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Small Steps Towards European Research Projects based on FLOSS principles - a case study.

Dr Tom Kane
Centre for Social Informatics
Edinburgh Napier University
t.kane@napier.ac.uk

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Closed-Source Business Model

eHealth Transformation project (£200million) – went live 26 October, 2014. First end-to-end installation of Epic in Europe… By November 2014 – serious problems being reported. Hospital placed in September 2015 Cambridge University Hospitals NHS Foundation Trust … put into "special measures" by health regulator Monitor, after over-spending an average of £1.2m a week. Epic system implicated.

Hospital eventually left special measures in January 2017, 16 months later.

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Wisdom from Setbacks… Case for FLOSS4eHealth

- All developed countries have knowledge of failures that could have been avoided, or solutions which could have been better right from the start.

- Bringing this knowledge to developmental work with partners in the developing world would be of great benefit.

- First Stage of Project Work: Learning from Previous Installation Work

Open-Source … IMS MAXIM…

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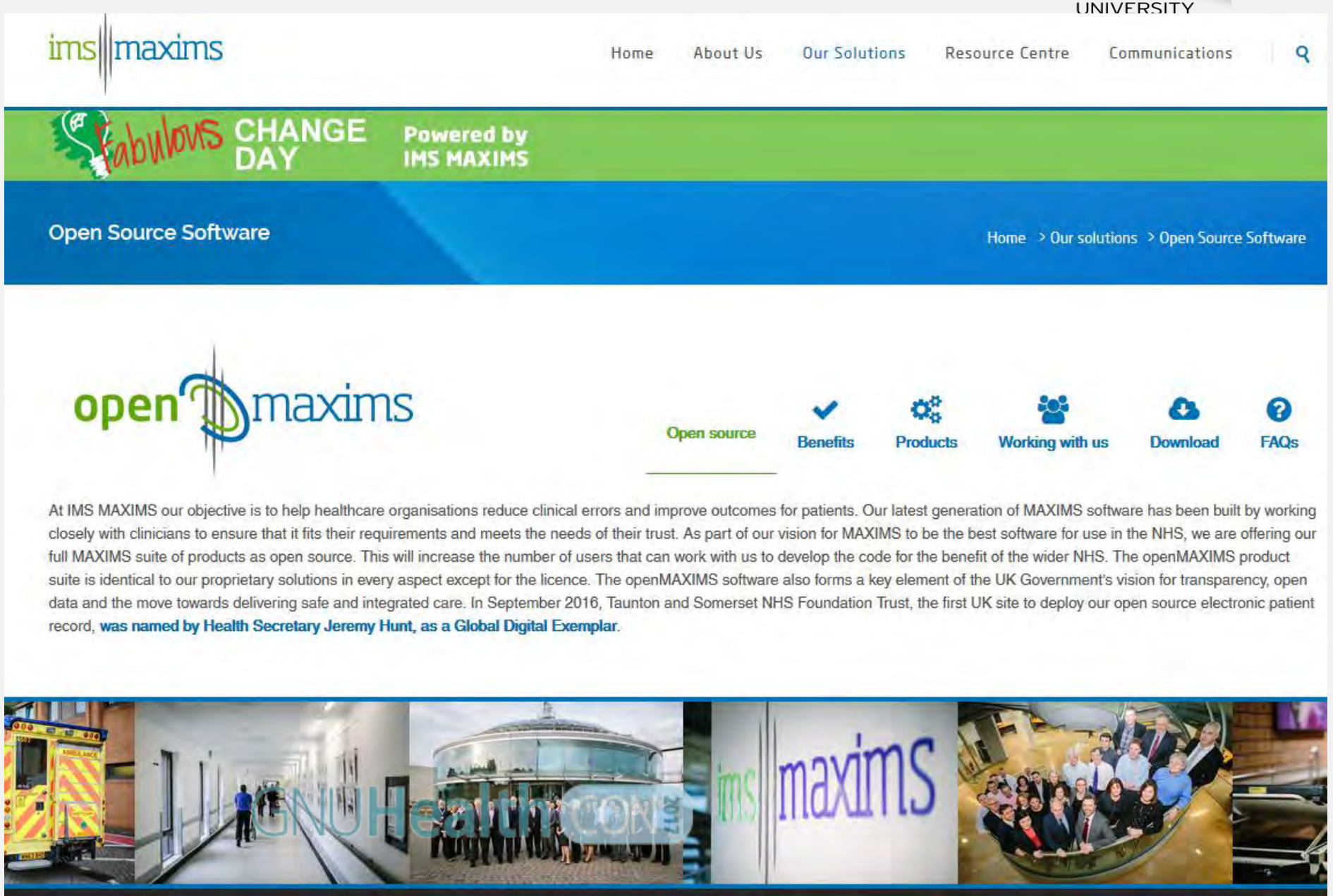
- £45 million software, made open-source
- In 2016, 8 million patient records loaded without a glitch, 7 done by hand
- Contract between company and NHS Digital
- Good money made by IMS Maxim



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Open Source Clinical Application Resource (OSCAR)

A suite of electronic health applications, including

Electronic Medical Records
Social Network for Medical Purposes
Clinician Information Resources
A self-check-in facility for Patients
An interoperability portal

Open-Source Licence operated and money made by McMasters University
Good income stream for development (donations) and support options (purchase).

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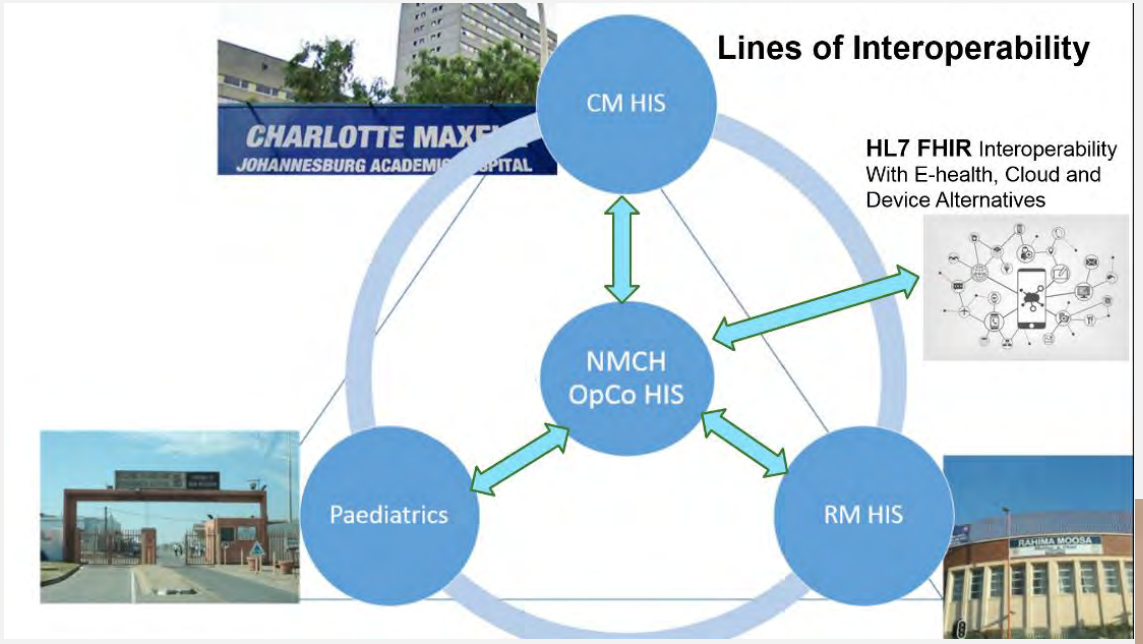
FLOSS4eHealth

Free/Libre and Open Source Software for eHealth Solutions to Satisfy National Healthcare Priorities in the Developing and the Developed World

- GNU Solidario
- Two Universities
- One International Society
- Two International Implementers



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FLOSS4eHealth for Bringing Free Software to National Procurement Competitions

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Development of a FLOSS Business Model Canvas, looking to future scenarios, involving commercial and non-commercial stakeholders, exploring by means of an empathy map the production of a GNU Health Business Model for implementation of eHealth solutions in the Developing World, addressing:

- Stakeholders?
- Values, What Values?
- What aspects of FLOSS and Gnu Health values can translate on to Economic scales?
- International Win-Win Partnerships
- How to establish technical trustworthiness, professional support?
- How to respectfully cost consultant expertise? Operational expertise?
- How to use specific scenarios to courageously explore the development of a bespoke GNU Health-friendly Business Model for any developing country wishing to employ it?
  - What are Appropriate Procurement Scenarios?
  - Societal Scenarios?

Research Questions:

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1. What are optimal value systems and conditions for the implementation of a sustainable business model for the national implementation of free software solutions in eHealth?
2. What are the issues involved in the co-design and co-creation of civic systems and services to support citizen's health?
3. What are the issues of the design and use of health informatics that rely on mobile computing technologies that cross a number of communication devices and channels?
4. What are the issues of security, privacy, governance and ownership of data about people in health care information systems?
5. What are the issues involved in procurement of FLOSS solutions, the use of open source software and the business models for sustainable citizen informatics?
6. What are the routes of economic growth and wellbeing from socialized medicine?
7. What are appropriate medical and nursing solutions to health care issues in poor, displaced or otherwise unstable societies?
8. What are the issues concerning social media, news, opinion and content development and deployment for citizen and civic informatics?

Tubitak

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- The **Scientific and Technological Research Council of Turkey** is a national agency of Turkey whose stated goal is to develop "science, technology and innovation" (STI) policies, support and conduct research and development, and to "play a leading role in the creation of a science and technology culture" in the country. TÜBİTAK was founded in 1963 as an autonomous public institution, governed by a Science Board.
- TÜBİTAK develops scientific and technological policies and manages R&D institutes, carrying on research, technology and development studies in line with "national priorities". TÜBİTAK also acts as an advisory agency to the Turkish government and acts as the secretariat of the Supreme Council for Science and Technology, the highest science and technology policymaking body in Turkey. Through monitoring and evaluating national and worldwide STI policies and by performing or commissioning research on policy making formulation methods, TÜBİTAK prepares STI policy proposals and carries out studies.

FLOSS4eHEALTH Work Activities

SOFTWARE AND HARDWARE INTEROPERABILITY

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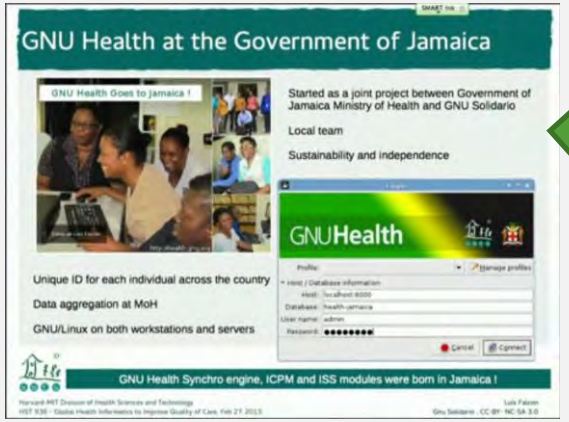
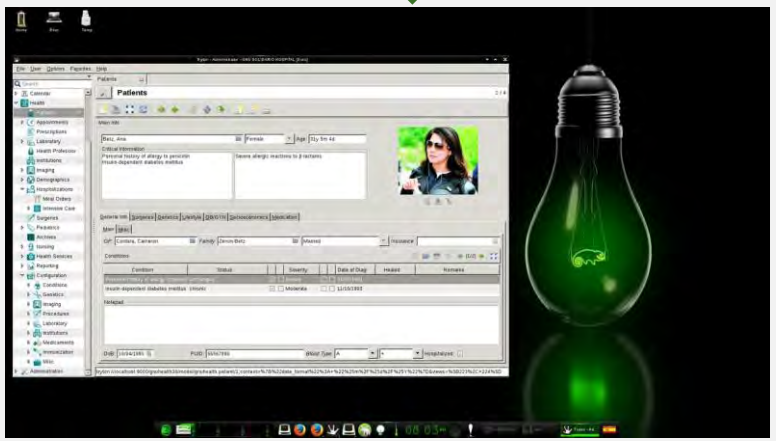
INTERNATIONAL PARTNERSHIPS



WP 3

NATIONAL IMPLEMENTATION TEAMS

WP 4

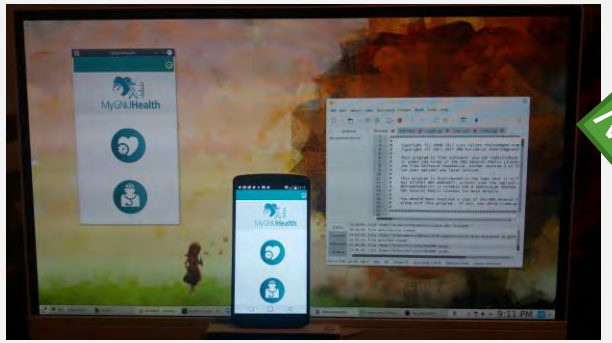


WP 5

GNU Solidario

LAOS

SWAZILAND



WP 2

NATIONAL PARTNERSHIPS & CIVIC CO-CREATION

ISfTeH International Society for Telemedicine & eHealth

Univerza v Ljubljani

GNUHealth

WP 7

PROJECT MANAGEMENT

WP 6

INNOVATION MANAGEMENT

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FLOSS4eHealth 7 Objectives – 1-3

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OBJECTIVE NO 1

- Civic partnerships for co-creation of multi-dimensional value definitions need to be placed on an economic model that allows economic growth to be monitored and measured.

OBJECTIVE NO 2

- Development of business models for FLOSS, encompassing multi-dimensional value systems, that bring FLOSS solutions to the procurement competitions of national implementers of government policy. Addressing the legal, ethical, professional and technical requirements of procurement competitions, as specified by national implementers

OBJECTIVE NO 3

- Creation of contractually responsible FLOSS4eHealth Local Implementation Teams, via contractual requirements, Invitation-to-tender, and business viability modelling for employment by national policy implementers. Specification, implementation and validation of FLOSS solutions for Laos and Swaziland with associated BMs, etc.

FLOSS4eHealth 7 Objectives – 4-7

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OBJECTIVE NO 4

- Implementation Support Service. Provision of training services, software interoperability services, hardware integrations.

OBJECTIVE NO 5

- Provision of a sustainability model to serve the needs of all relevant stakeholders in FLOSS4eHealth across governmental, political, economic, professional, and societal domains.

OBJECTIVE NO 6

- Establishment of international collaboration and partnerships in FLOSS implementations between neighbouring countries, and countries across the world

OBJECTIVE NO 7

- To ensure that FLOSS4eHealth is managed and delivered in line with the Grant Agreement and the Consortium Agreement.

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Participants

Participant No *	Participant organisation name	Country
1 (Coordinator)	**Edinburgh Napier University (ENU)**	UK
2	**GNU Solidario (GS)**	Spain
3	**University of Ljubljana (UL)**	Slovenia
4	**International Society for Telemedicine and eHealth (ISfTeH)**	Switzerland
5	**FHT Consultancies (FHT)**	Swaziland
6	**Calat ICT (CICT)**	Laos

Partnership Skillsets

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	Legal	Social	Medical	Psychology	Care Science	Security	User Interaction Design	Application Development	Architecture	Standardization	Validation	Medical Technology	Requirements Engineering	Health Economy	Digital Media	Commercialization	Modeling	Business and Administration
ENU	X	X	X	X	X	X	X		X	X	X		X	X	X	X	X	
GS		X			X			X	X	X	X	X		X				X
LJUB			X			X	X	X	X	X		X	X		X	X	X	X
ISfTeH	X	X	X	X						X		X		X				
CICT	X					X	X	X			X					X		X
FHT	X		X	X	X											X	X	X

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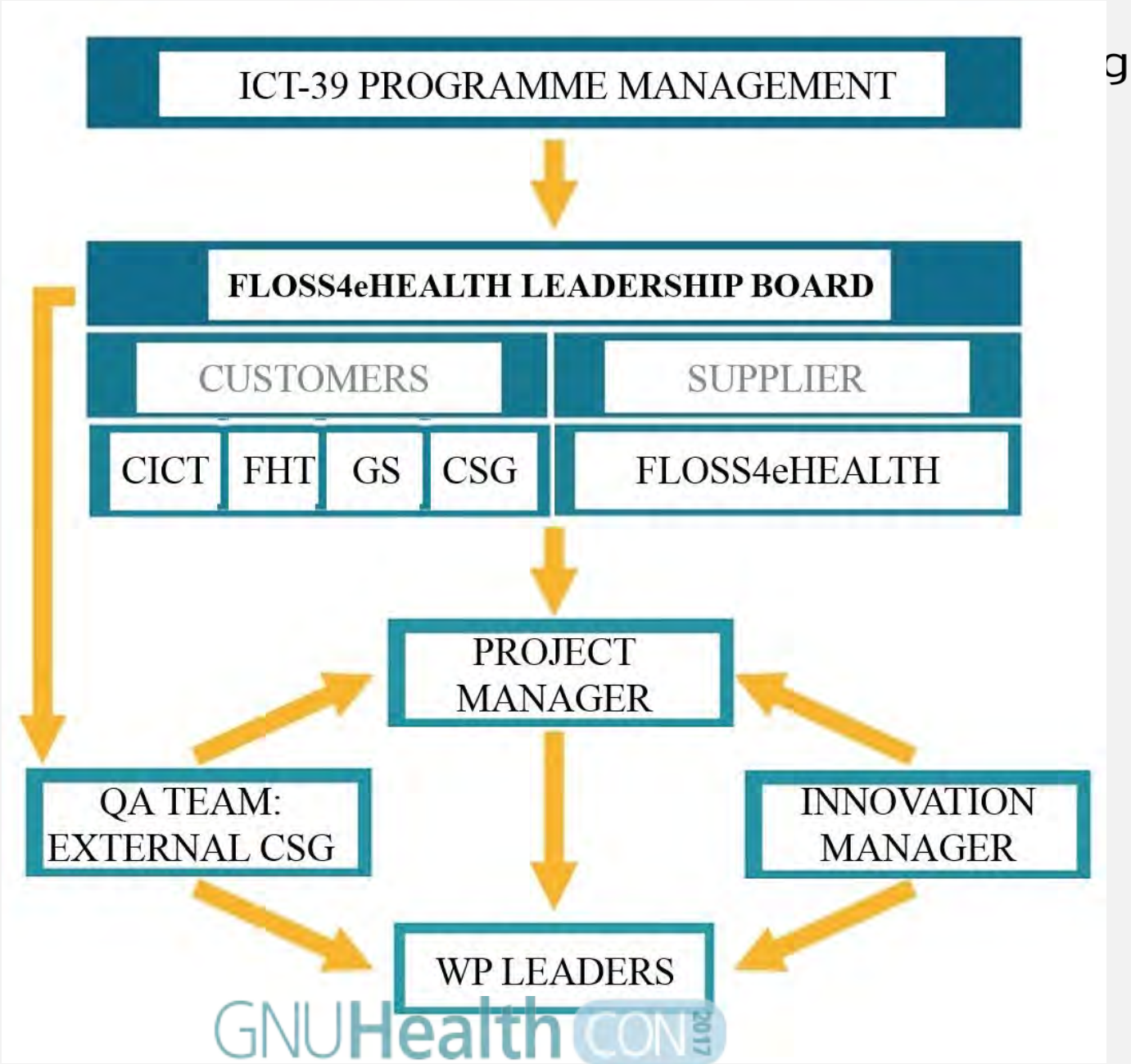
Organisational Structure

All work with GNU Solidario partners through GNU Solidario

All processes set up for payment



Working with EU Project Results …

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SNOMED CT – Interoperability

eHealth Standards and Profiles

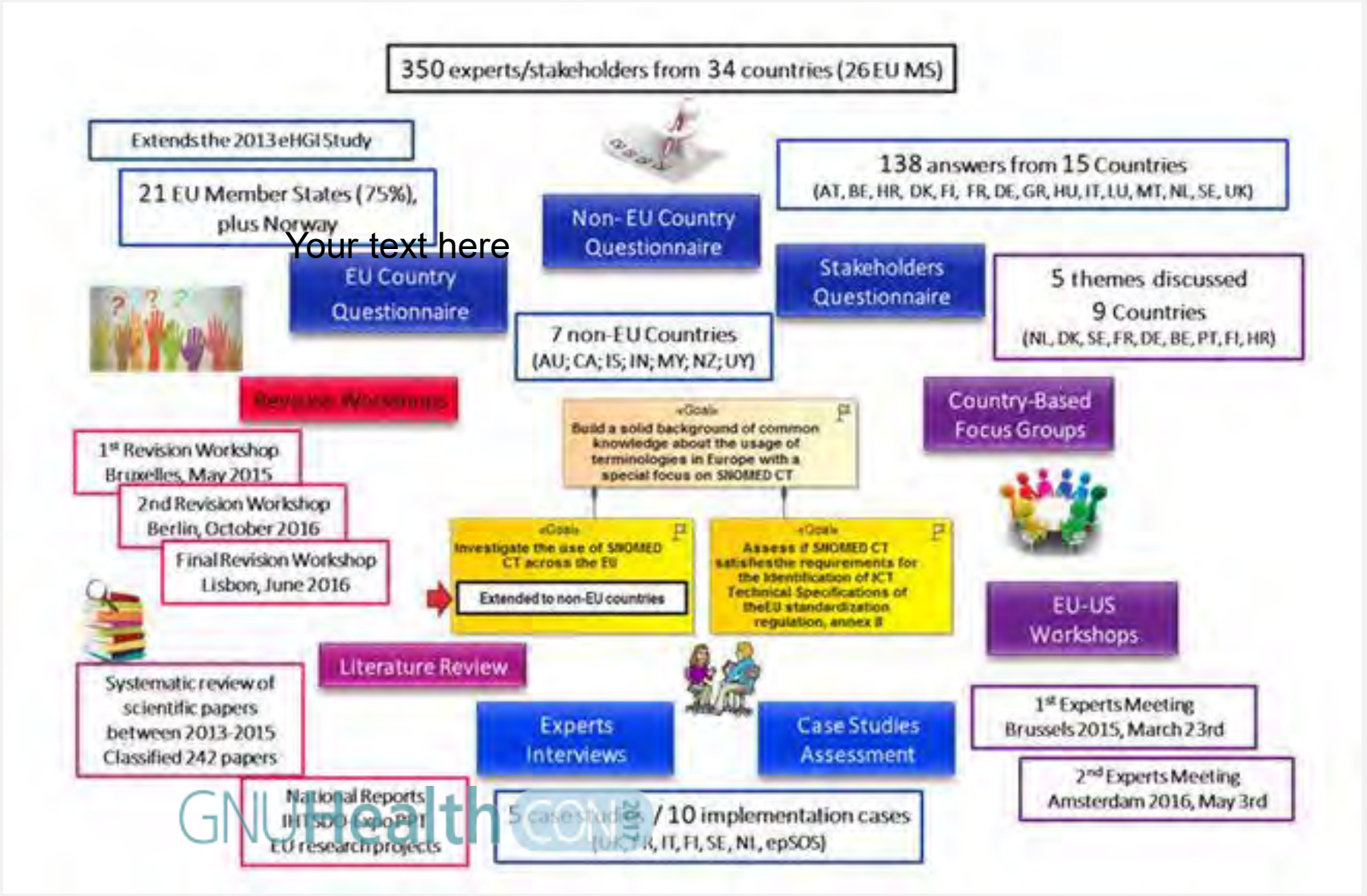
UPSIDE (User-driven Solutions for Innovation in Digitally-Centred Ecosystems)

AFRICA BUILD
Mobile Phones in Africa

VALUeHEALTH
Business Models

PHM ETHICS
Relationships between ethics, law, society, technology

OpenMedicine
CrossBorder Medical Delivery
eHealth Procurors
Understand Procurers needs



Ambition

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CURRENT PRACTICE	FLOSS4EHEALTH
Closed-source software solutions have advantages in procurement competitions that FLOSS solutions lack	Issues of invitation to tender, responsibility and legal requirements will be thoroughly investigated and solutions documented as templates and tools for FLOSS solutions
Governments ordinarily lease, or hire software over a contractual period	An appreciation of the real costs of FLOSS and the skill sets needed along with the support provided by national support centres for interoperability will allow governments to make more informed choices.
Governments have no data to turn to to make judicious estimates in comparing closed-source solutions for particular issues, against FLOSS solutions.	This data will be gathered from the studies of previous implementations in Jamaica and in the UK with further data coming from experiences of the team at McMasters university in Canada. The national support centre will develop software to make data and

Ambition

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CURRENT PRACTICE	FLOSS4EHEALTH
At procurement competitions, monetary values are the most compelling values in decision-making.	The novel concept of the local implementation teams (WP3) will broaden this concept and allow the procurement process to take into account many other factors in their decisions making. Co-creation processes and stakeholder analyses will become an increasingly important factor.
Inadequate economics models force inappropriate attitudes to FLOSS solutions.	Better models will be researched and developed in this project

Response from Commissioning Group

- Excellence (2.5)
- Impact (3)
- Quality of Implementation (2.5)

- Total 8

All between fair and good. Not at very good or excellent.

Projects need 13-15 to be funded, and we were 5 short.

Given where we came from, how long we had, and the fact that 8 is over half-way, we can view this as something to build from. And the criticisms were specific.

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Excellence

The following aspects will be taken into account, to the extent that the proposed work corresponds to the topic description in the work programme:

- **Clarity and pertinence of the objectives**
- **Soundness of the concept, and credibility of the proposed methodology**
- **Extent that proposed work is beyond the state of the art, and demonstrates innovation potential (e.g. ground-breaking objectives,**
- **novel concepts and approaches, new products, services or business and organisational models)**
- **Appropriate consideration of interdisciplinary approaches and, where relevant, use of stakeholder knowledge**

Excellence Feedback – in text and Score… 2.5

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- *The objectives are pertinent to the call but the ideas underpinning the proposal are too broad, lack clarity in terms of their achievability and are insufficiently precise, for instance, Objective 5 "provision of a sustainability model to serve the needs of all relevant stakeholders in FLOSS4eHalth across governmental, political, economic and societal domains. Likewise Objective 3 is described in an overly generic way.*
- *The conceptual ideas are sound and end-users' needs have been taken into account. However, the proposal lacks credibility since the level of detail does not correspond sufficiently to the ambition put forward by the proposal as targeted outcomes are insufficiently defined, e.g. in the area of business models (WP 3).*
- *The innovation potential is described. However, the formulation of the business model addressing all the pertinent issues is unconvincing.*
- *The proposed consortium provides a multidisciplinary approach from academia, SME-entrepreneurs (Opensource Founder), care scientists, medical professionals and representatives from the countries of interest.*
- *Whether there are a sufficient number of resources available given the magnitude of the objectives to be addressed is unclear.*

Impact

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The following aspects will be taken into account:

- **The extent to which the outputs of the project would contribute to each of the expected impacts mentioned in the work**
- **programme under the relevant topic**
- **Any substantial impacts not mentioned in the work programme, that would enhance innovation capacity, create new market**
- **opportunities, strengthen competitiveness and growth of companies, address issues related to climate change or the**
- **environment, or bring other important benefits for society**
- **Quality of the proposed measures to:**
- **- exploit and disseminate the project results (including management of IPR) and to manage research data where relevant**
- **Communicate project activities to different target audiences**

Impact Feedback – in text and Score… 3

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- *The proposed work has the potential to deliver what is expected by the Call.*
- *The proposal could create various other parallel ancillary services required for supporting such deployments, thus creating new opportunities for job creation within healthcare institutions and outside, both profit and non-profit organisations.*
- *However, the proposal lacks a proper assessment on the extent to which the outputs would contribute to each of the expected outcomes mentioned in the work programme of the Call.*
- *Moreover, the proposal is too ambitious to be able to confidently predict tangible impacts given the timeframes and resources, e.g. establishing a National Support Centre for Hardware and Software Interoperability.*
- *The prospects for sustainable uptake of results within the targeted countries are unconvincing.*
- *The choice of the various planned activities for dissemination of project results targeting different types of audiences is adequate.*
- *The exploitation plan is much less detailed than the dissemination plan.*

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Quality and Efficiency of the Implementation

The following aspects will be taken into account:

- **Quality and effectiveness of the work plan, including extent to which the resources assigned to work packages are in line with their objectives and deliverables**
- **Appropriateness of the management structures and procedures, including risk and innovation management**
- **Complementarity of the participants and extent to which the consortium as a whole brings together the necessary expertise**
- **Appropriateness of the allocation of tasks, ensuring that all participants have a valid role and adequate resources in the project to fulfil that role**

Impact Quality and Efficiency – in text and Score… 2.5

Resource allocation to the work packages is unable to be assessed effectively as the work packages lack clarity as to what will be achieved in the various tasks and what each deliverable will contain.

The plan has a number of shortcomings:

-Some deliverables lack clarity. D3.3 (numbered 2.3) Requirement and Templates under WP3 is missing details of what this will address (M24). The same applies to D3.2 (numbered 2.2) End-user workshop design, use and evaluation (M15, M30). The deliverables in WP3 are numbered incorrectly.

-It is unclear how the setting up of a national support centre (ENURI) will be financed in the long term and what will be its legal standing.

-Substantial overlap exists in the objectives of T5.5 examining management, policy and installation issues of existing working models of OSCAR and objectives of T3.1.

-WP6 lacks important details on exploitation and does not provide sufficient information on the tasks covered by this work package.

The management structures and procedures, including innovation management, are appropriate but lack some detail.

Specifically, risk management outlines only a limited number of risks and risk mitigation is unconvincing.

The consortium brings together an interdisciplinary group. Roles are well justified. Local key stakeholders are engaged via the African

Since there is lack of clarity with respect to the composition of tasks for what is a broad proposal, the resourcing to complete these tasks is unable to be assessed properly.

Issues of Our Proposal

- They liked our team mix, they felt our consortium could deliver
- Could see where the project was doing something never done before and pushing the boundaries of what was possible, but felt that not all promises were solidly addressed in how they would be met
- Sustainability of research institutes once they have been established was questioned, the links with international partners were not considered capable of guaranteeing the sustainability
- Plenty of ambition in the project, it wasn't clear how impact and dissemination would be monitored or maximised
- Management plan vague in places and some sections poorly numbered

- Commissioners looking for ambition, clarity, scope, proofs of delivery, quality, dissemination, impact and excellence…
- Not much then… but not impossible either

Positives

- We did it, we submitted a proposal to H2020
- The proposal was taken seriously
- Our partner arrangements were technically and professionally acceptable and respected
- We have a near 100 page project proposal and feedback from H2020 to examine, learn from and improve upon
- We have shown we have a good base of partners to work from
- We can improve our proposals, and it's probably only a matter of time before the benefits of Free/Libre Software for national implementations will be a major research area in research projects

- And Research calls are moving on…

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New International Research Interests

- Demonstration of Achievement and Potential of GNU Health Approach
- Artificial Intelligence and Medical Informatics
- Big Data, Massive Amalgamations of Data-Sets
- Technology and Medical Ethics
- Technology and Economic Models for Sustainability
- New Economic Models, Value for Money

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FLOSS Partnership: Ministry of Health in Jamaica

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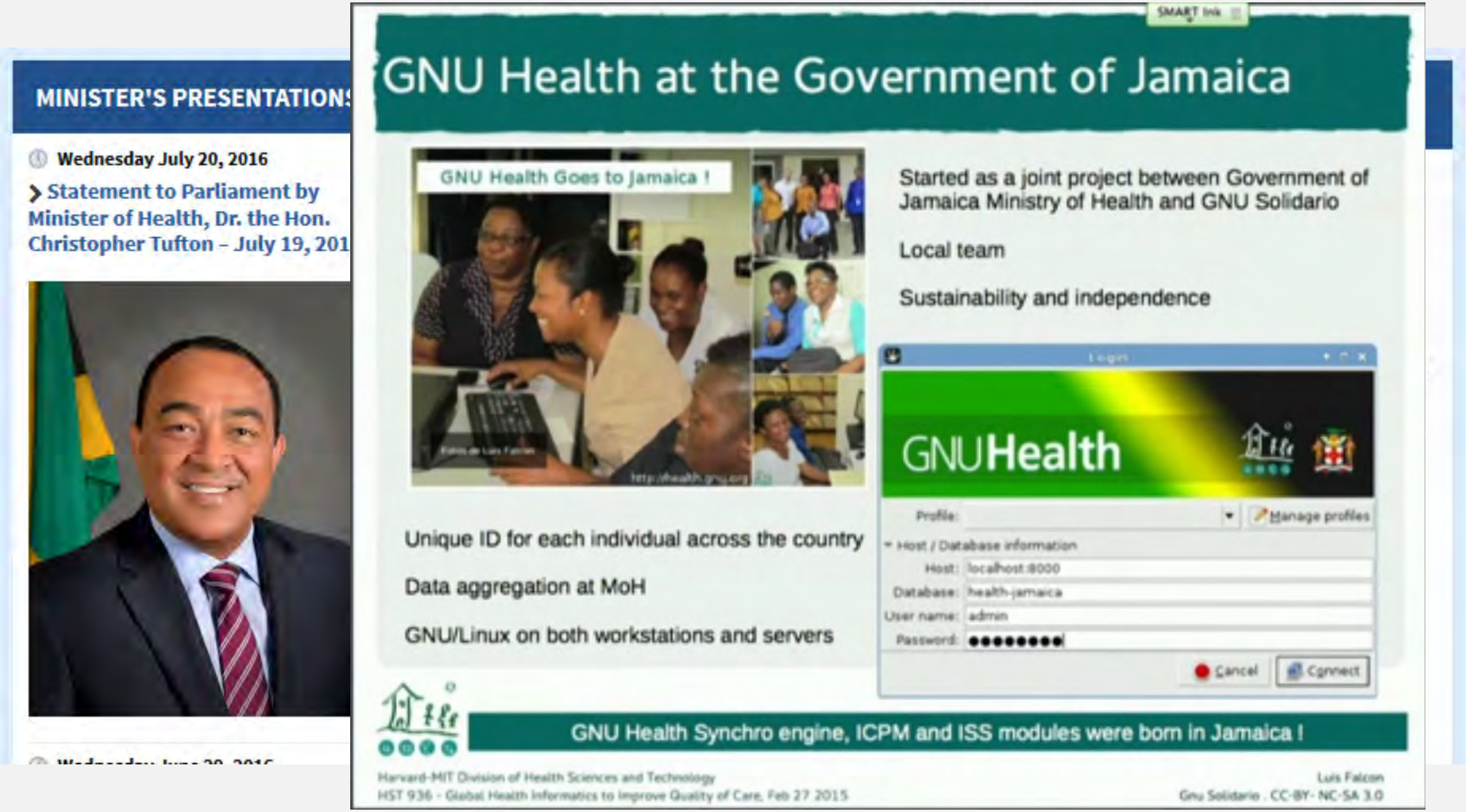

Need to gather data that shows the success of GNU Health in established settings

Need to gather statistics and facts that can be used to present an ethical case for having an alternative economic approach and national ownership over OS and CS solutions.

Question: How to Promote such Partnerships and Ensure Sustainability of GNU Health/Solidario?

Required as evidence for commissioners.

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Ethics and The AI Future

Google-owned artificial intelligence (AI) company DeepMind has access to 1.6 million NHS patients' records. Ensconsed with NHS England. Streams App, Massive Data Amalgations, e.g. care.data – social work, hospital appointments, GP visits

Medical Ethics… As a consequence of some issues, DeepMind now has an Ethics Unit

Ethics built-in to Free/Libre Solutions

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A Case Study – Care.data – NHS England

In 2003, NHS England launched care.data[TBKREF Presser 2015] to combine the healthcare records stored by general practitioners with information stored by social services and hospitals which would be loaded into national Health and Social Care Information Centre (HSCIC) databases. Another aspect of HSCIC databases is the Hospital Episode Statistics which collects and collates data from 125 million individual inpatient, outpatient and Accident and Emergency records yearly in England. All of this data fed into the HSCIC databases. Questions naturally arise regarding live data ownership.

Massive Data Amalgamations and Business Ethics

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This combined information was a valuable research resource for such tasks as resource allocation and monitoring of treatment effectiveness. Controversially, the combined data was used for other purposes, and was made available to pharmaceutical companies, insurance companies, health charities, hospital trusts, think-tanks and other private companies. In 2014, as part of an audit of sales, it was disclosed that anonymous, pseudonymous and identifiable data was sold to at least 160 organisations.

Regarding anonymous and pseudonymous data, Article 29 working party[TBK REF Art. 29 WP] has specified that “to identify if a person is identifiable account should be taken of all the means likely reasonably to be used either by the controller or by any other person to identify the said person.”

Healthcare charities say it is not possible to anonymise the 125 million records per year of hospital visits data, all patients can be identified, all persons likely to be identifiable.

After opt-outs over 1million, including 40% of GPs, and government scrutiny, care.data was scrapped in 2016. The technological process continues.

Ongoing Work with DeepMind

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- One of the outcomes from the DeepMind work has been the Streams app, which allows clinicians to remain informed of a patient's life signs. This app has been so successful that Taunton and Somerset NHS Foundation Trust and DeepMind Healthcare signed a contract in June 2017 for a 5-year to detect early signs of kidney-failure.
- Taunton and Somerset have been pioneers in the use of Open-Source software, with their contract with IMS Maxim.
- That said, over 1.6 million NHS data records were given to Google, via DeepMind, inappropriately, and it is not clear how the business relationship will develop over the years between DeepMind, Google and NHS England.
- It is encouraging to note the emergence of an ethics unit within DeepMind Health Systems[TBKREF Temperton 2017].
- Questions still exist over how well lessons are learned as technical rollouts proceed and whether pragmatic ICT solutions will prove to be at odds with ethical considerations.

Hippocratic Oath – For People

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“Whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets”.

“I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong-doing.”

What about a Hippocratic Oath for Systems Operating National Health Data, requires scrutiny, medical ethics, and enforcement.

Research Potential: Pursuit of Medical Ethics built-in to Free/Libre Solutions

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Economic Issues

Questions of Artificial Intelligence, Global ICT corporations, Big Data Sets, AI Platforms

European Commission currently calling for European Partner to host an run a European Platform for Artificial Intelligence tools for European Businesses to stay competitive as the AI Disruptions take place

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Anything they can do… we can do… why not?

Embedded Economy, Raworth + Mihotich

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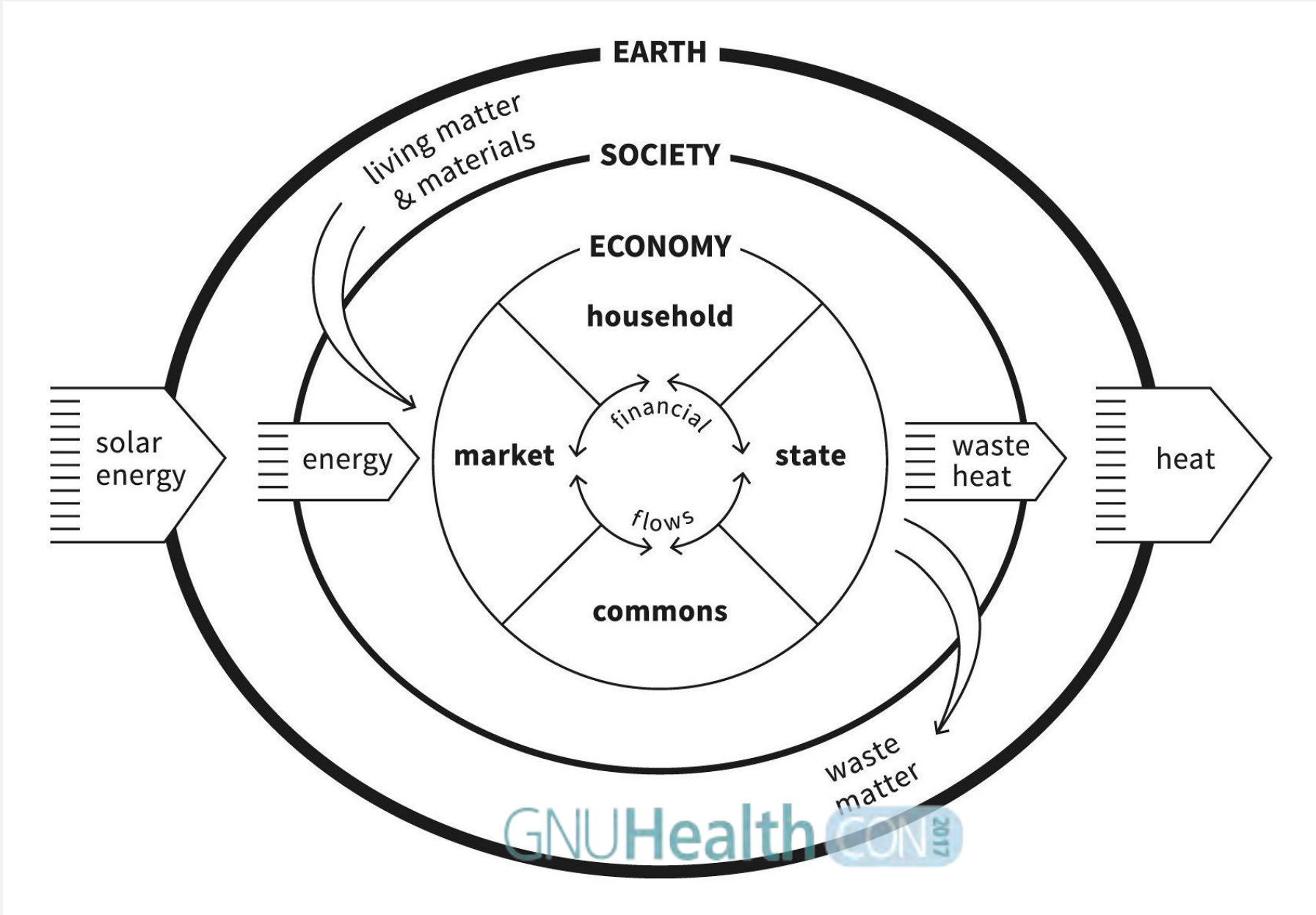

Double Doughnut, Raworth + Mihotich

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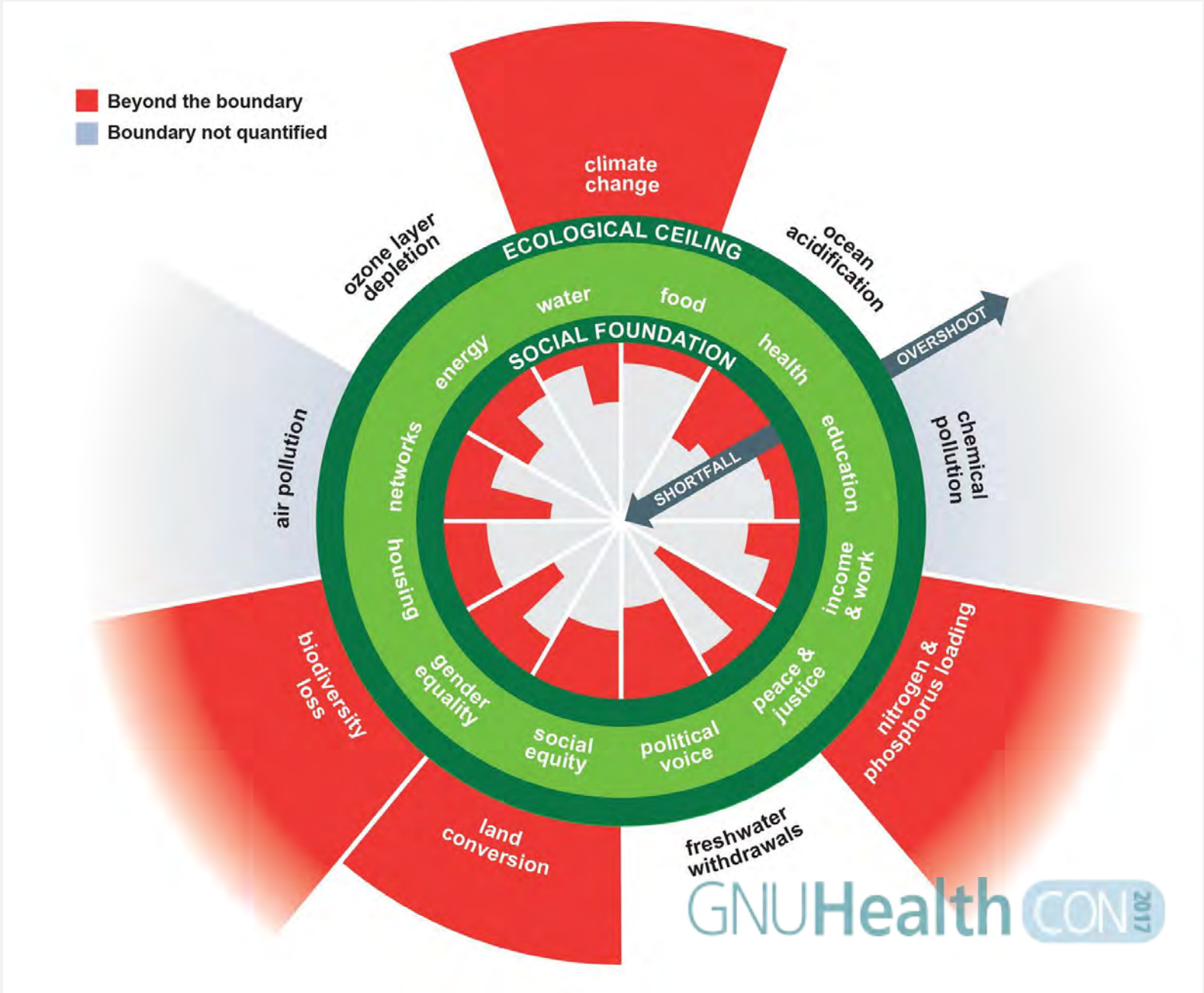

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Given a Multidimensional Grid for Value Definition … a feel for co-creation … a disruptive open-business model such as Apple's… what could we innovate?

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Free/Libre Attractions

Ethics that will be attractive to ethical AI solution providers

- The freedom to run the software as you wish, for any purpose.
- The freedom to study how the software works, and change it so it does your computing as you wish. (Access to the source code is a precondition for this).
- The freedom to redistribute copies so you can help your neighbour.
- The freedom to distribute copies of your modified versions to others. By doing this you can give the whole community a chance to benefit from your changes. Access to the source code is a precondition for this.

GNU Health an exemplary example of marriage to technical capacity and ethical standards.

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Conclusion

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- We reached a significant milestone by submitting a respectable research proposal to H2020 for ICT-39

- There is a need to provide research base results reporting satisfaction with and achievements of F/L approach

- Big Data and Artificial Intelligence issues pose new questions to the Information Society and new opportunities for societal adoptions of ethical F/L approaches – technologically, economically, ethically