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Evaluation of the On Cue Compliance Service Pilot

Testing the use of SMS reminders in the treatment of Tuberculosis in
Cape Town, South Africa

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Executive Summary

Tuberculosis (TB) is an increasing public health problem in South Africa, where one of the most alarming TB epidemics in the world is being faced. Cape Town has one of the world's highest incidences of TB due to socio-economic and climatic factors, and the prevalence of HIV/AIDS. The usual method of treatment is a six (or eight) month course of drugs, given by the directly observed therapy system (DOTS), in which patients are watched ingesting all their tablets. DOTS has been shown to produce the best results for adherence, but places a heavy burden on the health service, and on the patient. It follows that the health service is keen to investigate alternative, cost-effective methods for enhancing patient adherence to their treatment regimes.

This evaluation looks at a project led by On Cue, a small company based in Cape Town, which sends Short Message Service (SMS) messages to patients via mobile telephones, reminding them to take their TB medication at pre-determined times. The Compliance Service aims to provide an affordable solution to improve patient adherence to TB treatment and reduce the associated costs of the DOTS system for both patients and clinics. This evaluation report presents the lessons learned so far to inform decision-making about future rollout of this system, as well as other uses of cellular technology in the healthcare sector.

Methodology

The evaluation set out to (1) determine the effect that the use of the Compliance Service had on TB cure rates and treatment completion rates; (2) identify and describe any related social and economic impacts that may result from the use of the technology in this context; and (3) conduct an assessment of the Compliance Service in terms of whether, and how, best practice principles for project management have been implemented. The evaluation involved three groups of key stakeholders: patients receiving the Service, clinic staff, and TB experts and managers at the City of Cape Town Health Directorate. The project evaluation combined quantitative and qualitative data collection. Information was collected from patient records, background documents and reports, clinic visits, and structured interviews of patients and staff through the use of questionnaires.

Cure and completion rates were determined from an examination of 221 patient records and compared to those for the clinic as a whole. The bridges.org *Real Access/Real Impact* framework was used to examine the social and economic impact of the Compliance Service on patients and the health service. The *Real Access* criteria used to shape this evaluation were: physical access to cellular technology; appropriateness of cellular technology to health care in this context; cost impact: patient costs; cost impact: health service costs; capacity issues around using the Compliance Service; privacy and data protection; integration of the Compliance Service into daily routines; patient support and enthusiasm for the Compliance Service. The evaluation looked at how the project has been conducted in terms of: doing some homework and starting with a needs assessment; implementing and disseminating best practice; ensuring ownership, getting local buy-in, finding a champion; setting concrete goals and taking small achievable steps; critically evaluating efforts, reporting back to clients and supporters, and adapting as needed; addressing key external challenges; making it sustainable; and involving groups that are traditionally excluded on the basis of age, gender, race or religion.

Findings

The main finding of this evaluation is that the Compliance Service has potential as a cost-effective system that would be appropriate to complement DOTS in Cape Town clinics and beyond. However, a number of obstacles to the use of the Service have been identified, which need to be overcome in order to make this system work effectively.

The project management issues are so inherently intertwined with the technology that it is difficult to separate them. Project implementation clearly limited the effectiveness of the Compliance Service, but it is not a reflection on the usefulness of the technology itself. To the contrary, the Service has potential to provide more choice in the care of TB and greater convenience for the patient. However, the problems encountered underline the limitations of the Service and imply there are important conditions for its success.

Mobile phones and SMS have proven to be effective tools in the context of health care in South Africa in terms of accessibility, appropriateness and cost. But healthcare workers cannot rely on the technology alone to solve the problem of patient adherence. Both patients and healthcare workers liked the Service and were able to use cellular technology effectively. Yet a significant number of patients interviewed were not using the Service as instructed. The Compliance Service showed rates for TB cure and completion similar to those of clinic-based DOTS at the clinic. But they could not be used to gauge treatment adherence levels due to poor implementation procedures used in the pilot.

A number of obstacles to widespread rollout exist. Monitoring for treatment adherence is a problem where patients are not seen daily (as they are with DOTS). An overall lack of ownership of the project at the clinic limits the proactive participation of the staff, and no one on-site takes responsibility for ensuring the Service is implemented effectively. A lack of regular feedback and interaction between the City, On Cue, and the clinic creates a "disconnect" that hinders success in a number of ways. A number of practical implementation issues limited the effectiveness of the pilot. Clinic staff schedules are tight and many staff members feel that they are over-worked. City and clinic bureaucracy limits the add-on functionality that would expand the usefulness of the Compliance Service. Issues of privacy, data protection, and security will affect the widespread use of technology in healthcare in Africa over the long-term.

Recommendations

In our view, the Compliance Service pilot should be re-implemented and re-evaluated, leveraging on the lessons learned in this initial evaluation. The renewed pilot should be conducted according to clear, written procedure for running the Service, and recording data derived from it. The criteria for patient selection must be clearly defined. Patients must be educated such that the healthcare worker is satisfied they will remain adherent if selected for the Compliance Service. And to improve adherence levels, a purposeful effort is required to monitor adherence on the few opportunities healthcare workers have to see patients on the Compliance Service.

In the interim, the Compliance Service should be continued for those currently enrolled; given the level of enthusiasm for the Service, a return to clinic-based DOTS may have a negative impact on patients that are currently using the Service successfully. However, it would be advisable to recall these patients and remind them of what they should do upon receiving an SMS reminder. Scaling up will depend on the ability of On Cue to address the obstacles outlined here, but there is no reason that this could not be done.

Conclusion

The Compliance Service pilot has produced treatment outcomes in line with those reported for the clinic, but contrary to expectation, they were no better. However, these results are tied to the way in which the Compliance Service was implemented, and because there were many shortcomings in implementation, these treatment outcomes are not valid to judge the effectiveness of the system itself.

The technology works and it is effective. And on face value, it also provides a more cost-effective treatment option, both for the health service and patient. The convenience of TB treatment for the patient is also greatly improved. But, the Compliance Service is only a viable option if adherence levels are at least those of clinic-based DOTS. The evaluation has shown that implementing the Compliance Service involves a trade-off between the

gains made on cost and convenience and the losses from having to put extra efforts into getting to know, and monitor self-supervised patients. This technology is not a silver bullet to solve the problem of patient adherence: it is all down to the way in which it is implemented.

We believe that if the Compliance Service were re-implemented and re-evaluated, leveraging on the lessons learned in this evaluation, treatment outcomes would be improved. The findings presented here highlight the most important areas requiring attention, and starting over should not be difficult, provided sufficient thought is put into the process. Key to the success of the Compliance Service is an understanding of where the use of the technology ends and care giving begins. The Compliance Service could be a valuable enabler of the TB Control Programme but getting that fit right is all important.

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1 Introduction

Tuberculosis (TB) is a grave public health problem in South Africa, where one of the most alarming TB epidemics in the world is being faced. The World Health Organisation (WHO) categorises South Africa as one of the 22 "high burden" countries for TB. Although detection rates for the disease are satisfactory, the national figures for successful treatment of TB remain way below target.¹

The highest incidence of TB is in the City of Cape Town: 678 cases per 100,000 people were reported for 2003.² This is due to socio-economic and climatic factors, and the prevalence of HIV/AIDS. Cape Town's winters are cold and wet, and this poses a health hazard for people living in so-called "informal settlements". In these very poor communities, large numbers of people live in close proximity in wooden shacks, many of which are built below the waterline and flood during winter. Under these conditions, people are more prone to contracting TB. Free medicine is available, but TB patients have to follow a strict treatment regime (at least four tablets, five times a week for six months) and often do not adhere to their instructions.

Non-compliance with TB treatment is exacerbating the high incidence of TB and causing problems for the local, overburdened, healthcare service. Precious medicines are wasted when people do not take their medication, and non-compliance encourages drug resistant strains of the TB bacterium to develop. The internationally accepted method of giving treatment is the directly observed therapy system (DOTS), in which patients are watched taking all, or most, of their doses. But DOTS places a significant burden on the already over-stretched local health services. And in many developing countries, the DOTS system requires patients to travel to clinics, resulting in absenteeism from work and increased travel costs.

This report looks at a project led by On Cue, a small company based in Cape Town. On Cue's Compliance Service sends brief text-based messages -- called "Short Message Service" (SMS) messages -- to patients via mobile telephones, reminding them to take their TB medication at pre-determined times. It aims to provide an affordable solution to improve patient adherence to TB treatment and reduce the associated costs of the DOTS system for both patients and clinics. The Compliance Service has been piloted in a clinic in Cape Town, in order to demonstrate the viability of the service and its potential to improve TB treatment outcomes. The pilot has run since January 2002. On Cue has worked in partnership with the City of Cape Town Health Directorate to conduct the pilot. Should positive results be demonstrated, this evaluation is expected to lead to the rollout of the system across Cape Town, and to catalyse further field trials (including for HIV/AIDS treatment).

Bridges.org was engaged as an outside consultant to conduct an independent evaluation of the Compliance Service pilot in Cape Town. The bridges.org evaluation looked at the Service's effect on TB compliance by measuring cure and completion rates of patients on the pilot. It investigated the related social and economic impact of the use of the Compliance Service on the clinic, its staff, and patients, and also examined the project management practices used in implementation of the pilot. Both qualitative and quantitative data were collected during clinic visits and interviews conducted in June to September 2004.

This evaluation report presents the lessons learned in this project to inform decision-making about future rollout of this project, and to explore the potential of mobile phones and SMS in healthcare. It is also intended to provide resource materials for planning and

¹ "Global Tuberculosis Control: Main Findings" WHO, 2004,
http://www.who.int/tb/publications/global_report/en/.

² "Cape Town TB Control Programme Report", City of Cape Town Health Directorate, 2003.

implementing future steps in the Compliance Service project or related initiatives. This report was prepared for the City of Cape Town Health Directorate and the International Development Research Council (IDRC). However, it has been written with a wider audience in mind, including: the development aid community, future donors, technology companies, research and development organisations, government bodies, non-governmental organisations (NGOs), and healthcare practitioners working in the field of Tuberculosis and other diseases, where treatment compliance is a concern.

2 Background on the treatment of Tuberculosis

2.1 Tuberculosis: a worldwide problem

Tuberculosis is an infectious disease caused by the bacterium *Mycobacterium tuberculosis*. It primarily infects the lungs but can also infect other organs. TB is a global problem of startling proportions, causing around two million deaths per year. And although some developed countries have seen an increase in recent years, over 95% of cases are found in the developing world.³ Nine of the 22 countries in sub-Saharan Africa accounted for 80% of global TB in 2002.⁴ And over 300 per 100,000 people have TB across the Southern African region, due in large part to the high prevalence of HIV/AIDS.⁵ South Africa has both a high burden of TB (meaning the total number of people requiring treatment is high), and high incidence rate (the number of new cases per 100,000). TB is considered a priority disease for the South African health service. It follows that new, affordable methods for combating TB are needed to bolster existing efforts at controlling the disease.

A number of international health organisations support TB control programmes, foremost of which is the World Health Organisation (WHO), with an entire department dedicated to combating the disease. The WHO "Stop TB" department supports a global TB control programme based on the Millennium Development Goals (MDGs). The MDG targets are to detect 70% of new smear-positive patients and successfully treat 85% of them by 2005, and to halve TB prevalence and deaths rates by 2015 (as compared with 1990).⁶ Most countries with a high incidence of TB devise national TB control programmes based on the recommendations of the WHO, and aim to meet the WHO's targets for curing the disease.

Typical symptoms of TB are a persistent dry cough, fever, night sweats, chills, fatigue, weight loss, and/or appetite loss. TB is spread through the air, but not everyone who is exposed to the bacterium develops the disease, and of those that do develop the disease, not all are infectious. A number of people have latent TB where, although they carry the microbe that causes it, they may never develop the disease, do not feel sick and do not transmit it to others.⁷ Conversely, people with active, pulmonary TB are highly infectious.

Groups most at risk are those suffering from physical and psychological stresses, such as unemployment, poverty, homelessness and those in institutional settings. In sub-Saharan Africa, people who are immuno-compromised present the biggest challenge for healthcare services, where TB is associated with HIV/AIDS. Because the immune system of HIV+ people is compromised, latent TB has a greater chance of developing into the active disease. In fact, HIV+ people are 800 times more likely to develop active TB, and HIV is the leading factor in the progression of latent TB to active TB. As such, HIV+ people with active TB are said to have an "AIDS-defining condition", and TB is the most common

³ For more information see http://www.redcross.org/article/0,1072,0_440_1744,00.html.

⁴ For more information see <http://www.results.org/website/article.asp?id=955>.

⁵ For more information see http://www.who.int/tb/publications/global_report/2004/annexes/en/ see Annex 5.

⁶ For more information see <http://www.undp.org/mdg/Millennium%20Development%20Goals.pdf>.

⁷ "TB Facts for Health Care Workers: Identification of Persons with TB Infection and Disease", Centers for Disease Control and Prevention, January 14, 1999, <http://www.thebody.com/cdc/tbfacts/id.html>.

cause of death in AIDS patients globally.⁸ Diagnosis of TB in HIV+ patients (who's HIV status may not be known at the time), often relies on recognition of atypical presentations of the disease (where the patient has unusual symptoms), and high rates of extrapulmonary TB.

Multi-drug-resistant TB (MDR-TB) is on the increase and strains resistant to all major anti-TB drugs have emerged. MDR-TB is a "man-made" problem, caused by patients not adhering to their treatment regimes, health workers prescribing the wrong treatment regimes, or because the drug supply is erratic.⁹ Alarming, one MDR-TB strain is resistant to the two most powerful anti-TB drugs. Although MDR-TB is treatable, it requires extensive chemotherapy (up to two years of treatment), that is often prohibitively expensive (more than 100 times more expensive than treatment of drug-susceptible TB), and is also more toxic. Poorly supervised or incomplete treatment of TB is a serious problem, largely because once MDR-TB has developed, patients infect others with the same, difficult to treat strain. Indeed, from a public health perspective, poorly supervised or incomplete treatment of TB is a disastrous scenario. Consequently, WHO and its international partners have formed the "DOTS-Plus Working Group", which develops global policy on the management of MDR-TB, and facilitates access to second-line, anti-TB drugs for approved projects.¹⁰

2.2 How TB is detected, treated and controlled

The best cure results are seen when TB is treated without delay. Control of TB relies on the early detection and treatment of people with infectious forms of the disease. To facilitate this, the TB vaccination is given. It contains a live attenuated (weakened) strain of *Mycobacterium bovis*, which causes the recipient's immune system to build resistance to the disease.¹¹ Contrary to common belief, the vaccine does not prevent TB on its own; there are many other influences on immunity, including a family history of TB, or the patient being HIV+.

A tuberculin skin test is commonly used as an initial test to determine exposure to TB. Previous exposure to TB causes a reaction to develop within 2 days, usually causing a firm red bump at the injection site. The reaction is graded according to the appearance and size of this bump, which depends on the immune system. The tuberculin test provides a rough indication of exposure to TB, but to detect the disease with certainty, a smear test is carried out. Here, the patient produces sputum from the lungs which is sent off to a lab to be tested for presence of the bacterium. Those that carry it are said to be "smear positive". For HIV+ patients sputa tests are not as helpful due to increased rates of smear negative pulmonary TB and a greater frequency of extrapulmonary forms of the disease, making TB more difficult to detect.

The standard treatment regime for TB involves four drugs (or five for patients that had TB previously) administered via the directly observed therapy system, or DOTS, over a six-month (or eight-month) period.¹² Tablets are taken once a day with food and liquid to prevent any queasiness. The total number of tablets per day depends on the patient's weight, but is still at least four, and they are large. Tablets are taken on week days only, with a 2-day break at weekends.

After two months of treatment, new cases are usually reduced to two drugs per day, depending on the patient's progress. Re-treatment cases (where the patient had TB previously) are given injections of the antibiotic "streptomycin" at the beginning of treatment, and the regime is stepped down at two months, from five to four drugs per

⁸ "The Deadly Intersection Between TB and HIV". National Center for HIV, STD and TB Prevention, Divisions of HIV/AIDS Prevention, <http://www.cdc.gov/hiv/pubs/facts/hivtb.htm>.

⁹ For more information see <http://www.who.int/mediacentre/factsheets/fs104/en/>.

¹⁰ For more information see http://www.stoptb.org/Working_Groups/DOTS_Plus/default.asp.

¹¹ For more information see http://www.who.int/vaccine_research/diseases/tb/vaccine_development/bcg/en/.

¹² The anti-TB drugs are: isoniazid, rifampin, pyrazinamide, ethambutol or streptomycin.

day. HIV+ patients are given the same drugs plus "Bactrim" once a day to reduce the chances of contracting pneumocystis carinii pneumonia, a type of pneumonia that is common to HIV+ patients. Patients are closely monitored, especially in the first few weeks, for adverse effects to the medication, complications, and non-adherence to their treatment regime. For patients who tested smear positive at the beginning of their treatment, those that produce negative sputa before the end of treatment, and at the six-month mark, are considered cured of TB.

The impact of TB control programmes are measured by a number of indicators. Those commonly used are *cure rate*, which is the percentage of smear-positive patients that were shown to be smear-negative at the end of treatment and at least on one other occasion (each test being at least a month apart), ideally at 2 – 3 months into treatment. The *completion rate* is calculated from patients that have completed the full course of treatment but do not meet the criteria for "cured". And the *treatment success rate* is the sum of patients that were cured and completed as a percentage of the total registered in the cohort (a term that refers to a group of patients registered with the disease over a defined time period).¹³ The WHO and International Union Against TB and Lung Diseases set targets for these indicators, and statistics are calculated for each TB clinic to determine case findings and treatment outcomes. These statistics are essential for adapting TB control programmes to changes in factors that impact on the spread and containment of the disease.

2.3 The issue of patient adherence to treatment regimes

Patient adherence is one of the greatest determining factors in the control of and is also one of the most elusive. Because the bacterium is particularly resistant to drugs, it must be treated by a sustained bombardment of antibiotics over a relatively long time period. For most bacterial infections, antibiotics are taken for no longer than a week, but TB treatment requires a minimum of six months, and so it is not surprising that non-adherence is a problem.

There are many consequences of poor treatment adherence. The patient will likely suffer prolonged illness and disability, and because they remain infectious for longer there is a greater chance of transmitting the disease to others. Poor adherence also results in the development of multi-drug-resistant TB strains, which are more difficult to treat, placing extra burden on the healthcare service and leading to a higher death rate. Many healthcare workers try to predict which patients are more likely to adhere to their medication, but studies have shown they are only right on average 50% of the time.¹⁴

There are many reasons for poor adherence, including the personal and social characteristics of patients and the healthcare workers treating them; cultural beliefs on both sides; the infrastructure supporting the healthcare system; and the extent of the patient's knowledge and perception of the disease.¹⁵ There is evidence that a good, trusting relationship between patient and healthcare worker is key to obtaining good adherence levels.¹⁶ The healthcare worker needs to know the patient sufficiently to understand the reasons behind non-adherence (which can be diverse), and must get the patient's buy-in to complete the course of medication in the correct way. If this is done, putting measures in place to enhance adherence is much easier. For example, long waits at the clinic can demotivate patients; this can be solved by scheduling appointments. And for working people with no sick leave, TB clinics can stay open after working hours.¹⁷

¹³ For more information see: http://www.who.int/publications/global_report/2004/en/methods.pdf.

¹⁴ Ibid.

¹⁵ "Improving Patient Adherence to Tuberculosis Treatment". Center for Disease Control and Prevention, 1994, https://www2.cdc.gov/nchstp_od/piweb/tborderform.asp.

¹⁶ "Compliance in Health Care", Haynes RB, Taylor DW, Sackett DL, *Baltimore: The John Hopkins University Press*, 1979.

¹⁷ "TB Facts for Health Care Workers: Identification of Persons with TB Infection and Disease", Centers for Disease Control and Prevention, January 14, 1999, <http://www.thebody.com/cdc/tbfacts/id.html>.

The WHO recommend DOTS be used to treat TB in all countries with a treatment completion rate of less than 90%. Fundamental to DOTS is the patient ingesting medication in front of a trained care giver, but surrounding this is a compliment of services geared toward achieving patient adherence. Not least is will be to address the inconvenience to the patient of taking their medication via DOTS, especially if the patient has to make a daily visit to a clinic. Any treatment option that is both convenient to the patient and maintains adherence levels will be looked upon favourably by health authorities.

2.4 Tuberculosis in South Africa

South Africa reported 215,120 cases of TB in 2002, which represents 557 per 100,000 people and TB treatment cost the South African Government an estimated USD 300 million in 2003.¹⁸ The incidence of TB and HIV dual infection is one of the highest in the world and the age distribution of new cases reported in South Africa (where a large number of young and middle-aged adults contract TB) is typical of a population in which there is a high prevalence of HIV/AIDS. For example, over the last 6 years, there has been a 190% increase in registered deaths in females between the ages of 20 and 49 years old, which is largely attributable to HIV/AIDS.¹⁹ MDR-TB strains are a problem, costing the South African Government an average USD 3400 per patient to treat due to the higher cost of drugs needed to treat them.

TB case detection rates are good for South Africa, but treatment success rates remain unacceptably low. In 2001 (the latest national figures available), the national treatment success rate was 65% , due to high default rates, death (7%), and failure to follow-up with patients who transfer to other clinics. This figure is largely due to the latter, according to the WHO, such that patients are effectively "lost to the system" and the outcome of their treatment is unknown. To address this, the Minister of Health launched a new strategic plan for TB control in 2002. Provincial control programmes followed, together with investigations started in 2003 into the reasons why so many patients "disappeared" before the end of treatment.²⁰ Efforts to solve this problem include each province developing electronic TB registers, the standardisation of which is being coordinated by the State Information Technology Association (SITA).

NGOs, both local and international, play a key role in combating TB in South Africa. Some are supported financially by international aid organisations such as the United Kingdom's Department for International Development (DFID), the Belgium Government, and the United States Agency for International Development (USAID). Local health authorities frequently form partnerships with these organisations, as well as universities and other government departments, to tackle TB. The private sector also treats TB patients, (including private clinics and hospitals, as well as some companies with a large workforce), but only services a small proportion of the population. In 2002, the "Global Health Fund to fight AIDS, TB and Malaria", a global funding agency launched by the United Nations, gave over USD 24 million to South Africa to fight the disease.

2.5 TB in the Cape Town metropolitan area

Control of TB in the City of Cape Town is the joint responsibility of the Provincial Administration of the Western Cape and the Local Authority (hereinafter the "City"). The City's TB Control Programme has the following objectives: to reduce TB mortality and morbidity; prevent the development of MDR-TB; and accurately measure the Programme's performance. It has a short-term goal of reaching the WHO performance target of 85% cure rate for all new, smear positive patients.²¹

¹⁸ For more information see http://www.who.int/tb/publications/global_report/2004/annexes/en/.

¹⁹ "Unabated rise in the number of adult deaths in South Africa", Bradshaw, Laubscher, Dorrington, Bourne, Timaeus, 2003.

²⁰ For more information see http://www.who.int/tb/publications/global_report/2004/annexes/en/SouthAfrica.pdf

²¹ "City of Cape Town / Metropole region TB Control Programme, Progress Report", City of Cape Town Health

TB in Cape Town is split into 76% pulmonary TB, 16% extra-pulmonary TB (EPTB, or TB that extends beyond the lungs) and 8% primary TB, primarily found in children. The latest unpublished statistics for the third quarter of 2004 show a slight increase in the case load for this quarter. The highest incidence occurs in Khayelitscha, the third largest informal settlement in South Africa, which accounts for 23% of all cases, due to an incidence rate in excess of 1000 per 100,000. Although more recent statistics are available for some measures, treatment outcomes are only compiled after one year, and this can make it difficult for City health care workers to stay motivated and focussed on the TB Control Programme

Day hospitals are the entry point for people using the national health service in Cape Town. If the hospital suspects TB, they do an initial test and, if positive, the patient is sent to a clinic in their local area where the disease is further diagnosed and subsequently treated. There are over 120 TB treatment centres around Cape Town, with local NGOs providing support services to the City.

2.6 Enhancing TB treatment adherence in Cape Town

The use of DOTS is core to the City's TB Control Programme and aligns with the WHO recommendations of administering TB drugs using DOTS in areas where there is a high burden of TB. DOTS has been highly successful in improving TB adherence the world over and has been implemented in all countries showing a middle-to-high incidence of TB.

Clinic-based DOTS is still the most common system for giving treatment, but community-based DOTS (where patients travel to the houses of TB treatment supporters to receive DOTS) is increasing and has recently become a major treatment system for TB in Khayelitscha. The City's strategy is to increase community-based DOTS using NGOs, to reduce the costs and resources needed to support clinic-based DOTS. This decision was based in part on the results of a study in 2000, which found that community-based DOTS was between 2.8 to 3.6 times more cost-effective than clinic-based DOTS for new, smear-positive patients.²³ And a previous study in a rural area of KwaZulu Natal found community-based DOTS was the only strategy that could be implemented within the resource constraints of that time.²² DOTS can also be administered at patients' workplaces, by a supervisor or colleague tutored by the clinic on how to do so.

In 2002, the City set a target of 30–40% of DOTS to be given in the community. Unpublished statistics for the third quarter of 2004 show a gain for most clinics in the number of patients receiving community-based DOTS. Community-based DOTS relies on local volunteers trained and managed by NGOs to give DOTS to patients at the volunteer's home. However, volunteers are paid very little and managing the service has proven challenging so far. Despite the cost-savings to the health service from an increase in community-based DOTS, TB treatment costs the health service dearly. The City is therefore keen to investigate more cost-effective treatment strategies that can at least maintain (if not enhance) current adherence levels.

3 About the On-Cue TB Compliance Service

The On Cue Compliance Service is an initiative of Dr. David Green, a qualified medical practitioner and consultant in Cape Town. Dr. Green first conceived of the idea for using SMS reminders when he needed to help a family member remember to take her medication. He had treated a large number of patients for TB and reviewed literature on adherence, and learned that many TB patients do not take their medication simply because they forget. Given the mobile phone penetration in Cape Town (more than 71% of the population has cell phones)²³, he surmised that that SMS reminders might also

²²"Community-based, Directly Observed Therapy for Tuberculosis: An economic analysis", Floyd, Wilkinson, Gilks, February 1997,.

²³"Digital divide assessment of the City of Cape Town" bridges.org, 2002, <http://www.bridges.org>

help with TB treatment compliance. And as a result, he set up the On Cue Compliance Service.²⁴

The On Cue Compliance Service (hereinafter the "Compliance Service") takes the names and mobile phone numbers of TB patients supplied by a clinic, and enters them in to a database. Every half an hour the On Cue server reads the database and sends personalised messages to the patients, reminding them to take their medication. The technology is low-cost and robust: an open source software operating system, web server, mail transport agent, applications, and database.

Initially the SMS message sent to patients read: "Take your Rifafour now." When patients complained the message was boring, a variety of alerts were created, including jokes and lifestyle tips with the result that On Cue now has as database of over 800 messages that change on a daily basis. The patient can chose to receive messages in English, Afrikaans or Xhosa (the predominant African language in Cape Town).

On Cue approached the City in 2001 to run a pilot of the Compliance Service. The City chose Chapel Street clinic, which (like other state-run clinics) provides free treatment for infectious diseases, (including TB and sexually-transmitted diseases), inoculations, and free consultations for children under thirteen. The pilot intends to demonstrate that the Compliance Service can be used to reduce the number of TB patients on clinic-based DOTS, and thereby reduce the burden on the health service. To succeed, it must produce treatment adherence levels at, or above, those previously reported for the clinic overall.

When the Compliance Service pilot was first implemented, it was agreed that patients must first complete a month of clinic-based DOTS. This would allow staff to monitor their reaction to the drugs, detect any medical complications, and determine how adherent they are, prior to enrolling them on the Service. Patients were selected for the Service based on whether they had a mobile phone and whether they were considered by the health worker as adherent to their treatment regime. Patients were enrolled by sending On Cue their name and mobile phone number, initially via email, but later by fax. Patients visit the clinic at monthly intervals to collect more medication, at which time the nurse has the opportunity to inquire about how they are using the Service and gage whether or not they remain adherent. The pilot commenced in January 2002. To date, over 300 patients have taken part, with more than 280 having completed their six-month (or eight-month for re-treatment TB) course.

The Compliance Service should not be viewed as a replacement for DOTS (given that DOTS is the internationally-recognised method for achieving acceptable adherence levels for TB). Rather, it should be viewed as an auxiliary service, to supplement DOTS where possible, offering patients that are well settled on medication an enabler to continue treatment adherence at home and save money for both the health service and patient. Essentially, it is hoped the Compliance Service can lessen the burden of TB treatment in Cape Town and bolster the City's TB Control Programme.

4 Evaluation objectives and methodology

The evaluation was comprised of three components. The first objective was to determine the effect that the use of the Compliance Service had on TB cure rates and treatment completion rates, by conducting an analysis of patient records. The second objective was to identify and describe any related social and economic impacts that may result from the use of the technology in this context, by looking at the clinics, their staff, and patients. The third objective was to conduct an assessment of the Compliance Service in terms of whether and how best practice principles for project management have been implemented.

²⁴For more information see: <http://www.on-cue.co.za>

With these objectives in mind, this evaluation set out to:

- Determine treatment outcomes (cure and completion rates) of this system.
- Examine whether the use of the technology in this given situation and environment is appropriate and relevant, using the bridges.org "Real Access/Real Impact" framework (described below).
- Examine the social and economic impacts, including effects on treatment (pharmaceutical) costs, working hours, and travelling costs for TB patients.
- Measure levels of user satisfaction, including patients and health workers.
- Measure the effectiveness of the technology and the approach taken to solving this problem.
- Gauge the use of best practices in project implementation, using bridges.org's "8 Habits of Highly Effective ICT-Enabled Initiatives" (described below).

The bridges.org *Real Access/Real Impact* framework and 8 Habits

It is impossible to gauge technology impact by merely looking at the strictly technical performance of the equipment; it is important to also consider how people use the technology and what affects their use. It is not really about the technology, it is about the people -- the technology users. Bridges.org evaluated this project by using a concept it has coined as "Real Access / Real Impact". The idea is that, despite the potential benefits offered by ICT, computers and connections will mean nothing to people in developing countries if they do not use it effectively. People may have physical access to very useful technology, but they will not use it if it is not appropriate to their needs, if they cannot afford to use it, if technical support is unavailable, if it adds too much burden to their already busy day (or even if they just perceive that it will), or if there are laws that limit its use. So in order for ICT to have a Real Impact on ground level development, people in developing countries need to have more than just physical access to technology, they need to have Real Access. The *Real Access* criteria used to shape this evaluation were (see Annex 2 for a full description):

- Physical access to cellular technology
- Appropriateness of cellular technology to health care in this context
- Cost impact: patient costs
- Cost impact: health service costs
- Capacity issues around using the Compliance Service
- Privacy and data protection
- Integration of the Compliance Service into daily routines
- Patient support and enthusiasm for the Compliance Service

Even though the evaluation focused on the technology, it also took into consideration how the project itself was implemented on the ground to the extent that project implementation had an effect on the technology use. Sometimes an initiative addresses the key factors that determine whether technology can be effectively accessed and used by people at ground level, but their failure to use basic best practice in project implementation limits the impact of their efforts. The "8 Habits of Highly Effective ICT-Enabled-Development Initiatives" provide a framework for assessing how an ICT project has been planned and managed. This evaluation looked at how the project has been conducted in terms of (see Annex 2 for a full description):

1. Doing some homework and starting with a needs assessment;
2. Implementing and disseminating best practice;
3. Ensuring ownership, getting local buy-in, finding a champion;
4. Setting concrete goals and taking small achievable steps;
5. Critically evaluating efforts, reporting back to clients and supporters, and adapting as needed;
6. Addressing key external challenges;
7. Making it sustainable; and
8. Involving groups that are traditionally excluded on the basis of age, gender, race

or religion.

4.1 The evaluation process

The evaluation involved three groups of key stakeholders:

- *Clinic staff*: physicians, nurses, and other healthcare professionals;
- *Patients*: those who are, or have previously participated in the Compliance Service programme; and
- *City of Cape Town Health Directorate*: TB experts and managers of the TB Control Programme. In particular, *Dr. Virginia Azevedo*, a medical officer managing and supervising TB control in the City of Cape Town, was a key participant in the evaluation. Dr. Azevedo provided advisory input to the evaluation, helping to frame the questionnaires and assessed patient records for the collection of cure and completion rates.

The project evaluation combined quantitative and qualitative data collection. Information was collected from patient records, background documents and reports, clinic visits, and structured interviews of patients and staff through the use of questionnaires.

- *Background documents*. A literature review of TB and its treatment in South Africa was carried out by bridges.org, to gather background information and investigate facts provided by the Compliance Service and clinic staff.
- *Clinic visits*. The clinic was visited a number of times between May and September 2004, firstly to liaise with staff and work out the logistics of conducting patient interviews. These were carried out on four subsequent visits to the clinic in June and July 2004 and staff interviews conducted when convenient for health workers. Patient records were assessed on three occasions in September 2004.
- *Patient interviews*. 26 patients were interviewed as part of the evaluation. The interviews were anonymous (patient identities were confirmed by clinic staff and unknown to the evaluator) and conducted one-on-one after signing a consent form²⁵. The interviews were structured through a patient questionnaire that was developed jointly by the evaluator and City health officials, and approved by the City Health Directorate. (See Annex 3 for the patient questionnaire.) Patients were invited to the clinic to be interviewed, in exchange for an amount of free credit with their cellular network provider. Despite this offer, it proved difficult to get patients to participate in the interviews. Patients were asked a number of questions to determine whether they were adhering to the treatment regime exactly, and if not, how they deviated. It was hoped that because interviews were anonymous and the evaluator was not attached to the clinic, patients would feel comfortable describing exactly how they took their medication and their experience with the Service. For more detail on how the patient interviews were set up and conducted, see Annex 8.
- *Patient records and treatment outcomes*. 221 out of 309 patient records were reviewed as part of this evaluation, covering current and past patients that have been involved in the Compliance Service pilot (these represent all of the records that were available; the evaluator was unable to access the missing records). The patient information collected includes treatment outcomes, residence, age, cell phone number, occupation, HIV status, whether the patient was a new or re-treatment case, and whether the patient was smear positive or culture positive. Anything else that stood out from the records was also noted. As only health workers are allowed access to patient records, City Health staff reviewed patient records at the Chapel Street clinic with the bridges.org evaluator entering the findings into a spreadsheet. Annex 1 contains a spreadsheet of this data.
- *Staff interviews*. Seven clinic staff members were interviewed as part of the

²⁵ See Annex 6 for the consent form.

evaluation, including a clinical assistant, two nurses, a health worker from TB Care (a local NGO), one doctor, the clinic manager, and the receptionist. A brief staff questionnaire was developed with the City, to investigate procedural issues around the pilot at Chapel Street clinic and gather the opinions of healthcare workers on the use of the Compliance Service system. The interviews were conducted one-on-one, and the evaluator agreed to treat all views as anonymous. The evaluator used initial guiding questions to get the interview going, but the questions were mainly open and the conversation was allowed to move freely toward any direction of interest that came up. This method was used to explore broad topics and allow the participants to focus on the issues that mattered the most to them. The questionnaire can be found Annex 5.

- *Interviews of Cape Town Health Directorate officials.* The City's TB programme manager and the health district manager were interviewed and invited to give opinions of the Compliance Service pilot as well as their views on the most pressing issues the City faces in its TB Control Programme.

The following statistics were drawn from this data:

Cure rate = $S+ / (S+ - (\text{"not TB"} + \text{patients who have not completed 6mths treatment})) * 100$

Completion rate = $(S+ + TC) / (S+ - (\text{"not TB"} + \text{patients who have not completed 6 months treatment})) * 100$

Treatment Success rate = $(S+ + \text{"cured"}) + (S+ + TC) / (S+ - (\text{"not TB"} + \text{patients who have not completed 6mths treatment})) * 100$

Where:

S+ = number of smear positive patients

Cured = number of patients marked as cured at the end of treatment

TC = number of patients marked as "treatment completed" at the end of treatment

5 Findings of the evaluation

5.1 Treatment outcomes

Trends identified in the data collected The clinic doctor estimated that 60% of all the patients at the Chapel Street clinic are HIV+, which aligned with the review of patient records, where 58% of the patients in the pilot who were tested for HIV (50.6% of the total) were HIV+ (see Annex 1). A greater proportion of HIV+ patients have extra-pulmonary TB (EPTB); sometimes this is specified, for example, TB of the lymph nodes. Often these patients are culture positive (cult+), meaning that tissue culture examination produced a positive result for the presence of the bacterium. Culture examination is important because HIV+ patients often produce a negative smear, but are cult+, and the City considers it an important diagnostic tool for TB/HIV.²⁶

Statistics for treatment completion and cure rates Based on the data collected from 221 records of patients that participated in the Compliance Service pilot, treatment outcomes for new, smear-positive patients were (this data is also presented in a spreadsheet in Annex 1):

Cure rate = 62.35%
Completion rate = 10.59%
Treatment success rate = 72.94%

The latest statistics available for the City of Cape Town's TB Control Programme, on a per-clinic basis, are for the third quarter of 2003, and are calculated separately for new and re-treatment patients.²⁷ For all new, smear-positive patients treated at the Chapel Street clinic the outcomes were:

Cure rate = 66.4%
Completion rate = 3.0%
Treatment success rate = 69.4%

With the exception of a slightly higher completion rate for the pilot, treatment outcomes are very similar. It is not possible to assign any statistical significance to the difference in treatment success rates, due to the limited sample size. At first glance, all that can be said is that the Compliance Service has produced results that are normal for this clinic, but do not demonstrate a significant improvement.

²⁶City of Cape Town / Metropole Region TB Control Programme, Progress Report", City of Cape Town Health Directorate, 1997-2002.

²⁷"Treatment Outcomes for 2003", unpublished statistics from the Cape Town City Health Directorate (with permission).

5.2 Real Access to the Compliance Service

Physical access to cellular technology

Cellular network at national level It was important to consider whether cellular technology (mobile phones and SMS in this context) is available and physically accessible to the people that will use it. And this is particularly important when considering a scale-up of the Compliance Service. The cellular network in South Africa is based on the Global System for Mobile Phones (GSM) 900MHz standard, used all over Africa, Europe and most of Asia. As of June 2004, there were an estimated 18.7% mobile phone users, out of a population of roughly 45 million. The cellular network is on a par with many first world countries, covering over 71% of the population, and mobile phone users are found in remote corners of the country. There are three network operators in South Africa (Vodacom, MTN, and CellC) with market penetration of 9.7 million, 5.2 million and 3 million, respectively.²⁸

Availability of mobile phones in South Africa It is estimated that 65% of people in Cape Town own a mobile phone²⁹. Although new mobile phones are too expensive for most people (largely because they are imports), a thriving market in older model, second-hand and refurbished mobile phones means they can be purchased at a fraction of the cost. Consequently, mobile phones are widely accessible to South Africans and they are used across society. It is not uncommon to find family members sharing a phone, and often family members pass their old phones to children and siblings as they upgrade their phone. The cellular network operators are currently competing to capture the low-income end of the market, by offering slightly older, lower spec models for low prices, with a “free” starter pack to connect the user to the network.

Market reach was reflected in the findings of this evaluation, where half those interviewed were unemployed and yet still used mobile phones. Several patients reported they had upgraded their phones while on the Service; often this involves a change of number when the service provider is also changed, but only some thought to inform the clinic of their new number. This is likely to account for a large number of patients who reported an unexpected cessation in the Service, rather than it being due to a poor service from their cellular network operator.

Network coverage in Cape Town A reliable cellular network service is essential for the Compliance Service. If patients are situated in areas of poor coverage at the times they expect the SMS reminder, this will seriously impact on the Service. There will always be patches of poor signal strength, especially in city centres where high buildings and metal objects interfere with radio signals. But only one patient complained of a poor signal and this was only on the upper floor of her apartment. Not only did patients always have a signal at the time they expected their SMS reminder, all respondents said they rarely, if ever, experienced poor signal strength in the metropolitan area.

²⁸For more information see: http://www.cellular.co.za/stats/statistics_south_africa.htm

²⁹“Digital divide assessment of the City of Cape Town” bridges.org, 2002 bridges.org, <http://www.bridges.org>

Quality of service from the network operators Depending on the service provider, there may be times when SMS messages never reach their destination due to a variety of technical problems. Users also have to know how to clear the phone's memory when they have stored too many messages so that new ones can be downloaded, but the patients interviewed did not view this as a significant problem, as SMS is a popular feature which most people are familiar with.

15% of patients said they had expected to receive an SMS from the clinic and either it did not come for a number of days, or sometimes weeks. And one patient was enrolled in the Service but never received any SMS messages at all, but because he did not report this to the clinic, he received no help with adherence to his treatment regime. Clinic staff also indicated that several patients reported they had not received SMS reminders, or sometimes had received them for just a week or two and then they stopped, with no explanation as to why they had stopped. Many of the patient records reviewed contained a notation of the date the patient was enrolled in the Service, but no other notations confirming that the SMS reminders were being received.

Appropriateness of cellular technology to health care in this context

Electricity supply Poor access to electricity is now mostly a rural problem: most (not all) areas in the informal settlements and poor communities in Cape Town have power. But some people in South Africa cannot afford a constant electricity supply, so the evaluation investigated whether any patients could not keep their mobile phones charged at all times.³⁰

88% of the patients interviewed said they always have their phone charged and keep it with them at all times. Only two patients do not keep their phone with them. One said he only switched his phone on once a day (usually upon waking) to save on battery life, but when he did turn it on, he was immediately alerted to an incoming SMS and took his medication then. The other patient said that although he did not always keep a charged phone with him, he would definitely forget to take his tablets if it were not for the SMS reminder he received when he turned the phone on.

Environment and security Any project that uses technology to address a development issue must consider what ICT is appropriate for the environment that people live in. For example, personal computers can be inappropriate for use in disadvantaged communities in Africa, due to the expense of keeping them in temperature-controlled rooms and secured against fire and theft. Conversely, mobile devices, such as handheld computers and cellular phones are easy to protect against adverse environmental conditions, such as heat, damp or dust.

Mobile phones were found to be appropriate to the environmental conditions in the Cape Town area. No security fears were mentioned by those interviewed and because they are so ubiquitous, carrying a mobile phone (especially an older model) was

³⁰The evaluation team felt that asking directly if a patient could afford electricity would be insensitive, so the question simply asked whether they kept their phone charged and carried the phone with them at all times. For those that did not, lack of electricity would only have been one possible reason. See Annex 3 for the patient questionnaire.

not considered by the patients to be a great security risk.

Patients not hearing their phone alert them to an incoming SMS If patients do not hear their phone alert them to an incoming SMS, the Service will be compromised. This can easily happen in a busy City with high levels of background noise. It does not necessarily mean the patients do not take their tablets, only that they do not take them when the SMS reminder is received. A third of patients interviewed said they sometimes did not hear their phone alert them to an incoming SMS, but none considered it a problem. Some described their strategies for dealing with this, such as checking their phone display for the symbol announcing a new message (see Capacity findings below).

Psycho-social aspects of using mobile phone The psychological and social aspects of mobile phones also come to bear on their appropriateness in this context. Studies have shown that, unlike many other technologies, people are generally not intimidated by mobile phones.³¹ People that have no previous experience with technology are not apprehensive about learning to use them, and because they are so widespread in society, people are not shy about asking for help. Informal support from friends and family means, unlike computers, anyone can be shown how to use them proficiently without having to pay. Patients in the pilot were very open to the use of SMS and those of all backgrounds appeared comfortable with using the technology.

Cost impact: patient costs

Cost of using SMS in South Africa The average wage in South Africa is Rand 4442 per month (USD 778).³² But this figure is likely to be skewed from the inclusion of a relatively small number of very wealthy individuals. Half of the patients interviewed were unemployed, so were 36% of the patients whose records were reviewed.

“Pay-as-you-go” schemes are largely responsible for making mobile phone use accessible to people with low incomes in South Africa. On a pay-as-you-go scheme, a cell phone user can purchase a SIMM card with a telephone number and small increments of “talktime” (the number of minutes for calls) and “airtime” (the timeframe during which the SIMM card is activated to receive and make calls). Receiving calls and SMS messages is free. (Recently, MTN and CellC have done away with airtime, and the airtime from Vodacom is so long that the user must use his/her phone very seldom to fall out of the airtime window.³³) With a pay-as-you-go system, people who do not qualify for a service contract -- because they have no bank account, no verifiable mailing address, no credit history, or they are below an earnings threshold -- are still able to purchase credit from a cellular operator when they can afford to. However, charges for making calls on a cellular network are expensive for most people in South Africa; for example, Vodacom's standard pre-paid package costs R2.55 for calls to a land line and 80 cents per SMS.³⁴ Pay-as-you-go service usually works out to cost more per minute than for the contract-

³¹ Information from previous conversations with scientists at CellLife, an NGO at the University of Cape Town, South Africa. For more information see <http://www.celllife.org>.

³² For more information see http://home.aigonline.com/country_view/0,4605,1385,00.html.

³³ Vodacom offer 90 days of airtime for every R29 voucher purchased (the minimum denomination).

³⁴ For more information see <http://www.vodacom.co.za/prepaid/packages.asp>.

based service.

Affordability of "airtime" The Compliance Service only involves a patient receiving, and not sending, SMS messages. So long as the patient has airtime on their phone, there is no need for talktime credit. It was nevertheless important to ascertain that patients did always have at least airtime, but no one reported that they ever ran out of airtime. Even so, many patients complained that using mobile phones, especially to make calls, was expensive, and some of them said they only take incoming calls and SMS messages.

Impact of the Service on travelling costs Another aspect of affordability in the TB treatment context is the cost savings to the patient from not having to attend clinic daily to receive DOTS. The patient saves on transport costs and potentially on the wages lost from having to visit the clinic, especially important as many are paid by the hour. Some patients are reported to have lost their jobs because of the time away from work required for DOTS treatment, as corroborated by one patient interviewed. Despite efforts by the City to divert patients away from Chapel Street clinic to clinics closer to home, a significant number of patients insist on using Chapel Street. One reason is that it is on the way to work for many people. Another stems from the clinic's popularity as previously it was the TB headquarters for the central zone of Cape Town, with many senior staff and doctors based there. The legacy of the clinic's reputation as a centre for TB care may still make it more attractive to patients.

69% of patients interviewed travelled to the clinic by taxi, costing an average of R8 (or approximate USD1.40) each way.³⁵ The remainder walked, except for one person who drove. Some of the patients interviewed (primarily those who were unemployed) travelled to the clinic from home; others visited during their lunch hour; and some went to clinic either on the way to work, or on the way back. Extrapolating this data to determine the average travelling costs for patients on clinic-based DOTS as compared to the Compliance Service is not straightforward, and not within the scope of this study.

Impact of the Service on working hours lost The number of working hours lost due to clinic visits to receive DOTS will be a function of the time spent travelling to and from clinic plus the time spent at clinic waiting to see the nurse and receiving DOTS. The average time that patients reported they spent on a round trip to the clinic was 54 minutes. The Chapel Street clinic, similar to other primary healthcare centres, does not run an appointments system. The time that patients must wait to receive DOTS will largely depend on how many people happen to be at clinic that day, and the number of staff on duty. Assuming a 15-minute visit, the average number of working hours lost per visit will be approximately 1.25 hours. The Compliance Service requires a total of 27 visits, equating to 33.75 lost working hours (1.4 days), and clinic-based DOTS 120 visits (for new, smear-positive patients), equating to 150 lost working hours (6.25 days).

³⁵In South Africa, a "taxi" refers to a privately owned mini bus, typically carrying around 15 people. Taxis are the most common form of public transport being relatively cheap and are often the only transport affordable to people on low incomes.

Cost impact: health service costs

Estimated costs of the Compliance Service per patient

National health services in developing countries are under constant pressure to keep costs low and stay within inadequate budgets, and it is common for them to cut corners to make ends meet. For example, there are eight primary care clinics in the Cape Town metropolitan area, but only two managers between them. The City commissioned this pilot in the hope that the Compliance Service would help reduce costs and lessen the burden caused by human resource shortages. On face value, the Compliance Service should be a far more cost-effective means of ensuring TB treatment compliance than clinic-based DOTS, and possibly even community-based DOTS, but this assumption must first be proven with a comprehensive cost analysis of the Service, and comparison with other treatment systems.

Conducting a cost analysis was not within the scope of this study, but it is useful to show the cost components of community-based DOTS against those of the Compliance Service, as a starting point. The following information is based on a report on cost and cost-effectiveness of clinic-based and community-based DOTS in Cape Town published in 2000.³⁶ as well as expert opinion from the City. It was not possible to assign monetary values for clinic visits because the cost of a visit depends largely on whom the patient sees, how long they stay and that staff member's hourly cost to the health service: parameters this study did not measure. However, the total cost of just treating a (new, smear-positive) patient on community-based DOTS and the Compliance Service are given in bold. It is also important to highlight the extra cost components for the management and training of community DOTS supporters, which account for a considerable proportion of the outlay for community-based DOTS.

<i>Cost Component</i>	<i>Community-based DOTS</i>	<i>Compliance Service</i>
2-3 healthcare visits for initial diagnosis	X	X
10 clinic-based DOTS visits for first two weeks treatment (including enrolment to Compliance Service and adherence education)	X	X
Supply of 1 month medication at day 20 (2 months for re-treatment TB)	X	X
Further clinic visits to collect more medication at 2, 3, 4, 5, 6, (7 and 8 if re-treatment TB) months	X	X
120 DOTS visits (160 for re-treatment TB) at R1.5/visit	R180 (R240 for re-treatment TB) per patient /month	
120 SMS reminders (160 for re-treatment TB) at R13.90/patient/month		R69.50 per patient/month
Supervision of DOTS supporters	X	

Training and updating of DOTS supporters	X	
Adherence checks at monthly visits by facilitator (see page [])	X (done with DOTS supporter)	X
Drugs (6 months for new TB; 8 months for re-treatment TB)	X	X
2 x smear tests (3 for re-treatment TB)	X	X

Capacity issues around using the Compliance Service

Capacity of patients to use the Service The Compliance Service does not work unless patients understand exactly what to do upon receiving an SMS reminder, and they appreciate the importance of adhering to their treatment regime. Just as patients placed on DOTS are tutored about the importance of visiting the clinic daily to take their medication, patients on the Compliance Service also require training, and must demonstrate they have the capacity to use the Service correctly. All of the patients interviewed stated that they had no problems understanding how to use the Service. But questions around capacity revealed deviations from the treatment regimes and any deviation from the instructions given to them at the clinic, no matter how well-intentioned on behalf of the patient, will likely impact on adherence.

Similarly, the technology does not solve the problem of adherence for health workers. Interviews revealed some misunderstanding around the capabilities of the Compliance Service and how it fits into the TB Control Programme.

Language and adherence Language can be a problem related to adherence assessment that is particular to the cultural context of public health care in South Africa. Almost all patients at Chapel Street clinic have English as a second language; some can barely speak English. Health workers spoke English or Afrikaans, but only one spoke Xhosa, the predominant African language in the Western Cape. Clinic staff admitted that some patients probably did not fully understand the instructions given them. Several times during interviews the evaluator had to speak slowly, using short, common words, and felt that she was not always understood fully by some of the patients.

Issues around choosing the time to take medication Almost 40% of the patients interviewed said they did not choose the time the SMS reminder should arrive each day, but the nurse chose it for them. Of those that did specify the time, many said the time chosen was not actually the best time for them and with hindsight they realised that a better time could have been chosen. The majority took their tablets in the morning, either at around 5–6am (people in Cape Town often rise early for work and leave work at around 4pm), typically with a breakfast of porridge.

9am was another popular time, but interviews revealed that it was usually chosen by the nurse and not the patient. 9am roughly coincides with the time that many people in blue collar jobs take a tea break at work. However, this means that it is essential that they remember to take their medication to work with them every day. Roughly half said they always carry their medicine with them and the other half said they do not. Those that do not carry their medicine indicated that they took the

medication at home either with breakfast or dinner (since most of the patients were on a low income, they seldom eat out). One person said he kept his medication in his locker at work.

Issues around record keeping Patients are instructed to tick their record book (the "green card") immediately after taking their medication; 83% of those interviewed claimed to always fill in their green cards, and 70% of these patients said this was done immediately after taking their tablets. The evaluator felt that some of these claims may have been exaggerated. Two patients freely admitted they only filled out the book at weekends, after a week of treatment (one of whom was a medical student); however, when asked if they could have remembered incorrectly, they were certain they had not.

Patients taking their tablets before or after the SMS City TB experts set 15 minutes as the maximum time after receiving the SMS that patients would be likely to remember to take their medication. 16% of the patients interviewed said that they take their medication before the SMS arrives, 50% take them after the SMS and 34% do either. Of those that take their tablets before, roughly half claimed they would never have forgotten to take them if the SMS did not come and half said they sometimes would. Of those that took their tablets after the SMS, 62% took their tablets immediately, 19% took them within 15 minutes and 19% took them more than 15 minutes later. Regardless of whether their tablets were taken before or after the SMS reminder, 72% were adamant they had taken their tablets that day. And only 2 people admitted they would sometimes forget to take their medication despite the SMS reminders.

Typically, patients that reported taking their medication before the SMS reminder arrived were those taking unusual actions. For example, one patient used the SMS as a reminder to set her phone alarm to further remind her to take her medicine later in the day. Another used the SMS to alert his wife to giving him his tablets.

Privacy and data protection

Protection of patient data As technology becomes integrated into society, people need to understand what happen "behind the screen" so that they can trust their electronic communications and transactions with government, businesses, or others in terms of privacy, security, or cybercrime. This also holds true for cellular technology. Patients on the Compliance Service want to know that information about their medical condition is not being shared with non-medical staff and that the Compliance Service is storing it in a secure place. In future, the more technically aware can be expected to want assurance that SMS reminders are not being intercepted on route to their phone, or that their number will not be given to third parties. These were not concerns aired by health workers or patients interviewed, but are worth bearing in mind for scale-up.

The Electronic Communications Act of 2002 deals with South African law around new forms of electronic communication, such as email and SMS. Currently, SMS is under the spotlight due to the number of companies using SMS to market their products. Some of this is unsolicited, creating a problem similar to that of "spam" email. The Act does not contain anything explicit regarding the use of SMS to communicate medically-related data, and there have been no court cases in this area. Hence, no precedent has been set regarding the use of SMS in the context of health care. However, the Act does infer that

SMS is an acceptable means of communicating with patients, so long as they have given their permission and confidentiality is maintained.

Are patients worried the SMS reminders will be seen by others? In the context of this study, privacy issues were highlighted by patients who are concerned about people seeing the SMS on their phone. TB, like HIV/AIDS, is still a taboo in South Africa, and many people are keen to keep their medical condition secret. Although the reminders do not contain anything personal, or any identifying information, they are signed from the clinic, so that a reader can find out the patient is being treated for TB. For example, this can be a problem in families where a cell phone is shared (sharing material possessions is common in many South African families).

Only two patients interviewed shared their phone with others; in both cases these were family members and the patients were not concerned the message would be read by them. Overall, 20% were concerned that other people would see the SMS reminders. For example, one young person said it was usual to pass phones around within a group of friends to show each other amusing messages, and was worried the SMS reminders would be seen.

Integration of the Compliance Service into daily routines

How do patients view the Service in their day-to-day lives? People will not use technology if it adds further burden to their lives or does not integrate into daily routines, or even if they perceive that it will. If patients come to view the daily reminders as a nuisance, the Compliance Service will likely become less effective. (Conversely, the messages must not become so familiar that patients grow "fatigued" and begin to take them for granted or even ignore them.) The reminders must also come at a time of day convenient for the patient, when they have their medication, green card and food and water with them. Compared to being on DOTS, the patient is very likely to appreciate the convenience of the Compliance Service, but it remains to be seen whether this translates into satisfactory adherence levels.

None of the patients interviewed complained that they became tired or bored of receiving the reminders, although one person said that he received so many SMS messages each day that he sometimes did not recognise the SMS from the clinic. No one complained of having to carry their mobile phone with them at all times and to keep it charged. One or two patients did complain of messages continuing to come after their treatment had finished, and they found this irritating.

Patient support and enthusiasm for the Compliance Service

Public support for cellular technology in South Africa South Africans are enthusiastic users of mobile phones, SMS being a far more popular application than telephone calls. In the last two years, SMS traffic in South Africa has increased by an incredible 1000%. Public support for technology use -- and especially uses of technology that have a direct social and economic impact on people's lives (such as in the healthcare area) -- will help to influence the government to change laws and regulations and create a more favourable environment for widespread technology uptake. For example, widespread public support for technology use will engender the political will in

government to drive changes to the legal and regulatory environment (such as allowing competition in the telecommunications market) that can help bring down prices and make it easier for people to access and use technology.

How patients feel about the Compliance Service Every patient interviewed stated their support for the Compliance Service, and more specifically, for using cellular technology in this way. Most were very pleased with the Service and thought it a good idea. Some said they thought procedure at the clinic could be improved to avoid a gap between the time they enrolled in the Service and the time they received their first SMS reminder, and one person said this wait had been disappointing as she had not received an SMS for several weeks. Here are some comments:

"It makes you feel good to think nurses at the clinic care enough to SMS you every morning."

"It [the Service] makes you feel more connected to the clinic than usual."

"I think it is a great idea and should be used for other things in the health service."

"I would definitely forget to take my tablets if I didn't get an SMS from the clinic."

5.3 Project management and implementation of the Compliance Service

Doing homework and conducting a needs assessment

Why Chapel Street clinic was chosen The Chapel Street clinic usually performs below the targets set by the City for treatment outcomes. There are other, similarly performing TB clinics in Cape Town, but this one was chosen for the pilot because, being close to the city centre, it was thought there would be a large number of working patients able to afford mobile phones. In fact, similar numbers of patients at TB clinics in the informal settlements -- where incomes are lowest -- appear to have mobile phones.

Chapel Street clinic is fairly unique in that it serves no single community. Patients are scattered over many areas, and coordinating community-based DOTS is difficult. As such, only 12% of patients are on community-based DOTS and it was hoped the Compliance Service would help to get people off clinic-based DOTS and reduce the workload at the clinic.

Discussions with clinic staff at inception At the beginning of the pilot, On Cue met with the clinic manager, explained how the Compliance Service worked, how to enrol patients and communicate with On Cue to resolve any problems with the Service. This information was conveyed to the TB nurse by the clinic manager, but no further information about communication with the Compliance Service was provided to clinic staff, nor were there specific task allocations or specific procedures set up.

Needs of health Some health workers said enrolling patients in the Service created extra work for them. This is a problem because technology will either be used badly or not at all if it does not integrate smoothly into daily routines. Extra work is inevitable,

workers at the clinic but it should be as non-invasive as possible and this becomes increasingly important as the number of patients on the Service increases.

Needs of health workers at the City Decision-makers at the City need to know how the Compliance Service will fit into the TB Control Programme. To do this, there needs to be some way of translating the overall aims of the Programme into measurable parameters at the clinic that can be applied to the Compliance Service. Relying on cure and completion rates at the end of treatment only paints part of the picture. Even had the original procedure been followed rigorously, this would still be the case: something more granular is required.

Implementing and disseminating best practice

Deviation from the original procedure It was clear from both staff and patients interviews that implementation of the Compliance Service suffers from a lack of procedure, and the review of patient records confirmed this. The original procedure was to only enrol patients after one month of DOTS, but sometime during 2002 this began to change, so that by 2004 nearly all patients were being put straight on the Compliance Service. It is unclear why these changes took place. When asked, some staff said it was probably due to staff turnover, there being no written procedure to inform new staff. This view was contested by the City, who claim staff turnover at Chapel Street clinic is low. Two health workers interviewed (at the clinic and at the City) suggested that the Service made it possible for health workers to avoid having to persuade patients to come into the clinic for DOTS (which they normally have to do in the full knowledge of the inconvenience this brings to the patients). And one nurse commented: "It's hard to put people on DOTS when you know you are disrupting their life and the patient thinks he'll get into trouble at work."

Placing patients on the Compliance Service on the first day of treatment can have serious consequences. First, where it has not been ascertained that the patient is inclined to be adherent, it is unknown whether they are good candidates for the independent nature of the Compliance Service. Second, it could cause problems because there will be inadequate monitoring of adverse effects, resistance to the drugs, or unexpected complications, which are normally checked during early clinic visits. Several records were identified where patients who were enrolled in the Compliance Service from the first day of treatment should not have been, requiring close supervision during initial stages of treatment.

Lack of monitoring of the Service during treatment If the original criteria for enrolment are followed, then only patients shown to be adherent during the first month on DOTS, and whom are predicted as continuing to be adherent, will be chosen for the Compliance Service. But continued adherence (past the point at which the patient begins to feel better) depends on many things. For example, TB experts at the City stressed the importance of establishing friendly rapport between nurse and patient at the start of treatment. Putting in extra effort to get to know the patient and make them feel cared for at the beginning impacts on the likelihood of them remaining adherent, as well as the likelihood of them visiting the clinic toward the end of treatment for a smear test. But a number of

people will always be non-adherent, and when they are using the Compliance Service they will be harder to detect and deal with than those on DOTS.

Some health workers said that they asked patients at the second clinic visit (usually five days into treatment if enrolled immediately in the Compliance Service) whether they were receiving the SMS reminders. But it was not clear to the evaluator whether all health workers asked the patients about their receipt of SMS reminders, or if those that did ask always did so. Few patients were asked about the Service on subsequent clinic visits. Two patients who wanted to participate in the evaluation said they had been enrolled in the Service but had never received an SMS. Another patient said that she received SMS reminders over the weekend (when she was not supposed to take medication), but fortunately she knew not to take her tablets on these days. A problem reported to the evaluator by several people was that of changing phone numbers. These cases demonstrate the potential for patients to fall through the net through lack of supervision.

Most patients were asked questions around adherence at monthly visits, and their green card was checked. So, if the patient appeared adherent and their condition was improving, health workers usually assumed patients were using the Service as instructed. With no set procedures and given daily time constraints, staff usually did not investigate further, which resulted in a number of patients being entirely unsupervised. These patients were placed in the position of being entirely responsible for their own adherence, and some deviated from their treatment regime or stopped treatment all together.

Problems removing patients from the Service

Two patients and one member of staff claimed that reminders were still being sent after treatment had ended. However, On Cue claims that all patients are automatically removed from the database of active users after five months of treatment, so messages necessarily cease at that point. Apart from being irritating for patients, this is a waste of money for On Cue, and the issue needs to be resolved. This could be because patients did not understand the treatment regime sufficiently, and they thought that treatment was supposed to end before it actually did, so they stopped taking the medication prior to the end date.

Tightening the criteria for enrolling patients

Several health workers at the clinic said the lack of clear, written criteria for selecting patients to enrol in the Compliance Service is a problem. The evaluator was told that this decision is largely down to the intuition of the nurse to predict whether or not the patient will remain adherent. One said she chose patients based on whether they appeared responsible and "with it". At the same time, clinic staff recognised there were problems with this system for patient selection.

Review of patient records showed a large number were enrolled on the first day of treatment. This included HIV+ patients, who may have only learned of their HIV status recently. City health workers commented that this would likely have a negative effect on adherence, as the patient may still be learning to deal with their medical condition and not have the focus for adhering to a strict treatment regime.

Ensuring ownership, getting local buy-in, finding a champion

Staff buy-in All staff interviewed supported and liked the Service. Health workers feel that the Service has resulted in more negative sputum results (improved cure rate) and less patients defaulting. One said that she believes the overall clinic statistics will be improved by the Service, and another agreed that patients are less likely to default. One nurse said record-keeping is a problem with the patients in the Service, but it is no worse than for patients on DOTS who are supervised at home by a family member. Most said it freed up time for staff, especially during times of staff shortages, and that Mondays and Wednesdays when the doctor is at clinic and patient numbers are high, are now manageable because fewer patients have to be seen for DOTS. The external health worker from TB Care said the Service was useful for recalling defaulters.

When asked about the benefits of the Service to the patient, health workers said patients' jobs are no longer in jeopardy from attending clinic-based DOTS. They thought that the Service gives patients a greater sense of responsibility for their own health -- one of the factors thought to enhance adherence. And nurses indicated that they were more confident in giving patients a greater supply of medication at one time. Some thought the Service gives patients a more personal interaction with the clinic. This is curious because, assuming they were comparing Compliance Service patients with those on DOTS, one would assume physically attending the clinic each day would be considered to be more interactive. And yet two health workers and two patients mentioned this increased sense of connection with the clinic.

Lack of ownership Despite support for the Compliance Service, some staff members voiced their frustration that the Service had been imposed on them without consultation. Many felt that had care been taken to include their needs at the beginning, there may have been a greater sense of ownership among staff, engendering a greater level of conscientiousness around running the Service in the clinic.

No champion at the clinic This pilot project suffered from having no local champion of the Service resident at the clinic (or at least visiting the clinic frequently). One nurse at the clinic appeared to be responsible for collating a list of patients each week and faxing this list to On Cue, but there was no single person assigned to oversee the project, or who would go the extra step to resolve problems in a proactive manner. Interviews with clinic staff revealed that all recognised this lack of leadership as a major problem.

Setting concrete goals and taking small achievable steps

The pilot was not a staged process The pilot was not conducted as a staged process, but it was simply initiated in January 2002 and patients were added thereafter as they appeared. Some health workers interviewed indicated that they felt the project had tried to do too much too fast. Others suggested a staged approach with checks and balances would have helped create an environment where unexpected problems could be dealt with.

Critically evaluating efforts, reporting back, and adapting as needed

No reporting mechanism was put in place Without stopping to evaluate the pilot at regular intervals, the clinic had no clear way of knowing how it was progressing. The pilot had no reporting mechanism to enable TB experts at the City to critique the pilot from a distance. This is essential for placing the Compliance Service in the broader picture of the TB Control Programme, without being distracted by the day-to-day concerns of the clinic.

Address key external challenges

Lack of leadership The lack of on-site leadership to oversee the pilot had a significant impact on the outcomes. The clinic manager was involved at inception, briefing the TB nurse and helping to resolve initial problems. But the manager is shared among four clinics, which although small, may not leave her time for hands-on management of the project.

Cut backs in internal technology The City chose not to use all the features of the Compliance Service, notably the web-based interface that would provide health workers with an easy means of using the system. This would allow them to, for example, add and delete users, select the messages to send, and set up scheduling for the SMS reminders themselves. The web interface is currently being used at other clinics in South Africa that subscribe to the Compliance Service. Instead, the clinic initially relied on email to send On Cue a list of patient details every day. But at some point during the pilot, outgoing email was curtailed, so that the clinic could not directly email to On Cue, to update new patient information or report problems. Nurses could send an email to the City to be forwarded to On Cue, but they reported troublesome delays with this. Patient details were to be faxed to On Cue instead, but this proved to be problematic too because security is tight at the clinic and the fax machine is kept locked away in a cupboard in the manager's office, which is also locked when she is out. Further, faxes that are hand written are notoriously difficult to decipher, and this also contributed to errors. The sheer inconvenience of faxing patient details individually as they were enrolled, resulted in health workers deciding to collect names and numbers on a sheet of paper, which one nurse was (loosely) responsible for, and faxing it to On Cue on a Friday. It was clear that these short-comings in internal technology at the clinic inhibited the effective implementation of the Compliance Service.

Over-stretched clinic staff Staff shortages at the clinic may have been a problem, with health workers reporting that despite their support of the Service, no one had the time to look after it. Strictly speaking, only the TB nurse was in charge of the Service, as she is tasked with responsible for TB patients at the clinic, but the pilot had become more of a team effort at Chapel St clinic. Further, clinic staff reported that they were overburdened by their work schedules, but this is not corroborated by human resource figures for the clinic.

Problems tracking TI patients The study found a significant number of patients finished treatment as “treatment interrupted” (TI), either because they stopped taking their medication or, in many cases, moved from the area and could not be traced. This is consistent with findings reported by the WHO that note a large number of patients are lost to the system in South Africa. A member of the NGO TB Care was employed by the clinic to track down these defaulters, but was often unsuccessful because a number of patients give incorrect addresses. Often this was because the address was incomplete, the patient had moved, or was known by his neighbours by a nick-name not given to the clinic. And because there are a significant number of homeless people being treated by the clinic, this made her job even more difficult. Sometimes On Cue was contacted to send patients an SMS recalling them to the clinic, which she had found very useful. But bureaucracy at the clinic made it difficult for her to make such requests, and eventually she stopped asking.

Patients changing number, losing their phone, etc Some patients changed their phone numbers, lost their phones or their phones were stolen during their enrolment in the Service. This was a significant problem for the pilot because there were no procedures for patients to update their phone numbers in such cases. The Compliance Service could use SMS receipts at intervals to at least verify the number is still in existence, although this service has limited capabilities. But the extra cost, although small, would likely need to be passed on to the health service.

Making it sustainable

Costs of running the Service Ongoing costs can be a show stopper for ICT-for-development projects, especially if they increase unexpectedly. Price increases for bulk SMS purchases and/or sending SMS reminders are out of the hands of On Cue and the City. But cellular service costs are unlikely to rise significantly, due to market competition and the fact that prices in this sector show a global trend of falling.

Reliability of the Service Computer downtime is known to be a significant contributor to the sustainability costs of technology and is a factor that was largely ignored in this pilot. It is essential that the Compliance Service does not suffer from significant downtime that would impact on its service delivery, and this is definitely an issue for scale-up. There was a period of two to three weeks toward the beginning of the pilot when no SMS messages were being received. On Cue resolved this problem and it did not reoccur, but since then there have been several reports of patients not receiving their reminders for two weeks or so after enrolment. When asked if this was a problem for adherence, health workers said not, as adherence was usually 100% in the first few weeks and only began falling once patients began to feel better. That said, one nurse commented that the disappointment of not receiving the reminders was de-motivating for patients, which could affect their willingness to be adherent.

The evaluator did not find an adequate explanation for this problem; nor for the few that enrolled but never received an SMS. Healthcare workers claim all patients are placed on a list which they always fax to On Cue, and On Cue claim they add patients to the database as soon as they receive a fax. This aside, the enrolment information being collected was insufficient to run the Service efficiently. In January 2004, a site visit by the City to assess how the pilot was progressing found twenty-

five faxes containing a variable number of patients per fax. Each fax had patient names and numbers, but no corresponding TB registration number or patient record number. Because of this and some faxes not being dated, it was difficult to find records for a randomly selected number of these patients, or their entry in the TB registers. Several suggestions were made, including set up of a separate file to house the details of patients on the Compliance Service, but the evaluator did not find that they had been implemented at the time of the evaluation.

Involving traditionally-excluded groups and addressing socio-cultural factors

Groups the current Service caters for The Service has taken steps to include traditionally excluded groups by making the SMS messages available in Xhosa. It is also available in Afrikaans, and could be translated into other languages. However, the SMS protocol only allows for ASCII characters so languages that use non-Latin based characters, such as Kiswahili, cannot be catered for at this time.

People the Service is not suited to One nurse suggested that street people are not suited to the Compliance Service, not necessarily on the basis of poor adherence or having no mobile phone, but because attending clinic for DOTS had become part of their life. In her opinion, stopping those daily visits, sometimes the only positive human interaction they have all day, would be a mistake. This may also hold true for other people, such as the unemployed or lonely. This lends further support to the benefits of spending time with the patient at the start of treatment to determine their individual needs.

The effects of hierarchy Another problem in South African health care is that of hierarchy. Medical personnel, especially doctors, tend to be held in great esteem by many people in South Africa, particularly those with less education. This impacts on the way in which patients relate to, and communicate with them. For example, nurses reported that when assessing some patients, they felt that they were given the answer the patient thought they wanted to hear, rather than the correct one. But breaking down these barriers to engender a trusting, more equitable interaction is not simple.

6 Discussion and analysis

The main finding of this evaluation is that the Compliance Service has potential as a cost-effective system that would be appropriate to complement DOTS in Cape Town clinics and beyond. However, a number of obstacles to the use of the Service have been identified, which need to be overcome in order to make this system work effectively.

The project management issues are so inherently intertwined with the technology that it is difficult to separate them. Project implementation clearly limited the effectiveness of the Compliance Service, but it is not a reflection on the usefulness of the technology itself. To the contrary, the Service has potential to provide more choice in the care of TB and greater convenience for the patient. However, the problems encountered do underline the limitations of the Service and imply there are important conditions for its success. With this in mind, the recommendations below are suggested as a basis to frame next steps for the pilot and for scaling the system more broadly.

6.1 Key findings

⇒ *Mobile phones and SMS have proven to be effective tools in the context of health care in South Africa in terms of accessibility, appropriateness and cost. But healthcare workers cannot rely on the technology alone to solve the problem of patient adherence.*

There were no significant problems around the use of SMS in the pilot. Affordable handsets are available, and the cellular network and SMS are sufficiently reliable. Cellular technology is appropriate in terms of security, usability, and the local environment. It is affordable for patients -- even for many unemployed patients -- largely because the Compliance Service involves incoming messages to patients that can be received for free. And at face value, it costs significantly less for the health service to run this Service than to run clinic-based DOTS, and somewhat less for community-based DOTS.

Yet the simplicity of the Compliance Service may have led health workers (at Chapel Street clinic, the City, and On Cue) to rely too heavily on the technology to solve the problem of patient adherence. There is nothing complicated about SMS, or how the Service works, so it was difficult for health workers to predict where and how it might fall short. Rather than first identifying its limitations and working around them, the Compliance Service was just put in place and assumptions were made about its efficacy.

⇒ *Both patients and healthcare workers liked the Service and were able to use cellular technology effectively. Yet a significant number of patients interviewed were not using the Service as instructed.*

Public support is essential for the uptake of technology in society and this pilot provides a good example of this on a smaller scale. There was overwhelming support for the Service from both patients and clinic staff, largely because it helped make TB treatment more convenient. Patients had the capacity to use mobile phones and SMS proficiently and the Service integrated well into daily routines. And patients were relieved at not having to visit clinic daily for DOTS, while at the same time health workers felt they were no longer responsible for disrupting their patients' lives.

Nevertheless, a disconnect exists between patient's support for the Service and their ability (or willingness) to use it as instructed. Several findings point to this. Patients often forgot (or did not think) to tell the clinic of a change in mobile phone number, causing a cessation in service. Patients take a variety of actions on receipt of an SMS reminder, rather than taking their tablets immediately and marking the green card. And patient records show many completed their course of medication, but did not come to clinic for a final sputum test. This suggests patients were not sold on the idea

of adhering strictly to their treatment regimes, despite their enthusiasm for a service that was designed to help them do so.

- ⇒ *The Compliance Service showed rates for TB cure and completion similar to those of clinic-based DOTS at the clinic. But they could not be used to gauge treatment adherence levels due to poor implementation procedures used in the pilot.*

When the cure and completion rates for patients that participated in this trial are compared against the average rates for patients that use the DOTS system at this clinic, no major, statistically significant differences were seen. But reliable treatment adherence levels could not be ascertained due to poor implementation procedures used in the pilot. Patients were not monitored sufficiently, so their records hold very little information as to how they were actually using the Service and whether they were adherent. This meant treatment outcomes could not be used as a gauge of adherence.

There was no written procedure for using the Compliance Service. Again, this may be due in part to the simplicity of the system acting as a disincentive for clinic staff to carefully document its implementation. This -- along with the lack of clarity on how the Service should be integrated into TB care at the clinic -- together were significant factors that led to shortcomings of project implementation. Several findings support this, each having the potential for more far-reaching consequences. Patient names and numbers were being recorded on a piece of paper and faxed to On Cue every Friday, meaning those enrolled at the beginning of the week had no service for a number of days. Healthcare workers were not overly concerned because patients are almost always adherent in the first two weeks. But there will always be exceptions, and City TB experts are particularly concerned that HIV+ patients will be among this group. Many HIV+ patients will have just learned they are HIV+ when they are first treated for TB, as many are suspected of being HIV+ and advised to have a test. These patients have yet to adjust to the seriousness of their situation and will not be in the right frame of mind for committing to adhere to their TB treatment regime. HIV+ patients need extra attention, and putting them on the Compliance Service from Day One of treatment will likely be a mistake.

- ⇒ Healthcare workers tended to either chose, or suggest, the time of day to receive the SMS reminders, rather than agreeing a time with the patient as part of a discussion about their daily routines. A number of patients interviewed said the time chosen was not actually convenient, although they may only have discovered this after some time on the Service. This suggests that the healthcare workers have insufficient knowledge of the patient and their routines, and further emphasises the need to clarify procedure.

6.2 Obstacles to widespread rollout

- ⇒ *Monitoring for treatment adherence is a problem where patients are not seen daily (as they are with DOTS).* There are a number of ways that patients enrolled in the Compliance Service could be monitored better, none of which suffice in isolation. For example, extra effort could be put into the interaction with Compliance patients when they visit the clinic. The United States' Centre for Disease Control (CDC) suggests an information-intensive form of questioning in a "casual manner" to flush out issues that affect patient adherence.³⁷ But such interchange takes time, which most health workers at the clinic claim they do not have.
- ⇒ *An overall lack of ownership of the project at the clinic limits the proactive participation of the staff, and no one on-site takes responsibility for ensuring the Service is implemented effectively.* No one at the clinic is responsible for managing the day-to-day running of the Service, ensuring data is being recorded and reporting to managers at the City. Staff members do not receive training on how to use the Compliance Service, and no one checks that service standards are maintained. Enthusiasm and drive for change must come from the top, and getting buy-in and support from the clinic manager is key.

- ⇒ *A lack of regular feedback and interaction between the City, On Cue, and the clinic creates a "disconnect" that hinders success in a number of ways.* Current communication channels between the clinic and On Cue are insufficient. Procedural problems are left unattended. The City has not aligned the outcomes of the Service with targets set by the TB Control Programme.
- ⇒ *A number of practical implementation issues limited the effectiveness of the pilot.* The collection of data of any nature was not conducted, from patient comments on the Service to unusual events in their lives that may impact on adherence. Logistical problems were not tackled, such as dealing with phone number changes or difficulties in contacting On Cue. And health workers did not have guidelines for using the Service.
- ⇒ *Clinic staff schedules are tight and many staff members feel that they are over-worked.* Whether real or only perceived, it is crucial that the Compliance Service does not add to the burden of busy staff members. There seems to be some discord between the City and the clinic as to how over-worked the staff are, which will affect the uptake of the Service. And access to supporting technology (such as email) at the clinic is crucial to the integration of the Compliance Service into staff work schedules.
- ⇒ *City and clinic bureaucracy limits the add-on of functionality that would expand the usefulness of the Compliance Service.* For example, the health worker from TB Care wanted to use the Compliance Service to track defaulters, but often could not because bureaucracy at the clinic stood in the way.
- ⇒ *Issues of privacy, data protection, and security will affect the widespread use of technology in healthcare in Africa over the long-term.* Some concerns over privacy need to be addressed, but at this time, it is legal to use SMS in this way providing the patient has given consent. With the increased migration of patient records to electronic formats, existing legislation will need to be reformed and supplemented with more specific legislation to deal with the issues that will arise. For example, especially sensitive areas will relate to blood transfusions and the non-public disclosure of HIV status. Enforceable legal mechanisms and procedures should be implemented to protect patient data, and this is an long-term issue for the Compliance Service.

7 Recommendations to the City Council

In our view, the Compliance Service pilot should be re-implemented and re-evaluated, leveraging on the lessons learned in this initial evaluation. The renewed pilot should be conducted according to clear, written procedure for running the Service, and recording data derived from it.

In the interim, the Compliance Service should be continued for those currently enrolled; given the level of enthusiasm for the Service, a return to clinic-based DOTS may have a negative impact on patients that are currently using the Service successfully. However, it would be advisable to recall these patients and remind them of what they should do upon receiving an SMS reminder. Scaling up will depend on the ability of On Cue to address the obstacles outlined here, but there is no reason that this could not be done.

7.1 Re-implementing the pilot

- ⇒ *A renewed pilot should start with a staff needs assessment and staff training on how the Compliance Service works.* Canvassing clinic staff for their opinions on how the Compliance Service should be implemented is key to its future success. The staff members involved in this pilot have useful experience that should be drawn upon, to understand what works best and what is not working. Staff should be encouraged to propose, implement and support adaptations of the Service. To initiate this, a short training session could be held with clinic staff to remind them how the Compliance Service works and the objectives of the pilot, and to place it in the larger context of the City's TB Control Programme.

- ⇒ *Guidelines should be developed for monitoring treatment adherence, and tracking treatment outcomes of patients participating in the Compliance Service.* A new procedure should be developed by the City in consultation with the TB nurse at Chapel Street clinic. The procedure must identify the criteria for patient selection, such that those selected for the Compliance Service are more likely to remain adherent while not being supervised. It must provide instructions on how to educate the patient, to make sure every effort is put into gaining the patient's buy-in to their treatment regime prior to them finishing an initial period of clinic-based DOTS. And it must contain guidelines on how to conduct rigorous adherence checks on the few opportunities healthcare workers have to interact with patients on the Compliance Service.
- ⇒ *After the initial phase on clinic-based DOTS, patients should be more carefully selected to participate in the Compliance Service, and a means of ongoing assessment is needed.* The criteria for patient selection will include those who: are shown to be highly compliant during the initial phase of clinic-based DOTS; are progressing well on treatment and fit the medical criteria for the pilot; have a basic level of literacy; can demonstrate to the TB nurse that they understand the importance of adherence and the procedure to follow upon receiving an SMS; are responsible enough to inform the clinic of a change in phone number or circumstances; and buy-in to finishing their treatment and commit to visiting the clinic for a final smear test. It is also critical that the nurse understands what motivates the patient to be adherent and what is going on in their life that may impact on this. Getting to know the patient in this initial phase of clinic visits presents the only opportunity for her to do so.
- ⇒ *The pilot should have a dedicated facilitator on-site at the clinic to carry the burden of running the Service.* Among other responsibilities, the facilitator would conduct adherence interviews with patients on the Service, for example, when they visit the clinic to collect monthly supplies of medication. The best candidate would be a bilingual person of African origin, with whom patients would feel comfortable (preferably not a medical professional) such as someone from a local NGO working in the TB field. This person should be pro-active about implementing the Service and act as a local champion for it.
- ⇒ *There are a number of options to address the problem of patients changing their cell number, and a mix of solutions is recommended.* SMS receipts could be used, but the costs of using receipts so frequently may make it unfeasible. And as mentioned above, an SMS receipt only shows the SMS was received by the recipient's SMS server, but does not prove it was delivered on to their mobile phone. At monthly checkups, health workers should ask patients if their number has changed or if they intend changing it. And depending on the scale of the problem, the On Cue system could be configured to SMS patients at intervals reminding them to inform the clinic of a change of number, or indeed other personal circumstances.
- ⇒ *Reporting structures that involve regular feedback and interaction between the City, On Cue, and the clinic must be implemented so that procedural problems can be recognised and addressed early on.*
- ⇒ *Internal technology at the clinic must be reviewed to enable the smooth running of the Service.* Initially, to improve communication between the clinic and the Service, the City could check outgoing email can be sent to On Cue, and that staff know how to use it. But the service would be greatly improved were clinic staff able to use the web interface provided by On Cue, to access the database of patients directly.
- ⇒ *An SLA should be adopted to guarantee service delivery from On Cue.* A minimum turn-around can be specified by the City to set expectations for the timeframe for processing of requests to enrol patients and resolving technical problems. Similarly, processes for dealing with system downtime should be agreed. For example, an apology could be sent to the patients and the clinic would be informed immediately. As more patients are put on the system, the City should obtain written assurances that backup services are in place should the On Cue server fail.

⇒ *An ongoing evaluation of the pilot should be conducted, starting with a thorough project planning exercise in the beginning that sets measurable benchmarks against which future indicators can be gauged.*

7.2 Suggested new procedure for a Compliance Service pilot

A new procedure for re-implementing the pilot, based on the lessons learned from this evaluation, is represented in Diagram 2. It hinges on the City nominating a member of staff (or employing someone) as a Compliance Service facilitator. The main purpose of a facilitator is to remove the day-to-day burden of running the Service from healthcare workers, especially the TB nurse. For re-implementation at Chapel Street, if there are no funds to employ someone, the HIV/AIDS councillor may be a good candidate to fill this role; if not, the clinic receptionist could be considered, although she does not speak Xhosa.

Assuming the new procedure is being followed, once the TB nurse has decided a patient is suitable for enrolment to the Service, and has briefed them on the importance of adherence, they can be passed to the facilitator. The facilitator needs to work with the patient to find out the most convenient time and place for taking the tablets with food and water. The patient needs to be given explicit instructions on actions to take upon receiving an SMS and solutions must be found for patients with irregular lifestyles.

According to the City, new, smear-positive patients could be started on a minimum of two weeks clinic-based DOTS (this equates to ten days of treatment as weekends are excluded). For re-treatment TB patients, a minimum of two months clinic-based DOTS is required. It would be best to start the Compliance Service immediately (on Day One of treatment), to identify and resolve any problems with the Service itself, such as the SMS reminders not arriving, or errors in patient information given to On Cue. The facilitator would also use this time to check the issues that have come out of this evaluation, such as ascertaining the time the SMS is received is as convenient as first thought, that the patient can read and understand the messages, and that they are following instructions correctly and have no problems with the Service, for example, privacy issues.

Key to the role of facilitator is having the time to get to know the patient sufficiently in those first two weeks to enable them to judge their suitability for un-supervised treatment. The facilitator may consider a patient ready after the first two weeks of DOTS, or she may not, and keep them on DOTS longer until she is convinced they will remain adherent. This decision cannot be made in isolation, because the facilitator is unlikely to be a medically-qualified member of staff, and needs the TB nurse to give expert opinion both on the patient's suitability in terms of their medical condition and her own opinions of their adherence.

The facilitator would also complete the Compliance Service record book, which acts as a central point for all information on patients currently in the Service (see Diagram 1), and emails a list of patient names, numbers and TB registration numbers to On Cue at the end of each day. When On Cue verifies that the patients have been added to the Service, the names and numbers should be re-checked against the record book the next day. It is important to provide space in the Compliance Service record book for comments about the patient, to enable the City to evaluate the Service. Anyone (including the doctor) could add to this column, although it is likely to be most often the facilitator, and a copy of the book should be sent to the City at intervals. Ideally, this should all be done electronically, and again, enabling clinic staff to use the web interface to the Compliance Service would be best. If necessary, the pilot could start with a carbon copy book, but should the Service be scaled up, switching to digital format will become necessary.

Diagram 1: Suggested contents for the Compliance Service record book

TB registration number (also used to identify patient record)	Name (including any "nick names" or aliases)	Mobile phone number	Backup phone number or contact details	Address (or, if the patient is homeless, a description of the places they frequent regularly)	Enrolment date	Initial DOTS phase (number of days)	Service checks (according to written procedure) Keeping track of this is a lot of extra work	Adherence checks (according to written procedure) Keeping track of this is a lot of extra work	Comments
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Diagram 2: Suggested new procedure for a Compliance Service pilot

Tasks for the Clinic

Guidelines containing a description of the Service, how it fits into the TB Control Programme, On Cue contact details, criteria for enrolment, procedure for monitoring adherence...

Service record book (carbon copy useful)² containing patient name, number, a second contact number, TB registration number, date of enrolment, type of TB, details of treatment regime, treatment outcome and an extra column for comments.[#]

Facilitator establishes a relationship with the patient, and their buy-in to adherence

TB nurse selects patient

Patient educated about Service and adherence.*
Service record book filled in by nurse.

Patient name, number, TB registration number emailed to On Cue at EOB.*

On Cue sends reply within 24 hours, verifying new entries to database. Clinic double checks these details.*

Min 2 weeks DOTS for new, S+ patients, and 2 months DOTS for re-treatment TB.*

Facilitator and TB nurse decide if patient can be placed on self-supervision, if not, DOTS is continued.

Service and adherence checks done at months 2, 3, 4, 5 and 6 (7 and 8 for re-treatment TB). All data recorded in the Service book*

One week before end of treatment, On Cue to send email informing clinic of date patient will be removed from the Service.

Tasks for the City

TB experts to provide specific criteria for enrolment, based on an initial group of "low risk" and "predicted as adherent" patients. Arrange "refresher" training at clinic with emphasis on how the Service fits into the TB Control programme, and how special care must be taken to monitor patients for adherence. Train Service facilitator.

Ensure the clinic is able to send and receive email from On Cue (also allow html to On Cue web server at a later date).

Provide clinic with procedure for Service check, e.g. verify patient is receiving SMS at correct time and in desired language. Adherence check, e.g. patient to be asked what they do upon receiving an SMS, check the time chosen is suitable, and if not, request On Cue to change it (via email).

Request carbon copy of Service record book at intervals, for evaluation.

* Denotes activities handled by Compliance Service facilitator at the clinic.

This should be done electronically, but the staff may not have the capacity to deal with learning to use a new system efficiently without training and practice.

+ On Cue could provide an HTML form on their website for ease of use; this will be necessary for scale up.

7.3 Scaling up the Compliance Service

The following are a list of recommendations for scaling up the Compliance Service across the province, and beyond.

- ⇒ *Planning a comprehensive procedure, testing and evaluating it thoroughly, and refining it based on lessons learned is key to an effective scale-up of the Compliance Service.*
- ⇒ *Scale-up requires dedicated responsibility to ensure the Compliance Service is implemented uniformly across all sites.* This is necessary to enable successful integration of the Service into the TB Control Programme.
- ⇒ *On Cue must have the capacity to scale-up across the region, and the technical details should be discussed between the City IT Department and On Cue.* On Cue should carry out a needs assessment with TB experts at the City and the clinic TB nurse to ensure the Compliance Service meets their needs, before scaling up. At this stage, it would be prudent to liaise with other groups involved in moving health service data to electronic formats, to ensure the Compliance Service system is compatible.
- ⇒ *All new patients should be required to sign a legal consent form to give their permission for the clinic to communicate with them via SMS.* This will ensure that the Compliance Service falls strictly within the law, and avoid the potential of litigation against the City from dissatisfied patients.
- ⇒ *Expansion to other languages should be undertaken, to continue extending the reach of the Service.* On Cue has indicated that the Compliance Service can be translated to other (Latin-character based) languages with few difficulties. This may not be an immediate concern for the City, but should nonetheless be explored with an eye toward extending to health services in other provinces.

8 Concluding remarks

The Compliance Service pilot has produced treatment outcomes in line with those reported for the clinic, but contrary to expectation, they were no better. However, these results are tied to the way in which the Compliance Service was implemented, and because there were many shortcomings in implementation, these treatment outcomes are not valid to judge the effectiveness of the system itself. Only by tightening up and following an agreed procedure will meaningful values for treatment outcomes be obtained.

Frankly, there is not much to say about the technology. It works and it is effective. And on face value, it also provides a more cost-effective treatment option, both for the health service and patient. The convenience of TB treatment for the patient is also greatly improved.

But, the Compliance Service is only a viable option if adherence levels are at least those of clinic-based DOTS. If they are less, non-adherent patients are likely to stay infectious for longer, worsening their condition and spreading the disease. A six-month (minimum) course of any medication, especially if it has to be taken under strict conditions, is difficult for anyone to adhere to. And if a patient has little contact with the clinic, it is likely some will forget the gravity of their medical condition, especially once they begin to feel well. But adhere they must, and so the Compliance Service essentially presents a trade-off between the gains made on cost and convenience and the losses from having to put extra efforts into getting to know, and monitor self-supervised patients. The technology is not a silver bullet to solve the problem of patient adherence: it is all down to the way in which it is implemented.

We believe that if the Compliance Service were re-implemented and re-evaluated,

leveraging on the lessons learned in this evaluation, treatment outcomes would be improved. The findings presented here highlight the most important areas requiring attention, and starting over should not be difficult, provided sufficient thought is put into the process. Key to the success of the Compliance Service is an understanding of where the use of the technology ends and care giving begins. The Compliance Service could be a valuable enabler of the TB Control Programme but getting that fit right is all important.