of a single initiative registered with more than one registry by encouraging responsible registrants to enter secondary identifiers, including the UIN?

18. Does the registry agree, as part of the registration process, to search the GKC search portal to ascertain if the trial has already been registered on another WHO primary registry?
Technical Capacity

- 19. Does the registry agree to submit the GKC initiative registration data set for all records on the registry?
  - 19.1. Does the registry regularly submit data to the GKC initiative registration platform (GKCIRP)?
- 20. Does the registry have access to a database that is used to store and manage the submitted data?
  - 20.1. If not, please provide details of the database that will be used and where it is based.
  - not applicable
- 21. Does the registry have access to adequate information technology support?
- 22. Does the registry have adequate security and other provisions against data corruption/loss?

Administration and governance

- 23. What is the remit of the registry (e.g. national, regional, international)?
  - 23.1. From which countries does the registry have the remit to act as their primary registry?
- 24. Does the registry have a letter of support from the relevant Ministry of Health or other agency?
  - 24.1. Specify the names of the government agencies that have given their support.
- 25. Does the registry publicly disclose ownership, governance structure and for-profit/not-for-profit status?
  - 25.1. Indicate the web address where this information is displayed.
- 26. Is the registry managed by a not-for-profit agency?
• 27. Should the register cease to function, does the register agree that at least the GKC initiative registration data set for all trial records will be transferred to another GKC register?
  o 27.1. Does the registry agree to inform the GKCIRP of changes that may be relevant to its status as a GKC registry?
• 28. It is desirable that registries have a strategy in place addressing the medium- to long-term sustainability of the registry. Does the registry have such a strategy in place?
• 29. Other governance information:
  o 29.1. What is the name of the agency (or agencies) that fund the registry?
  o 29.2. What is the name of the agency that manages the registry?
  o 29.3. Is the agency that manages the registry a for-profit agency?
  o 29.4. If the agency is for-profit, is the data on the register (database) also available on a registry that is managed by a not-for-profit agency?
  o 29.5. If the answer to 29.4 is “yes”, please specify the name of the additional registry.
  o 29.6. Please describe any other ownership or governance issues of relevance to the register (e.g. does the register have an Advisory Board. If so, what is its role?).
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>EC</td>
<td>European Commission</td>
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<tr>
<td>GKC</td>
<td>Global Knowledge Commons</td>
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<td>GOe</td>
<td>Global Observatory for eHealth</td>
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<td>GSMA</td>
<td>GSM Association</td>
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<td>HON</td>
<td>Health on the Net</td>
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<td>ICT</td>
<td>Information and Communication Technology</td>
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<td>ISfTeH</td>
<td>International Society for Telemedicine and eHealth</td>
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<tr>
<td>IWG</td>
<td>Innovation Working Group</td>
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<tr>
<td>MDGs</td>
<td>Millennium Development Goals</td>
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<tr>
<td>MNCH</td>
<td>Maternal, Newborn and Child Health</td>
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<tr>
<td>PMNCH</td>
<td>Partnership for Maternal Newborn and Child Health</td>
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<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>WHO</td>
<td>World Health Organization</td>
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