The Infonomics *Letter*
Plain Language about Leadership and
(Corporate) Governance of Information Technology

May 2011 Edition

Seeing the Future

Welcome to the Infonomics Letter for May 2011.

This journal straddles a remarkable dichotomy. On the one hand, we spend a great deal of time looking over our shoulder at the lessons to learn from the things that go wrong with information technology. On the other hand, we look forward with unbridled excitement to our intensively IT-enabled future.

The split personality exists for one purpose – only by learning lessons from past mistakes do we develop the capability to move forward into our future.

Last month I introduced The Infonomics Dream: *At Infonomics, we dream of a worldwide boost in well-being and wealth, driven by a sustained improvement in innovative and highly successful use of information technology, underpinned by business leadership and effective governance.*

During my recent briefings in the Middle East, and over the coming weeks as I travel through Latin America, I emphasise that dreams do not come without hard work, persistence and determination. In these sessions, we use the US Space Program to illustrate the point – that great achievement comes through incremental development, that there are transition points where generations of technology give way to new developments, and where failure is subject to the most intensive and rigorous analysis in a determined effort is made to avoid repeating the same mistakes.

But aside from the hard work, the thing that drove the US Space Program, and I believe still drives it, is a dream. A vision of a future different and better, but still indelibly linked to what we have today.

I am indeed fortunate to know a man who has a dream. I met Chris Ogden in London in 1987. We worked helping deploy technology innovation through the British banking system. Since then, Chris has suffered the misfortune of developing a rare degenerative nerve disease. But far from retiring and allowing this disease to limit his capacity, Chris has developed a new vision. I am proud to share with you, my friends in more than 55 nations around our world, the vision developed by Chris Ogden and his colleagues, for innovative use of information technology in advancing the fight against not only his specific condition, but the myriad of conditions that are collectively known as "Rare Diseases".

I hope that the vision Chris paints can serve as inspiration to us all, to seek and exploit opportunities to use information technology in innovative ways, to enable change, and to generate beneficial outcomes.

How can we help him realise his dream?

Mark Toomey 31 May 2011

WikiRare: Innovation Vision

"Rare diseases impact more individuals, in total, than cancer or heart disease in the UK"

We think of rare diseases as unique; unlike any other. They have long scientific names, undecipherable to the layman. People with rare diseases often feel isolated and lonely. Every disease seems to the sufferer quite unlike another. To the lay person they evoke sympathy, but little understanding.

Actually, we now know that most rare diseases don't exist isolated on their individual, lonely islands. They have bridges and causeways that connect them, some narrow and fragile, others more robust and well-travelled.

WikiRare will catalogue and make available all the data that define these bridges and causeways between disease islands. These linkages are the *disease mechanisms* – how a rare disease originates (in a majority of cases, genetically) and how it expresses itself – its pathology.

WikiRare will not be built as a complex, centralised project. It will be a Web–based capability, accessible globally and built on Wikipedia principles. It will be added to continually by the scientists who will benefit from the new understanding it provides. By shedding new light on the interconnectedness of many diseases, new opportunities for effective therapies will be uncovered, and patients suffering from these often debilitating conditions will be given new hope.

But WikiRare will not limit itself to rare diseases. Many disease mechanisms have similarities to those found in common diseases. WikiRare will therefore evolve over time to become a vital global resource that potentially improves medical outcomes for people anywhere suffering with any disease.

Why is WikiRare needed?

a) The scientific goal: building a Web database to enable exploration of genetic and pathological mechanisms that affect multiple diseases.

Evolving understanding indicates that many rare diseases – those with incidences of less than 1 in 2,000[1] - have underlying genetic or pathological mechanisms at work that resemble those in other rare diseases. These mechanisms may resemble those in more common diseases. As well, common diseases such as cancer are now understood to have many

[1] As defined by Orphanet, for Europe

variants that, taken individually, make them look increasingly like rare diseases.

While these disease similarities may be known to specific research groups they remain globally undetected and unexplored.

No tool exists that could enable such common disease mechanisms to be systematically and comprehensively explored. The WikiRare Web database will open up new, multi-disease, avenues for research leading to effective therapies that will benefit many such linked diseases – both rare and common - rather than a single one. And the Wiki strategy and approach is the only realistic way to manage the huge human effort required to maintain and develop this database and Web site.

b) The wider goal: shifting from silo-based to cross-disease research funding

Disease research over the last 50 years has been driven by research funding focused on specific and widely-prevalent diseases: cancer, heart disease, diabetes are examples. Research has thus been predominantly silo-based, with scientific understanding progressing along narrowly-focused avenues with limited opportunity for exploring potential linkages between diseases.

This is unsurprising. Governments, faced with the huge human, financial and even political consequences of the big "killer" diseases, have channelled research funding towards these high-profile conditions. At the same time, pharmaceutical companies, to justify huge research costs have focused on the massive income streams that can only accrue from drug development & delivery on a global scale.

The increasing scientific understanding of rare diseases has helped to illuminate the weaknesses of this silo-based approach. Some – perhaps many - rare diseases have a well-defined genetic contribution, providing unique opportunities for understanding how pathologies arise and progress.

The world is thus poised to enable a significant shift in medical research funding from a silo-based, disease-specific focus, to a cross-disease approach predicated on the understanding of how diseases are linked by their common disease mechanisms. This shift will also recognise the significance of rare diseases in advancing disease research more generally.

c) The public goal: shifting public awareness about the significance of rare diseases

A key goal of WikiRare is to facilitate a significant counterbalancing in the way funding for disease research is pursued, moving from silo-based, disease-specific research to one that recognises cross-disease linkage. But, raising funds for this type of research has to compete globally with other, more readily-recognisable high-profile causes. Everyone understands the threat of cancer or heart disease, and so charities raising funds in these areas already have a willing and receptive audience.

Not so for rare diseases. While the public is sympathetic to the problems of those suffering from these conditions when they are presented individually, they have no easy focus for the wider problem.

By exposing the real significance of rare diseases to everyone, WikiRare can act as a new and dramatic catalyst for disease research.

What will need to happen for WikiRare to succeed?

At the core of WikiRare is a web-based database, accessible globally by scientists, which will provide the underpinning capability needed to achieve the ambition set out above. The database will be structured, robust, standardised, quality-annotated, hierarchically-organised and rigorously maintained. Creating such a capability, and demonstrating its practical value, is the first and essential step. A fully functioning database, embraced enthusiastically by the scientific community, is the essential platform for WikiRare.

However, the construction of such a resource, though complex and ambitious in its own right, will not reach its full potential without other parallel and supporting initiatives and capabilities. These are:

a) Enabling and encouraging patient access

Disease information and scientific data are largely inaccessible by the lay patient community. Without explicit action, such data within WikiRare would also remain out of reach. Enabling patient access to understandable summary data is thus a vital component of success. By making this possible, patients can play an active role in endorsing research proposals, publicising rare disease research initiatives (e.g. through Google and Twitter), assist in securing funding, and lobbying for government intervention where this would be useful. Patients can thus be the unpaid, volunteer army to help mobilise the funds needed for research.

Perhaps more important is the emerging influence of patient groups who now gather together, in significant numbers, in Web support groups, influencing upstream science, funding agencies and pharmaceutical drug development. As well as being influencers, these groups have the potential to organise themselves to form clinical trial groups that, with technology support, can assist in more rapidly connecting patients to trials, clinicians and scientists.

b) Automatic linking to other databases containing vital scientific information

There are a number of existing web-based databases that cater to the needs of scientists working in rare diseases. Orphanet captures much basic information on rare diseases. OMIM captures detailed genetic information. The ALZ Forum is an example of a disease-specific web site.

WikiRare must avoid duplicating the excellent facilities offered by such sites. Hyperlinks will be provided from within WikiRare to corresponding sections within external sources. Options for providing bi-directional data feeds to these other databases in real-time, or near real-time, will be investigated. This will ensure that new data being loaded into these related databases are immediately reflected within the WikiRare database.

c) Exploiting evolving web and internet technology

The last two or three years has seen further rapid development in Web-based services such as social media as well as new access technologies based on smart phones and tablets. We are now rapidly converging on an "always connected" world. Further technological innovation is inevitable. We believe that technology can and will influence future scientific exploration in many ways. Possible examples are:

- Bioinformatics

  Bioinformatics is defined as the application of statistics and computer science to the field of molecular biology. It entails the creation of databases, algorithms, computational and statistical techniques and theory to solve formal and practical problems arising from the management and analysis of increasingly large amounts of biological data[2].

  We already expect WikiRare to exploit computer algorithms such that potential linkages between diseases can be identified without direct human involvement. Google has led the way in developing such innovative search algorithms.

  More advanced bioinformatics also enable potential drug targets to be matched with specific genetic characteristics. We anticipate rapid progress in these areas which can be exploited stage by stage.

- Social media

  Social media are now established phenomena in the commercial world. Two predominant technologies are Facebook and Twitter. As well as providing a means for individuals to connect globally, make new connections and share information, they are now being seen as platforms by which commercial organisations can monitor customer needs, deliver products and services or manage financial transactions.

  WikiRare will aim to harness features provided by social media for the purpose of enabling scientists to find new collaborators and explore possible avenues for research.

- Gaming

  Gaming hardware and software aimed at the youth market has experienced rapid growth in the last few years. Gaming is now an on-line experience, enabling players to compete or collaborate with others world-wide. More recently, at least one organisation has begun to experiment with using gaming techniques, inviting hundreds - perhaps thousands - of participants to interact in order to suggest strategies to address a hypothetical disease situation[3].

  WikiRare intends to pursue gaming opportunities that will support scientists to explore disease mechanisms and strategies for effective therapies.

d) Providing specific capabilities geared to the needs of funding agencies

Funding agencies include charities, government and pharmaceutical industries. WikiRare's prime objective is to drive innovative research in cross-disease science that can accelerate understanding and lead to effective therapies. It follows that WikiRare must provide capabilities that enable in two areas.

First, scientists must be able to quickly construct joint research proposals on-line, harnessing the ideas from multiple scientific sources and from other scientists. This suggests that WikiRare should provide tools that can assist this process. One rapidly-developing area is in collaboration tools that let participants work together in on-line environments.

Second, WikiRare will support and enable access by funding agencies. Such agencies are not generally scientific experts, even though they have scientific specialists to assess research proposals. As well, smaller, patient-managed charities that could raise research funds are hampered in not being easily able to compare research proposals. WikiRare will, at later stage, seek to provide tools and experts who can quickly summarise research proposals so that they will be accessible by much broader audiences that nevertheless have access to, or can influence research funding.

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[2] Adapted from the Wikipedia definition

[3] Breakthrough to Cures, http://info.breakthroughstocures.org/

e) Creating a branded appeal to enable national or global funding campaigns.

Rare disease research does not currently have a mass-market charitable appeal, despite the fact, as was recently pointed out, rare diseases impact more individuals, in total, than cancer or heart disease in the UK[4]. It is therefore imperative that consideration be given to finding a branded appeal for WikiRare that can, over time, be instantly recognisable and supported by the general public. Indeed, the name WikiRare has been chosen in part to begin this process of creating awareness. However, a more cogent and targeted branding strategy needs to be pursued as a key part of the WikiRare proposition.

Next Steps

The originators of the WikiRare concept have secured initial interest and seed funding from the Wellcome Trust. This will allow a major workshop to take place, involving leading UK and international scientists. This event, now at the planning stage, will examine the concept in more detail, assess its viability and initiate more detailed implementation planning.

The originators now seek additional interest and potential funding support from scientists, interested parties and technology companies to take this work forward. Such involvement could also include:

- Practical involvement by scientists in the design of "proof-of-concept" examples of rare-disease linkage;
- Active participation in the workshop by technology visionaries to inspire scientists about the future possibilities afforded by technological advance;
- Technical assistance or advice in the design, planning and implementation of a prototype WikiRare;
- Financial support for the evolution of WikiRare.

For further information please contact Chris Ogden at chris@business-next.com.

Afterword

The vision Chris paints is, I believe, compelling and powerful. One aspect of it bears some emphasis.

Using information technology as an enabler of change, as a key to achieving new capability and to create benefits requires attention to a great deal more than the mere implementation of the technology. To realise the vision that Chris paints also requires researchers and bureaucrats to develop new ways of working, with refined approaches to sharing of knowledge – especially knowledge that may yet be uncertain. It requires an organisation to be created to moderate the content in the system. It may require other changes – whether evolutionary or revolutionary in the established scientific, ethical, legislative and bureaucratic systems not just within a single nation, but spanning many nations.

The technology that Chris needs is, for the most part, readily available and well proven. The skills to envision, orchestrate and deliver the overall system change essential to WikiRare are less well developed. Perhaps this can be not just a case study in innovative vision, but also a case study in governance of change, guided by the powerful principles in ISO 38500.

Infonomics Education Program

The Infonomics education program continues to draw substantial interest, especially in the international arena.

Two day ISO 38500 Foundation Class

Kuala Lumpur (Malaysia)	June 6/7

One day ISO 38500 Immersion Class

San Salvador (El Salvador)	May 31
Buenos Aires (Argentina)	May 26

ISO 38500 Introductory Briefing

San Salvador (El Salvador)	May 30 (in Spanish)
Buenos Aires (Argentina)	May 27 (with the National Office for Information Technology for Argentina).

For more information about events in San Salvador and Buenos Aires, please contact BITCompany.

For events in Malaysia, please contact Expitris Worldwide Sdn Bhd.

[4] Sir Liam Donaldson, Dept of Health Annual Report, 2010