



Case Study 11

Cell-Life

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Introduction

This case study analyses the ways in which the Cell-Life initiative, a collaboration between UCT's departments of Civil and Electrical Engineering and the Cape Peninsula University of Technology (CPUT), utilises technology-based solutions (in particular, cellphone technology) for the life management of patients living with HIV/AIDS.

The Cell-Life initiative

Cell-Life originated in 2000 following discussion between Dr Ulrike Rivett and Professor Jon Tapson from UCT's Faculty of Engineering and the Built Environment. The idea was initially for it to be a research project, and a collaboration was initiated with the Department of Electrical engineering at CPUT. The ideas raised in this discussion were explored with other researchers and interest groups, such as the Treatment Action Campaign (TAC), and eventually evolved into a proposal to develop a system that utilised a combination of mobile technology and the internet to monitor adherence of HIV-positive patients to ARV treatment.

South Africa currently has one of the highest HIV infection rates in the world. Statistics on infection figures are contentious, but in July 2008 UNAIDS/WHO published an estimate of 18.1% prevalence in the 15—49 age group (as at the end of 2007) (UNAIDS/WHO, 2008). According to the UNAIDS/WHO estimate of total population, this implies that approximately 5.7 million South Africans were living with HIV at the end of 2007 – including 280 000 children under 15 years of age. Additionally, It is predicted that by 2015 there will be more than six million South Africans living with HIV, by which time around 5.4 million will have died of AIDS (Dorrington et al., 2006).

It is against the backdrop of these staggering statistics that Rivett began looking into ways in which the infrastructural limitations to the successful roll-out of South Africa's antiretroviral (ARV) programme could be overcome. It is widely acknowledged that use of ARVs is the only treatment which has been shown to prolong the lives of people with AIDS, and the successful roll-out of this medication is therefore crucial. The Cell-Life website reports that South Africa currently has the largest ARV programme in the world, but it is severely hampered by limited resources, which hampers the flow of information between doctors, hospitals and patients. In addition to this, ARV treatment is only successful when taken as part of a complex time-and-diet regime, which must be adhered to with a 95% compliance to prevent the virus from mutating and drug-resistant strains developing.

In 2002 Cell-Life was officially launched with funding from The Vodacom Foundation and in August of that year it distributed its first ten cellphones to the Hannan Crusaid Centre, an ARV treatment site in Gugulethu outside Cape Town – a first for Africa. Simple software was loaded onto the SIM cards of these phones, enabling carers to collect information on patients' status during home visits, and to upload this data via SMS to a central database. The project has grown substantially from its humble origins, and the Hannan Crusaid Centre saw a rise in the number of patients (from the initial 20) to more than 850 in 2005. Another site soon followed in KwaZulu-Natal, and in 2005 an additional grant from The Vodacom Foundation enabled Cell-Life to establish a dedicated office and register as an NGO.

The project left UCT in 2006 and is currently housed in offices sponsored by the CPUT. Its founder, Dr Rivett, is still employed by UCT and lectures in the Engineering faculty. Other than the investment of her time and expertise, UCT does not provide Cell-Life with any other form of support -- financial or otherwise.¹

¹ Dr Ulrike Rivett, *In Litt.*, 2 October 2008.

How Cell-Life works

Cell-Life utilises the fact that more than 90% of South Africa is covered by cellular networks – and that more than a third of South Africans currently use cellular phones – to bridge the gap in the flow of information between doctors, hospitals and patients in the successful application of ARV treatment. There is a particular need to support those living with HIV/AIDS in rural areas where infrastructures are limited and sometimes non-existent. Coupled with this, it is acknowledged that effective data collection and communication are intrinsic to a health information system which can effectively service these communities. This is the challenge which Cell-Life aims to address.

Cell-Life integrates the expertise of healthcare professionals and engineers to develop solutions that support the management and monitoring of HIV/AIDS and meet specific requirements in other areas. The solutions offered by the Cell-Life system include the following:

Intelligent Dispensing of Antiretroviral Treatment (iDart)

The central focus of iDart is pharmacy supply chain management and the patient monitoring process. The system aims to manage and monitor ARV treatment through barcode labelling and scanning, a basic stock control system, and cellular- and internet-based remote monitoring of ARV drug collection.

Aftercare

Aftercare is a cellphone data collection tool. Typically, counsellors liaise with between 15 and 20 HIV-positive patients. Aftercare enables counsellors to gather vital information about their patients using a cellphone equipped with customised application software developed by Cell-Life. Using this menu-based software, counsellors are able to capture treatment-relevant data such as symptoms, drug adherence and socio-economic factors. Once loaded onto the phone, this information is instantly uploaded to a central database. The solution is effective in that eliminates the need for paperwork and enables the logging of accurate data on a large scale with minimum cost (and relatively little human error).

Remote Booking System for VCT (RBVCT)

RBVCT is an internet- and cellphone-based system that enables large corporate organisations and research institutions to manage the bookings for Voluntary Counselling and Testing (VCT) sessions. The system is currently being implemented at UCT and plans are underway to expand to other university campuses facilitating VCT for students and staff.

Cell-Life projects

Cell-Life has a number of projects underway in the area of health and technology. An outline is provided here, but full details are available on the Cell-Life website.

Open source GIS to empower disadvantaged communities

The Promotion of Access to Information Act (2000, Amended 2002) aims to to increase transparency and accountability by making information held by public sector bodies available to the community. There are however obstacles to this goal when it comes to spatial information. These include a lack of technical (hardware and software), financial, and human

resources. The Cell-Life website states that is investigating open source GIS components -- including spatial databases, spatial data servers and application toolkits -- 'as a means of making relevant, meaningful data available to communities'. In this regard, it is exploring mobile devices and the GSM network as an economical means of collecting data about communities so that they may be shared data with government and other relevant decision-makers.

Overcoming obstacles to data capture in rural Africa

There are many devices and systems designed to fulfil the global need for remote data capture. Cell-Life, however, states on its website that in its experience these systems are costly and complex, making them inappropriate for use in the contexts in which it works. The website lists the reliance on infrastructure such as telephone connectivity or continuous access to electricity as one of the biggest limitations to current technologies, which are often complex and require training in order to be utilised correctly.

Another problem with current devices and systems is the cost factor. In the context of capturing data in rural Africa, the problem is twofold: first, there is the actual (often very high) cost; second, there is problem of who will carry the costs. This situation is aggravated by the fact that costly equipment often becomes a target for theft. The Cell-Life website observes that even the use of mobile phones can be problematic in certain contexts in that their owners become vulnerable to crime.

In line with this, Cell-Life is currently looking into how to produce 'a cheap device (low in manufacturing costs, with little re-sale value) that is less reliant on existing infrastructure, which is simple to use and does not require extensive training'.

Cutting out links in the chain of dispensing ARV drugs

Cell-Life has identified a severe lack of trained ARV pharmacists working in the public health sector in South Africa, while there is an exponentially increasing number of patients on ARV medication. Pharmacists are seen as playing a crucial role in the management of HIV patients, as they have contact with these patients on a regular basis.

The Cell-Life website states that technology can be the key to improving the process of rolling out ARV medication in that can provide an electronic record of when and where patients collect their medication. It also has the potential to improve upon the system of using paper-based methods of monitoring by providing electronic stock records. Cell-Life is currently investigating systems such as 'Store and Forward' and the use of existing cell-phone networks in order to better dispense ARV drugs.

Creating a national electronic patient record

The Cell-Life website states that South Africa currently has no national electronic record of patients, and that the majority of healthcare institutions in the country have no means of sharing their patient records (electronically or otherwise). This is problematic in that records cannot be easily accessed when a patient moves between healthcare institutions. It also makes it very difficult for government to compile accurate statistics on healthcare in South Africa. The South African government has indicated its intention to have a National Health Information Record (NHIR) in place to collect and share health-related information on a national scale by 2010. As the Cell-Life website states: 'This would require four technical aspects: network architecture for communication between institutions and external sources of data; a set of communication protocols for transmission and sharing of data; application software for users to use and share data; as well as the maintenance of confidentiality and security of data.' Factors such limited or no access to the internet, low bandwidth, computer

illiteracy, varying systems across provinces, and differing capacities with regards to infrastructure and personnel, mean that it would be necessary for the network to cater for different institutions and possibly envelope legacy systems.

There is much speculation and theory around the architecture of a distributed network for creating a national electronic patient record, and Cell-Life currently has a project underway to evaluate the different architectures available for this purpose, based on the needs and capacities of the various stakeholders involved.

Teaching

The teaching aspect of Cell-Life takes place mainly within the communities the project interacts with, as counsellors are trained to utilise the cellphones and the software associated with a particular application.

The training of counsellors in the community is done on an ad hoc basis as it is required by Cell-Life's team of Business Analysts in collaboration with a local "champion" of the project, such as an NGO or a pharmacist. The trained counsellors then train others in turn, a system which Rivett reports works very well. On the point of training in the community, Rivett stresses that staff turnover in the Public Health Sector is very high and that this needs to be accommodated "by developing software that is really intuitive". "I believe we have achieved that," she says, "and therefore the ongoing training between users has been very successful."

Cell-Life also provides follow-up and support after its initial training. In training the iDART software, for instance, trainers call on each training site once a week after the initial training to ascertain how things are running and to provide counsellors with a simple flowchart to help people identify possible problems. This kind of follow-up is crucial, as most of the people in the communities Cell-Life is working with have no internet access and there are no other options for reporting back or requesting support.

At an institutional level, there is an absence of Cell-Life's work in the curriculum of Civil and Electrical Engineering at both UCT and CPUT. A situation which Rivett regards as "unfortunate". Cell-Life does however currently (in 2008) have three employees who are postgraduate students in the Department of Computer Science at UCT; and Rivett personally supervises four postgraduate students who are not employed by Cell-Life but work in a very similar area and are registered in the Department of Civil Engineering.

Research

Cell-Life is dedicated to conducting ongoing research that assures relevant and effective solutions for the public health sector. This research takes place across institutions as it is a collaborative effort between UCT and CPUT, as well as other institutions and government. Cell-Life's research collaborations are not restricted to the local context, as it also works with numerous overseas partners.

One of the most innovative areas of research is Open GIS, which will expand the existing database to incorporate geographical information about patients and regional resources. Collectively, this information will form a powerful spatial GIS database that will facilitate further research, effective information analysis and better support within affected communities.

The Cell-Life website

Cell-Life has identified the publication of its findings as a key priority area and the organisation is actively involved in the production of reports, submissions, monographs, discussion papers, learning materials and booklets. The organisation's website is also an important aspect of communicating with people outside of the academic environment, and the site has numerous links and download options for accessing popularly accessible material as well as research done by members of the organisation (most of which is in academic journals).

The Cell-Life website² has a link from its Research and Innovation portal to a publications page which lists research papers, theses and conference presentations. The research papers listed here are have been published in journals and conference proceedings, and all material listed on the publications page are freely available as downloadable pdfs.

Other output

Cell-Life researchers publish both nationally and internationally, often in collaboration with other researchers in the HIV sector across various faculties (such as Prof. Nicoli Nattrass from the commerce faculty).

The Cell-Life home-page on UCT's Social Responsibility website³ lists an impressive curriculum vitae of Cell-Life's output. The project had six postgraduate and honours students in 2006 and has undertaken strategic contract research with the Desmond Tutu HIV Centre (Faculty of Health Science, UCT) and the South African Medical Research Council. The website also lists numerous presentations at conferences, workshops and seminars in South Africa, Australia, the UK and Zambia; as well details of conferences where Rivett has appeared as the keynote speaker. Cell-Life also plays an important advocacy role, providing expert advice in the area of mobile technology and health. It has participated in task teams, reference groups, commissions and assessments. It is important to note that this work is not restricted to the academic realm, and the initiative's collaboration with the corporate sector has, amongst other things, led to its involvement in a Vodafone Research and Development forum in Spain and the European Venture Market in Germany. Representatives of the organisation have also done various radio interviews, providing members of the public with information on their initiatives.

Community engagement

Cell-Life is one a of a number of projects underway at UCT which focus on addressing the problem of HIV/AIDS. In his *Responses to HIV/AIDS at UCT: Report to Council*, UCT's Deputy Vice-Chancellor, Prof. Martin Hall states that: 'The annual survey around HIV/AIDS initiatives on UCT campus in 2005, has demonstrated that UCT continues to respond at a significant level to one of the biggest challenges facing Africa in the areas of management, teaching, consulting and outreach' (Hall, 2006: 4).

In the Commerce faculty, the CSSR's AIDS and Society Research Unit has produced a diverse range of research and working papers, focusing on issues such as impact of HIV, stigma and treatment. Research conducted by the Democracy in Africa Research Unit has tackled the impact of HIV/AIDS and the Centre for Actuarial Research has also looked at impact (developing the ASSA2003 model that predicts HIV-impact) and has modelled the impact of HIV vaccines. Cell-Life therefore fits into a complementary

² <http://www.cell-life.org/> [Access 18.09.08]

³ http://www.uctsocialresponsiveness.org.za/Activities/detail.asp?prj_ID=7 [Accessed 18.09.08]

network of initiatives that aims to better understand the pandemic, and provide relief to the communities hardest hit by it.

Cell-Life's benefit to the communities it interacts with is substantial -- not only in the management of the ARV medication regime, but also in the empowering role it plays in training counsellors from various communities to use the software required by its various systems and to become part of the 'Cell-Life solution' to the HIV/AIDS crisis. Beyond its immediate municipal borders, Cell-Life also plays a role both nationally and internationally as its applications have global use, particularly in developing-economy countries which are beset by similar communication and infrastructure limitations.

A culture of sharing and partnership

Cell-Life is guided by a culture of sharing and partnership, which extends to its use of ICTs. This is manifest in the fact that all technological solutions developed by Cell-Life are created as open source software. As its website states: 'The code can be modified by anyone, allowing customisation, interoperability and integration. The software carries no user license costs, incurring only relevant service costs. Adaptations for local conditions, such as translations into local languages and simplified graphical displays for semi-literate users, can be incorporated into to the system.'

In addition to this, the organisation's commitment to the public health sector means that it aims to release all its software under a modified version of the GNU General Public License⁴. To date, it has released iDART on its website, which can be downloaded with its source code. Cell-Life is currently in the process of releasing its code which can be viewed from its Trac environment⁵.

Central also to the project's success is the idea of public/private partnership. As mentioned, the project has relied heavily on corporate support (such as that received from cellphone service provider Vodacom) for its establishment and continued existence. In addition to this, it has sought help from the business sector in various other ways, and the project's ADSL connection has, for instance, been sponsored by Internet Solutions since 2005. In this sense, the project provides a model for collaboration between private business, an academic institution and the community in terms of addressing one of greatest current social and economic challenges.

Lessons learned and key recommendations

The key lessons learned and key recommendations are as follows:

Lesson 1: Research and development of open source enabled mobile technology is directly supporting a vulnerable community

Communication and connectivity is at the core of the Cell-Life endeavour, and mobile technologies are being exploited on an unprecedented level for the public good. The fact that Cell-Life shares its innovations in an open source environment means that the work done by the organisation can be shared globally, and continue the cycle of care which the organisation promotes.

⁴ <http://www.gnu.org/copyleft/gpl.html>

⁵ <http://trac.cell-life.org>

Potential ways forward

Use the affordances of ICTs to further enhance and extend the effective use of technology. Especially relevant in this area is not only making the code of its technological products available, but also providing instructions and information necessary for utilising the code effectively. A manual for utilising the code and the software should ideally be made available under a GNU Free Documentation or Creative Commons license to ensure that the code is not only available, but also fully utilised.

Lesson 2: Research publications are freely available, but not full optimised as they do not contain metadata to be easily located by machine readable search engines

The publications available under the 'Research and Innovation' link on the organisation's home page are downloadable via a 'downloads' link, which takes the user to a 'Main Repository Page' link. In the Repository section of the website, the user is able to access publications, articles about Cell-Life, and company information. Searching information contained in these resources via a Google search, for instance, does generally not direct users to this content as the metadata is not curated and pdfs are not necessarily searchable.

Potential ways forward

Curation of metadata is a challenge for all organisations and institutions who use websites and archives for storing content. The practice of identifying metadata such as authors, keywords and article abstracts – and then tagging that metadata so that it is picked up by search engines – is however crucial if users are to access content via search engines (as opposed to finding it by going to the organisation/institution website and following links from within the site). This curation needs to be formalised and form part of institutional practice. Utilising a check-list for various fields of metadata is useful way to ensure that this information is captured when content is first loaded onto the web; and is preferable as organisation of metadata in retrospect can become a lengthy and expensive process.

Lesson 3: The institutions affiliated with Cell-Life have not incorporated the project into their curriculum and the opportunity for students to learn from this applied project is not being exploited to its full potential

Cell-Life is a model example of inter-disciplinary collaboration (across the medical and electrical engineering fields) for socially responsive action and research. However, neither UCT nor the CPUT have incorporated any of the project's endeavours in the curriculum of Civil and Electrical Engineering or Medicine.

Potential ways forward

Lecturers in various fields related to the work of Cell-Life (such as engineering, IT and medicine) could be targeted and provided with more information about the organisation and the projects it has underway. This promotion of awareness within the field would encourage reference to the organisation in the everyday lecturing environment, and promote interest at a postgraduate level.

Conclusion

Cell-Life is a model example of a socially responsive endeavour which utilises technology to overcome limitations and constraints. The use of cellphones to save lives by aiding adherence to the ARV medication regime and gather data is a remarkable contribution to the fight against the HIV/AIDS pandemic and signifies an intersection between the academic endeavour, innovation and the lives of ordinary people on the ground. The open approach taken by the organisation in sharing its work also illustrates how research is able to

contribute to the 'undead count' (i.e. the number of lives saved) of academic research, which must surely be considered the greatest achievement of any endeavour.

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