CASE STUDY

IT-enabled innovation to prevent infant blindness in rural India: the KIDROP experience

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Abstract

Purpose – The purpose of this paper is to share the IT-based experience of the first tele-ophthalmology initiative in infant blindness prevention set up to serve rural India.

Design/methodology/approach – The paper describes the two-plus years of experience of the "Karnataka Internet Assisted Diagnosis of Retinopathy of Prematurity (KIDROP) initiative" pioneered by one of the leading private tertiary eye care providers in India, Narayana Nethralaya Postgraduate Institute of Ophthalmology, Bangalore. KIDROP was the first tele-ophthalmology initiative in the world to use trained non-physicians ("trained technicians") to capture images of the retinas of infants a few weeks old for a potentially blinding condition called retinopathy of prematurity (ROP) and validated them to store, process and analyze those images at the rural centre itself. In addition, these images were uploaded to a specially customized software-hardware platform that allowed remotely situated experts to view these images and report real time either on a PC or on their smart phones. The success of this private initiative paved the way for the first public-private partnership in infant blindness prevention in India which is poised for a statewide and subsequent nationwide expansion.

Findings – In a country like India, where experts are few and far between and found mostly in the big cities, the human ability of "image processing" allows non-physicians to quickly gain the expertise to screen seemingly difficult cases by using the medium of digital images and a logical algorithm of triage. With an increasing caseload of these conditions, the standard of care can be delivered to the most underserved of areas with this little IT-based innovation served with dollops of passion.

Practical implications – The experience of KIDROP is being used as a cornerstone for similar tele-ophthalmology programs in India and other developing countries with similar demographics. A case for propagating the innovation as an example of "reverse innovation" for more developed economies to emulate has also been made.

Originality/value – The project described in the paper was the first that used non-physicians to report images of infants for ROP screening, the first ROP network to cater to rural India and is currently the world's largest single hospital-managed tele-ROP network.

Keywords Information technology, Opthalmology, Blindness, Infants, Rural areas, India

Paper type Viewpoint

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One blind child is a tragedy, a million blind is a statistic.

One out of every four blind children worldwide lives in India. Approximately, 40 percent of India's population is below 15 years of age, making pediatric eye disease a major public health scourge. In terms of etiologies, 22 percent of childhood blindness is said to be due to "retinal" causes. This compares with China and other emerging economies but lower than Latin America and the former Soviet Bloc (Gilbert *et al.*, 2003). However, there is a risk of underreporting in India because retinal causes are "not obvious" unlike "corneal" causes, reported at 28 percent in India. A rather new age problem that has taken on epidemic proportions in India and other middle-income countries is a retinal problem called "retinopathy of prematurity (ROP)", which has been increasingly reported in India since 1995 (Charan *et al.*, 1995). ROP affects premature infants and in its worst form makes them irreversibly blind. Fortunately, ROP blindness is largely preventable, if appropriately screened and treated on time.

The problem is one of skewed demand and supply. The demand is highlighted by the staggering numbers. Of the 27 million babies born in India annually, over 8 percent are born below 2,000 grams, a critical weight that makes them vulnerable to ROP (National Neonatology Forum of India, 2005). Almost 47 percent of these low birth weight babies born are prone to the disease, with over 15 percent of these requiring treatment (Charan *et al.*, 1995). To tackle this scourge are fewer than 400 retinal surgeons of which fewer than 15 (nationwide) provide comprehensive ROP care. It is estimated that every two hours three infants somewhere in India may require ROP treatment. Adding further insult to injury, more babies are at risk in India than their counterparts in the USA or the UK (Vinekar *et al.*, 2007).

Another key determinant is the timeline. ROP sets in within the first month of a premature infant's life and destroys vision within two months, even before the parents can become "aware of the problem". Until its advanced stages, it may provide no external clue, and when it does, it is too late. What is necessary, therefore, is an expert peering into the retinas of these infants (often, a few times several weeks apart), to determine if the baby has indeed developed ROP and if so, whether treatment is required. Both the ability to screen and treat requires a high level of expertise. In the USA, fewer experts volunteer ROP screening due to the medico-legal liabilities and poor compensation. In India and other developing countries, experts are few and are mostly concentrated in the larger cities (Pejaver *et al.*, 2010).

This leaves a large reserve of rural infants at risk of preventable blindness. With improving neonatal care, a reduction in infant mortality, better maternal and child health policy penetration down to the grass roots, today more than ever before, infants as tiny as 700 grams or less are surviving in small towns and even at sub-district (taluk) level hospitals with good outcomes. Of course, they are exposed to blindness because there are no experts to manage ROP in their neighborhoods.

In early 2008, Narayana Nethralaya Postgraduate Institute of Ophthalmology, Bangalore initiated the "Karnataka Internet Assisted Diagnosis of Retinopathy of Prematurity (KIDROP)" project to address this issue. The philosophy of the KIDROP can be summarized by "3T's" – Tele-ROP, Training of peripheral ophthalmologists and Talking to neonatologists and gynecologists to increase awareness (Vinekar, 2008).

The tele-ROP component provides ROP screening in rural areas by the use of digital imaging of infant retinas using a specialized camera called the Retcam Shuttle (Clarity MSI, Pleasanton, California, USA). This portable camera is transported by a dedicated

team from centre to centre in unscreened areas on a fixed schedule every week. Trained technicians have to be enrolled who not only are adept at imaging these infants at their bed-sides but also processing, storing, analyzing and reporting ROP using a triage-based algorithm using the principle of "pattern recognition" (Vinekar, 2008; Kreatsoulas, 2010).

The images are uploaded by the technician on a specially managed server, using customized software which is accessed by the ROP expert situated remotely. The expert views these images on his or her PC or on the Apple iPhone, a capability added since November 2009 with a technology partner, Bangalore-based i2iTelesolutions. This was voted as one of the top ten medical innovations in 2009 (*India Today*, 2009), and allows the expert real time access of these images "on the go" for the very first time (Rai, 2010). The reports produced by the doctor are transmitted to the rural technician(s) using the cellular network (over the cell phone) or the internet (on the PC) into the secure data server complete with a digital signature before the child can be handed over to the mother. Treatment is also provided at the rural centre itself by the KIDROP team of experts or locally trained ophthalmologists. The flow of information is shown in Figure 1.

The business model of KIDROP can be at best likened to the "Robin-Hood principle". Over 76 percent of the service is offered free or with heavy subsidy. Only those who can afford it are charged. The running costs are covered under this revenue model. Perhaps, what influences this model's financial sustainability are the large numbers. In October 2010, Clarity MSI compiled a list of tele-ROP networks worldwide. KIDROP was the largest with 24 centres, followed by Houston, USA (15) and Budapest, Hungary (12). In a single month, approximately 550 infants are screened, over 4,500 kilometers are traveled in a radius of care that is about 300 kilometers within the southern six districts of Karnataka state with Bangalore as the epicenter.

A formal cost-utility analysis is pending; however, some of the benefits are obvious. The travel and opportunity costs of bringing an infant from the village to the city from a centre just 100 kilometers from Bangalore (per visit) is about USD15-18 compared to less than USD3 to go to the nearest centre on the KIDROP map. This, of course,

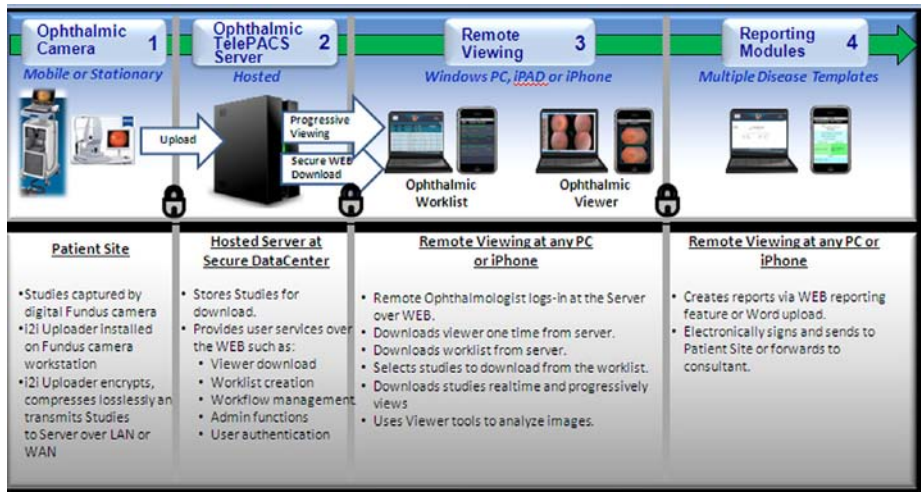

Figure 1.
Workflow of image transfer from rural centres to remote experts using ABO compression, a secure transfer and a web-based customizable user interface

does not consider the obvious motivational advantage of the latter which appeals to them better than traveling to the "big city" to a "big hospital". Follow-up attrition is also minimized and with that the risk of blindness.

In its first 30 months (up to November 2010), KIDROP has thus far screened over 3,200 infants and treated over 371 at their respective centres. The return on investment in the national perspective may be calculated as follows: each of these 370 infants will survive to an average of 65 years (average life expectancy) and earn approximately USD900 per annum (per capita income). This is a federal saving of over USD21 million! All this for an investment of less than USD250,000! The social returns are, of course, priceless.

The way forward

The National Rural Health Mission, Ministry of Health & Family Welfare has entered into a public-private partnership to expand this project. In this scale up, 12 more districts, and over 36 new centres at the district and taluk (sub district) level will be included in two separate zones. Under this USD0.52 million initiative (2009-2012), Narayana Nethralaya's contribution will include free training, image reading and treatment. The government will provide for the equipment, its maintenance and team salaries. With over 80 percent of the training completed, 2011 will mark the beginning of the project in the new areas. The exciting possibilities that the 3G spectrum promises will enhance the speed of image transfer both from and to the rural centres.

Countries like Thailand, Sri Lanka, Ghana, Kenya, Mexico and some others have approached KIDROP to help them set up similar programs in their respective countries. The future holds the promise of international social collaboration with a model of medical tourism as a possible revenue model. The Ministry of External Affairs has hailed the initiative as a unique model of delivering super-specialty care to rural areas (*India Perspectives*, 2010). More recently, the *Harvard Business Review* cited this initiative as an example of "reverse innovation" (Govindrajan, 2010).

Whereas, all this augurs well for the project, barriers of cost and infrastructure must be met. The cost of the camera alone is currently approximately USD135,000 in India. The greatest barriers, however, are not costs, bad roads or poor internet speeds, but the "mental barrier" of the care-givers created by a cocktail of poor awareness, inadequately trained personnel and unwillingness to adapt to innovation. However, there is hope that with time, patience and passion, these barriers can be overcome.

Like any other initiative, the measure of success of any program would be assessed by its sustainability and replicability. In the context of KIDROP, this would mean nationwide expansion to include every centre that deals with premature births. This is a mammoth task and cannot be accomplished without the collaboration of private hospitals, social entrepreneurs and government backup. They say a journey of a 1,000 miles begins with a single step. We must derive inexhaustible strength from the words of our first Prime Minister Pandit Jawaharlal Nehru who, in the landmark midnight speech at freedom said:

> The ambition of the greatest man of our generation has been to wipe every tear from every eye. That may be beyond us, but as long as there are tears and suffering, so long our work will not be over.

We must not give up, not if we ever want to prevent blindness in our tiniest and most precious citizens.

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