Savings lives through changing systems and practices

→ Anna Wagstaff

There is no secret about the steps needed to improve cancer survival and revolutionise the patient experience. But change is a challenge for professionals and managers alike. The first ever CancerWorld conference focused on this challenge – how can you change systems and practices to improve quality of care across the board?

7hen C*ancerWorld* magazine invited politicians, health policy makers and administrators, health insurers, clinicians, nurses and patients to the first ever CancerWorld conference, it took the risk that it might be organising a brainstorming session in the tower of Babel.

Though each might talk with great eloquence to others in their own field, differences in terminology, perspective and conceptual approach could make it hard to achieve coherent discussion and reach meaningful conclusions. Yet just such a dialogue is essential if Europe is to implement the changes to its cancer services necessary to achieve the best results at a sustainable cost.

Saving Lives in Cancer: Policies and Practices that Make a Difference looked at what is needed to move from the current patchy picture of cancer care in Europe to one in which high-quality, safe and patient-centred care is available to patients of all ages and backgrounds, whether they live on remote farms or in a bustling city.

The reasons for this focus were three-fold. The first was a question of fairness. One statistic

widely quoted by those who argued for a national cancer plan in France was that cancer patients were up to six times more likely to survive if they came from an area with the best cancer services compared to the worst. That level of inequality is not acceptable between countries, and it's certainly not acceptable within a single country with a strong centralised health system.

The second reason was strategic. We have a good idea about what makes the best cancer services better than the worst. Bringing cancer services in the worst areas up to the level of the best could improve survival of some French patients by up to six fold. When was the last time that science delivered improvements on that scale?

The third reason is economic. The combination of an aging population and escalating costs in cancer care creates a risk that public health systems and health insurers will no longer be able to cover the costs. In identifying which policies and practices make a difference we also identify those policies and practices that do not, thereby identifying resources that could be put to better use.

Management issues rarely fire people up in the



Championing change. The story of how videotechnology came to be embraced by staff and patients throughout the South West Wales cancer network provided an interesting case study at the Saving Lives conference (p71), illustrating how good ideas and strong leadership can overcome resistance to change and how successful pilot projects can be rapidly spread. The picture below shows a colorectal cancer team meeting at Bronglais Hospital in a remote corner of West Wales. In the room are the consultant colorectal surgeon and his team, including the clinical trials nurse, the oncology nurse, and the lead clinician for cancer services. The right-hand screen shows the consultant radiotherapist and oncologist in his room at the cancer centre 75 km away in Swansea. The double screen allows people in the meeting room to see the image relayed to the remote location from the camera in front of them, but it can also be used to show X-rays, histopathology slides etc (see left)



way that human stories from the frontline of cancer care can do. But system errors are deemed to account for around 90% of errors that result in cancer patients failing to get the right care at the right time from the right people. It is therefore to improvements in management that we should look if we are serious about improving the service for all cancer patients.

Organisation – the third dimension

The scene was set by Bruce Barraclough, President-elect of the International Society for Quality in Health Care, who oversaw a major reshaping of the safety and quality agenda in Australia's health systems. A surgeon by profession, Barraclough chaired the Australian Council for Safety and Quality in Health Care from 2000 to 2005 and now heads the New South Wales Clinical Excellence Commission.

Europe can learn from the Australian experience, not least on the issue of equal access. The Australian population is more dispersed than anywhere in Europe, but people in remote areas - including a high proportion of the aboriginal population – now have a cancer survival rate only 10% below the average. Compare that with the six-fold difference in survival within the far more concentrated French population, and the four-fold difference in lung cancer survival between hospitals five miles apart reported for Scotland (see p 67), and it becomes clear that Australia must be doing something right.

Barraclough talked about four 'dimensions' of health care:

- The personal dimension care of the individual patient, which must also involve their carers
- The professional dimension the training, skills, experience of health care professionals, and the culture in which they work
- The organisational dimension the structures and processes involved in deciding on and delivering care
- The political dimension determining major policy decisions and whether there is political will to push through major changes to the status quo

Although all four play a role in determining the quality of patient care, Saving Lives focused on the organisation of services. This is the most complex dimension, going through the greatest change, and where there is the greatest scope for improving the service.

Barraclough argued that the way healthcare is delivered has changed radically, and demands a new management approach.

Perhaps the most significant change is due to increased specialisation. This has the potential to fragment services, with many patients likely to see 20–40 different health professionals at different locations throughout their cancer journey. It is a major logistical challenge to coordinate the patient journey while ensuring that all patients have access to appropriate specialists. Getting things wrong can cause the patient unnecessary frustration and stress, needlessly reduce their quality of life or even lead to the death of patients who, cared for properly, could have been saved.

The traditional 'doctor knows best' culture is also facing an increasing challenge. This is both because treatment decisions are increasingly subject to evidence-based guidelines and multidisciplinary discussion, and because patients demand more information and a greater say in the way they

The cultural change towards a more patient-

centred approach is also opening health services to greater scrutiny on such key issues as waiting times, complications rates, and patient satisfac-

No-one who has worked in health care over the past 20 years can be unaware of these changes, yet Barraclough argues that there has been a reluctance to grasp the implications for how health services are managed, leading to a substandard service, that puts patients in danger and wastes resources.

He characterised healthcare provision as highly complex and process-based, because it involves multiple interactions between people doing different activities in different environments, using different methodologies and communicating different types of information. It is also 'high-risk' because of the possible consequences of doing something wrong or failing to do the right thing. Barraclough argued that these characteristics are not unique to healthcare and that health managers can learn from industry.

He cited McDonald's as a provocative role model for standard operating procedures: "A promise of a free one if you don't get it on time, and if you don't like the fatty meat patty in between the bits of bun, then they offer you a salad." If people expect minimum standards and remedial action in their fast food, why should they not have the same rights in health care, where so much more is at stake?

This is more than a rhetorical question. To assert this right is to challenge the traditional autonomy (some might say impunity) enjoyed by medical professionals and administrators, and to argue for key aspects of the service to be subject to evaluation, external audit and accountability.

Barraclough stresses that this is not an attack on health professionals – though it may feel that way to surgeons who see their complications and mortality rates published or to hospital administrators challenged about long waiting lists. It is intended to create an environment where health professionals can use their skills to maximum effect.

In complex enterprises, about 10% of errors are due to individual failings, while 90% result from systems failures. Getting the system right is the key to getting many other things right – correct

The cost of fragmented services

Serbia and Switzerland pay the price for poorly structured cancer services

Patients do better if their care is in the hands of multidisciplinary teams of specialists who have the right equipment and who spend much of their working lives treating patients with their particular type of cancer. Smaller centres cannot provide this, because they treat too few patients. They can, however, reduce the distances patients need to travel by coordinating with larger centres to deliver some treatments – chemotherapy for instance – closer to home.

The previous issue of *CancerWorld* (January–February 2007) looked at the way some countries are restructuring their cancer services based around regional specialist centres, with links to local hospitals, and primary and community healthcare.

The *Saving Lives* conference heard two examples of what happens when patients are treated in more fragmented systems: Serbia, which, at \$373 (2003 figures), has one of the lowest per capita spends on health in Europe, and Switzerland, which has a per capita health bill of \$4,077.

Vesna Kesic, who chairs the Serbian Society of Gynaecological Oncology, told the conference how patients are paying the price in unnecessary suffering and death of a badly structured cancer service. The country does have a cancer network, consisting of two national centres, three regional centres and 28 outpatient centres. However, most patients do not undergo their initial treatment at these centres. A recent survey conducted by the Serbian Society of Gynaecological Oncology, found that patients are operated by 223 gynaecologists at 43 different hospitals. Each surgeon operates on an average of seven patients a year — little more than one every two months. Almost half the gynaecological departments care for fewer than ten patients a year.

One consequence of this highly fragmented service is that in almost half the cases, the surgeon decides on treatment without any multidisci-



Vesna Kesic

plinary consultation. The quality of the surgery is also substandard. Radical surgery, the standard for cervical cancer, is not performed in 70% of regional hospitals; omentectomy, standard for ovarian cancer, is performed in just over half. Though Serbia has national clinical guidelines for gynaecological cancers, these are not followed in one-third of cases.

Switzerland also suffers from fragmented services. Swiss hospitals have far more staff and better equipment than their Serbian counterparts, but far too many hospitals try to do everything. The conference heard how, in the canton of Ticino, a population of 300,000 is served by four public hospitals and three main private hospitals, which between them care for around 240 women newly diagnosed with breast cancer every year. In 2005, 160 women were treated in the public sector by 21 gynaecologists, eight of whom performed only two operations a year. Only one performed more than 30 breast operations.

In this highly competitive environment, each hospital employs its own team of specialists, many working well below full capacity. This wasteful use of resources is mirrored on the equipment side: Ticino has three CT scanners within an area of a few square kilometres.

In Switzerland, the price of badly structured cancer services is paid by the people through their health insurance. Per capita health spending is not just ten times that of Serbia, it is almost 50% greater than in Sweden, where cancer survival rates are higher for women and only marginally lower for men.

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diagnosis, appropriate and timely referral, proper application of guidelines, response to symptoms, effective communication, and many other things that contribute to quality patient care.

Part of this, said Barraclough, citing Avedis Donabedian the guru of health policy analysts, comes down to delivering the care through appropriate 'structures', related to who (accredited to what level) does what and where, and how different bodies relate to one another (see The Cost of Fragmented Services p 65). Barraclough focused on the larger and harder part, which relates to getting the 'processes' of care delivery right – how things are done.

GUIDELINES AND PERFORMANCE AGREEMENTS

Barraclough argues that health care facilities should have a legal responsibility to ensure that services are provided in an environment where the safety and quality of the delivery of health care is properly addressed. Performance agreements should spell out what is expected of the facility, with external review, incentives and penalties to promote compliance. Agreements can cover ethical practices, treating patients with respect and dignity, maximum waiting times and compliance with clinical guidelines, but are at their most effective if they can also tie in with national disease management guidelines on agreed standards of care for particular cancers or procedures.

These guidelines already exist in some parts of Europe, notably in the UK where the *Improving* Outcomes Guidelines specify agreed standards of care for each cancer, including, for instance, diagnostic and staging procedures every patient has a right to expect, or the requirement that treatment decisions are made in a multidisciplinary meeting at which specified disciplines should be present, or that certain procedures be carried out by doctors with a minimum accredited level of expertise. They also include the right, for example, to breast conserving therapy, to specialist palliative care, to join appropriate clinical trials and so on.

Greater use should also be made of performance agreements between facilities, to ensure a smooth passage for patients on their cancer journeys from one provider to another. An example given from Denmark was an agreement between general practitioners and a regional cancer centre over where each diagnostic test should be done – to prevent identical procedures being carried out twice, an irritating, time-wasting and costly problem.

If this sounds very 'top down', Barraclough was unapologetic about the need for external levers of control to deliver the best quality care. He did make the point, however, that this sort of regulation is increasingly operating at a network rather than a national level, "less reliance on topdown government action, more on mobilised networks of power". This approach was neatly illustrated in a contribution about how the Christie hospital in Manchester, UK, had gone about reducing waiting times that were beyond their immediate sphere of control (see Targets Help You Focus, p 69).

Measures should be taken to set minimum standards, benchmarks and targets and to evaluate healthcare facilities, and reward or penalise them on the basis on their performance. However, Barraclough stressed that the key to improving services lies in the ability of staff and the organisation to detect where things are going wrong, to understand why and to make the necessary changes to set them right.

Much of the effort towards improving healthcare services in Australia went into changing the culture. The Australian Council for Safety and Quality in Health Care promoted a no-blame system of open disclosure of adverse effects, using 'root cause analysis' (imported from the US Veterans Administration) to identify underlying

Audit as a key to improvement

How Scotland improved its lung cancer survival for the first time in 30 years

Scotland has long been near the top of the European league table for lung cancer incidence, and near the bottom of the table for survival. While other countries saw small steady improvements in survival during the 1980s and 1990s, in Scotland the 5-year survival rate hovered obstinately around 6-7%.

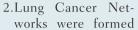
Noelle O'Rourke, lead clinician for the West of Scotland Lung Cancer Network, was therefore delighted to bring good news to the *Saving Lives* conference: statistics just published for one-year survival for 2003–2004 showed an improvement of 5% on the '97–'98 figures, from 23% to 28%. The true survival increase may prove to be even higher once the statistics are adjusted for cause of death, and will improve further following recent efforts to increase the proportion of patients treated surgically.

O'Rourke attributes this success to 10 years of a very active cancer strategy. A retrospective audit of all patients registered in 1995 documented the cancer stage, what treatments were given where, and survival. This 'highly labour intensive' exercise revealed significant undertreatment of patients, with 41% offered only 'best palliative care'. Only 10% of patients were offered surgery, compared to the 15–20% that would normally be expected. The three-year survival rates most clearly showed the need for improvement. Patients were four times more likely to survive if they were referred to one hospital than if they were referred to a neighbouring hospital five miles down the road. A closer look revealed big differences in the use of radiotherapy, chemotherapy, surgery and palliative care only.

Turning this situation around involved three main steps.

1. Targets were published outlining what the service should be aspiring to in terms of treatment rates,

based on national clinical guidelines adapted to the realities of the local situation.





Noelle O'Rourke

- within each of Scotland's cancer networks, bringing together all health professionals involved in the treatment of lung cancer, as well as patients and carers. Network protocols for diagnosis and treatment were put in place to ensure that every patient is offered the same treatment for the same stage of disease and access to the same clinical trials. All patients have access to multidisciplinary teams, which have been set up at almost every site. Every patient now gets a folder of information developed by a patient-led group, relevant to their own case and telling them what they should expect in terms of treatment.
- 3.An audit of every facility is carried out annually to detect weak spots and anomalies and to identify areas for improvement. One thing that recently came to light is that multidisciplinary teams often cannot get surgeons to their meetings, and that the less frequently surgeons are present the smaller is the chance that a patient will be offered surgery. Ensuring there is a surgeon at every team meeting is therefore a major target for the coming year.

There is no miracle cure for lung cancer, but to O'Rourke, there is something miraculous about what the Scottish lung cancer service has achieved. "This is the first time in 30 years there has been a change in lung cancer survival in Scotland, and I cannot tell you how good it feels to stand up here and publicise that," she said.

Ensuring there is a surgeon at every team meeting is therefore a major target for the coming year

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problems. In New South Wales, this led to a 30fold increase in adverse event reporting in the first year, which in turn led to important changes in practice. The discovery, for instance, that the majority of serious errors in drug administration take place around shift changes led to significant risk reduction simply by ensuring that dangerous drugs such as anticoagulants are administered well before the end of the day.

The Council encouraged a culture of internal review and audit so that teams and departments could measure how they were doing against agreed standards and compare this with what was happening elsewhere. (For an impressive example of how a similar system was used to improve lung cancer survival rates in Scotland, see Audit as a Key to Improvement, p 67).

The Council identified various ways to achieve changes in behaviour and practice: audit and feedback to address a mismatch between staff perceptions and results; educational courses and aids to decision making where lack of knowledge was the problem; leadership, sanctions and incentives to address lack of motivation; and so on.

They also drew up an action plan to implement national cancer guidelines at local levels giving leadership responsibility to 'clinical champions', staff who are convinced of the need for change and can enthuse those around them. They introduced audit to compare guidelines or new procedures to current practice, to build an understanding of the need for change and to review progress (see also Don't Sideline the Guidelines, p 14).

SIMPLIFYING THE PATIENT JOURNEY

If it is difficult to ensure that everyone within a single health facility works to agreed standards and guidelines, understands their role and responsibilities, and communicates effectively with colleagues, patients and carers, the challenge is far greater where more than one facility is involved.

This is always the case in cancer, where most

patients start their cancer journey by being referred for tests by a primary health care practitioner. These tests may be done at a local hospital, with the results then being sent to a tertiary facility with a specialist cancer unit. Following the diagnostic workup and staging, and decisions over the treatment package, the patient may be referred to yet other facilities for the actual treatment. They may have their chemotherapy or palliative care delivered at clinics closer to their home or they may have to travel elsewhere for radiotherapy. Several specialists, community health workers and family carers may all play a significant role in their care.

Ingvar Karlberg, from the Gothenburg Centre for Health Systems Analysis, told the conference that health providers should be aiming for a 'seamless' coordination, so tight that the patient is unaware that different elements of their care are provided by different teams and institutions.

Sadly, he said, the reality is often very different, with patients and information frequently getting lost in a 'Bermuda triangle' at the interfaces between facilities.

Patient tracking procedures may be poor or non-existent. Cultural differences and a lack of understanding about roles can create problems. Karlberg cited the tendency for hospitals to refer patients to home or community care with detailed notes about the medical procedures they have carried out, while failing to mention critical functional information such as "this patient is unable to walk," or "cannot eat unaided".

Inflexible financing and reimbursement systems can lead to patients being cared for in an inappropriate setting – receiving unnecessary medical intervention in a hospital bed when they would do better receiving care and rehabilitation in a community or home setting.

Lack of integration can lead to lack of clarity over lines of responsibility and accountability, with the danger that healthcare facilities play 'Old Maid', trying to duck their responsibilities or pass them on to others.

Targets help you focus

How Christie's slashed waiting times and helped other parts of the cancer network do the same

When Christie's cancer hospital in Manchester, UK, was set a target of treating 100% of patients within 31 days of a decision to treat, and within 62 days of the patient being urgently referred by a general practitioner, staff said it couldn't be done. They were wrong.

Within 13 weeks, the proportion of patients treated within the 31-day target rose from 39% to close on 100%. The only additional resource was an extra 30 minutes of linear accelerator time, two days a week.

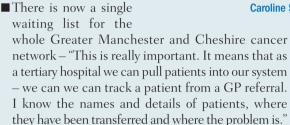
Faced with financial penalties if the target was breached, staff examined the patient pathways through the various hospital departments and systems, and they found ways to cut out much of the complexity by changes to working practices.

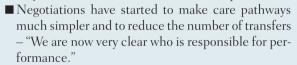
Caroline Shaw, Chief Executive at Christie's, told the Saving Lives conference that the new arrangements had proved hugely popular, not just among patients, but also among staff. "Our medical director said, 'It's fantastic - I don't have to give any more excuses. I can give my patients a treatment date when they need it, and make sure that they get their treatment on time."

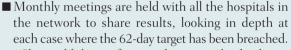
The 62-day target was harder to tackle, because patients are often referred for tests to any one of 15 hospitals in the Greater Manchester and Cheshire cancer network before being referred to Christie's. As an incentive to get things right, Christie's faces shared penalties for breaches of the 62-day target, even if the fault lies elsewhere in the system.

They took the time to look at what was happening to patients during this part of their journey, and again unnecessary complexity became apparent. "We have too many hospital transfers. We make systems far too complex. We make things difficult for patients and clinical staff."

Redesigning the patient pathway proved to be the key to meeting the 62day target.

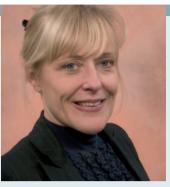






Shaw told the conference that strong leadership, a 'can do' approach, and 'a culture of managing performance' had been essential to getting results. But she also strongly endorsed the use of targets and penalties for breaching targets - including shared penalties when waiting times involving more than one facility are breached.

"I think targets are fantastic. Quite often doctors in my organisation don't like targets. But targets make us focus and achieve things better for our patients. Hospitals shouldn't be paid for activity if they breach targets." She is very keen to work with the health authorities that commission and pay for patient care to improve care pathways and clinical outcomes and to develop an incentive-based commissioning framework.



Caroline Shaw

"We can pull patients into our system –

we can track a patient from a GP referral"

Regional centres have drawn up disease management guidelines covering a patient's entire cancer journey

A number of steps have been taken to improve integration in Sweden. These include simple measures such as putting together local directories of people who need to cooperate. Regional oncology centres have drawn up clinical guidelines on disease management, which extend over the full length of the patient's cancer journey. Sweden has also started making legislative changes to allow co-financing between health care, social insurance and social services, giving a single regional organisation responsibility for handling each care package as a whole.

THE PATIENT PERSPECTIVE

Lynn Faulds Wood, President of the European Cancer Patient Coalition (ECPC) reminded conference of what management issues mean in human terms. Her closest friend had recently been diagnosed with metastatic stomach cancer and was referred to a major London hospital, where she was to receive four cycles of aggressive chemotherapy. "She goes in once every three weeks for her chemo. They don't know when she is coming. They tell her to lie across three chairs because she can't sit up and they don't have a bed for her."

Faulds Wood got her friend moved to another hospital, where things improved dramatically. "They consult her; they write within days with her next appointment; they know she is coming; they give her a bed. They smile, introduce themselves, say what they are doing and why. It is just simple stuff, but the previous hospital did none of that."

The ECPC has almost 300 member organisations from more than 30 countries. Surveys conducted by keypad voting or a show of hands at ECPC master classes established a rough picture of the effectiveness of cancer care delivery across

Around half of the patients said there were no disease management guidelines for treating cancer patients in their country

- Patients are, more often than not, provided with no information on their disease and its treatment – two-thirds of respondents said they had to find the information themselves
- Many patients are still not given a full say in matters concerning their treatment - 66% said patients in their country are 'sometimes' allowed to be involved
- Waiting times were deemed unacceptable or 'sometimes' unacceptable by three-quarters of respondents
- Half the patients said timely access to palliative care was not available in their country
- Only a tiny minority of respondents had been made aware of clinical trials they might be eligible to join

The ECPC surveys show that poor management practices in cancer care lead to loss of quality of life and widespread unnecessary suffering. Putting serious political will and leadership into improving structures and processes for cancer care is a relatively simple way to get results on three fronts: healthcare, economics and political popularity. It is the easiest way to improve survival rates, quality of life and patient experiences throughout their cancer journeys. It will deliver more effective care for the resources, without breaking the bank. And probably, in the long run, it is better appreciated by the electorate than simply opening state-of-the-art facilities.

French President Jacques Chirac chose to make the overhaul of cancer services a major part of his legacy. Restructuring the UK's cancer services will also be one of the positive factors in the legacy of UK Prime Minister Tony Blair. Given the escalating cost of health care, political leaders who fail to take action now risk being remembered for being the one who oversaw the beginning of the demise of Europe's public health systems and erosion of the principle of high-quality and affordable healthcare for all.

The power of local solutions

How a local team raised the standards of care for a highly dispersed population

Speedy access to quality diagnosis, treatment and care has been steadily improving in the South West Wales cancer network, ever since one isolated district hospital turned to video technology to help solve its problems.

The region's one million population is dispersed over a large area with poor transport links. Now many will benefit from access to palliative cancer care, 24/7, thanks to a pilot scheme linking general practitioners and community-based palliative care nurses to a specialist palliative care service by video.

The network recently implemented an electronic tracking system from referral to treatment, helping to avoid unnecessary waiting times and loss of information through the cancer journey. It is piloting an electronic referral scheme for general practitioners (GPs), which cuts out postal delays. It is also using videoconferencing to conduct seminars for clinicians and nursing staff at district hospitals and to offer distance learning programmes to GPs. Pathologists routinely consult one another on camera for second opinions.

One of the best changes means that all cancer patients receive care from multidisciplinary teams that include specialists from the main cancer centre in Swansea on the south coast. These specialists are able to take part in discussions with clinicians and nurses who deliver much of the treatment closer to home.

It all started when the Bronglais hospital in Aberystwyth was asked to refer all cancer patients to Swansea. Although Aberystwyth is only 117 kilometres from Swansea, it is tucked away on the West Wales coast, two hours away by car and four hours by bus. To travel by train means crossing into England – the journey is more than five hours each way and hardly possible in a day.

Alan Axford, cancer lead clinician at the Bronglais hospital, put together a working party to look at how

care could be shared between the Swansea centre and his unit to minimise unnecessary travel. The team travelled to the US to get



Alan Axford

ideas for using communication technologies, and used charity money to purchase equipment to link the district hospital with the cancer centre. This enables video link discussions about the diagnosis, treatment plan and delivery of treatment to be carried out in multidisciplinary meetings involving the local team, specialist teams at the cancer centre and staff elsewhere in the network.

Axford told the conference: "There was a great deal of scepticism among some of my colleagues at the time. The secret is to identify the sceptics and harness the enthusiasm of those who you feel will be prepared to accept the challenge. Some of the greatest sceptics in our hospital and the Swansea centre are now so enthusiastic about this technology that you would imagine they had invented it."

Impressed by this pilot, the South West Wales Network appointed a telemedicine project manager, who rolled it out across the area, mobilising clinicians from every hospital to promote the scheme and organise needs assessments, training, equipment, technical backup, directories and user guides. Communications technology has been quickly embraced throughout the cancer service, and staff and patients are coming up with new ways it could be used to improve services – such as the improvement to palliative care services and smoothing cancer journeys through electronic patient tracking. But it all started with local efforts to solve a problem at an isolated hospital in a small corner of the network.

"The secret is to identify the sceptics and harness the enthusiasm of those you feel will accept the challenge"