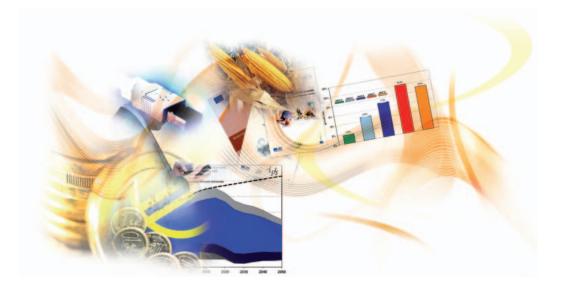
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# Nudging lifestyles for better health outcomes: crowdsourced data and persuasive technologies for behavioural change

Authors: Brigitte Piniewski, Cristiano Codagnone, and David Osimo



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## **Table of Contents**

Preface	5			
Executive Summary				
	9			
Introduction				
1. Thesis One: A tsunami of preventable poor health has hit us	13			
	10			
2. Thesis Two: The tsunami is a lifestyle-induced shift in phenotype	19			
	0.5			
3. Thesis Three: Acute care model fails to counter the tsunami	25			
4. Thesis Four: Health knowledge engines are underperforming	29			
5. Thesis Five: Need of a paradigm shift in policy making	35			
6. The Solution: Crowd-based strategic health intelligence	45			
7. Conclusions and next steps to advance policy	55			
References	63			

# List of Figures

Figure 1:	Thinking in 1964	11
Figure 2:	New thinking and disruptive innovations	11
Figure 3:	Modernisation and health status	13
Figure 4:	Prevalence of obesity (BMI $\geq$ 30) in adult population (20-79)	14
Figure 5:	Crowd health outcomes appear 60-80% preventable	18
Figure 6:	Evolutionary and modernising factors clashing?	22
Figure 7:	Making sense of the health outcomes, spending, and institutional systems	27
Figure 8:	HIT deployment in acute hospitals: EU27 representative sample (2010)	29
Figure 9:	Traditional science data sharing: the tip of the iceberg	39
Figure 10:	Evidence in policy making: today and tomorrow	40
Figure 11:	ICT 'nuts and bolts' in support of paradigm shift	41
Figure 12:	Health crowd sourcing high yield data: high-level functioning model	47
Figure 13:	Proposed policy initiatives and instruments	59

# List of Boxes and Tables

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Evidence Box 1:	The global Insulin Resistance epidemic proxied by obesity and diabetes	15
Evidence Box 2:	Selective estimates of direct and indirect costs	16
Evidence Box 3:	The potential gains from lifestyle modifications	17
Evidence Box 4:	Globalisation of fast-food	20
Evidence Box 5:	Additional lifestyle pressures	21
Evidence Box 6:	Discovery to practice and information explosion	33
Evidence Box 7:	Opportunistic sensing example: Asthmapolis	43
Table 1:	Health outcomes, spending, and obesity in selected countries:	26
Table 2:	Elements for an ICT driven paradigm shift in policy making	44
Vignette Box 1:	Breast Cancer today	45
Vignette Box 2:	Breast cancer rate reduction secondary to policy nudging	46



This report is the result of a collaborative undertaking between Dr. Brigitte Piniewski<sup>1</sup> (PeaceHealth Laboratories and Continua Health Alliance), Cristiano Codagnone<sup>2</sup> (IPTS IS Unit) and David Osimo<sup>3</sup> (formerly at IPTS, IS Unit, and currently at Tech4i2 Limited).

The topic covered, which can be broadly defined as the potential contribution of ICT within a Health 2.0 perspective to prevention for better health outcomes, falls within the scope of research activities carried out during the past three years by the Information Society Unit at IPTS<sup>4</sup> both in the specific domain of eHealth and in that of social computing and public services 2.0.

The Techno-economic Impact Enabling Societal Change (TIESC) Action of IPTS IS Unit manages since 2009 the three-year project Strategic Intelligence Monitor for Personal Health Systems (SIMPHS) and focuses also on prevention and wellness.<sup>5</sup> In the past four years IPTS IS Unit has also carried out extensive research on social computing and public service 2.0 including also on Health 2.0.<sup>6</sup>

It is, thus, clear that this report by focussing on the ICT enabled co-production of better health outcomes through the involvement of users in collaboration with scientists and professionals bridges these two streams of activities within the IPTS IS Unit. Moreover, with its insights into modelling the report also tap into the new modelling activities of the IPTS IS Unit.

The three authors have synergically leveraged their respective expertise and experience to produce this report. Their contributions, and how they relate to their current and past works, are briefly illustrated below.

Brigitte Piniewski has generated the main insight that underpins the core message of this paper: the need of leveraging crowds-based data in order to cope with the Tsunami of poor health that has hit us in recent decades. Moreover, she contributed to substantiate such insight by providing the clinical knowledge supporting it and by highlighting the clinical relevance of crowd-based high yield data intensive modelling to pro-actively prevent the preventable. Dr Piniewski is both the Chief Medical Officer at PeaceHealth Laboratories<sup>7</sup> and Vice Chair for the Market Adoption Working Group at the Continua Health Alliance. In

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<sup>4</sup> IPTS (Institute for Prospective Technological Studies) is one of the 7 research institutes of the European Commission's Joint Research Centre.

<sup>5</sup> See the core deliverable of SIMPHS 1: F. Abadie, C. Codagnone et al, (2010), Strategic Intelligence Monitor on Personal Health Systems (SIMPHS): Market Structure and Innovation Dynamics, available at: http://ftp.jrc.es/EURdoc/JRC62159.pdf.

<sup>6</sup> See for instance in : a) I. Punie et al, eds. (2009), The Impact of Social Computing on the EU Information Society and Economy, available at: http://ftp.jrc.es/EURdoc/JRC54327.pdf; b) I. Punie et al, eds. (2009), Public Services 2.0: The Impact of Social Computing on Public Services, available at: http://ftp.jrc.es/EURdoc/JRC54203.pdf

<sup>7</sup> PeaceHealth is a Bellevue, WA-based not-for-profit health care system with medical centers, critical access hospitals, medical group clinics and laboratories located in Alaska, Washington and Oregon. Founded by the Sisters of St. Joseph of Peace, PeaceHealth has provided exceptional medicine and compassionate care to Northwest communities for more than a century. For more information about PeaceHealth Laboratories, please visit www.peacehealthlabs.org.

these roles, she draws on many years of front line medical practice exposing the urgent need to integrate technologies to drive conscious proactive decision making by households and individuals. Health does not occur in isolation. Crowd based approaches will be the foundation upon which evidenced-based successful policy decisions will forever depend.

Cristiano Codagnone is Senior Scientist, at the Information Society Unit of JRC-IPTS (Seville) where he works TIESC Action on the Strategic Intelligence Monitor for Personal Health Systems (SIMPHS). In the last three years he has focussed his research efforts in the socio-economic analysis of ICT enabled services for prevention and management of chronic diseases, with a particular focus on the evaluation and modelling of their micro and macro level impacts. He contributed to this paper with the sociological, economics, and modelling underpinnings to: a) the critique of supply side efforts; b) the proposed paradigm shift in policy making; and c) the linkage between data, analysis, and behavioural changes

David Osimo, director of Tech4i2 ltd elaborated the three-layered ICT for policy (data, analysis and action), which he adapted and re-elaborated in this report, in the context of the CROSSROAD project,<sup>8</sup> co-funded by the European Commission). He also provided expert insights into how persuasive technologies and serious gaming can work on the less rational elements of human behaviour and, thus, support the behavioural changes needed for crowds to collaboratively co-produce better health outcomes.

<sup>8</sup> See www.crossroad-eu.net.

7

# I Executive Summary

In this paper, the authors discuss the recent decades of preventable poor health that have spread across the globe with Tsunami-like intensity. Despite the massive health impact we are witnessing today, adequate prediction and/or prevention mechanisms remain grossly underdeveloped. Hence this Tsunami continues to threaten the future prosperity of our nations bringing economies throughout the globe to their knees.

Yet, core to this discussion is that preventable poor health is by definition *preventable*. This Tsunami appears almost entirely mediated through unintended consequences of modernisation. In the pure pursuit of profit, we have unwittingly supported the choice architectures that overwhelmingly enable poor lifestyle choices in preference to optimal choices.

The authors then go on to explain why aggressive attempts at improving health care delivery (supply side) has left us remarkably inept at transforming the health as well as the health costs of crowds. This almost singular focus of Health Information Technology (HIT) on care delivery may be largely responsible for the underperformance of our predictive and preventive capacity at this time. Relying on institutional (hospital and clinic) data tracking care delivery to proactively manage the health expression of crowds may be similar to using a rear view mirror to drive a car.

Hence an urgent and paradigmatic shift in public policy making is proposed. Communities and individuals must play a key role in co-creating the knowledge engines that support evidencebased investment of public health funds. New scientific truths (*eScience*) must be supported through complex free living system analysis of networked communities, nudging simulators and emerging data intensive advanced modelling techniques.

Building upon this background, the authors propose the core principles of modern actionable solutions. In short this involves: the provision of mundane yet high yield health data through light instrumentation of the crowd, real time living epidemiology linked into advanced algorithms sorting the per unit co-occurrences into wellness or illness promoting event streams, simulated and actual nudging through persuasive technologies such as serious gaming to reward optimal behaviours and most importantly, timely visualisation and reliable simulation to preevaluate and proactively direct public health investments in evidence-based ways.

Here data and insights from disparate sources and disciplines ranging from clinical and biomedical research, economics, public health policy, information systems and data mining advances, and more have been expertly organized. Discussed and defined in this paper is the malignant spread of environmentally induced human underperformance and the emerging data intensive and crowd sourced science of **reachability management**, which holds the promise of robust prediction and prevention.

Information technologies must be integrated with the expressed purpose of optimizing human performance and lifting our collective health talents. Gone are the days of choice architectures that silently and systematically erode our health and our economies; may our nations reclaim their heritage of a robust and prosperous future through the co-production of an effective eScience.

# Introduction

We have a dream! The utopianism of the trans-humanity [1]<sup>9</sup> and singularity [2] movements resound today the vision that Francis Bacon had formulated already in 1626 in his science fiction novel The New Atlantis: the possibility through science and technology to improve and prolong life, heal once-incurable diseases, relieve pain, optimise the temper and psychology of individuals, create new food, and so on[1] [p. 69]. Today the potential to optimize the human body and mind through the convergence of information and communication technology (ICT) with micro-, nano- and bio- technologies is indeed a near term reality. No longer must our communities pre-accept the terms upon which the universe operates. Through wilful self-effort, and advanced information environments, modern society may purposefully shift destinies molecules and optimize human performance.

*Yet, entrenched thinking is missing the point*. Human performance optimization is barred by a persistent obstacle well termed by Barabási as the reductionist assumptions of 20<sup>th</sup> century science [3]<sup>10</sup> [p. 6]. Medicine and health care suffer from both an outdated institutional design as well as sub-optimal procurement mechanisms of underlying scientific knowledge. One might argue that this industry has taken the 20th century reductionist mindset the furthest. Widespread specialisation has led to the treatment of disease states rather than the comprehensive optimization of human performance.

In recent years, throughout the globe we have witnessed an unprecedented effort to use (HIT)<sup>11</sup> to affect population health outcomes by focusing almost entirely on improving the delivery of care (supply side). In doing so, the Tsunami of preventable poor health has remained under the radar, free to sweep across our shores. Traditional care delivery models assume crowds are basically well or accidentally well until they are ill. Yet advancing modernization pressures expose that health is as much a process as it is an outcome. It requires continuous attention or we risk failure to safeguard the minimal biological expectations of our human condition. While using technology and HIT for the expressed purpose of advancing better *health care*, we have neglected to optimize the use of technology to advance better *health*.

# This paper is organised into *Five Theses followed by a proposed Solution and Closing Conclusions*.

For at least three decades, a Tsunami of preventable poor health has continued to threaten the future prosperity of our nations. Despite its effective destructive power, our collective predictive and preventive capacity

<sup>9</sup> From where we have also taken the reference to Francis Bacon view expressed in the *New Atlantis*, and Internet Wiretap edition of which can be accessed at: http:// oregonstate.edu/instruct/phl302/texts/bacon/atlantis.html

<sup>10</sup> Scientific research in the 20th century has been driven by the reductionist assumption, according to which to comprehend nature we first must break it done and see it through its components. This approach ended up running into the hard wall of complexity. This complexity, where everything is linked to everything else, makes it hard to recompose in a mechanistic way the various small components into which we broke down the world and our knowledge of it.

<sup>11</sup> Whereas in the European context, and especially in the context of European Commission policy, the term eHealth is dominant, in the USA context the more common expression is Health Information Technology (HIT). Neither fully reflect intuitively what they are referencing. In the expression eHealth the 'e' suffix may be interpreted as concerning only online application, whereas HIT seemingly excludes the communication and online side. Neither interpretation is correct. Both eHealth and HIT are used to broadly refer to the use in health care of Information and Communication Technology and of other technologies with which ICT is converging. The best expression better capturing all the facets would be ICT for Health. Yet, henceforth we use HIT only for the sake of brevity.

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remains remarkably under-developed (Thesis One, Section 1). This Tsunami is almost entirely mediated through the passive and unintended consequences of modernisation. The malignant spread of obesity in genetically stable populations dictates that gene disposition is not a significant contributor as populations, crowds or cohorts are all incapable of experiencing a new shipment of genes in only 2-3 decades (Thesis Two, Section II). The authors elaborate on why a supplyside approach: advancing health care delivery cannot be expected to impact health outcomes effectively. Better care sets the stage for more care yet remains largely impotent in returning individuals to disease-free states. (Thesis Three, Section 3). Today, HIT leverages institutional data or care delivery data from clinics and hospitals, which limits the performance of our legacy health knowledge engines (Thesis Four, Section 4). The authors urge an expedited paradigmatic shift in policy selection criterion towards using data intensive crowd-based evidence integrating insights from system thinking, networks and nudging. Collectively these will support emerging potentialities of ICT used in proactive policy modelling (Thesis 5, Section 5). Against these five theses, Section 6 proposes a solution that stated in a most compact form consists of: the provision of mundane yet high yield data through light instrumentation of crowds enabling participative sensing, real time living epidemiology separating the per unit co-occurrences which are health promoting from those which are not, nudging through persuasive technologies, serious gaming to sustain individual health behaviour change and intuitive visualisation with reliable simulation to evaluate and direct public health investments and policies in evidence-based ways.

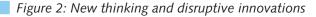
*Holistic approach*: It is imperative that the reader expects a holistic treatment of the supporting evidence. In this paper, data and insights from disparate sources and disciplines ranging from clinical and biomedical research, economics, public health policy, information systems data mining advances, and more have been expertly organised. Equally imperative is the authors' need to emphasize that the reader must not equate the Tsunami of preventable poor health with more talk about obesity and diabetes. These outcomes plague our press but are simply an artefact of our underperforming information environments that only *pick up* the visible or easily measurable tip of the iceberg. Discussed and defined in this paper are, the malignant spread of environmentally induced human underperformance, and the emerging data intensive and crowd sourced science of **Reachability management** that holds the promise of robust prediction and prevention.

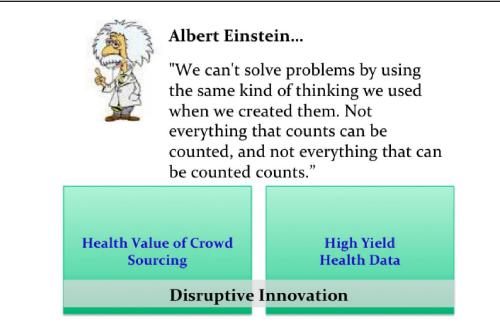
Not reinventing the wheel: The authors acknowledge previous work such as: a) scientific contributions (many of which are referenced throughout the paper); b) policy statements and documents, such as the 2007 European Commission White Paper on nutrition and obesity [4]; c) classical public health and community measures prevention being implemented (spanning from agricultural, food, educational, commercial, and territorial policies). However, in contrast to this previous work the authors propose the directed light instrumentation of crowds linked to gentle policy nudging. Furthermore, the gap between what public health policies have achieved so far and what is reachable as defined by crowds is the focus of Section 7. In short, ICT for ageing must advance to ICT for living well to support smart and healthy kids and enable legacy knowledge systems to be augmented by dynamic crowd based approaches.

**Entrenched thinking is missing the point:** Many recent policy reports on health care systems begin with statements such as the following found in the executive summary of the latest OECD report: 'Improving health care systems, while containing cost pressures, is a key policy challenge in most OECD countries' [5]. There is remarkable similarity to the 1964 thinking illustrated in Figure 1 below. Without question the need to improve care and contain costs remains real. Yet the conversation seems to be locked into this one-sided (supply side) approach proposed



Source: Look magazine 3 November 1964.12





at least 47 years ago. New thinking with the potential for disruptive innovation is core to this paper and visually rendered in Figure 2.

**Country examples are selective by necessity:** The geographical scope in this paper is the result of a US-EU collaboration. Data and references concerning both areas have been reviewed and, when possible, Japan has been included as an external reference point. Clearly the US and EU27 (taken as a whole) are of comparable size. However the US is one nation while the EU is comprised of 27 Member States. Thus, often US data is available while EU data requires separate searches Member State by Member State. Regrettably a comprehensive treatment of all the data from all 27 EU Member States was beyond the time and resources available for this paper.

11

<sup>12</sup> Retrieved from: http://2neat.com/magazines/index. php?main\_page=product\_info&cPath=1\_34&products\_ id=804

A reasonable compromise was to choose only internationally aggregated data such as OECD (and of the International Diabetes Federation). However, the authors were able to select a representative sample of countries in Europe to be compared with the US and Japan. Taken together (Austria, Finland, France, Germany, Italy, Japan, Netherlands, Spain, Sweden, United Kingdom, and United States) these areas would be representative of: a) different health care institutional model (see more in Section 3); b) different cultural and lifestyle traditions (Anglo-Saxon, Nordic, Central European, Mediterranean, and Asian); c) different ranking in terms of standard indicators of health outcomes.



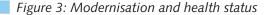
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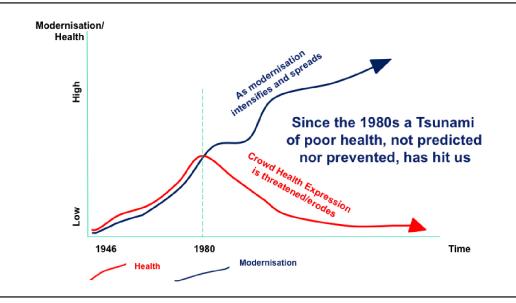
# 1. Thesis One: A tsunami of preventable poor health has hit us

# Importantly: *This tsunami threatens our future prosperity*.

*Thesis*: The above claim is impressionistically rendered in the figure below. Western lifestyle or

*Evidence*: Between 1990 and 2007 Life Expectancy at Birth (LEB) has increased on average in OECD countries by 2.5 years [5], which might seem to contradict the above claim. However, this indicator may suffer from outdated





Source: authors' view of expanding diverse literature base.<sup>13</sup>

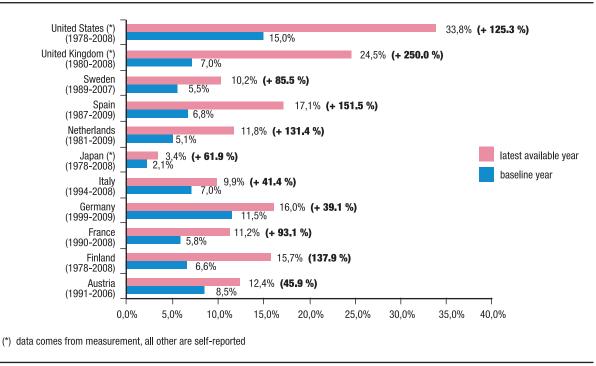
modernisation intensifies and spreads while in contrast the health status of the population erodes. Sustainable well-being and the future prosperity of nations are threatened. Evidence for this trend is robust in the developed world. However, no protection against these trends appears to exist within the developing nations as well. Notably China and India recognize that as economic growth spreads and Western lifestyles globalize, they too have grave reason for concern.

13 Authors' view of expanding literature base: A simple graphic is a vivid and intuitive means of proposing key concepts that might otherwise require several written paragraphs and single point references while still risking that the reader fails to "see it." This and other similarly

assumptions that fail to account for the growing obesity trends (see Figure 4) and type II diabetes (see Evidence Box 1) rates that plague our modern era. These LEB gains are produced by the last of the *accidentally well*, a category of individuals that are becoming vanishingly few, as will be discussed in Section 3.

From 1980 to 2010, obesity prevalence increased in the United States 125%. The United Kingdom, however, tops this with a staggering 250% increase in the same time period and

rendered views represent the authors' intent to integrate and summarise overwhelming key messages from the medical, public health, and socio-economic literature superimposed upon many years of front line clinical practice (Dr. Piniewski).



Source: OECD Health Data 2010.

several other European countries score also poorly, particularly Finland + 140% and Spain + 151% (OECD Health Data 2010).

Perhaps dwarfing all previous trends will be the Tsunami of poor health outcomes currently evidenced in the Asian nations (see Evidence Box 1). Without question, these trends (with their free-fall intensity) are the result of passive and insidious effects that require no work or concentrated effort on the part of the individual or the community. Our choice architectures simply have succeeded in making the shift towards weight gain the passive default and avoiding weight gain has become the process requiring work or expressed effort today.

Rising obesity and diabetes type II overwhelmingly suggests that crowds across the globe may be suffering an epidemic of lifestyle mediated Insulin Resistance (IR). This is a potent mechanism to advance premature multiple adverse health outcomes [37-44], including cardiac disease, hypertension, liver failure, renal failure, stroke, some cancers,<sup>14</sup> Alzheimer's disease (AD) and dementia. This growing epidemic of IR may foreshadow a future dementia epidemic.<sup>15.</sup>

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<sup>14</sup> The levers that can be activated to prevent colon cancer [37], for instance, are mostly the same that would help fight insulin resistance.

<sup>15</sup> Hyperinsulinemia and IR increase risk for AD through deleterious and interrelated effects on: Glucose metabolism Amyloid regulation, inflammation, and effect on brain vascular function [38-42]. Glucose homeostasis is critical for energy generation, neuronal maintenance, neurogenesis, neurotransmitter regulation, cell survival and synaptic plasticity. It also plays a key role in cognitive function. In an insulin resistant condition, there is a reduced sensitivity to insulin resulting in hyperinsulinemia; this condition persists for several years before becoming full-blown diabetes. Toxic levels of insulin negatively influence neuronal function and survival, and elevation of peripheral insulin concentration acutely increases its cerebrospinal fluid (CSF) concentration. Peripheral hyperinsulinemia correlates with an abnormal removal of the amyloid beta peptide (Abeta) and an increase of tau hyperphosphorylation as a result of augmented cdk5 and GSK3beta activities. This leads to cellular cascades that trigger a neurodegenerative phenotype and decline in cognitive function. Chronic peripheral hyperinsulinemia results in a reduction of insulin transport across the BBB and reduced insulin signalling in brain, altering all of insulin's actions, including its anti-apoptotic effect. Similarly has been noted that early (in mid life) cholesterol changes and cardiovascular risk can be followed decades later by the onset of dementia [43, 44].

#### Evidence Box 1: The global Insulin Resistance epidemic proxied by obesity and diabetes

The rising prevalence of obesity and type II diabetes in the last three decades has been amply documented in a large body of literature only selectively reported below as evidence of these phenomena:

- Diabetes epidemics worldwide [6-13]:
  - According to International Diabetes Federation (IDF) data and estimates the prevalence of type II Diabetes has increased 847% between 1985-2010 (from 30 million to 284 million)
  - IDF forecasts the total number to reach 439 million in 2030 (a 1363% increase since 1985)
  - It is important to note that, once considered a disease of the West, type 2 diabetes is now a global health priority: IDF forecasts for 2030 expect that more than 60% of the world's population with diabetes will come from Asia (most notably India and China)
- Clear evidence that obesity is linked to diabetes and more generally to the metabolic syndrome [6-8, 12]:
  - 75% of risk of type II diabetes attributable to obesity [8]
  - Rank correlation between obesity and diabetes II is 0,64 with p<0.0001 [12]
- The alarming speed at which the prevalence of paediatric obesity has increased in the last two decades had made it into a recognised public problem[14-18]:
  - Such trend is linked to clear future Type II diabetes and metabolic syndrome risks [19]
  - US children born in the year 2000 have a lifetime risk of developing Type II diabetes greater than 30% [20]

• Not surprisingly, we are also witnessing an upsurge of type II Diabetes among children [19, 21-33]: youth disadvantage results in rampant conversion rates to type II diabetes [20, 34-36]

Increasing rates of type II Diabetes suggests an underlying and advancing IR burden. Beyond type II Diabetes, however, IR appears associated with multiple premature adverse outcomes as listed above. Thus it may be prudent to be very cautious about the LEB gains reported by the OECD[5], as these may be soon reversed [45, 46]. In the same way the evidence on paediatric obesity and diabetes alerts us to the fact that the chronic diseases historically associated with old age are moving into early life; not by months or years, but by decades [35, 47, 48].

How is it possible that such a dramatic redirection of crowd health futures could occur in less than half a lifetime? A good part of the answer is well summarised by Sterman who, after listing a series of problems (including rising prevalence of obesity, diabetes, cardiovascular diseases and much more), affirms:

"Most disturbing, many of these afflictions are the unintended consequences of the extraordinary prosperity and technical progress that enabled us to treat disease and decrease daily toil so successfully over the past century" [49][p. 505]. The extraordinary *prosperity* resulting from modernisation suffers unintended consequences and these are discussed in Section 2. The technical progress mentioned above may refer to the health care delivery model (treated in Section 3), and the specifics of ICT utilisation in health care (Section 4).

unmentionables: The The staggering costs. Direct Medical Costs (DMC) and other opportunity costs (i.e. loss of productivity), are documented selectively in Evidence Box 2. Most audiences become numb to the staggering figures over time. Lost in this message is the fact that our children and youth represent the sources of future prosperity and sustainability of our nations. This current Tsunami of poor health is not without collateral damage. Perhaps grossly underdocumented is the insidious ability to affect human potentials beyond simply physical health such as cognitive, psychological, and social potentials. Failure to collectively reach optimal levels of success in these areas is certain to have widespread ramifications including a potent mechanism poised through direct and indirect means to bankrupt our nations.

## Evidence Box 2: Selective estimates of direct and indirect costs

Direct Medical Cost (DMC) Obesity

• USA:

- Adult obesity \$ 147 billion + Child Obesity \$ 15 billion yearly [50, 51]
- 1987-2001 obesity account for 27% of rise in health care expenditure [52]
- EU27: 7% of all health care expenditure that is about 80 € billion yearly[53]

Other burden of obesity

- Productivity/cognitive/educational losses:
  - After controlling for education and cognitive ability, obesity=lower wages [54]
  - Obese adults absenteeism is worth \$ 4.3 billion annually [55]
  - Presenteeism loss of productivity: \$ 503 per obese worker annually [56]
  - Delayed skills acquisition for obese children [57]
  - Higher absenteeism at school for obese children [58]
- Having obese child cause parents absenteeism/ presenteeism [58]:
  - Caring for child, taking him/her to medical visit, stress (as in care for elderly)
  - Parents child related absenteeism is 9 days per year (higher for female)
  - Working women with children 22% greater absence and 70% more tardiness
  - Household study: self-reported loss of 2 to 4 hours of productivity per day due to psychological stress when a child is sick

DMC and other costs of diabetes and cardiovascular diseases

- Diabetes USA:
  - Currently \$ 194 billion yearly, tripled since 1980 and will reach \$ 500 billion by 2020 [59]
  - Causes an extra \$ 58 billion in lost productivity [19]
- Diabetes worldwide: 11.6% of total health care expenditure [19]
- Diabetes Europe: between 5% and 13% of health care expenditure for a total of € 110 billion in 2010 expected to grow to € 130 billion in 2030 [19]
- Cardiovascular disease in EU27: DMC € 109 billion, productivity loss € 41 billion, costs of informal care € 42 billion [60][p. 104]

Thus our national Human Capital Agenda must adopt a more appropriate and holistic approach. More explicitly: ICT assisted chronic disease management should expand to include explicit ICT enabled disease prevention. Simply managing ageing to reduce costs leaves the nation vulnerable and at risk of loosing its most valuable human capital.

The aggregate health status of a population has been recognised as an important contributor to economic growth in economic theory and this contribution has been formally tested and documented empirically.<sup>16</sup> In the 1990s economists started to include health markers among the factors of standard growth models alongside capital deepening and technological growth. Stated simply: Health = Wealth. Empirical evidence has shown various channels by which good health has an impact such as reducing productivity losses (days of work lost due to illness or its disabling impacts) and increasing the motivation to invest in education and lower the human capital depreciation rates. As such, wellness affects productivity directly (fewer days of work lost due to health problems) and indirectly (increased educational level). Moreover, improved health conditions and slowing down of human capital depreciation can prolong the productive life of older workers (those aged 55-64) to curb early retirement. These effects positively reverberate on GDP. Conversely, as mentioned above, as chronic diseases move into early age most of the above

9 Definical Report Series

<sup>16</sup> Among many others, good examples of such approaches include those conducted by Bloom and Canning [50-51] and by Strauss and Thomas [52].

promoters of improved GDP suffer dismally and opportunity costs must also be considered in addition to the already profound growth of direct medical costs.

The tsunami is avoidable. Not surprisingly most recent US and Australian simulations on future prevalence of obesity and types II Diabetes under different scenarios (no action, primary and/or secondary preventive interventions, management) conducted using sophisticated modelling techniques found preventive interventions to be absolutely dominant in terms of cost-effectiveness, which confirms they are overwhelmingly cost-effective using widely accepted criteria [59, 61-64]. Spending \$ 2 billion a year would be cost-effective even under the conservative scenario of reducing obesity only by one percentage point among twelve-yearolds [64]. Banning television advertisements in Australia for Energy-Dense Nutrient-Poor (EDNP) food and beverages during children's peak viewing times appear to be 'dominant' as it results in both a health gain and a cost offset compared with current practice [63]. A modelling diabetes application conducted by the Sustainability Institute for the US Centre for Diseases Control and Prevention showed that what matters is prevention rather than management and monitoring: improving diabetes management and detection does not reduce prevalence and the associated costs, which decrease only when prevention reduces obesity [62]. According to the latest (November 2010) simulated estimation of possible savings in treating diabetes prevention yields a combined total of \$237 billion worth of gains, whereas improved medication adherence produces \$34 billion of gains [59]. Finally, the results of a micro-macro modelling simulation of preventing diabetes in Australia confirm that such intervention are a matter of Human Capital Agenda and economic growth: beyond the reduction of prevalence and costs the interventions produces increased employment and impact on GDP [61].

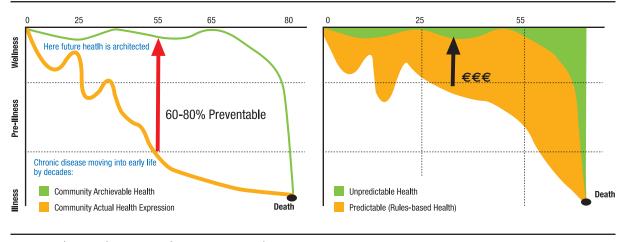
The above modelling simulations represent a conservative use of the findings of a large body of scientific literature. This literature consistently confirms that large portions of adverse health prevalence can be avoided through life-style modifications [8, 37, 65-71]. Further details are available in Evidence Box 3.

Perhaps most compelling is the literature suggesting that if society did nothing else (no new drug, no new procedure) but enabled the choice

### Evidence Box 3: The potential gains from lifestyle modifications

- Type II diabetes: lifestyle modification treatment showed a reduction of incidence of 58% [69];
- Lyon Diet Heart Study:
  - Intermediate analysis (after 27 months) and follow up (after 46 months) showed that good diet and activity have striking protective effect against Coronary Heart Diseases (CHD) with 44% reduction in incidence [66]
- A sub-analysis showed 61% less cancer incidence as well [65];
- Nurse Health Study: among 84,129 women followed up to 14 years those with good lifestyle showed 83% less incidence of heart diseases [71];
- HALE Project: among 1507 apparently healthy men and 832 women, aged 70 to 90 years in 11 European countries adherence to a Mediterranean diet and healthful lifestyle is associated with a more than 50% lower rate of all-causes and cause-specific mortality [68];
- Indo-Mediterranean Diet (\*): reduces the rate of fatal myocardial infarction by 33% and the rate of sudden death from cardiac causes by 66% (consistent with percentage symbol use in rest of this box) [70]
- (\*)Traditional diets from the Mediterranean and Asian countries share most dietary characteristics, such as a relatively high intake of fruits, vegetables, nuts, legumes, and minimally processed grains, despite the use of different sources of plant oils [67]





Source: authors' qualitative view of current prevention literature.

architectures to nudge crowds to collectively advance their high density lipoprotein level (HDL) by 10 mg/dl, the crowd cardiovascular event rate would decline by 50% [72-76]. This strategy, if successful would represent a profound redirection of crowd health expression. Stepping up this approach might include optimizing the triglyceride (TG)/HDL ratio of the crowd. TG/ HDL appears to be a reasonable surrogate for measuring Insulin Resistance (IR) in a population [77-80]. Individuals with poor lifestyle as possibly measured by IR burden have high rates of chronic adverse health outcomes [69, 70, 81-83]. Thus it becomes reasonable to separate out health into two parts: more modifiable health (nudge-able through strategic choice architectures) and less modifiable health (background health dependent upon gene disposition and age-related decline). See diagrams below the evidence boxes for clarification.

Importantly, many of these outcomes are preventable and mediated through choice architectures that drive community lifestyle behaviours. In short, it is the crowd that controls the bulk of future health expression. Moreover, the message in is that in the upper two thirds of the graphic is where future wellness or illness is architected. Yet, as we explain in Section 4, this is exactly the area where our health knowledge engines are underperforming despite billions of \$ and  $\in$ spent in recent years for ICT in health care. Thus this Tsunami that hit us, could be neither predicted nor prevented while appearing to be 60-80% avoidable and possibly worth billions of \$ or  $\in$ .

In the US, there is a growing body of corporate health studies [84-108], from which it can be safely concluded that excess risks (that is lifestyle choice that could be improved) account for between 25% and 30% of medical costs per year across a wide variety of companies regardless of industry or demographics[84, 98, 99]. This is a realistic benchmark to start any business case for company health promotion programmes. A simulated business case is offered at the end of Section 6.

18

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# 2. Thesis Two: The tsunami is a lifestyle-induced shift in phenotype

# Importantly: Gene disposition is no match for environmentally induced alterations in gene expression.

To illustrate this point, the authors gather modern examples of environmental pressures which generate widespread shift in phenotypic outcomes. Moreover, the evidence supports that this dramatic shift in phenotype must occur through repetitive passive and involuntary event structures. In short, unfavourable communitywide choice architectures are infinitely effective at shifting crowd phenotype and moreover, effective within a few short decades. Widespread failure of individual responsibility would simply be insufficient to mount such a successful response.

It is well understood that shifting health outcomes through gene disposition mediated events requires hundreds of years to accomplish. Yet societies exposed to modernization appear almost universally to violate the basic expectations of their genetic disposition; namely individuals fail to execute a minimum threshold of daily activity and repeatedly replace whole foods with factory foods. As a result of these and other contributing factors, the Tsunami of preventable poor health is able to sweep over a nation in the space of a few decades. Some countries appear affected earlier than others but no nation appears to be immune to the effects of drastic reductions in activity and profound adjustments of nutritional intake.

*The dark side of modernisation*. 'Modernisation' and 'industrialisation' may have different meanings during different historical periods<sup>17</sup> and/or different

geographic areas,<sup>18</sup> which are discussed in a vast body of literature. Naturally it is beyond the scope of this paper to ground our usage of the term within available literature. The modernising effects referred to in this effort are those identified in the literature concerning 'nutritional transition' [109-112]. In general, societies across the globe have converged or are converging toward: a) diets high in refined carbohydrates, saturated fat, and low in dietary fibre b) decrease in Physical Activity Level (PAL) due to changes in transportation, occupational structure and other pressures.

Part and parcel of industrialisation and modernisation have been the demographic transition from high fertility/high mortality to low fertility/low mortality and until recently increased longevity. There has also been a move away from infectious disease, famine, and poor sanitation which has been replaced by a secure food supply and better sanitation. While not entirely ubiquitous, most of the Western World has accomplished these advances in the first half of the 20<sup>th</sup> century. The effort to spread these conditions to an ever-wider share of the population is well summarised in the passage below:

"Early-twentieth-century research suggested that when hungry children were given diets higher in added fats and sugar they grew. Following World Word II, raising production

<sup>17</sup> Modernisation/industrialisation in the work of the classical late 19<sup>th</sup> century and early 20<sup>th</sup> century social scientists analysing the transition from 'traditional' to 'modern'

society in the West meant something different from how the same terms have been analysed since the mid 1970s to analysis already modern society and arguably characterising them as 'post-industrial', 'post-modern', or in terms of 'late/heighten' modernity.

<sup>18</sup> Analysis of the 1950s and 1960s of the possible path to modernisation of new post-colonial states differ both from the classical study of Western modernisation and from the current analysis of developing countries where elements of what we could call late modernity co-exist with elements of unfinished modernisation. Still different is how the term can be used in the context of analysing the transition from Soviet to Western Modernity.

### Evidence Box 4: Globalisation of fast-food

- Coca Cola 2000: worldwide sales of the unit case (24 8-oz. servings) were \$ 17.1 billion;
- Haagen Dazs 2001: franchises in more than 55 countries, with more than 800 outlets;
- Kentucky Fried Chicken 2001: 5,231 outlets in the United States and 5,595 outlets outside the US, with 290,000 employees and worldwide sales of \$8.9 billion;
- Pizza Hut 2001: 12,000 units and kiosks in more than 88 countries serving more than 1.7 million pizzas a day to four million customers;

• Dunkin Donuts 2001: 5,000 locations in the US and 40 other countries with daily sales of 6.4 million doughnuts and 1.5 million cups of coffee to two million customers. On an annual basis, Dunkin Donuts sells 2.3 billion doughnuts and 650 million cups of coffee;

of commodity crops and their associated fats and sugar was seen as an answer to undernutrition in the United States and throughout the world... As a cheap calorie policy, it has been a success" [113] [pp. 406-407]

As a consequence of industrialisation, globalisation delocalisation, and of food production, less healthy food became less expensive and more widely available. Widespread reduction of micronutrients resulted as packaged crackers and cereals displaced nutrient rich vegetables and fish from regular diets. This profound loss of micronutrients and the expansion of non-nutritive substances may have had a significant impact on energy metabolism and disease risk [114].

The 2010 OECD Health Data reported nutrition statistics of the selected countries appear to confirm this picture. The average per day per capita consumption of kcal in the 11 countries is 3,400 kcal, well above what is considered the normal intake on average considering all the different socio-demographic groups (i.e. 2,800 for a middle aged moderately active male and 2,400 for an equivalent female). Only Japan, with an average of 2,800 kcal per day per capita in 2007 is within the normal interval and this is reflected in its staggeringly low level of obesity prevalence. In the US, the average daily intake of calories has increased by 18% and in the UK by 11% (the two countries with the highest obesity prevalence amongst those considered here).

Recall that the regulation of energy stores has been selected for over centuries and under conditions very different from those of our contemporary dietary ecology [115]: a small 10% variation in either intake of calories or output of energies can lead a normal non-obese individual to gain or loose 13.6 Kg in a year[116]. Considering that activity levels have dropped dramatically (see below), it is not surprising that an 18% increase in caloric intake over 30 years can dramatically impact obesity prevalence. Bray (27, 28) calculated that the "average" non-obese American male consumes approximately one million kcal a year. Yet a small 10% alteration in either intake or output can lead to a (13.6 kg, or 30 pound) change in body weight in a single year. If an individual gains 11 kg (24 pounds) of weight during a 40-year time span, the mean daily discrepancy between intake and expenditure is a mere 5 kcal/day.

Comparison of PAL level for contemporary sedentary workers and earlier human populations confirms that our level of activity has decreased drastically [115]:<sup>19</sup> we generate less than half the activity that earlier humans did and, thus, our muscles require and consume much less energy. The same source also indicates that the number of motor vehicles worldwide will increase from 580 million in 1990 to a projected 816 million in 2010 (a proxy of further reduction in activity) [115] [p. 360]. Evidence implicating a global spread of

<sup>19</sup> See in particular the table on page 350.

#### Evidence Box 5: Additional lifestyle pressures

• In the US between 1985 and 2000, inflation-adjusted prices for soft drinks went down 24% at the same time as those for fruits and vegetables went up 39% [113]

• TV is the dominant form of advertising to children and:

- A 2009 report found almost perfect overlap between cereals with the worst nutrition rating and those marketed most aggressively to children [117]
- Despite ?, high exposure of children to EDNP foods advertisements while watching 2-3 hours of TV per day in Australia [118, 119]; (this statement is not complete)
- There is increasing evidence of the existence of a logical pathway from exposure to advertising to unhealthy weight gain in children [120, 121]
- Ecological study found a strong and significant association (r=0.81, P<0.005) between the proportion of overweight children and the number of ENDP food advertisements per hour on children's TV [63, 122, 123]

Put a TV or play station in a child's bedroom and they are 1.5 times more likely to be overweight or obese [124]

• Obesity is higher in neighbourhoods perceived unsafe by parents and/or lacking parks [125]

• Maternal employment explains 11.8%-34.6% of the rise in child obesity [64]

fast-foods chains as an important contributor is reported in the Evidence Box 4 [115] [pp. 361-362]. The availability and affordability of energydense, high-fat foods is growing throughout the globe.

In parallel to the above events, modernisation may enable healthy foods to be relatively more expensive and less available. TV advertising directed at children select specific watch times to stream cute character commercials promoting Energy Dense and Nutrient Poor (ENDP) foods (see Evidence Box 5).

Our evolutionary legacy was formed under entirely different environmental choice architectures over thousands of years. Our physiology preferentially selected for adaptive genotypes and phenotypes well suited to survive low nutritional exposures. Modernization has effectively launched us into a new paradigm of over nutrition in a micro-second relative to our evolutionary timeline. At this rapid pace, our biology is powerless to adapt and remains a victim of chronic excess energy intake coupled with dramatic reductions in energy output [115].

Not surprisingly, obesity and related adverse outcomes occur especially aggressively among indigenous populations when modernised food and lifestyle spread [114, 126]. A similar event is feared as over-nutrition replaces under-nutrition in many developing countries such as India and China.

In summary, starting in the US at the last quarter of the 20<sup>th</sup> century and then spreading globally, poorer quality nutrition became increasingly more convenient and less expensive. Activity based employment gave way to knowledge based employment. The personal automobile replaced walking to public transit and, in general, the collective community activity level plummeted. With modernization, our environments increasingly provided the choice architectures that would violate the minimum expectations of our genetic material and our biology remains powerless to adapt with such short notice.

Man's physiology may have advanced in response to environmental pressures historically by becoming larger, stronger and more sophisticated mentally. In 2003, the cartoon featured in *The Economist* (see Figure 6) may have been offered in jest, but hints effectively at the unintended sinister truths of modernization.

Meanwhile, as attention and resources are poured into automating health care delivery



Source: Authors re-elaboration of The Economist 2003 cover.<sup>20</sup>

## (supply side), we risk ignoring the silent tsunami that is driving increasingly aggressive demand for health care.

Individual responsibility: As cited in the introduction, The European Commission White Paper states "Firstly, the individual is ultimately responsible for his lifestyle, and that of his children, while recognising the importance and influence of the environment on his behaviour" [4] [p. 3]. This sentiment can be found in most policy statements and may reflect the need to accommodate the position of the concerned industry, whose mantra is clearly focussed on *individual responsibility*. Perhaps the community is meant to understand that individual responsibility supersedes corporate responsibility.

In 2009, in the face of proposal for taxes on sugared beverages, this card was clearly played as testified in a *Wall Street Journal* oped by Mr Kent, Coca-Cola's CEO, who affirmed that "Americans need to be more active and take greater responsibility for their diets".<sup>21</sup> In the most brutal understanding of individualism and individual responsibility this is the rhetoric "you get what you deserve" that goes together with the most offensive stereotypes about obese people being lazy and irresponsible. Individuals uniformly do not deliberately choose to become obese and most certainly the children are not actively choosing to become obese! The research reported earlier in Evidence Box 5 about the effect of TV advertising on children is the object of rising international concerns [120, 127-129]. Young children are unable to understand the purpose of advertising, nor distinguish advertisements from programs, nor understand the relationship between food choices and future chronic nutritional diseases or dental caries. But the situation is also difficult for adults for it has been shown that advertising food taps directly into the limbic brain, thus potentially subverting responsibility personal [50]. Moreover, surveys about various attitudes and behaviour consistently fail to show that the majority of people have become totally irresponsible [117]. We maintain traditional values and engage in respectful and responsible behaviours throughout our daily lives. It remains highly unlikely that the vast majority of individuals are both responsible and irresponsible at the same time.

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<sup>20</sup> Retrieved from: http://www.cutthewaist.com/images/ impact/economist.jpg

<sup>21</sup> Wall Street Journal Oct 7 2009.

When 300 million US individuals become 66% overweight or obese in less than half a century, the press is accurate in trumpeting that a tsunami of poor health has hit US shores. If any amount of work, heavy lifting or deliberate choice were required, this outstanding prevalence of 66% would not be possible in the space of a few decades. Clearly, trillions of lightweight everyday decisions have been nudged by a choice architecture effective in producing the current tsunami. Passive, silent, insidious micro events have collectively adjusted the regulatory elements of crowd health expression. Moreover, the individual has been left blind to these subclinical effects until it was often too late for effective reversal. In this way, the profound power of choice architecture successfully drives

crowd health outcomes without the expressed knowledge or consent of the crowd.

Suggesting that poor health behaviours are due to individual disposition (personal character, undisciplined personal habits, poor attitude, or low intelligence) rather than to the situational factors nudging individual behaviour is a dangerous misperception [49] [p. 210]. On the contrary, by recognizing the power of choice architectures to structure behaviour, individuals are not relieved from personal responsibility but in fact may be better enabled through deliberate design of optimizing choice architectures to achieve extraordinary performance [130]. This principle inspired the work leading to this paper.

25

# 3. Thesis Three: Acute care model fails to counter the tsunami

Importantly: More spending and more ICT to deliver better care (supply side) fail to impact the growing tsunami of preventable poor health (demand side).

Thesis. Historically, the traditional medical model assumed we were all accidentally well or mostly healthy by default. Once illness was identified, medical care was instituted by experts to hopefully return the victim of poor health to reinstated health. In this model, the family and the household were innocent bystanders and not likely to meaningfully contribute to future health outcomes. Community was responsible for the basics such as reliable drinking water, families followed principles of general hygiene and avoidance of toxins such as alcohol and drugs. That's it. No more work to be done. Today, the accidentally well are vanishingly few and younger communities have become the passive recipients of preventable poor health as discussed at length above.

Yet, entrenched thinking prevents radical change and health system inertia persists. Thus community baseline health continues to erode and chronic disease advance into early life by decades. Once the individual is chronically ill, there is little an expert medical community can offer to reverse the process.

Currently OECD countries spend on average no more than 4% of their total health care budget in prevention.<sup>22</sup>

**Does spending make a difference?** According to the latest OECD comprehensive analysis of health care systems outcomes efficiency, total health care per capita spending increased on average in the OECD area by 70% Using the data of Table 1 and its reelaboration in the matrix of Figure 7, the authors provide an answer suited for a layperson less familiar with, or less trustful of, sophisticated statistical techniques. This should not be seen as an alternative systematic answer to those presented in the OECD report but simply a basic interpretation of the facts.

In Table 1 we report data for our group of countries divided into the three main institutional models according to which health care delivery is organised.<sup>24</sup> Among the various indicators

<sup>(</sup>in real terms) between 1990 and 2007 [5] [p. 33], which confirms its structural tendency to grow more than income. Does spending level make a difference? This report provides an answer to this question by applying sophisticated statistical techniques (panel regression and Data Envelope Analysis, DEA) to a set of input (i.e. spending, capital equipment proxied by numberof-beds and scanners, a vector of socio-economic and lifestyle factors), output (i.e. number of consultations, number of hospital interventions) and, most importantly, outcome indicators, which include: Life Expectancy at Birth (LEB); Life Expectancy at 65 (LE65); Potential Years of Life Lost (PYLL); Infant Mortality (IM); Health Adjusted Life Expectancy (HALE) at birth; Amenable Mortality (AM).<sup>23</sup> The authors intend to return to the results of such analysis and to other similar analysis done earlier. However, let us first make use of the data presented in the OECD report to consider intuitive and qualitative insights.

<sup>23</sup> In practice, however, the panel regression and DEA use as dependent variable only LEB.

<sup>24</sup> This is a slight simplification compared to the institutional typology developed by the OECD [5] [p. 15] where systems are distinguished more granularly using also other criteria such as presence or not of gate keeping and reliance on market mechanisms in service delivery.

<sup>22</sup> OECD Health Data 2009.

	LEB (M&F) 2007		HALE (M&F) 2007		Average total rank	PPP \$ per capita	Obesity prevalence (M&F)		
	Value	Rank	Value	Rank	2007	2008	Latest available year		
NHS systems									
Finland	79,5	17,0	72,0	16,0	16,3	\$3,008	15,7%		
Italy	81,4	3,0	74,0	3,0	3,3	2,870	9,9%		
Spain	81,0	6,0	74,0	3,0	8,3	2,902	17,1%		
Sweden	81,0	6,0	74,0	3,0	4,3	3,470	10,2%		
United Kingdom	79,5	17,0	72,0	16,0	18,0	3,129	24,5%		
Social insurance systems									
Austria	80,1	13,0	72,0	16,0	11,5	3,970	12,4%		
France	81,0	6,0	73,0	8,0	8,3	3,696	11,2%		
Germany	80,0	14,0	73,0	8,0	13,0	3,737	16,0%		
Japan	82,6	1,0	76,0	1,0	2,0	2,729	3,4%		
Systems with higher private insurance role									
Netherlands	80,2	11,0	73,0	8,0	7,8	4,063	11,8%		
United States	78,1	24,0	70,0	24,0	23,3	7,538	33,8%		

Source: Columns 1-4 [5] [pp. 20-21]; Column 5;<sup>26</sup> Columns 5-6 OECD Health Data 2010.

of health outcome for the sake of simplicity we selected only LBE and HALE<sup>25</sup> and report their value and the position ranking of the county with respect to the values taken by all 30 OECD countries. Column 5 contains the average ranking we calculated, not only from LBE and HALE, but from the position each country took on all of the previously mentioned outcomes indicators. As a control, the last two columns show per capita total health care spending in real terms and the obesity prevalence data from Figure 4 presented earlier.

It is difficult to make sense of the data in the matrix of Figure 7, where countries are plotted against their spending level and their relative rank in health outcomes indicators within the 30 countries' OECD areas. The various forms within which countries' abbreviations are placed render the institutional model. There seems to be no clear and unequivocal relationship between spending level and institutional model on the one hand, and their respective health outcomes on the other.

Relatively lower health outcomes are associated both with a NHS model (UK and FIN) and with a private insurance model (US), whereas relatively much higher outcomes are associated both with a social insurance model (Japan) and a NHS model (Italy). Relatively lower spending can produce either relatively better outcomes (Japan and Italy) or relatively worse outcomes (Finland and UK). What is clear is that relatively higher levels of spending are not necessarily associated with relatively better outcomes as demonstrated above all by the US, but also to some extent by the Netherlands, Austria and Germany.<sup>27</sup>

The more sophisticated statistical analysis and conclusions of the OECD report taken in

26

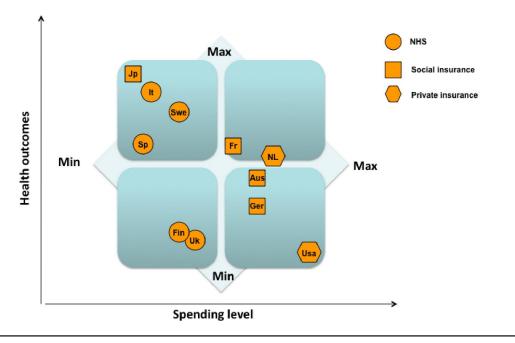
<sup>25</sup> All the earlier mentioned indicators are significantly correlated among each other [5] [p. 23], which means that one can be taken as a proxy of most others. We selected LBE as the classic one and HALE as a way for accounting also for the prevalence of diseases and disability and so to some extent for the quality of LBE.

<sup>26</sup> Our re-elaboration of data presented in [5].

<sup>27</sup> The wide variation in health care spending level, in fact, can be explained by various factors, not all related to health, as they include the age structure of the population, patterns of disease, the number of health professionals, the use of technology and the efficiency of resource utilisation and administrative costs [131].

27





Source: Authors' elaboration on data from Table 1.

aggregate for the all OECD areas<sup>28</sup> show that there is little correlation between health outcomes with either output (measured by number of consultations and of hospital interventions) or capital equipment (measured by number of beds and number of scanners in hospitals). The OECD report also rules out any robust or systematic correlation between the type of institutional system and health outcomes. This supports the claim that the better provisioning of care (supply side) is not necessarily conducive to improved health experience (demand side). On the other hand, the panel regression analysis conclusion suggests that per capita spending contributes in statistically significant ways to the increase of LEB registered between 1990 and 2007<sup>29</sup> and seemingly more than other socio-economic and lifestyle determinants such as diet. However diet in this case was measured only by the

per capita yearly consumption of fruits and vegetables. Obesity data have been omitted due to problems of comparability. These results thus appear in contrast with previous studies finding inconclusive results on the relations between spending and health outcomes and on average more robust correlations with lifestyle and socio-economic determinants [132-141],<sup>30</sup> which the OECD authors scrupulously report [5] [pp. 84-88].

More interesting are the results of the DEA. This analysis identifies the efficiency frontier of health care and shows which country could improve LBE while holding input (in the model two input are used: spending and a vector of socio-economic and lifestyle factors) constant if they were to move closer to the best performer [5] [ pp. 65-77]. On average in the OECD area, LBE could be increased by 2.7 years while holding spending constant. Or to put it differently, a 10% increase in spending would only yield 3 to 4 months' increase in LEB. The question is how to increase efficiency without spending more.

<sup>28</sup> There are, however, some country variations fully illustrated in the report.

<sup>29</sup> Here, however, it is worth noting that some countries seem to do significantly better than others. Some countries have increased LEB more than what the model extracted from the panel regression would forecast whereas other could have done much better, for instance the USA increase in LBE is 4 years lower than what the model would forecast given the level of spending and other factors considered.

<sup>30</sup> This is only a selective list of those surveyed in the OECD report.

Remember that here we are speaking about 'outcome efficiency' which refers to good health. The recommendations provided by the OECD are based on the assumption that unexplained variations in health status across countries reflect efficiency differences in the use of inputs (spending and or socio-economic factors). Since socio-economic and lifestyle factors are not easily manipulated, the reforms have focussed on spending more to improve care delivery (the supply side). Yet the total lack of correlation between spending output and health outcomes was established above.

To further illustrate this point, consider one of the possible levers of output efficiency such as in-patient care Average Length of Stay (ALOS). Here Japan is by far the best performer in terms of health outcomes indicators with a stunning 35 days ALOS in 2007, which is more than three times the OECD average (10 ALOS). Puzzling? Many more examples of counter-intuitive data exist. The expected relationship disappears when combined with other examples and subjected to number crunching statistical software.

Demand side factors drive the bulk of health outcomes: To simplify this discussion, the authors have adopted the supply and demand metaphor. The term 'supply' refers to measures aimed at providing better care and often concerns health care systems' internal functioning such as spending, health care output and capital equipment (technology), reimbursement methods and more.

The term *demand* refers to pressures generating early inappropriate or preventable

need for health care. *Demand* altering measures can affect individuals' poor health behaviours and/or their surrounding environmental pressures. These include an array of factors such as TV advertising of energy dense nutrient poor (EDNP) foods to children, availability of fresh fruits and vegetables as well as classical environmental factors such as air pollution.

In reviewing the data presented above, demand side factors appear to explain individual country variation in health outcomes more robustly than do supply side factors. Once variables such as obesity, diet, and activity level are appropriately measured and entered into the equations, the results of the OECD panel regression would very likely change. One cannot be convinced that the superior performances of Japan and Italy are explained more by spending and not by lifestyle (especially diet). It is no secret that the US spends more than double the amount of the OECD average and yet achieves remarkably low performance ratings. Ranking near the bottom of the group cannot be due to administrative or other inefficiencies embedded in the US's predominantly private payer oriented model.

If demand side drives outcomes, then actively managing demand side contributors will help reach the desired efficiency frontiers. Today, technology can be distributed to lightly instrument communities and support trillions of light-weight every day decisions by individuals. ICT use must be expanded for the expressed purpose of actively enabling the detection and deployment of choice architectures that optimize the health performance of crowds.

29

# 4. Thesis Four: Health knowledge engines are underperforming

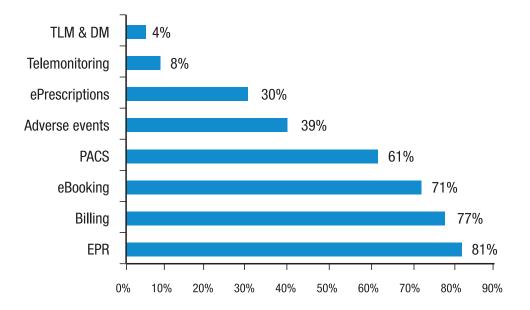
Importantly: *Design constrains of Legacy knowledge approaches dictate their poor predictive capacity* 

**Entrenched HIT spending and deployment.** Recently throughout the globe, we have witnessed an unprecedented effort to affect population health outcomes by leveraging technology in health care delivery. According to WITSA data between 2003 and 2011 the US will have spent in HIT approximately \$500 billion, Western Europe<sup>31</sup> \$531 billion, Eastern Europe<sup>32</sup> \$25 billion, and Japan \$128 billion [142]. Another source<sup>33</sup> indicates that investments in HIT have grown substantially and in most countries account for between 2% and 6% of total health care spending. In stark contrast, relative spending for prevention is almost non-existent.

Below, the data of a recently completed survey of HIT deployment within a sample of more than 1,000 acute hospitals in EU27 is visualized.<sup>34</sup>

Clearly the administrative and billing oriented solutions listed at the bottom of the chart are significantly more widespread than are the patient oriented solutions such as telemonitoring and others listed at the top of the chart. Interestingly, only 4% of the hospitals with

Figure 8: HIT deployment in acute hospitals: EU27 representative sample (2010)



EPR= Electronic Patient Record; PACS= Picture Archiving and Communication Systems; DM= Disease Management; TLM= Telemonitoring

Source: See footnote 34.

<sup>31</sup> Includes Norway, Switzerland and Turkey, but does not include Malta, Cyprus, Luxembourg, and Iceland.

<sup>32</sup> Including also Russia and Ukraine.

<sup>33</sup> Market research company IDC, cited in [143].

<sup>34</sup> These results are further analysed elsewhere in a forthcoming report [144]. The survey was funded by the European Commission and realised by a consortium comprised of Deloitte Consulting and IPSOS. One of the authors of this essay was part of the steering committee of this project and has been provided permission to use such data.

an EPR give citizens access to their personal records. An EPR with no personal access clearly cannot qualify as Personal Electronic Health Record. In this case the EPR is basically an inward facing instrument recording institutional data gathered during an episodic hospital stay. Furthermore, the proportion of hospitals with an EPR that can be accessed remotely by their personnel is a mere 34%. This drops to just 24% when measuring the proportion of hospitals providing remote access to other health care providers such as offsite general practitioners, specialists or outside laboratories.

Where is the health value return on this robust investment? Theoretically, HIT has the potential to deliver all sorts of benefits. In fact, most will often adopt HIT strategies in the hope of realizing these potential promises. HIT could reasonably be expected to improve quality of care in various ways: better decision making through access to state of the art knowledge, less medical errors through computerised adverse events tracking systems, prescription compliance monitoring systems, better general patient monitoring systems and so on. Remarkably the available evidence regarding cost-effectiveness remains inconclusive as discussed in several reviews and meta-reviews [143, 145-151]. In view of these findings, the number of studies evaluating HIT impact continues to grow exponentially: in 2002, 652 studies focusing on telemedicine were identified for the period 1980-2000 [151]; in 2006, 252 evaluation studies of more broadly defined HIT were found for the period 1994-2005 [145]; the latest available review report identified an additional 1,300 studies published between 2005 and 2009 [143].<sup>35</sup> Perhaps not surprisingly within this growing body of literature one can locate both authors who herald the vast untapped potential of ICT as well as authors who bemoan health care's backwardness and unmet expectations [146]. Similarly the evidence to confirm a positive health impact of HIT remains inconclusive. [143] [179].

Perhaps the "Productivity Paradox" helps explain why large HIT investments may struggle to deliver expected results<sup>36</sup> [131]. Robert Solow famously stated "You can see the computer age everywhere but in the productivity statistics".37 This was later coined the Productivity Paradox [184, 185]. Between 1970 and 1990 remarkable advances in computing power fuelled IT investments by corporations yet was paradoxically met by relatively sluggish productivity and slow economic growth. Initially this paradox was explained by measurement errors thought to lag behind the full manifestation of benefits from introducing IT. Over time, it became clear that productivity did in fact improve but only when IT deployment occurred together with real reorganisation, change management, and retraining of employees [147].

The full magnitude of computing power benefit lagged until corporations advanced their ability to both procure and mine data rich customer information. Fundamentally three key functions required integration before corporate ICT reached its full potential. These functions include: the ability to integrate the value chain upstream (supply chain) as well as downstream (delivery) and better connect with inter- as well as extra-organisational networks of cooperation.

The parallel between the corporate world and that of health care appears real. The Productivity Paradox of HIT Health care, *mutatis mutandis*, may also exist until such time as our health systems also engage in internal reorganisation, change management and training of personnel. This re-organization would involve more than procurement of remote patient monitoring, more than EPRs with remote access

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<sup>35</sup> An illustrative selection of such reviewed studies have been retrieved and consulted in preparation of this essay [152-183].

<sup>36</sup> On this see more in [147].

<sup>37</sup> R. Solow, We'd better watch out. New York Times, July 12, p. 36.

and more than system wide administration solutions. To break the productivity paradox in health we would need to integrate institutional data with upstream household and individually procured 'customer's data' that reliably predates preventable health outcomes. Data integration across medical silos, vertical specialties and between practice and research would advance health value of HIT. Clearly, corporations invest in educating or nudging customers to achieve desired customer behaviour regarding their products through advertising, competitive pricing and other means.

Similarly, health systems might use HIT to educate and nudge citizens to achieve desired health behaviours. In short, the data intensive customer focus that drove IT success within the corporate world remains grossly underdeveloped in HIT systems. Legacy knowledge approaches depend on institutional data and this data is too little too late to advance robust predictive capacity. This missing link may be largely responsible for the difficulty in documenting a solid return of investment in HIT.

We are no longer accidentally well in this modern world. Within our modern choice architecture, the community or crowd selects and accumulates trillions of lifestyle related choices daily. These *lightweight* decisions regarding nutrition and activity result in physiological regulatory events that collectively drive 60-80% of crowd health outcomes. Importantly, these *lightweight* decisions continue for years and during a time when the reversal potential of suboptimal physiological events may be the highest; that is before chronic disease sets in. In contrast, the *heavyweight* decisions made by health professionals occur often after full reversibility is no longer available.

Furthermore, evidence-based care is a product of our legacy knowledge approaches and depends upon a minimum level of measurable pathology to support a randomized control trial (RCT) approach. Failure to provide high definition or high resolution understanding of pre-clinical adjustments of preventable crowd health outcomes is a design flaw inherent in legacy knowledge approaches. One can no longer rely on tradition knowledge generation because of two key developments in our modern era: 1) We are not accidentally well and would actually benefit from preventive high resolution information environments and 2) Crowd-based approaches are a realistic and practical way of securing ultra large data sets supporting new informatics approaches beyond the RCT and traditional epidemiology.

In short, the crowd controls the bulk of the cards while health professionals are left to pick up the pieces through evidence-based chronic care management. Here lies the important paradox of our HIT efforts. HIT tracks in detail the *heavyweight* data stream of health professionals and health delivery systems providing chronic care management yet paradoxically, health systems secure very little lightweight high yield health data from the pre-chronic care community. Thus while our legacy knowledge systems have to some degree defined the natural history of disease, the functional landscape of wellness or pre-illness remains largely undefined and therefore unmanageable. Communities remain in the dark regarding their health trending until reaching sufficiently pathological states. One cannot manage that which has failed to be measured.

Moreover, current epidemiological approaches gather islands of specific group data over time. In this way, average group caloric consumption can be reported for a specific number of years. However, without access to the per-unit or per-person co-occurrence data, it is impossible to organize the more benign or health neutral event streams from the more malignant or health threatening event steams. Iso-caloric loads consumed during periods of either low or high activity patterns may result in clinically relevant differences in physiological caloric processing (the per unit regulatory events). Over time the clustering of these micro events control the regulatory elements that drive the crowd health outcomes. In this way, the future prevalence rates of preventable health outcomes are being *dialled in* decades before the medical industry can detect or intervene effectively.

Until recently, tracking high yield micro events was not a realistic possibility. Today the ubiquitous spread of internet use, smart phones and social networking has dropped the barriers to real time micro event processing across crowds. Per-unit co-occurrence data may be captured by lightly instrumenting crowds using low cost tracking devices. Access to just a few high yield health contributors would advance the predictive and preventive capacity of HIT dramatically and are discussed in the solutions section below.

Again, recall that the tsunami of poor health mentioned above was not triggered by failure of medical records to be interoperable, nor was it fuelled by poor medication compliance rates. In fact, this devastating tsunami continues full force and not dependent upon any of the many targets of current HIT projects. Thus mining and managing institutional supply side data streams cannot be expected to protect against rapid and robust premature preventable poor health outcomes (demand side explosion).

Critics may harbour unrealistic fears of systems engaged in permanent and perpetual *life-logging* every detail of all citizens. This fear is completely unnecessary. As mentioned, by tracking just a handful of mundane yet high yield health factors, it may be possible to reliably predict the vast majority of preventable crowd health outcomes.

It is true that ultra large data sets generated through crowd sourced mechanisms stand

to change the politics of knowledge. The knowledge asymmetry of yesterday is already being challenged by internet successes such as patients like me.<sup>38</sup> ('me' is out of context) As clinically relevant and effectively personalized high yield health information is enabled, citizens may engage in wilful self effort to actively optimize personal performance. In addition, the timely correction of undesirable event streams will be enabled through crowd sourced approaches.

Historically, post market surveillance of new pharmaceuticals was relatively challenging and products persisted while risks outweighed benefits. In the absence of real time crowd-based check and balances, we ran the risk of delayed correction of unintended consequences. For example, the well-known case of Rofecoxib (Vioxx) documented by Graham et al in 2005 [186]. The drug was approved in 1999 by the US Food and Drug Administration (FDA) and was withdrawn from the market by Merck only in 2004, despite evidence of its lethal effects building much earlier, though in an uncoordinated and fragmented fashion. With hindsight, the FDA calculated that the drug in five years may have contributed to as many as 27,000 heart attacks or sudden cardiac deaths and 140,000 cases of heart disease. Our digital natives may shake their heads in disbelief of the magnitude of these figures as they are confident in their connected era of never repeating a similar event.

Finally, translating scientific discovery into practice and managing health knowledge through literature-review is unacceptably inefficient and no longer sustainable given the explosion in the output of health science (see Evidence Box 6).

Crowd-based approaches to procuring data intensive scientific truths provides a pathway into *knowing* the once *unknowable*.

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38 See www.patientslikeme.com
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#### Evidence Box 6: Discovery to practice and information explosion

#### From discovery to practice.

About 250 years elapsed from the moment when citrus fruits were unequivocally demonstrated to prevent scurvy until the British merchant marine made use of citrus mandatory, despite countless loss of lives among sailors and unambiguous evidence supplied by controlled experiments. Things have improved but the time from discovery to practice in medicine remains slow and inconsistent [[187-190]]: on average 17 years [191], too long to possibly prevent us from saving a large number of lives.

#### Information explosion.

The outputs of health science have been growing exponentially [192]and the quantity of health data exceeds capacity to process [188, 193]. This situation can be conveyed with the following data [191]:

- A typical primary care doctor must stay abreast of approximately 10,000 diseases and syndromes, 3,000 medications, and 1,100 laboratory tests;
- Research librarians estimate that a physician in just one specialty, epidemiology, needs 21 hours of study per day just to stay current;

Faced with this flood of medical information, clinicians routinely fall behind, despite specialization and sub-specialization and this is also responsible for late introduction into practice of scientific discovery.

# 5. Thesis Five: Need of a paradigm shift in policy making

# Importantly: *Paradigmatic shift in policy making to harness the power of crowd-based data intensifies scientific approaches*

**Thesis.** Current policymaking strategies as well as the means of procuring supporting evidence for policy decision making are no longer able to cope with complex multidimensional and highly dynamic societal challenges. Timely and evidence-based approaches to reliably successful policy making will no doubt require harnessing the power of crowd-based procurement of high yield health information.

Critics may wonder if the inherent complexity of our free living systems increased. Is today's society and economy more unstable and unpredictable than ever? Certainly changes are ubiquitous. The world is increasingly interconnected via the internet and other new media. Most would agree that complexity and unpredictability were also robust thirty or forty years ago. *The only constant in life is change... Isaac Asimov.* 

In short, the intellectual framework upon which policy making rests is no longer adequate.

Our legacy knowledge approaches have supported classical hypothesis driven studies successful in uncovering some major and key determinants of disease specific health information and *hard* environmental pressures such as water quality, general sanitation and reduction of infectious diseases. However, these legacy knowledge approaches may be ill equipped to tackle the *softer* issues such as collective crowd lifestyle shifts so powerful that widespread destructive phenotypic adjustment occurs in just a few decades.

At our disposal is a radical increase in computing power along with outstandingly wide spread distribution of networked communities. The possibility of collecting and processing ultra large amounts of data at moderate costs was unthinkable only a decade ago. These developments have led to the emergence of futuristic visions such as the advent of 'singularity'<sup>39</sup> suggesting computers will exceed human cognitive capabilities and an 'intelligence explosion'40 will advance, among other things, the prolongation and quality of life.

Other signs that we are entering into a new information era of data intensive science and policy making are found in discussions of the Fourth Paradigm.<sup>41</sup> Yet most health care industries remain entrenched within legacy knowledge approaches dependent upon institutional data. Unless the move to advance household and individual data into the mix effectively is accomplished, this industry is unlikely to generate the skill set required to participate in this new paradigm. Crowd sourced approaches in data procurement to support evidence-based investment in public health will be a key ingredient of robust predictive and preventive informatics capacity. The paradigmatic shift underlying this new policy framework is not, however, simply a matter of more computing power and more data. Multiple longstanding challenges may also need to be addressed.

<sup>39</sup> In mathematics "singularity" defines the moment when an object changes its nature so radically as to assume characteristics no longer expected as the norm for its class. The term has been popularised by American sociologist R. Kurzweil [2], according to whom Moore's Law and the growth in parallel and distributed computing architectures by 2045 the world will reach a singularity status.

<sup>40 [2] [</sup>p. 136].

<sup>41 [194, 195].</sup> 

**Policy resistance**: For more than 60 years, society has often failed to eradicate dire social challenges through investing increasing resources into state policy activity [196][ pp. 8-9]. *Policy resistance* appears responsible for these failures. *Policy resistance* occurs when an intended policy outcome is defeated intentionally or unintentionally by complex and dynamic elements, agents, factors, first order and second order feedback loops, and so on. The causes are typically multidimensional and found throughout history[49].<sup>42</sup>

Real world human behavioural complexity and classical policy tools: Herbert Simon was the first in 1957 to challenge the neoclassical homo oeconomicus (fully rational human) introducing the concept of 'bounded rationality' [197]. He argued that many times we do not search for optimal solutions but are content with satisfying ones given the boundaries we face. Such a boundary is lack of perfect information coupled with the incapacity to fully process the information we possess ("a wealth of information produces a scarcity of attention"). In 1985 the American sociologist Marc Granovetter [198], advancing beyond his first 1973 classic on the 'strength of weak ties' [199], argued that rationality is socially embedded and not exercised in a social vacuum. In other words, we act according to the socially shaped structure of opportunity we face, using and being influenced by, the network of social relations into which we are embedded. More recently these insights have been further developed in the brilliant work of behavioural economists and economic psychologists [200-204].43

These important social pressures may go unobserved and not be considered in policy design and implementation. Thus enabling a mounting systemic policy resistance and defeating the policies using only the traditional tools of policy making such as regulation and incentives.<sup>44</sup> In other words, when changing tastes and preferences are influenced by social interaction, a simple 'stick and carrot' incentive based policy or regulation may be impotent in effecting desired change. In addition, restricting full freedom of choice may backfire and trigger unintentional systemic resistance to the policy.

However, opportunities for policy-making may be enhanced precisely because we do not act strictly according to instrumental rationality. Our actions are not always self-interested yet may still lead to contributions that can be harnessed to achieve policy goals. Moreover, citizens can be unobtrusively and intelligently helped to make optimal choices supporting both their individual well-being as well as group well-being policy goals.

The next step: nudging plus networks. The above insights have been used to support the popular and innovative approach to crowd management strategies presented in the best selling book Nudge [205]. The authors contrast the stylized agents of classical economics called Econs to more human-like agents called Humans. The Econ reliably reacts using his reflective cognitive system, whereas the Human is frequently unreliable in his reaction secondary to an automatic cognitive system. An example of an Econ is Star Trek's Mr. Spock who typifies the always-in-control person. The Human may be typified by Homer Simpson; who is a typical "yeah-whatever" person.

The fundamental game changer presented by *Nudge* is that traditional simulation efforts

<sup>42</sup> See pp. 505-506 for a very telling exemplificative list of policy resistance cases.

<sup>43</sup> Just exemplificative of a vast and growing body of literature.

<sup>44</sup> Regulation can forbid certain behaviours, such as smoking in public places. Financial incentives can alter the behaviour of individuals, by making more costly the dysfunctional ones (i.e. through taxes). Financial incentives are used when market price does not reflect positive or negative externalities: for example, high taxes on fuel and cigarettes are designed to reflect their negative social externalities for health and environment.

that depend on Econs will under-perform dramatically today as Human behaviours are significant contributors to crowd outcomes. Folks will spend money every year paying for magazines that are not read only because they fail to pay attention to an automatic renewal or malignant nudge. The authors claim that left to their own devices, Humans unlike Econs will often continue to make poor decisions affecting their own wellbeing. Humans are especially vulnerable when *mapping* (view to the future) outcomes is delayed or unclear at least for the moment. In this way it is possible to consume fast food and soda daily for decades while effectively denying clear and immediate feedback regarding tangible consequences.

Policies hoping to improve collective health behaviours can harness the power of nudging groups through choice architectures. Here the principles of libertarian paternalism: free choices are fully preserved but the context of choices is organised to enable the choices leading to better, healthier and longer lives. Architecting choices is less intrusive than imposing regulation and less costly than introducing disincentives. Taxing poor food choices is a costly proposition and likely to be aggressively opposed by industry.

Effective nudging by policy makers would require developing a more refined or high definition understanding of socially embedded desires, tastes, preferences, and behaviours of the *policy recipients* they would like to affect. In addition, an understanding of how networks are born, grow and develop over time would be important. The effects of Nudging do not occur in a vacuum. They occur within a social network. Thus nudging alone will not be sufficient. Nudging plus network approaches raises challenges but also creates tremendous opportunities for innovative policy making [196].

In a system of interconnected agents, changes by a few agents may produce a cascade of changes in many agents as they learn from each other, copy each other, and seek each other's acceptance. If the network is scale-free (characterised by a power law) then changes enacted by the hubs can even more likely lead to a cascade effect.<sup>45</sup> Such cascade effects may drift a policy into unknown or unexpected directions. Thus by understanding the basic structure and flow of a network, a small nudge can be applied to relevant hubs to trial the cascade effect at a smaller scale. Once confident that desired policy outcomes are reliably attained, a larger nudge can be applied to the network with the intention to scale effective policy. This can be repeated in cycles enabling continuous improvement coproduction of effective community strategies.

Integrating information from classical surveys into agent-based modelling or other innovative ICT supporting modelling and simulation tools, policy makers would have access to a reasonable understanding of a network structure. This has been demonstrated in a study of binge drinking in the UK [207] and in the Framingham Heart Study. In the latter, a longitudinal cardiovascular study following residents since 1948, suggested that the chances of a person becoming obese rose by 57 per cent if they had a friend who became obese [208, 209]. Other common health-relevant habits such as smoking, sleeping patterns, alcohol use and more appear subject to network influences as well.

**Co-Production, participation and shared responsibility**: A paradigm shift in policy making includes supporting a framework enabling meaningful participation of multiple stakeholders. Citizens at large must have an effective voice to inform policy, to better understand choices affecting their futures and to take a wilful and

<sup>45</sup> The best, more comprehensive and yet accessible analysis of network in general and of scale-free network in particular is that provided by Barabasi [3]. Originally the idea emerged from a study of epidemiologists who discovered that most people have only a few sexual partners in their lifetime but a few have hundreds and even thousands and are the catalyser of sexual disease transmission [206].

personal ownership of the actions that affect their daily life and future health outcomes.<sup>46</sup>

Willingness to passively trust policy makers, professionals and perhaps even scientific experts appears to be declining across crowds. Thus a fully transparent, multi-stakeholder, coproduction approach may be welcomed.

Providing open access to data currently lying inert and silent in *public* databases may be an obvious place to start. By lowering the barriers for crowds to share data they can take an active role in solving problems affecting their lives. These are already in operation. Crowdsourced information about street lighting and road conditions drive decisions regarding corrective actions within a neighbourhood.<sup>47</sup>

At first glance, the classical policy making perspective might be to view crowd based nudging as a tremendous challenge. Effects of socially embedded and bounded rationality may be compounded to make the classical 'stick and carrot' approach even more ineffective. Connected crowds may easily architect intentional policy resistance. Yet, the question is not *if* crowds connect but *now what since* connection has already arrived at ultra large scale via Facebook and others.

The good news may be the huge opportunity to vastly improve the evidence base upon which the policy cycles depend (design, implementation, evaluation). Lightly instrumented crowds within co-produced choice architectures enabling easy and sustainable participation will be a valuable source of high yield health data. In this way the wisdom of the crowd will not solely depend upon citizen opinion or personal insight. Both opinion and insight by definition are above the level of perception. In our modern world much health adjustment occurs below the threshold of perception. Gathering and mining socially networked data can occur within the constraints of a standardized and transparent social contract. In this way, collaborations between governments, industry and private citizens may benefit from a level of trust needed to continuously co-produce effective nudging strategies.

**Collaborative open science models.**<sup>48</sup> Although scientists, researchers, and experts throughout the world have been producing vast amounts of data, this data is only minimally shared (tip of the iceberg Figure 9). Both raw and combined data are often not publicly available. Real-time data usage by multiple groups to spur increased scientific productivity and expedited extraction of new solutions to resilient problems is the hope of *Science 2.0*. This is a global, transparent and open sourced approach to knowledge generation.

The Science 2.0 effort moves beyond the expert community to include the non-expert community as well. Today an ordinary citizen using Google to research information on a rare disease affecting his child may end up spotting an important article from the most recent research. Yet, this taxpayer's access to the article may be barred pending a subscription or other requirement. Often this is the case even when the research may have been co-funded with taxpayer money.

Although complex intellectual property issues and other challenges related to the peer review process exist, the open access movement is gaining ground within the scientific community

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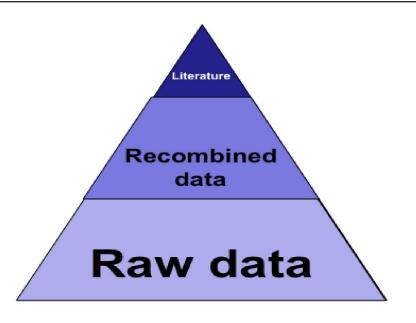
<sup>46</sup> This new trend should not be exaggerated, as it is not clear to what extent it concerns large sectors of society. Yet, it is enough that a small active minority participate to contribute to a policy, or conversely mobilise to oppose it, to produce large cascade effects. For an overview of such approach for what concerns co-production of government services see [210].

<sup>47</sup> See for instance Steven Johnson "The Quantified City; What millions of calls to 311 reveal about the Big Apple." Nov 2010 Wired Magazine, p 156.

<sup>48</sup> For a comprehensive and wide state of the art review on this topic see the anthology edited by Hey et al on the topic of data intensive science [195] and particularly the transcript of a seminal talk delivered by Jim Gray in 2007 [194]. On the concept of Science 2.0 see also [211].

39





Source: Adapted from [194].

as well. As scientists and experts connect so too do implications for policy-making. As large data sets are shared across disciplines, across national and state boundaries these can be paired with more sophisticated analysis as well as presentation techniques. International collaborations may provide benchmarking targets that out perform locally-derived targets. In this way communities are not destined to achieve merely locally demonstrated goals but to perhaps exceed these and build the choice architectures that move the crowd beyond the status quo. By using global data to actively co-locate the items that matter most, crowds may move beyond the historically accidentally well state to achieve a relative super-wellness.

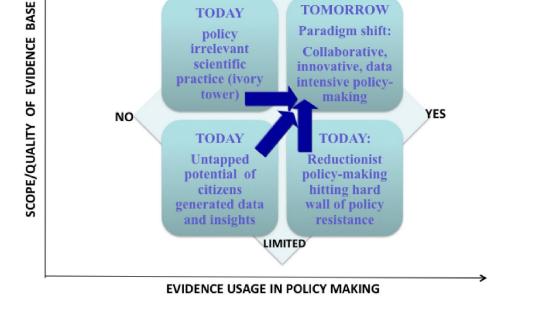
Navigating between challenges and opportunities. Clearly policy recipients are not the only participants for who bounded and embedded rationality applies. Likewise, one cannot blame policy failures simply on the imperfect rationality of agents. Policy makers as well as the scientists and experts providing evidence may also be rationally bounded. Collectively, their toolbox of instruments may be outdated due to the expressed underutilization of powerful crowdbased sources of information. Furthermore, a reductionist intellectual framework may poorly navigate increasing systemic complexity. Below is a short list of challenges current policy making models face.

1. Limited data paradox. Policies are made by governments and large public institutions possessing a wealth of amassed data which may remain largely inert as mentioned above. General awareness of the data and its availability may be low. Connecting different data sets has traditionally been difficult. Given the volume of Public Sector Information (PSI), addressing this paradox has become a policy priority in the European Commission.<sup>49</sup> Broadly speaking, public institutions collect, reproduce and disseminate a wide body of information such as social, economic, geographical, weather, tourist, business, patents and educational information. The value of this PSI has been estimated in the range of €27 billion in the EU. Clearly this data asset could be more

<sup>49</sup> See EC Directive 2003/98/EC of the European Parliament and of the Council of 17 November 2003 on the Reuse of Public Sector Information: (http://ec.europa.eu/ information\_society/policy/psi/docs/pdfs/directive/psi\_ directive\_en.pdf)



Figure 10: Evidence in policy making: today and tomorrow



Source: Authors' visual essay.

effectively mined and re-used by third parties if an open access policy were enabled. In addition to the above, the potential wealth of crowd based citizen-generated data remains largely untapped.

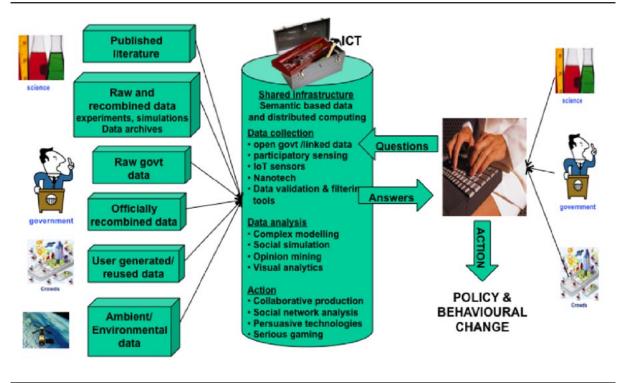
2. *Reductionist analysis*. In the classical reductionist approach a treatment policy is chosen in hopes of obtaining a desired effect. This assumes that choice consists of short linear causal chains. Additional complexities are introduced by an agent's socially embedded and bounded rationality within related network effects. Although policy makers may blame failures on forces outside their control, they often claim success when things go well [49].

3. *Ineffective policy tools:* Recall that 'stick and carrot' instruments of regulation and incentives are often ineffective in the long run.

This situation is summarised by the matrix below. The y-axis *evidence dimension* must be interpreted broadly to encompass both the data and the analytical framework used to process and represent data in support of the entire policy cycle (from design and *ex ante* evaluation and simulation, through *in itinere* implementation monitoring, up to *ex post* evaluation).

Theoretically, a community of scientists and experts would produce the most comprehensive and robust form of evidence support for policymakers. However, this insight may be delayed, difficult to use or not directly useful for specific policies. In turn, citizen-generated data may not be fully comprehensive (self-selected, biased, opinion) or robust (in need of filtering/ validation). Sensitive issues such as security and privacy must also be addressed. For these reasons, citizengenerated data are slow to enter the policy making arena.

The paradigm shift in policy effectiveness will occur when the top right quadrant of the matrix characterizes the bulk of policy evidence activity. In a cycle of continuous improvement, collaboration across the three key groups of stakeholders (policy-makers,



Source: Authors' elaboration from [212].

expert scientists and non-expert citizens) will drive evidence-based investment of public health funds. Together these stakeholders will support innovative data intensive policy action, capable of timely reaction and redirection within networked systems. By expressly instrumenting the crowd to track clinically relevant health behavioural adjustments, timely and contextualised policy nudges can be delivered back to the crowd.

*ICT* for data intensive and collaborative policy co-production. In summary, ICT alone cannot solve everything. For the desired paradigm shift to occur, both institutional and cultural changes are needed. Figure 11 is a visual summary of the elements needed for evidencebased effective policy making.

Table 2 lists the elements needed for ICT to advance as a powerful instrument across the value chain of data collection, data analysis, and support for action. The FP7 project *Crossroads* reviewed a large body of literature to provide the

elements in Table 2 and to generate a roadmap for ICT use in policy modelling.<sup>50</sup>

Figure 11: Various agents (policy makers, citizens, scientists and expert) share and collaboratively use data through distributed computing. Inside the ICT *tool box* are tools for data analysis, data presentation, and for persuasive feed-back. Together, all stakeholders are able to obtain answers to their queries and collectively optimize policy to optimize citizen behaviours.

Table 2 (in exhaustive ways) displays the various nuts and bolts of ICT against some of the topics analysed in this section. On the right end column are the three gaps of current

<sup>50</sup> The figure and the table have used the monumental body of literature reviewed and transformed into the most comprehensive and up to date roadmap on the topic of ICT for policy modelling produced as part of the FP7 project Crossroad [212]. We simply mapped some of the Crossroad finding against the key issues discussed in this section, only for exemplificative purposes with no claim to provide an exhaustive and clear-cut taxonomy.

policy making, next to them are the challenges/ opportunities that current developments and new insights propose as the basis of a paradigmatic shift in policy making. The last three columns include the ICT toolbox for: a) data collection, curation, and validation; b) for data computation, analysis, and representation; b) decisions, actions, behavioural change.

Data and information are a fundamental building block upon which the paradigm-shift in policy depends. However different data may come in different formats and be difficult to link correctly. For instance, point data gathered by sensors on the ground may need to be reconciled with spatial resolution remote sensing made of imagery [213]. Data gathered by Personal Health Systems applications to monitor patients present different modalities such as strings and graphs [188] [p. 112]. The World Wide Web is rich with data that is not easily linkable.

Science is actively solving these problems. Specifically, eScience deals with issues of data curation and the semantic web [213] [214]. This effort is spreading to other domains, including health care and the life sciences. Semantic Web Health Care and Life Sciences (HCLS) Interest Group<sup>51</sup> is very active in advancing data interoperability [215].

In the field of Personal Health Systems, research and implementation of multi-modal data fusions as well as data pre-processing are a core priority of research [188]<sup>52</sup> [pp. 112-114].

Beyond data curation, data validation is important. Diverse user generated data can be validated through collaborative filtering tools, reputation management systems, and various privacy and authentication techniques.

The strongest drivers for a data intensive shift stems from the vast capacity of citizens and their surrounding environment to contribute data easily today. Citizens are taking a proactive role in publishing their comments and complaints online. They use technology to record and publish videos, photos, audio recordings and other items. Smart-phones remain the preferred vehicle for uploading data and participating in social networking sites.

Today, strategic and critical information can be volunteered by users and in some cases can save resources as well as lives.

A dramatic reduction in cost of consumer electronics is increasingly making sensor-based devices less expensive and more popular. Such sensors enable both *participatory sensing* (requiring a minimum level of efforts from users) and *opportunistic sensing* (no user effort required, users to simply carry around smart devices that spontaneously collect and transmit relevant data). All of this can be integrated with the ambient data collected by Internet of Things (IoT) sensors and other devices capturing important information (i.e. satellite images).

Today citizens also readily provide information on changing traffic conditions. They report the extension of wildfires. Citizens report urban noise levels and even participate in reporting large scale disasters such as the Haiti 2010 earthquake.

<sup>51</sup> http://www.w3.org/blog/hcls

<sup>52</sup> The literature on data fusion and multimodal data integration is vast and spans several disciplines and we use an introductory handbook to define the two terms [216]. Fusion is a term describing the integration of data from multiple sensors using a combination of mathematical algorithms and data transfer architecture. Fusion algorithms allow data from various sensors to be combined. In some contributions data fusion and multimodal data integration are used in an alternate manner implying that there is no substantial distinction among them[217]. In this way one may talk about "multimodal data fusion" as a particular case of data fusion, when the data not only come from different sensors but also have different modalities (typically strings and graphs). Data pre-processing is a useful technique instrumental to improve data fusion.

In general, when we obtain a database, it is necessary to select the appropriate variables used as the inputs to eliminate the noise contained in the selected variables and to normalize the filtered variable. Achieving this is termed data pre-processing [218].

#### Evidence Box 7: Opportunistic sensing example: Asthmapolis<sup>53</sup>

Asthmapolis is a good example of opportunistic sensing. A use-tracker is simply attached to the top of the asthma inhaler. It records the times and locations when the inhaler is used and this data can be viewed in real time over handheld devices (e.g. phones) to create a complete clinical diary of events. This helps the individual map and track his/her asthma patterns. Likewise, physicians can remotely monitor a patient's asthma symptoms and their use of medications. In this way if any patients are identified as in need of additional attention, an action plan to achieve better asthma control can be communicated in a timely manner. This would also provide valuable real time data on trends in Asthma attacks amongst various populations and in specific geographical areas to assist with evidence-based policy making.

In short, the time for Personalised Mobile Participation Paradigm has arrived. With advanced participation, new modelling and simulation techniques will advance. Innovative applications pushing the boundaries of analytics and visualisation techniques will help bridge the knowledge asymmetry between the experts, the policy makers and the citizen. Highly specialized knowledge and analysis will become more accessible while retaining the robustness of rigorous analysis. Static visual analytics will advance to interactive visualization with supporting analytical reasoning to help make well-informed dynamic decisions in changing complex situations.

Problems once *unknowable* due to their size and complexity may become quite *knowable*. Visualisation techniques will provide policy modelling extending from the presentation of discussion arguments in argumentation map formats for minimizing the complexity of policy debates to the creation of virtual environments which can simulate the behaviour of both policy makers and citizens in a real-life like environment. Such techniques will be the building blocks of new user friendly Decision Support Systems.

<sup>53</sup> See www.asthmapolis.com

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44	

Table 2: Elements for an ICT driven paradigm shift in policy making

		ICT TOOLBOX		
GAPS	Challenges/opportunities	Data collection, curation, validation	Data computation, analysis, representation	Decisions, actions, behavioural change
	Citizen participation/ambient data	User generated data, participatory and opportunistic sensing, IoT sensing, smart cities, reputation management systems, collaborative filtering, cloud data exposure	Possibly as the computation techniques become more user-friendly (i.e. visual analytics) and data fully open, citizens may also contribute to data analysis	Visualisation for behavioural change Persuasive technologies Serious gaming
Limited evidence base	Collaborative science	Linked data, (Semantic, data fusion, data pre-processing), cloud data exposure	Distributed computing, complex modelling, self-adaptive algorithms, machine learning, neural nets, connectivist models (models inter- operability)	New Decision Support Systems for professionals (i.e. Health Avatars, Virtual Physiological Human)
	Re-use of PSI	Open government, mash-ups, Semantic, cloud data exposure	Distributed computing	Not applicable
Doductionict from ourorly	Systemic complexity	Using all of the data collected and curated through the tools mentioned in other cells	Distributed computing, complex modelling, self-adaptive algorithms, machine learning, neural nets plus visual analytics and visualisation, augmented reality, natural user interface	Maw Decision Currood Svetame
	Real world behaviour	User-generated data	Opinion mining, sentiment analysis	entrance i nucluo i nucleo no man
	Network (analysis)	User-generated data, social network sites, distributed online panel with data link to other sources	Agent based modelling, self-adaptive and recursive algorithms for network analysis	
Ineffective policy tools	Networks (simulation)	Data as in cell above	Social network analysis software. Machine learning based elaboration of probabilistic graphical models in which the relevant variables, including observed data, are expressed as a graph	Simulated cascade effects with nudges
	Choices architecture	Opinion mining, sentiment analysis	Natural user interface feed back	Visualisation for behavioural change, Persuasive technologies, Serious gaming

Source: Authors' elaboration from [212].

# 6. The Solution: Crowd-based strategic health intelligence

This proposed solution is separated into four main elements:

- 1. A case example is provided to illustrate the conceptual framework
- 2. An outline of the basic functional solution highlighting the added value
- 3. The solution is linked effectively back to the ICT tool box mentioned above
- 4. A preliminary high level view of the business case

Case Example. The health expression of crowds is a process as mentioned previously. Collectively the micro-event streams resulting from lifestyle choices drive the physiological regulatory elements that dictate future health outcomes. Yet, our outdated medical model still assumes all is well until we are ill. Medical management is more accurately termed illness management. It is the evidence-based damage control activity of medical experts. However, in our modern world, the highest potential to transform health outcomes occurs during health management that would predate medical management. Scientific knowledge of evidencebased preventive strategies must depend upon crowd based strategic intelligence. Consider the example below contrasting the breast cancer experience of today with a future model of crowds co-producing effective reduction of future crowd breast cancer rates.

Mammograms are part of preventive screening programs but they do not prevent the onset of cancer. They are case-finding tools. Mammograms help identify the woman who might benefit from evidence-based management of cellular dysplasia. Increased rates of dysplastic change occur in later decades in women. Thus based on these conversion rates (conversion from no pathology to possible pathology) the experts recommend screening, not to prevent disease onset but rather to prevent a delay in the onset of evidence based care.

Primary prevention of breast cancer would depend upon rendering the once *unknowable* knowable through crowd sourced approaches. Lifestyle mediated contributions to breast cancer rates appear rules based across crowds. Activity levels and body mass index optimization appear to play a key role in breast cancer expression [219-221].

Thus although experts will never know everything about the contributors to an individual case such as Beth, cohorts of women appear more alike than they are different.

#### Vignette Box 1: Breast Cancer today

Beth is a 34-year-old woman. She was breast-feeding her fourth child when she noticed a lump. Within weeks, Beth went on to receive bilateral mammograms, a number of breast biopsies, four lumpectomies and eventually underwent bilateral mastectomies. Beth was provided with evidence based care.

Yet, breast cancer appears to be one of many cancer outcomes with a significant lifestyle component when studied in groups of breast cancer cases.

The high yield co-occurrences that predated Beth's outcome were not captured or catalogued to help protect Beth's daughters or others who might travel a similar path. Despite thousands of women having already walked this path, communities still have little concrete knowledge of the basics such as "How much activity should one accumulate by 10, 15 or 20 years of age to help avoid a lifestyle contribution to any future cancer diagnosis?"

#### Vignette Box 2: Breast cancer rate reduction secondary to policy nudging

The pink ribbon is a symbol uniting crowds against a common enemy; breast cancer. Policy makers have enabled crowds to go beyond the pink ribbon and don low cost accelerometers tracking accumulated activity. Citizens easily become data donors within a transparent and standard social contract that enables a community data commons to grow over time.

As well as activity data, the community tracks minimally invasive blood results to monitor the effect of diet on cancer risk through quantifying insulin resistance levels.

These data are analysed in real time by researchers identifying the benign or health promoting cooccurrences from the more malignant or health threatening co-occurrences.

Within a relatively short period of time the community has co-developed a valuable health asset that will protect future members from premature and preventable poor health outcomes.

Armed with this knowledge, daughters can connect through social networks to ensure the group attains the minimum level of activity as well as insulin resistance targets necessary to avoid a lifestyle contribution to their collective future breast cancer rate.

In short, the collaboration between policy makers, crowds and expert community may slash future breast cancer rates thus transforming the health performance of the crowd.

In other words, the health impact of high yield health contributors appear rule based across age, socio-economic, ethnic and other backgrounds. The silver lining in what ails the globe is not that which makes us different, but in fact, that which makes us the same.

Uncovering rules based event streams within complex free living systems is enabled through crowd based approaches. Insights into pre-clinical, potentially reversible life events will enable active redirection and in turn enable significant transformation of crowd health expression.

Here in lies the opportunity for policy makers to nudge the crowd towards a lightly instrumented monitoring to enable prudent, timely and corrective actions.

Mundane, yet high yield health data from households are analysed with innovative ICT based modelling tools generating potent insights. These insights will drive policy nudges delivered via persuasive technologies /serious gaming to optimize human performance and in a continuous improvement model, form the basis for evidence-based responsible investment of public funds.

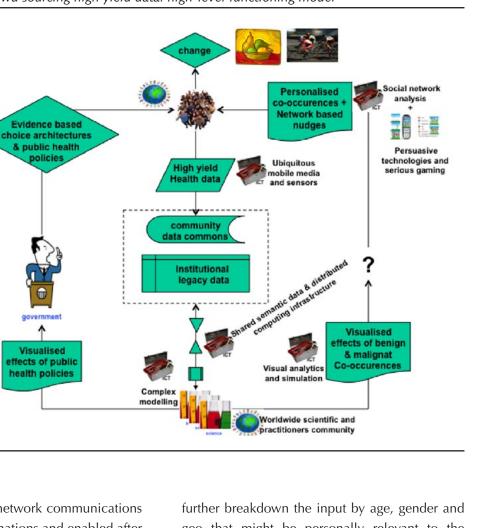
## Basic functional solution highlighting the added value.

Clearly, insights exposed through data sharing must move bi-directionally between the crowd and the policy making government. In this way, a continuous improvement model is enabled to evaluate past public health interventions and simulate ex ante new direct interventions and define updated choice architectures. As the insights are being generated in a continuous fashion, the confidence regarding evolving community *truths* that reach sufficient correctness (a pre-defined confidence level) must still be delivered back to the crowds through a trusted intermediary (rendered by the question mark in Figure 12).

Figure 12 is a visual summary of the proposed solution. It highlights the key elements that together provide a substantial advantage over legacy knowledge approaches. Details regarding operationalisation and implementation are not fully addressed here and will be introduced in the following section.

In general, a community data commons is enabled with the expressed purpose of safeguarding community resilience. Various models of custodianship, security and privacy are selected locally for intra-network

9 Technical Report Series



Visual analytics

and simulation

Data extraction

nternal archives

Data union

Decision

Data input

Archived data

= Analysis output

communications. Extra network communications are standardized across nations and enabled after sufficient de-identification of the participant has been assured.

The community data commons accepts continuously donated high yield data elements from individuals and households. At a minimum this includes easy access to a minimally invasive surrogate for insulin resistance level, device tracking of activity level and basic parameters such as age, gender, height and weight. Ubiquitous mobile technologies will lightly instrument the crowd and ease the burden of data capture and transmission. User friendly systems remain transparent to all participants at all times. As one person enables his daily activity to be shared, he will be able to see the collective totals of numbers of individuals and activity data spectrum from de-identified crowds who have also shared their data. The individual can query the average amount of activity documented and further breakdown the input by age, gender and geo that might be personally relevant to the individual. In this way, the participant has full and continuous insight into his achievement while effectively benchmarking against his cohort. Nudging lifestyles for better health outcomes: crowdsourced data and persuasive technologies for behavioural change

47

Meanwhile, a community of scientists and informatics specialists with granted access to the data will add value through linking such data to legacy institutional data or other scientific archives data. With access to outcomes data, complex modelling and simulation techniques may link pre-event trends efficiently. By linking per unit co-occurrences to future health outcomes, the combined patterns that predate optimal outcomes can be identified. Similarly, the per unit co-occurrences that reliably track toward sup-optimal health outcomes can also be identified. Together this information sets the fabric of evidence-based strategic design of community choice architecture able to nudge participants towards optimal health expression.

Source: Authors' visual essay.

Data analysis leading to feedback and action will take on a more participatory model rather than the traditional instructional model. Traditionally, experts delivered instructions based on current best understanding or known scientific truths. In this open-source model dependent upon large numbers of individuals sharing clinically relevant health data, the insights will reach sufficient correctness (to be defined and standardized by informatics experts). Rather than delaying, this access to sufficient correctness will advance crowd insight and adjust choice architectures accordingly. No longer will the crowd be required to remain passive recipients of premature poor health outcomes. Together with the expert community, they may wilfully participate in co-producing the insights that reliably predate the onset of measurable pathology thereby transforming the health outcomes of crowds.

Legacy knowledge systems, once dependant upon RCTs and institutional data will no longer be under-equipped to predict and prevent the preventable. Coupled with this crowd sourced augmentation, these hybrid knowledge generation approaches will be catapulted into levels of performance never seen before. Adding crowd sourced high yield health behaviour to the current understanding of the natural history of disease will be akin to putting science on steroids in the generation of *eScience*.

Advancing Analytics. *eScience* may be considered the next frontier of rapid continuous improvement through *sufficient correctness scientific truths*. This model can be applied to human performance world wide and depends upon three levels of Health Information Technology (HIT) innovation:

- HIT for secure **data collection and sharing** through crowd sourced participatory sensing and self-reporting.
- HIT for data analysis, through multidimensional data modelling of high yield co-occurrences which separate benign from malignant cooccurrences. The new analysis model is shared in a collaborative way globally so that

the provision insights occur where and when they might be needed most.

 HIT for behavioural change, through transparent persuasive technologies and serious gaming.

#### 1. Data collection and sharing.

A Personalised Mobile Health Paradigm is supported through all kinds of sensors including portable, wearable, ambient based, and nanosensing implantable sensors[188] [pp. 124-148]. Through smart-phone applications and digital cameras, citizens report their behaviour and their personal data, such as blood pressure, food they eat, with different degrees of user effort. A smartphone application such as "myfitnesspal" requires the user to upload data about the food they eat.<sup>54</sup> While BodyMedia created a host of full-body monitors to collect almost 900 inputs such as physical activity, calories burned, body heat and sleep efficiency.<sup>55</sup> GlowCaps, is a medicine bottle cap that effortlessly detects when the patient has taken his medication.<sup>56</sup> Nanotechnologies may track blood glucose levels by embedding nanosensors directly into the human body.57 In this way, individual and household data will often predate and ultimately augment institutional (clinic and hospital) data stores.

The electronic health record (EHR) has traditionally housed institutional health data but suffers still from a significant lack of inter-operability standards as well as a lack of common security and privacy regulations and guidelines[188] [chapter 5].Thus the **health industry** leadership in data integration is widely expected to be unreasonably slow. This may have fuelled the trend towards increased user control over personal health data supported by **data industry** giants such as Microsoft and Google with the advent of platforms such as Microsoft HealthVault and Google Health. These platforms promise that the user owns the

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<sup>54</sup> http://www.myfitnesspal.com/iphone

<sup>55</sup> http://www.bodymedia.com/

<sup>56</sup> http://www.vitality.net/glowcaps\_howglowcapswork.html

<sup>57</sup> http://www.nanotech-now.com/news.cgi?story\_id=38443

data and controls the data transfer at all times. Beyond providing data aggregation, Microsoft also provides the Amalga solution which is a conduit for data to fill patient data clouds. Example of health care establishments that have started to pioneer such solutions include:

- New York-Presbyterian's hospital-based Amalga aggregation system and its patients' HealthVault service;<sup>58</sup>
- Mayo Clinic, which in 2009 launched the Mayo Clinic Health Advisory, a privacy- and security-enhanced online application that offers individualized health guidance and recommendations built with the clinical expertise of Mayo Clinic and using secure and private patient health data from Microsoft HealthVault.<sup>59</sup>

Of note, the WHO has recognized the important role of the individual in co-development of personal and community health insight and has convened a group of experts on this topic [222].

#### 2. Data analysis

Just as data collection can be crowd sourced, so too can data analysis be crowd sourced in a world of integrated informatics that enable experts to produce the scientific rigor of eScience.

In the field of ecological studies, crowd sourced data has given rise to *citizen science*. Here the security and prosperity of our globe, with nearly 7 billion people, depends increasingly on our ability to gather and apply ambient information [223]. Synthesis ecological studies are being produced through collaborative efforts involving hundreds of scientists tasked with the integration of information provided by citizens [224]. Crowdsourcing of analysis has proved to be extremely effective also in the field of astronomy: data made available to the wider public on the web as part of the Sloan Digital Sky Survey resulted in 50 millions accurate classifications of a million galaxy

and also led to the discovery by a schoolteacher in the Netherlands of a galaxy that is now the bluest known galaxy in the universe [225]. In the domain of natural disasters, researchers at the EC JRC-ISPRA, used 1,645 voluntarily crowdsourced SMS reports to almost perfectly predict the structural damage of buildings in Haiti caused by the 2010 earthquake.<sup>60</sup> This prediction was exceptionally close to that produced by 600 experts from 23 different countries deployed by World Bank-UNOSAT-JRC (WUJ) joint mission, who used highresolution aerial imagery of structural damage.

Of note, in 2010 a Harvard-based crowd sourcing project started seeking new answers and question to diabetes. "We want questions as well as answers, and we need them from a broader community because the same old people asking the same old questions in the same old way with slightly newer technology is not moving things fast enough or broadly enough for us to cope with these incredibly complicated diseases".<sup>61</sup>

There may also be a dark side to data analysis as recently reported in the press.<sup>62</sup> Citizens leave traces of their behaviour everywhere much like dust or exhaust. This data survives inside data warehouses via tracking online shopping details, catalogue purchases, magazine subscriptions, leisure activities, and information from social-networking sites. Insurers are finding that analysing such public domain data will often reliably identify customer's risk profiles effectively at substantially lower costs and in much shorter time than traditional methods and without expressed consent of the data donors. Thus a culture of continuous improvement must also enable the active spread of *desirable* data practices while dampening or dismantling undesirable data practices.

<sup>58</sup> http://chilmarkresearch.com/2009/04/06/healthvault-ny-presbyterian-closing-the-loop-on-care

<sup>59</sup> www.microsoft.com/presspass/press/2009/apr09/04-21MSMayoConsumerSolutionPR.mspx .

<sup>60</sup> Reported at http://irevolution.wordpress.com/2010/10/13/ crowdsourced-prediction/

<sup>61</sup> Reported at: http://www.wired.com/epicenter/2010/02/ crowdsourcing-rewires-harvard-medical-researchersbrain/#ixzz0eZgmCr3t

<sup>62 &</sup>quot;Insurers Test Data Profiles to Identify Risky Clients" Wall Street Journal, 19 November 2010.

Technical Report Series

50

Ultimately a vision of 'singularity health care' foresees data intensive approach enabling the translation from crowd co-developed medical knowledge discovery to widespread medical practice to become nearly instantaneous [191]. EHR's will link to high-performance accurate databases of patient records to promote preventive medical care, discover successful treatment patterns, generate causeeffect hypotheses and run virtual clinical trials to deliver personalized treatment plans [226, 227]. Another future model includes health avatars [228]: data from multiple sources are unified into a model of that person's health. The health avatar is the electronic representation of an individual's health as directly measured or inferred by statistical models or clinicians and a basis to provide feedback and lifestyle guidelines. This paradigm can be extended to communities where multiple individual avatars interact with a community avatar to provide a unified model of the community's health.

Beyond these examples of futuristic health care, the futuristic vision of health progress throughout the stages of our lives will depend upon crowd sourced household data collection. Without more complex and sophisticated modelling and simulation tools designed specifically to manage household data, legacy knowledge engines designed for institutional data will continue to fail to transform the health expression of crowds.

Hypothesis-driven research and reductionist approaches to causality, based on the limited potential of traditional randomised control trials, are no longer suited for the more complex problems health care is facing today [228] [p. 93].

A brief historical digression...We know today that the square on the long side of every right angle triangle has the same area as the sum of squares on the other two sides. The Greek provided the universal analytical proof of this. On the other hand, Babylonian engineers simply measured the sides of a thousand right triangular stones and heuristically concluded that this would apply to all the rest. The history of science and knowledge is not linear and spans thousands of years, but it may be summarised as follows.

Initially science was exclusively empirical, experimental, descriptive, and inductive at best. Next the theoretical and analytical approach based on model and hypothesis testing developed (using empirical data). As the complexity of the phenomena analysed increased, the theoretical models became too complex to be solved analytically with empirical data. Especially in the last few decades we have witnessed a boom of computational approaches whereby scientist started to simulate the dynamic evolution of ecosystems with the introduction of what if 'shocks'. Experimental, theoretical, and computational science continue to progress without displacing each other. Biomedical informatics, for instance, operate alongside computational biology.

Likewise ICT can provide science with shared, curated, linked data as well as large computing power through distributed computing, and potent algorithms and modelling techniques. Thus eScience or an ultra-data intensive science emerges where empirical, theoretical-analytical, and computational approaches can be merged into a linked data exploration approach with greatly enhanced predictive power. We can now unify experiments, theory, and simulation simultaneously thus blending the Greek and Babylonian approaches (*back to the future*?).

The Babylonian approach takes advantage of a very large n which should pre-empt the objection that the crowdsourced data might result in non-probability sampling like bounded sampling or snowball sampling which may introduce bias.

Recall in probability sampling: every unit in the population being sampled has a known probability (greater than zero) of being selected. This makes it possible to produce relatively **unbiased** estimates of population totals, by

51

weighting sampled units according to their probability selection. Probability sampling requires many years, a large amount of money, is plagued by non-responses and sampling errors...

In crowd based non-probability sampling some agents or units may have no chance of being selected or the probability of their selection cannot be accurately determined. Thus at first glance it may seem difficult to extrapolate from the sample to the population. Yet, with much lower investment and over the space of days or weeks, the nonprobability crowd-sourced **n** grows dramatically effectively diluting the contribution of selection probability such that bias is eliminated and the predictive power soars. Recall the example using 1,600 crowdsourced SMS describing the structural damage to buildings after the 2010 earthquake in Haiti. Researchers used them to almost exactly predict the actual damages. Ultimately, crowd sourced data was more representative than high resolution aerial images.

Increasingly, ICT can provide a growing mix of complex computation, modelling, pattern extractions, and simulation in the domain of Personal Health Systems [188] [pp. 114-116]. Pattern extraction from crowdsourced data may be greatly enhanced using machine learning and neural nets tools. New automatic self-adaptive algorithms such as machine learning [229-231] can automatically identify patterns learning recursively by example. Such approaches can scale datasets of hundreds of millions of records. Knowledge of outcomes, interventions, and confounding or modifying factors can all be captured and represented through the framework of probabilistic graphical models in which the relevant variables, including observed data, are expressed as a graph. They can, thus, be easily rendered in visualisations relatively intuitive also to non-experts. No longer simply the domain of R&D, these tools are available in ready-to-use forms, such as Infer.NET.63

In summary, there is an increasingly rich toolbox of advanced statistics and computational techniques[234]. These can be applied and adapted, as needed, to extract patterns and co-occurrences from crowdsourced mundane yet high yield health data. Eventually, similar processing capacity may be embedded directly within *opportunistic* sensors.

Finally the convergence and synergy between community co-production of evidencebased solutions and the EC funded efforts in the domain of Personal Health Systems (PHS) appears overwhelming.

However, PHS with non-intelligent remote monitoring may increase the overload of low value information and generate alert fatigue for health care professionals [234, 235]. PHS applications may be rendered context-aware and dynamically capable of learning and adapting to users very unique characteristics and conditions. For instance, a practicing clinician might learn by direct experience, through repeated observation, that vital sign X for patient A goes above a risk threshold due to very specific personal characteristics or under certain situations. Invariably, this over-the-threshold-event does not require any treatment. This represents a benign co-occurrence and the alert may be silenced. If patient A changes doctors, this information may be lost. Suppose the same patient is part of a

Artificial neural networks, decision trees, support vector machines and Bayesian networks are all examples of methods used today to mine data. The challenge of data curation and linkage is in transforming attributes of different scales into mathematically feasible and computationallysuitable formats. Among this new breed of algorithms, there are bio-inspired techniques such as the **evolving connectionist systems** modelled following brain functioning and using intelligent computational models and systems. Thus real world problem solving using computer science, engineering, bioinformatics and neuroinformatics continues to advance [232, 233].

<sup>63</sup> http://research.microsoft.com/infernet

remote monitoring pilot: many false positives and unnecessary alerts may be produced.

Thus building intelligent systems within health care delivery may be plagued by unacceptably high risk as the therapeutic window may often be narrow. For this reason, our current challenges regarding adequate quality control and design of a workable regulatory environment for mobile personal health devices advances at a snail's pace. Without question, uncovering the working principles of smart systems will need to be tackled first within wide therapeutic window domains prior to ever migrating into the high risk domain of health care delivery. Thus we have the cart before the horse as well as taken on the much bigger challenge of building intelligence across high risk environments before investing in achieving smart systems in low risk environments such as crowd health behaviour management.

Communities sharing mundane (wide therapeutic window) data such as activity level and current insulin resistance burden will enable the crowd–based intelligence engines to be continuously tested and improved while maintaining safety.

# 3. Impacting behavioural change within a wide therapeutic window

Below are some inspiring examples of transitioning from data and analysis to action.

IBM has launched a web-based platform for employees who are parents with the following characteristics and reported results: a) children health rebate: 150 \$ to family completing 12 weeks program for children weight behaviour; b) food preparation in the family, family meals, physical activity; c) Web platform for action plans, assessments, scoring; d) 22,000 families enrolled and 12,000 completed the program receiving the rebate; e) Physical activity doubled and health meals up by 12%[58].

In Austin Texas various local actors joined forced to set up a GIS system allowing to share and visualise data fostering understanding of children obesity: prevalence, concentration of fast food versus fresh food outlets, green recreation space, students failing cardiovascular test and this helped launch neighbourhood tailored interventions [236].

In the last 10 years we have seen the emergence of "persuasive technologies", as a specific development of "serious gaming": in the Wikipedia definition, it is a technology that "is designed to change attitudes or behaviours of the users through persuasion and social influence, but not through coercion". To do so, they act on irrational aspects of human behaviour, such as fear, peer-pressure, fun, competition and vanity.

It is a growing multidisciplinary research field. combining technology with wellestablished research methods and traditions from epistemology, rhetoric, social psychology, communication, and information science. The Persuasivetech Conference<sup>64</sup> is at its 6th edition in 2011, and a search for this keyword on bibliographic engine reports nearly 2,000 articles on this theme. At the market level, a particular growth has been visible with the emergence of the "apps" markets for Smartphone: according to PEW, 9% of all cell owners in the US have apps on their phones that help them track or manage their health[237]. According to Gartner worldwide mobile application stores' download revenue exceeded \$4.2 billion in 2009 and will grow to \$29.5 billion by the end of 2013, of which we assume a sizeable part will be health related: the iTunes Apps Store has a category entirely dedicated to health care and fitness apps.

The key features of persuasive technologies are:

 Appealing graphical visualisation and intuitive information display of previously hidden information, such as displaying of the glycemic level of the food (Sweetbee carb counter), or the distance walked every day (Walkmeter).

<sup>64</sup> http://www.persuasive2011.org/

- A gaming approach that stimulates fun, competition and vanity. For example, the Toyota Prius engages in a "fuel saving" game with the user that induces him to consume less.
- Proactive and carefully designed empathic interaction with users by sending direct stimulus, at the exact time when it is needed - thereby not via the web, but through other devices and "internet of Things". For example, the Glowcaps send reminders if the patient has not taken its pill; the Ubifit display shows butterfly and flowers to indicate met goals for physical activity.
- Sharing of personal behaviour among the users' network friends and doctors, in order to stimulate positive feedback loops by vanity and peer-pressure. For example, Endomondo allow users to share their physical exercise data with their friends, increasing the motivation to exercise.

These features enable a new in paradigm policy making because they take into account:

- The inherent bounded rationality of individuals who do not always do what it's best, even if they know what best is
- The deriving need for nudging, feedback and timely inputs that help sustain "doing the right thing"
- The opportunity to exploit social network and contacts, that deeply affect the behaviour of individuals.
- The growing empowerment of citizens that take a more active role handling their health care.

There are many examples of applications encouraging healthy behaviours[238]. Participants given an awareness display were able to maintain their physical activity level (even during the holidays), while participants without the display failed to maintain activity levels and significantly lowered their engagement. The GlowCaps or smart medication bottle caps increased medication adherence from 70 - 98%.<sup>65</sup>

Looming within most crowd-based discussions is the threat of failure to protect privacy and security. Meanwhile, citizens continue offering increasingly personal data online. The absence of a standard social contract for data management, privacy and security appears unlikely to stop these on line data sharing trends. It would be prudent to sort out a reasonable and widely acceptable privacy approach within relatively non-sensitive data such as dietary regimes and physical exercise. After thorough testing across diverse crowds, lessons learned via models built within this low risk environment can be then advanced to more high risk environments involving health data of greater sensitivity.

Data agnostic researchers pose less risk as they are often skilled in the field of advanced data processing and privacy preserving algorithms [239, 240]: such algorithms may control the released data either through random perturbations or by hiding recognizable attributes, so that individual privacy is not compromised while useful data mining can still be performed.

Data security is also crucial. Microsoft and Google are applying state-of-the-art technology to ensure data protection. Security that locks in a user's data will impair the ability to transport or switch platforms. The user may become locked in. Thus interoperability between data sources and data platforms is key to ensuring that the user retains control over his data at all times.

#### Ok but what if...

What if I am *healthy,* why should I participate if I do not see an immediate reward? If I am obese, why should I want to expose this? If I am in denial of my bad lifestyles, why should I participate? I doubt this will help me change behaviour?

<sup>65</sup> See: http://mobihealthnews.com/8069/study-glowcapsup-adherence-to-98-percent/

Technical Report Series

Recall such objections are based on rational thinking:

- If I am healthy and no direct reward, participation may not add to my utility function while costing me time.
- If I am obese, non disclosing my status may avoid stigma and social-psychological costs.
- If I am in denial, anything or anyone reminding me of my behaviour would not be welcomed.

Again, humans are rarely homo economicus: we are not rational planners and will do bad and good behaviours in respond to nudges. Our preferences are dynamic and learned through social networks: we do not live in isolation; we pay attention to what others do. The *New York Times* article: 'Health from a little help from my friends' (18 September 2010)<sup>66</sup> confirms that the Social network may have important negative and positive effects on health. If most of our friends are obese we are more likely to be obese. But if some, the most influential, start loosing weight they can drive bandwagon effects. Networks can be nudged by design to bring in individuals or groups likely to set positive cascade effect into motion.

In conclusion, the technology for participatory health is emerging and the overwhelming trend is for many to engage to some degree. As mentioned above, 9% of all cell owners in the US (virtually 9% of the US population) have apps on their phones that help them track or manage their health [226]. According to Gartner worldwide mobile application stores' download revenue exceeded \$4.2 billion in 2009 and will grow to \$29.5 billion by the end of 2013. Many of these apps are likely to be health related.

#### The business case: a preliminary sketch.

Effectively managing the health process of crowds to prevent the preventable are expected to generate benefits that dwarf, by orders of magnitude, previous effects on direct cost. Here the authors share information from an international company with a large portion of employees based in the US. Then using parameters from this case example a similar approach is applied to a EU27 scenario.

A typical company with 40,000 US employees pays about \$600 million a year for health care costs. A wellness promotion programme with light instrumentation of the employed population and their social unit would likely require a \$12-15 million per year investment. Tracking devices would include an accelerometer to quantify activity level and a home collection minimally invasive lab test to look at insulin resistance burden. The user interface would use innovative graphics to help the user visualize both his trends as well as the trends of similar cohorts. On line serious gaming and competition would enable sustainable engagement while back end analytics would dynamically adjust evidence based nudges. A conservative estimate of cost benefit might be a 25% reduction in annual health care [84, 99] cost or \$ 150 million. This equates to a 1:10 dollar return on investment.

**Translating the above to a European population.** The costs per user from the above case would be €292 per user per year to achieve the same the benchmark reduction of 25% of medical costs through optimized lifestyle eliminating excess avoidable health risk. Let us now recall from Evidence Box 2 (p. 12) that the total combined medical costs for Diabetes (€130 billion) and for Cardiovascular Diseases (€109) add up to €239 billion yearly in Europe. A 30% reduction of such costs would approach €80 billion.

If 100 million Europeans (20% of all the population) the up front per year cost of the program might be close to a  $\in$ 30 billion investment. It would not be unreasonable to expect a positive ROI of 1:2,5 euro. However, if the 50-60 million Europeans with the highest lifestyle risk were engaged through light instrumentation this would likely both reduce the up-front cost as well as double the ROI.

<sup>66</sup> See: http://www.nytimes.com/2010/09/19/health/ research/19stream.html?\_r=2&adxnnl=1&emc=eta1&adx nnlx=1284908452-A1LZH5m05lalCE7/YuAzWQ

### 7. Conclusions and next steps to advance policy

Conclusions. Unintended consequences of Modernization continue to erode human performance in every corner of the globe. No nation appears protected against these spreading dangers that effectively threaten future prosperity. Yet, the opportunity to literally transform the health of crowds has arrived through widespread adoption of connected technologies. Still entrenched thinking is missing this opportunity as it continues to be consumed with using HIT to advance the supply side of health care delivery. Our health care systems are a relic of the acute care model which assumes we are all still accidentally well. Thus overwhelmingly our investment in HIT and policy making is spent to advance better care practices by professionals while remaining inept at advancing better health behaviours by citizens and literally transforming the future health expression of crowds.

Obesity and related chronic diseases prevalence is increasing through passive mechanisms of modernization and moving by decades into earlier life. Children are no longer accidentally well. The lifestyle contribution in modern society likely accounts for 60-80% of crowd health outcomes. Sadly, this tsunami of preventable poor health has not been effectively predicted nor effectively prevented. Yet a silver lining in all this spread of poor health may be that it is essentially rules-based across crowds and involves just a few mundane or low risk data elements. Thus health adjustments to changes in health behaviour occur within a wide therapeutic window involving low privacy-risk as well as low regulatory-risk data. Together, this mix of events sets the stage for co-producing a functional participatory model of crowd-sourced data intensive eScience. Prudently co-designing eScience within low risk settings will generate the necessary learnings to enable advancing an eScience approach into more high risk, narrow therapeutic window settings. Doing so will lead effectively to widespread *eKnowledge* that will be relatively easily consumed by both experts as well as non-experts.

Legacy reductionistic approaches have generated health knowledge engines that rely on institutional (hospital and clinic data) and provide a view into the natural history of disease. These engines enables an evidence-based approach to the practice of *picking up the pieces* once chronic disease has set in and is relatively impotent in transforming future health outcomes. Unlike institutional data, crowd sourced granular low risk household data may best provide the means to finally understanding the natural history of pre-disease at a time when reversal remains accessible. Evidence-based adjustments within pre-disease states may powerfully redirect future health outcomes and the future health costs of crowds.

If passive and unintentional factors can combine to drive poor health as effectively as seen with the current tsunami, then intentional policy nudging must be able to be at least as effective in actively nudging to prevent the preventable. A conscious move beyond the traditional 'stick and carrot' tools of regulation and incentives towards nudging choice architecture based on well understood and simulated social networks is needed.

**Next steps** are organized into three sections: open issues, existing intervention landscape and implications for the European Commission Information Society policies.

**Open issues not covered within this paper.** Clearly all innovative proposals are challenged by the need to secure appropriate funding to co-define and co-produce the functional target. Questions such as; who launches it? Who manages it? Who can access the data? Who is responsible for providing users with nudging through persuasive technologies? Who pays for the initial lay out of infrastructure and set of tools to be provided to the crowds?

It is beyond this paper to generate with a detailed operationalisation plan as this must a crucial next step which will depend on robust policy support. However, this next step can already anticipate strong guiding principles such as the following:

- Standards for privacy and security within crowd based information systems must be rendered functional within low risk information settings in order to garner the learning applicable for higher risk or more sensitive information settings.
- Regulatory oversight within low risk crowd based community data commons efforts must be sufficiently light to enable novel insights to emerge. Defining *intended use* will occur through a continuous improvement model based on co-development of sufficient correctness insights.
- Policy must lower the barriers to participation (lightly instrument crowds and accept data transport to a community data commons via the smart phone).
- Policy must provide a standard social contract regarding privacy, security and the general purposes for which community data can be used. Crowd benefit must exceed crowd such that crowds "create more value than they destroy".
- Provide a compelling reason to share data, advance survival of the pack culture; we are in this together, unit against a common enemy such as childhood obesity, breast cancer or any of the more preventable health outcomes.

- Customization should occur at the level of the user (User-supplied: content, design and engagement model).
- Avoid push and instructional models, strive to deliver "PULL and call-to-action" participatory models.
- Provide a suite of compelling user interfaces to choose from (games for health, quantified self, Traitwise, cure together and others).
- Ensure a flexible, rules-light back end to the community data commons. Continuously scan the co-occurrences for high clinical utility, high predictive capacity and expose malignant pattern burden as well as best practice combinations in a timely manner.
- Expect Citizens/ Crowds to become the ultimate purveyor of value: enable community custodianship of crowd management practices.
- Design a cloud-based ultra large scale data commons to support a continuous improvement model targeting *sufficient correctness* as the basis for choice architecture adjustment strategies.

**Existing Intervention landscape.** Many innovative approaches to promote optimal choices by individuals have been proposed by others. Some are listed below ranging from imposing taxes on junk food to increasing awareness through more education:<sup>67</sup>

- Impose new taxes on less desirable food (in 2009 the US considered taxing soft drinks).
- Alter the relative price of food through agricultural policy.

99 Technical Repo

<sup>67</sup> The array of policy interventions being launched and implemented at a local level to tackle the issue of better and healthier lifestyles is vast and would require a review clearly outside of the scope of this paper. A good overview of all possible approaches and interventions focussing, for instance, on tacking child obesity can be found, for instance, for the US throughout the March 2010 issue of the journal health affairs (Volume 29, Issue 3). For Europe a good starting point is to look at the various local initiatives launched under the umbrella of the European Commission sponsored "European Platform for Diet, Physical Activity and Health" (http://ec.europa.eu/ health/nutrition\_physical\_activity/platform/index\_en.htm) reviewed in the second progress report[241].

- Ban school vending machines or ban the poor food choices within vending machines.
- Restrict TV advertising of Energy Dense Nutrient Poor (EDNP) food during children pick times hours.
- Advance availability of healthy foods through:
  - Fruits and vegetables available in schools;
  - Logistic and distribution measures to support fresh and healthy food shops in neighbourhoods.
- Better consumer information through:
  - More effective and wide spread food labelling;
  - Menu labelling in fast food premises;
  - Educational and awareness campaign targeting specifically children and schools.
- Encouraging physical activity by using community funds for more parks, walking and cycling paths.

The European Commission White Paper cited earlier [4] mentions some of these interventions. This EC white paper was presented and contextualised in 2008 by Robert Madelin who was at the time, Director General of the European Commission DG for Health and Consumer Protection [242].

Though these proposals are likely to encounter resistance from industry, they may well be a valid target of the crowd sourced participatory ICT model proposed in this paper. Such an ICT framework would act as the fabric by which evidence based judgement on the efficacy of the above proposed interventions could reliably be made. Enforcement models such as imposed taxes could be compared to nudging models such as peer pressure to determine which approaches work best for specific cohorts over time. Restricting personal choice and personal freedoms may back fire in some age groups; nudging to make better choice look as if the individual made the right selection himself may be both more effective and more sustainable.

As the crowd advances towards better choices, the market will invariably follow demand. When demand for healthy food increases, this choice will become less expensive and more available while junk food hopefully will be pushed to the periphery of the market.

Decades of educating and raising awareness with the hopes of encouraging people to move in the right directions have been largely unsuccessful. Clearly, education approaches assume rational responses yet more education fails to generate more rational responses. Hence the need to motivate individuals through less rational-response-dependant persuasive technologies such as serious gaming may make sense.

Finally, the potential of social networks to produce positive cascade effects make provide a potent means to spread desired behaviour. Together these considerations are relatively easily supported by technology that is readily available today. The next step is to enable policy efforts to launch the technology into action.

The Commission White Paper also stresses the importance of building monitoring systems to track the evolving evidence base supporting current policy directions [242]. Crowdsourcing of health data plus innovative modelling to extract high yield health patterns dynamically will offer a steady stream of evolving and reliable crowd relevant evidence.

*Implications for the European Commission Information Society policies.* Fundamentally, as the infrastructure supporting crowd based strategic intelligence becomes core to the Information Society policy of the European Commission, this utility may transfer easily to other areas of policy such as environmental health and future areas of research and science. This effort would fall squarely within the eHealth sub-policy domain with multiple components within the remit of DG INFSO. This DG already supports contributing efforts such as Framework

Technical Report Series

58

Programme (FP) research including the domain of Personal Health Systems, nanotechnologies, clouds computing, ICT for policy modelling, and more. Of note, the Competitiveness and Innovation Programme (CIP) and the Future Emerging Technologies (FET) initiatives include some early persuasive technologies and serious gaming already.

The institution of a community data commons depends upon data sharing by users. Thus a **standard social contract** delivering privacy and security while ensuring authentication are likely to be DG INFSO priorities.

Today, as mentioned earlier, private insurance is already actively repurposing *public data* with the specific intent to stratify customers and without the expressed consent of the public to provide data for such purposes. Meanwhile the growth of public data exhaust continues and the Google's and Microsoft's of the world continue to build platforms to capture and store as much as the public is willing to provide.

Given no end to this trend, it may be prudent for the Commission and Member States to secure harmonised solutions and avoid having to ratify the uncoordinated outcomes of a bottom up effort. The urgent need to harness the power of the crowd against preventable poor health outcomes stresses the importance of a data intensive and collaborative science approach. Fundamentally such a crowd based eHealth perspective may advance the European Agenda for Science in 2030 towards defining health reachability across free living systems.

Of note as well is the upcoming European Innovation Partnership (EIP) for Active and Healthy Ageing. This is the first of the innovation flagship initiatives envisaged in the overall strategy of the European Union known as EU2020 Strategy[243]. The EIP remains in the public consultation phase at the time of this paper. The goals and contents are in preliminary stages and can be obtained from both the consultation website<sup>68</sup> and from the website dedicated to the innovation union concept.<sup>69</sup> Combining the information from these two websites we can make the following high level overview:

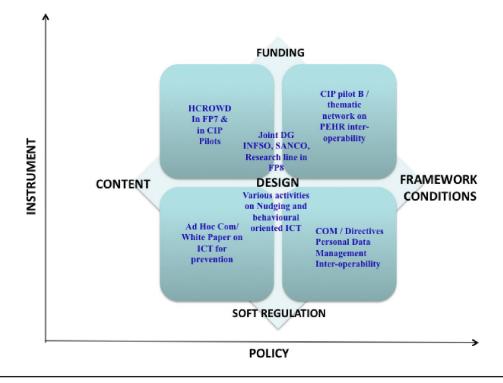
- Main Target: add 2 years to the average healthy lifespan in the EU by 2020;
- Areas of focus:
  - Prevention and health promotion medical technology, medicines and treatment for age-related chronic diseases and others;
  - Integrated health and social care for the elderly, improving home-based care and self-care; and new large-scale, innovative solutions for long-term care of the elderly
  - Independent, active living for elderly people, supported by innovative products, devices and services
- Triple wins sought:
  - Enabling EU citizens to lead healthy, active and independent lives while ageing;
  - Improving the sustainability and efficiency of social and health care systems;
  - Boosting and improving the competitiveness of the markets for innovative products and services, responding to the ageing challenge at both EU and global level, thus creating new opportunities for businesses.

Moving to the overwhelming message of this paper, the authors urge the European Partnership on Active and Healthy Ageing to expand to include the following two additional pillars:

- ICT for living well
- ICT for healthy and smart kids

<sup>68</sup> http://ec.europa.eu/yourvoice/ipm/forms/ dispatch?form=ahaip

<sup>69</sup> http://ec.europa.eu/research/innovation-union/index\_ en.cfm?section=active-healthy-ageing&pg=home



Source: Authors' elaboration.

Local trans-national partnerships to integrate crowd sourcing health intelligence may be launched within the classical interventions currently under the umbrella of the European Platform for Diet, Physical Activity, and Health. This would strengthen policy developments between DG INFSO and DG SANCO.

Then joining up this effort with DG Research in contribution to the strategy for Science 2030, the ultra large data set processing and modelling advances enabled through crowd sourcing could become themes for ongoing research. This would essential link currently separate deployments within the ICT for Health, FET, and Health chapters of FP7. Moreover, transatlantic cooperation would enable research projects using ultra large-scale data mining, modelling and simulation. Recently a Memorandum of Understanding (MOU) was signed by Commissioner Nellie Kroes with United States Secretary of Health and Human Services Kathleen Sebelius. The MOU will promote a common approach to interoperability between electronic health records and advance common education programmes in information technology

for health professionals.<sup>70</sup> It would be prudent to include language regarding a common approach to interoperable crowd sourced data as well.

The visual below uses a matrix to present key policy recommendations offered to the Commission based on the contents of this paper. The horizontal axis implies the focus of the suggested policy initiatives and spans two extremes of specific recommendations *content* to general recommendation *framework conditions*, passing through the intermediate level *design*. The vertical axis considers the instruments commonly available to the Commission such as funding and regulatory actions (i.e. from soft forms such as communications, white paper, etc to harder forms such as directives).

Below the authors offer a brief expansion of suggested initiatives including relevant instruments.

59

<sup>70</sup> http://www.eurorec.org/news\_events/index. cfm?newsID=236

*Content.* We propose both *funding* and *soft regulatory* initiatives:

- Advance the present spending programmes to add in crowd based approaches to within both FP7 and CIP:
  - As an initial step, the PHS budget line of FP7 should include new projects tackling jointly sensors (with on board data processing), data processing and modelling techniques, and persuasive technologies;
  - Launch Pilot type B on crowd sourced health data involving local health authorities, employers, ICT industry, clinicians, public health practitioners (i.e. epidemiologists).
- Issue a communication or white paper on ICT for prevention focused on the value of the crowd sourced approaches, raising awareness of the concept of ICT for living well and for smart and healthy kids, setting targets, and calling Member States to act.

*Design.* We recommend a change in the existing health and technology policy, which should take into account the innovations presented respectively in section 5 and 6:

- The paradigm shift in policy-making that moves from a "stick and carrot" approach to a more sophisticated set of tools that account for the full breath of the human nature.
- The recognition that HIT should develop solutions taking into account the human psychology, thereby adapting technology policy to an interdisciplinary focus that includes psychology, social networks analysis, behavioural economics, and last but not least design.
- The design of innovation funding instruments should be updated by adopting prize-based competition to address specific challenges. For instance, the US First Lady Michelle Obama promoted in 2010 a prize-based competition for the best apps and games that encourage healthy eating: www. appsforhealthykids.com. The competition, with 60K dollars in total prizes, ensured the

development of 95 new applications: the difference in impact with existing innovation programmes can't be overestimated. Prizes and competition have a demonstrated high effectiveness in generating high quality results and high return on investment,<sup>71</sup> US President Obama recently promulgated the "America Competes" act that dramatically simplifies the usage of prize–based competition by government. The key advantages of prize-based competitions are that:

- they reward the actual results rather than the capacity to write proposal;
- they open to any idea, rather than rigidly predicting the needs;
- they reach out to a totally new audience of innovators, excluded from traditional funding and not traditionally engaged in research projects, showing the open and serendipitous nature of innovation.

The issue of human nature and policy has started to enter European Commission policy making as evidenced by the DG SANCO workshop that took place in Brussels on January 20 2011 on the topic "human behaviour and its implications for policy-making, the governance of markets and society". It is also seen in the 2010 report written by Ulf Dahlstein and published by DG INFSO [244]. The background paper prepared for the above-mentioned workshop report the following European Commission initiatives inspired by behavioural studies:

- DG MARKT and DG SANCO tested policy remedies with a behavioural study, in the sector of retail financial services;
- DG SANCO used behavioural insights in the drafting of the Consumer Rights Directive, to regulate the use of defaults;
- DG ENV is exploring policy options influencing consumer choice for products and services with environmental impacts;
- DG RTD has explicitly recognised the need for a better understanding of consumer

<sup>71</sup> See for instance the 2011 Prize Summit conference: http:// theprizesummit.com/

behaviour, and this has been introduced for the first time in FP7;

- DG JUST is actively following the results of the first large behavioural study financed by the FP7 (Consent Project, on privacy and the digital economy);
- DG COMP has used behavioural insights for the design of remedies in antitrust policy (Windows IE case).

Absent in this list are initiatives focussed on lifestyle changes for healthier living supported by ICT. This represents a clear gap and an opportunity for crowd based eHealth policy to fill this important gap and avoid being left behind.

In this eHealth domain two initiatives are recommended:

- Unit H1 ICT for Health, possibly in collaboration with JRC-IPTS, should organize workshops and launch studies on the topic of nudging healthier behaviour using crowdsourced health data, modelling, and persuasive technologies;
- Future FP7 and FP8 research projects should support themes of research in this area jointly defined by DG INFSO, DG SANCO, and DG RTD.

Finally, the authors offer a plea to urge policy makers to seriously and urgently advance a common enabling infrastructure to support all these collaborative efforts. May issues of privacy, security and interoperability be delivered through a common social contract that is respected world wide. In this way, viral and global spread of effective choice architectures can be expected.

In conclusion, the Tsunami of preventable poor health is occurring on our collective watch. Our institutes of higher learning, our corporations as well as our governments have all collectively contributed to enable a silent and insidious threat to future prosperity spread across our shores.

We cannot solve this problem using the same kind of thinking that created it (Einstein). Technology is ready to support crowd based strategic intelligence approaches to dynamically *know* the once *unknowable*. This paper attempts to articulate effectively the potential gains available through innovative crowd-based multi-disciplinary collaboration. The power to aggressively prevent the preventable has arrived. Evidence-based co-occurrence analysis across international data sets may effectively bench mark poor performance nations towards reachable optimal health through crowd based approaches.

Our younger generations remain increasingly vulnerable with each passing day. National prosperity erodes while the Tsunami continues to spread. The technology to rescue the future is here. The time to act is now.

Decemical Report Series

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#### Abstract

For at least three decades, a tsunami of preventable poor health has continued to threaten the future prosperity of our nations. Despite its effective destructive power, our collective predictive and preventive capacity remains remarkably under-developed. This tsunami is almost entirely mediated through the passive and unintended consequences of modernisation. The malignant spread of obesity in genetically stable populations dictates that gene disposition is not a significant contributor as populations, crowds and cohorts cannot receive a new shipment of genes in only 2-3 decades. The authors elaborate on why they take a supply-side approach: advancing health care delivery cannot be expected to impact health outcomes effectively. Better care sets the stage for more care, yet it remains largely impotent in returning individuals to disease-free states. The authors urge an expedited paradigmatic shift in policy selection criteria towards using data intensive crowd-based evidence integrating insights from system thinking, networks and nudging. Collectively these will support emerging potentialities of ICT in proactive policy modelling. Against this background, the authors propose a solution that consists of: the provision of mundane yet high-yield data through light instrumentation of crowds enabling participative sensing; real time living epidemiology separating the per unit co-occurrences which are health-promoting from those which are not; nudging through persuasive technologies; serious gaming to sustain individual health behaviour change and intuitive visualisation with reliable simulation to evaluate and direct public health investments and policies in evidence-based ways.

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