Informing Healthcare
Hysbysu Gofal Iechyd

Achievements report 2009
using information and technology
for better patient care
Informing Healthcare is a Welsh Assembly Government programme set up to improve health services in Wales by introducing new ways of accessing, using and storing information. Our approach is to present new processes through incremental service improvement projects in full co-operation and partnership with clinicians, local health communities, patients and public. Since Informing Healthcare’s inception in 2004, we have upgraded networks, designed new systems, delivered several million pounds of new IT equipment to health organisations across the country and made a positive difference to the quality of healthcare in Wales.

To know more about Informing Healthcare, learn about our projects, read the latest news about the programme, and access key publications, visit our website: www.wales.nhs.uk/ihc
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chairman’s Introduction</td>
<td>2</td>
</tr>
<tr>
<td>Chief Executive’s Foreword</td>
<td>3</td>
</tr>
<tr>
<td>Information for Better Care</td>
<td>4</td>
</tr>
<tr>
<td>– The Single Electronic Health Record</td>
<td>4</td>
</tr>
<tr>
<td>– The Individual Health Record</td>
<td>5</td>
</tr>
<tr>
<td>Consent and Confidentiality – the right balance</td>
<td>8</td>
</tr>
<tr>
<td>– Safety and security</td>
<td>8</td>
</tr>
<tr>
<td>The Technical Blueprint</td>
<td>10</td>
</tr>
<tr>
<td>– The National Architecture</td>
<td>10</td>
</tr>
<tr>
<td>Delivering Core Systems</td>
<td>11</td>
</tr>
<tr>
<td>– New all-Wales pathology information system</td>
<td>11</td>
</tr>
<tr>
<td>– Radis2</td>
<td>11</td>
</tr>
<tr>
<td>– Picture Archiving and Communications System</td>
<td>12</td>
</tr>
<tr>
<td>– Welsh Demographic Services</td>
<td>12</td>
</tr>
<tr>
<td>– Master Patient Index</td>
<td>13</td>
</tr>
<tr>
<td>– The Cancer Information Network System Cymru</td>
<td>13</td>
</tr>
<tr>
<td>– Cancer Histopathology Reporting Project</td>
<td>14</td>
</tr>
<tr>
<td>– Palliative Care</td>
<td>14</td>
</tr>
<tr>
<td>– Medicines Management</td>
<td>15</td>
</tr>
<tr>
<td>Supporting Best Practice</td>
<td>16</td>
</tr>
<tr>
<td>– Map of Medicine</td>
<td>16</td>
</tr>
<tr>
<td>– Nurses get involved</td>
<td>17</td>
</tr>
<tr>
<td>– Patient Safety</td>
<td>17</td>
</tr>
<tr>
<td>– Welsh Language</td>
<td>18</td>
</tr>
<tr>
<td>Supporting Independent Living</td>
<td>19</td>
</tr>
<tr>
<td>– Chronic Care Demonstrators</td>
<td>19</td>
</tr>
<tr>
<td>– The Predictive Risk Stratification Model</td>
<td>19</td>
</tr>
<tr>
<td>Developing the Right Skills</td>
<td>20</td>
</tr>
<tr>
<td>– UK-wide career tool for health informatics</td>
<td>20</td>
</tr>
<tr>
<td>Service Management</td>
<td>22</td>
</tr>
</tbody>
</table>
It is once again my pleasure to prepare a short introduction to the Informing Healthcare Achievements report, which sets out our progress over the past 12 months.

Against a background of change for NHS Wales, I am pleased to report that Informing Healthcare is leading on the strategic direction for Welsh health information and technology and is continuing to make progress across key areas.

Since the programme was formed by the Welsh Assembly Government in 2004, we have evolved to take on new aspects of work required by the health service and policy direction. One example is work to identify the technology requirements for palliative care. However, our primary objective remains intact—to create the information and infrastructure services necessary to create a shared view of the patient’s clinical care where and when it is needed.

This commitment to our original vision was recognised when the Assembly Government approved two business cases, in January 2009, for the Individual Health Record and a replacement Laboratory Information System. These were significant highlights and key enablers that make it possible for us move ahead with delivery of these new and necessary national systems. Progress in both areas is testimony to the collaborative efforts of Informing Healthcare’s staff and the people who work on the frontline of care.

Another of my personal highlights was the recognition of Informing Healthcare’s incremental and collaborative approach to healthcare technology, featured in the Guardian newspaper, which suggested Barack Obama should look across the Atlantic to Wales for lessons in how to manage the computerisation of USA medical records.¹

We want information and technology to make a meaningful difference to the way NHS Wales develops and delivers services to Welsh citizens and have spent time listening to citizens’ views through established patient groups and forums. Of equal importance is the need to make sure new systems are safe to use in a clinical environment. To this end we have integrated clinical risk assessments into our quality assurance process to ensure patient safety is central to all our work.

The Health Informatics Professional Development Programme (Hi-Profile) has continued to make progress and to give health informatics staff a common voice, to match that of doctors and nurses. We are justifiably proud of the leading work carried out by Informing Healthcare staff to develop and implement the ‘career framework’ in health informatics, which has become the central plank of professional development programmes across the four home nations.

Once again, I would like to commend the exceptional efforts of staff both within Informing Healthcare and NHS Wales and the collaborative working partnerships that are proving to be the key to the successful delivery of improved services enabled by technology.

¹ http://www.guardian.co.uk/technology/2009/jan/29/computing-nhs
Working Together

As I write the introduction to our achievements report for 2009, we are at a pivotal point in the direction of NHS Wales, with the creation of new health boards bringing primary and secondary care together in the move away from the internal market model for service delivery. We are also facing a period of economic and financial stringency when it will be necessary for all of us to work even more closely together to make sure we get best value out of the funding that is available for Information and Communication Technology across NHS Wales.

Against this background, we have taken stock of our successes to date and looked at how we are using information and technology to support better care for the citizens of Wales. We have already initiated new activities that will make a significant contribution to a healthcare environment where most encounters take place outside the hospital setting. Delivering ‘Care Close to Home’ is the future direction of travel and this cannot be achieved safely or efficiently without deploying information technology in support of patients and care providers in both health and social care.

This report shows we have made steady progress over the last 12 months, due in no small measure to the collaboration and support we have received from our colleagues across NHS Wales. Looking forward, our goal is to accelerate and build on existing co-operation to create a unified approach to information technology and service management. In practical terms this involves full coordination of local and national staff working in an integrated way within the Informing Healthcare national programme. There is now both an opportunity and a need to utilise information technology in ways that are blind to the traditional boundaries between organisations.

A strong theme within our work to date has been on linking together existing systems within the NHS to share information more effectively and our achievements in these areas which are driven by the national technical architecture are covered within this report. The incremental approach we have adopted has successfully managed the risks associated with National IT Programmes and has provided vital evidence and experience to inform larger scale delivery. The Individual Health Record, which started as a pilot in Gwent and is now about to roll out nationally, is just one example. It also demonstrates how existing information, in this case a view of data from the patient’s GP-held record can be used effectively to improve care.

In response to policy directions within NHS Wales we are now looking at how information and technology can support people with chronic conditions such as diabetes, arthritis and respiratory diseases. With one in three adults in Wales diagnosed with a chronic condition, care for these individuals accounts for around 60% of hospital bed-days and around 80% of GP appointments and 78% of the health spend.2

To support better services, our role is to look at the technology we need to move more care out of the hospital building and closer to the patient’s home. To do this we are working in partnership with professionals from both health and social care through the Chronic Care Demonstrator Programme. Our next step is to replicate and integrate the systems at Informing Healthcare’s research laboratories at Swansea University – where they will be available for health and social care professionals to try out and use. Learning from this exercise will inform integration of systems in real life settings.

Information and its associated technology is one of the most important resources for both health and public services and is now more relevant than ever to help Wales deliver real improvements in health and public services.

---

2 Designed to Improve Health and the Management of Chronic Conditions in Wales
The concept of the single electronic health record is at the core of Informing Healthcare’s approach to support staff and citizens of Wales. Its aim is give health professionals access to the information they need wherever care takes place.

The single electronic health record also has to be safe and secure to ensure data is accessed only by people who need to see it to support patient care.

Patient information is currently stored in separate computers or in paper files across the health community. This means the necessary information to inform a clinical decision is not always immediately to hand and patients may have to repeat information about their recent care or medication.

The single record will enable information to be shared and will mean that vital clinical data is always available, irrespective of time or organisational boundaries.

Informing Healthcare’s approach is to replace paper-based systems and use new technologies to link existing computer systems so that data is available when and where required. This means data can be held in many locations. It does not need to be held in one central store or data warehouse.

Making it work is complex and is based on a national technical architecture for NHS Wales that takes into account authorisation, access, security and patient confidentiality. Significant progress has been made in many of these areas and is described in this report.

The single record is being delivered through four key components:

- The Individual Health Record
- The Welsh Clinical Portal
- The Welsh Clinical Communications Gateway
- My Health Online

To manage development and implementation, Informing Healthcare has adopted an incremental approach based on service improvement projects. These allow new processes to be tried and tested before national adoption; enable full engagement with local health communities, and an in-depth understanding of the technical and process requirements needed to integrate existing IT and networks.

The single record is founded on what people do as part of the healthcare process. It will enable:
• Health professionals to carry out day to day tasks, such as order a test or make notes
• View the past medical record, for instance see part of the patient’s GP record
• Measure what has happened, quality, performance indicators
• Access knowledge services, such as clinical journals or the Map of Medicine
• Communicate with citizens and colleagues via email
• Allow citizens to carry out day to day tasks, such as make a GP appointment, order repeat prescriptions

The Individual Health Record
The first stage towards the single record has been use of the Individual Health Record (IHR) to connect GP practices (primary care) with emergency and out-of-hours care providers. This bridges the information gap when the GP surgery is closed and gives health professionals providing unscheduled care access to essential information from the patient’s GP-held health record. An outline business case for national roll-out of the IHR has now been approved by the Welsh Assembly Government. More about the IHR is described on page 7.

The Welsh Clinical Portal
The portal is a secure web based healthspace which both supports routine care tasks and unites key information, such as pathology, radiology, cancer and GP data, from the various computer systems in NHS Wales.

By using the portal a doctor or other health professional is electronically supported in completing the day to day tasks of patient care. For example, he or she can request diagnostic tests and access important diagnostic data from a number of sources. Support is given for vital clinical decisions about a patient’s care and treatment and staff can avoid logging on to many systems or chasing paper records.

The portal will help clinicians undertake care tasks for individual patients, supported by information technology with all the benefits of safety, effectiveness and efficiency now commonplace in all other walks of life.

Welsh Clinical Communications Gateway (WCCG)
The Gateway will manage electronic referrals and other clinical communications between GP surgeries and hospitals.

Currently, GPs across Wales refer around 650,000 patients a year, each requiring an individual paper letter.

The WCCG was pioneered in Scotland as the Scottish Care Information Systems or SCI Gateway, where it is used by over 90% of GPs. Collaboration between Informing Healthcare and NHS Scotland has meant this technology can now be used in Wales. Further development of the system can be undertaken jointly.
The Gateway can manage messages ‘from any to any’ healthcare setting — including other GPs or professions allied to medicine, from consultant to consultant or from organisation to organisation.

GP practices in Cardiff and the Vale of Glamorgan will be the first in Wales to use the new Welsh Clinical Communications Gateway and refer patients onto hospital consultants. As ‘early adopters’ of the new Welsh Clinical Communications Gateway 46 practices in the area are due to replace traditional paper referral letters with an electronic communication or e-referral.

Abertawe Bro Morgannwg University, Gwent and North West Wales trusts, have also registered an interest in adopting the clinical communications gateway. Initially, e-referrals will be available to GP practices using EMIS, PCS or In-Practice Vision GP Systems.

Benefits of WCCG

- Referrals can be handled more easily
- Communication of clinical data is secure
- Referral letters will not be ‘lost in the post’
- The use of templates can ensure hospitals receive a standard set of information about each patient
- Easy access to the referral gateway from the GP’s computer system
- Sections of the referral form are automatically populated by data extracted from the GP system, so minimal keying in of information is required
- The system supports the way GP practices work
- The quality of referral information will be improved i.e. more legible and complete
- The system integrates with existing GP systems

### Single Record Clinical Information Flow

**Support unscheduled care**

- Individual Health Record
- GP Systems
- My Health Online
- Current Hospital Systems
- New Hospital/Community Services
- How clinicians view patients records in hospital & community
- E referrals
- Discharges
- Welsh CC Gateway
- Patient access over the internet
My Health Online
To complete the picture patients will be able to access health services, using the internet in a similar way to shopping or banking online.

My Health Online will allow patients to book appointments with their GP, order repeat prescriptions online, send notifications such as change of address and keep a health diary.

In future, features focusing on self care may also be developed to include alerts, access to the patient’s own medical record and links to personalised health content.

Patient Records when and where they’re needed

Individual Health Record
Inside the busy out-of-hours clinic at Newport’s St. Woolos Hospital, Dr Pete Thomas has a decision to make. A man’s been admitted into clinic. He’s a diabetic and has a catheter that’s blocked.

“Just changing the catheter could be very dangerous,” says Dr Thomas. “Without knowing all the details, the patient could have renal failure, or any number of complications. You need the right blood information. I can access that information just by checking the Individual Health Record. It’s a very useful tool.”

Doctors in unscheduled or emergency care settings often need immediate access to a patient’s vital medical information, but it’s not available because the GP’s surgery is closed for the evening or weekend. Fortunately, having the Individual Health Record (IHR) can help clinicians like Dr Thomas access those records easier, creating an information bridge between a GP and urgent care. Through the IHR, authorised clinical staff can acquire (with the patient’s consent) a limited synopsis of a patient’s latest medical records kept with the patient’s GP, ensuring the doctor on duty has vital information when it is needed most.

Doctors who access the IHR can immediately view patients’ prescribed medications, major diagnoses, blood pressure readings, test results and procedures.

In Gwent, where the technology was first introduced, local health professionals say the IHR is proving invaluable. Gwent has a population of nearly 600,000 people. The OOH alone receives 90,000 calls a year. For many of these calls, the IHR is used to help clinicians make the right clinical decisions.

The IHR has seen some dramatic developments since its inception in Gwent’s out-of-hours clinics in 2006. In June 2008, the IHR was implemented into the Royal Gwent Hospital’s MAU ward marking the first time any emergency unit had electronic access to GP-held patient records.

“We use the IHR in the Medical Assessment Unit very frequently,” says Pearl Gaspar, Clinical Nurse Lead in the Royal Gwent’s MAU. “We like it because it speeds up our admissions, transfers to different hospitals or different wards and our discharges. It’s really great.”

Building on the success of the IHR pilot in Gwent, delivery of the IHR to the rest of Wales is underway following approval by the Welsh Assembly Government.
Consent and confidentiality – the right balance

Safety and security

Sharing information is vital to deliver the care that citizens of Wales expect from a modern health service. At the same time, patients want assurance that only the right healthcare professional has access to their personal health information.

Informing Healthcare, in collaboration with healthcare professionals and patients, has developed a balanced model of individual consent that recognises the need to protect patient confidentiality while sharing information to improve the care each patient receives.

This approach to consent and confidentiality has been tried out in Gwent as part of the Individual Health Record pilot and will be adopted across Wales as the new IHR services go live.

As the IHR is rolled out, patients will be informed that a set of the medical information held about them by their GP, will be made available to their local out of hours service in order to enhance the care they receive. This will take place at least six weeks before the Individual Health Record is available in their area. The patient will have the option to ‘opt-out’ at this stage, or at any time in the future if they so wish. To opt-out a patient will need to notify their GP who will then add a special code to their record to prevent the release of information. In a similar way, patients who have opted-out can opt back in at any time.

“As a patient and a carer, as well as a patient representative, I’m extremely concerned about security.” Nina Weaver, a retired primary care manager and member of the patient’s panel at Gwent Healthcare Trust and the National Information Governance Advisory Group. NIGAG is a group of experts promoting good clinical, patient, legal and ethical practices that has reviewed and endorsed the models of confidentiality used in IHC projects.

“Nowadays our details are contained on so many databases that I think it is essential patients can be confident that these details are only accessed by those who ‘need to know.’ I don’t want this information shared with someone other than my GP or consultant.”

“I’m impressed with Informing Healthcare.” Mrs Weaver adds, “and their determination to protect patient confidentiality. I believe they are committed to making sure that the patient is at the centre of their work.”
As part of the consent process, the patient’s family doctor signs to agree that information held by the GP practice can be shared with out of hours and emergency providers, within the local health community. This is ‘implied consent’ – the doctor agrees on behalf of his or her patients.

There is a further ‘explicit’ stage to the consent process. A doctor, or nurse, caring for the patient in an out of hours or emergency situation must always seek the patient’s agreement before viewing the patient’s Individual Health Record. An audit trail is kept for assurance.

While the IHR will become a national service, the information shared between GPs and unscheduled care providers will remain within each local health community.

Caldicott Manual for Wales
A new manual and online guide to further improve the way NHS Wales handles patient data was launched in December 2008 by Dame Fiona Caldicott.

Dame Fiona led landmark improvements to the way the NHS handles patient data a decade ago, which resulted in the appointment of a Caldicott Guardian in each organisation.

The new guide for Wales called Caldicott: Principles into Practice, takes into account today’s healthcare environment, in which data is processed and shared in ways not anticipated a decade ago.

It was produced by Informing Healthcare in collaboration with Caldicott Guardians in Wales and Public Partners, an advice, consultancy and training firm.

Speaking at the launch event at City Hall, Cardiff, Dame Fiona welcomed the revised guide, which builds upon the original principles of the Caldicott report. She remarked: “Who could have foreseen the potential scale of the sharing of information, and the increased concern about confidentiality of patient identifiable information when my Committee reported in 1997?”

Personal Information Promise
Informing Healthcare joined 40 UK-based organisations and companies in signing the Personal Information Promise, an initiative from the Information Commissioners Office. The Promise reminds organisations of their responsibilities when processing personal information and sends a strong message to service users and customers that personal details must be handled and protected properly.

Protecting patient information
Recent breaches of data protection laws by organisations across the UK public sector have enhanced the need to ensure patient information is protected, particularly when the information is vulnerable, such as when it is transported outside organisations on memory sticks or CDs.

To protect against such events within NHS Wales, Informing Healthcare is putting together a framework of standard encryption products and services, which can be installed to help organisations look after sensitive information.
The technical blueprint

The National Architecture

The central aim of the Informing Healthcare programme is to create a ‘world class’ technical infrastructure for NHS Wales that will allow information to be shared securely irrespective of organisational boundaries.

How NHS Wales will achieve this is described through the National Architecture. This is a dynamic technical blueprint that sets out how NHS Wales will build, develop and use its information and technology resources to ensure clinicians have the right information at the right time.

At its heart is the development of a consistent set of information and technology services for all organisations in NHS Wales. Key principles are based on:

- a national co-ordinated approach
- incremental change
- best use of existing infrastructure and systems
- a balance between immediate improvement and investment in future improvements.

Consideration is also given to local priorities, whilst migrating to national designs and solutions.

Components of the architecture cover infrastructure, application design and development to form a technical footprint that will enable the delivery of service redesign within NHS Wales, which is described in Welsh Assembly Government strategy documents One Wales and Designed for Life.

The national infrastructure strategy sets out the common standards for hardware, networks, operating systems, mobile technologies and messaging services. Over time this will allow NHS Wales organisations to move from their current diversity to a corporate arrangement that is based on a design not dependent on the way one particular organisation works.

The infrastructure strategy is already supporting real service improvement through:

- migration of health organisations to the new Public Sector Broadband Aggregation (PSBA) network – a communications platform that spans the Welsh public sector
- a national framework contract of standard encryption products and services, which can be used to help organisations protect sensitive information.
- availability of a national email and directory service

This strategy has been followed in 2009 by an applications strategy, which will support delivery of the single health record. The applications strategy identifies existing core information systems, such as cancer, pharmacy, laboratory, radiology, and other existing and new systems that integrated will deliver a set of common safe information services across Wales.
Delivering core systems

New all-Wales pathology information system

Work is moving ahead to deliver a new Laboratory Information Management System (LIMS) that will improve pathology services across Wales for the benefit of patients and staff.

The new system will replace the 13 computer systems currently operating in the 18 main pathology laboratories in Wales. It will reduce the number of duplicated tests and mean that, no matter where a patient receives care, the results of tests will be readily available.

Pathology services cover a range of diagnostic and laboratory tests from routine blood and tissue samples to post-mortem services. More than 21 million diagnostic tests are conducted every year in Wales and form a crucial role in patients care.

A single system will help improve the efficiency and effectiveness of pathology services and provide more opportunities for staff to work together. This is important as demand on the service is expected to grow and this new system will enable NHS Wales to meet this increasing demand.

The new LIMS system is specified to integrate with other systems in use across NHS Wales and will begin to be available from 2010.

Radis2

In Wales today there are approximately 2.5 million radiology examinations carried out every year. To help ease the pressure on radiology departments a new and improved radiology system, called Radis2, is now in the process of being implemented across Wales, and will eventually lead to an All Wales Radiology Management System.

Radis2 replaces the existing RADIS, which is over 18 years old. The new system allows for better integration of systems such as PACS (picture archiving and communications system) and digital dictation. It also brings an improved database, making it easier to extract management information. All hospitals in Wales will have access to RADIS2 by 2010.

“Radis2 has allowed us to integrate radiology with our picture archiving and communication system (PACS) and our digital dictation system, used by radiologists to record observations which are then transcribed by clerical staff. This means staff can access all three systems from the Radis2 login screen, making it easier to manage and view related radiology and digital image information for an individual patient.”

David Lewis, Director of Finance, Cwm Taf NHS Trust
PACS (Picture Archiving and Communications System)

Radiology is the specialty dealing with medical imaging technologies such as x-rays, computed tomography scans, magnetic resonance imaging, positron emission tomography and ultrasound. Picture Archiving and Communications Systems (PACS) manage the storage, retrieval and transfer of the images and results from all these across different departments, healthcare settings and hospitals in Wales. But sometimes access and transfers can be a cumbersome process because different settings use different PACS – there are six different PACS currently in use across Wales.

Informing Healthcare is starting a pilot project to test out image-sharing between hospital PACS. The pilot aims to explore how image sharing can support the care of cancer patients. It will take place in South East Wales covering Cardiff, Velindre, Cwm Taf, Abertawe Bro Morgannwg University and Gwent hospitals and is scheduled to begin in early 2010 and run for 12 months.

As care and treatment for patients with cancer can take place in more than one care setting and involve a number of health professionals a key objective is to make multi-disciplinary teams (MDTs) more effective by providing easy access to images, wherever care takes place.

The images may be retrieved using any general web-based work station, making it easier for clinicians to retrieve images taken and stored at any of the hospitals in the South East Wales area.

The PACS image sharing project will also give access to ‘relevant priors’. These are images of the patient taken before cancer was diagnosed or in its early stages, and in a different setting from where the cancer treatment is taking place, that provide the radiologist with vital information.

Welsh Demographic Services

For two decades the NHS in Wales shared demographic services with the NHS in England. In June 2009 this changed and for the first time NHS Wales had its own service.

The Welsh Demographic Service (WDS), developed by Informing Healthcare in collaboration with Health Solutions Wales, gives access to NHS numbers (unique to every patient), up to date demographic details (for example full names, addresses etc), and the patient’s registered GP practice. It is needed for the:

- management of patients’ paper medical records between GP practices
- call and recall of women into the cervical and breast screening programmes
- call and recall of men and women within the bowel screening programme
- allocation of NHS numbers for patients and babies
- payment of contractors such as pharmacists and GPs
- tracing patient details to facilitate payment for non-contract activity
Delivering core systems

- tracing patient details as part of child protection processes
- to maintain blood and organ donor details

In addition, the Welsh Demographic Service can “trace” patients from England that are being treated in Wales. Similarly, English healthcare organisations can do the same for Welsh patients being treated in England using their own Person Demographic Service. This helps to send the results of treatment to the right place, and ensures that payments for treatment can be transferred between the two countries.

The change was prompted by Connecting for Health the English National Programme for Information Technology, which closed the shared demographic service, known as NSTS – the National Strategic Tracing Service.

Master Patient Index

Ensuring that patients are correctly identified and receive the correct care underpins all Informing Healthcare programmes and projects. An extensive data quality improvement project led by Informing Healthcare between 2004 and 2008 reduced the incidence of missing NHS numbers on records within Patient Administration systems across Wales from over 30% to just over 9%. Within radiology systems, the incidence reduced from around 62% to about 21%.

Despite these recent improvements in data quality there are still instances that can cause patient misidentification. Often patients can have more than one record in a healthcare information system, or they may have records in different systems, such as pathology or radiology, which cannot be matched because their name or address may have changed.

To further improve data quality and minimise risk to patients, Informing Healthcare is leading a procurement for an electronic Master Patient Index system (e-MPI). This will provide a central patient registration service, for each health community, and ensure that in future all patients are registered in the same way on each computer or information system used within the health community.

The E-Master Patient Index will hold a definitive source of patient demographic data for each patient (name, address, date of birth, sex) and will help to maintain consistency of patient information across various systems and will provide signposts to the location of clinical information in those systems.

A UK study has shown that around 8-10 per cent of patients in NHS hospitals may experience some kind of harm, of which up to a half may have been to some extent preventable. A Welsh report shows that clinical negligence claims cost the NHS in Wales £43 million in 2007-08. Misidentification is a significant cause of these patient safety incidents. The National Patient Safety Agency has reported that in the UK over the 12 month period from February 2006 to January 2007, the NPSA received 24,382 reports of patients being mismatched to their care.
National Cancer Information

Cancer patients, because of the nature of their illness, often have to travel from hospital to hospital for the most appropriate care. The Cancer Information Network System Cymru (CANISC) binds treatment settings together, allowing doctors in one hospital to access a patient’s up-to-date medical records from another hospital.

In April 2009, Canisc was established as a national service making it easier for information about treatment to be shared. More than 100,000 patients are now linked into the system, which originated at Velindre NHS Trust in 1991. The service gives cancer care clinicians throughout Wales accurate pictures of each individual’s care wherever that person happens to be treated.

Informing Healthcare, along with Velindre and Health Solutions Wales delivered CANISC throughout Wales, and management of the new service will be under the Business Services Centre.

The new CANISC national service allows any number of NHS Wales organisations to record assessments, treatments and follow up care into a common patient casenote, which any healthcare professional caring for that patient can access, thus giving a full picture of each individual’s care wherever that person happens to be treated.

Clinical information in the system includes cancer data for reporting, outpatient and discharge letters, investigation results, treatment details, clinical trials, palliative care and therapy services information. The system also allows monitoring of waiting lists.

CANISC is also the information source in all trusts for national audits in bowel, lung, head & neck, and stomach & oesophageal cancers and is the used as the first national breast cancer audit in Wales.

Cancer Histopathology Reporting Project (CHIRP)

Detailed histopathology information is fundamental to the diagnosis and treatment of cancer. This information is required at each point of care in the patient pathway. Current practice is to provide a report on a pathology specimen, which is then stored in the hospital’s laboratory pathology system (currently Telepath).

However, the data captured within this histopathology report is in an unstructured text format which makes the information difficult to analyse and transfer electronically to CANISC. Consequently, the present reporting process is quite labour intensive involving re-keying of information.

An Informing Healthcare service improvement project to streamline and improve the quality, completeness and availability of cancer histopathology information across Wales called CHIRP will integrate existing laboratory systems in trusts with CANISC. Significant cost benefits are also expected from the initiative.

The new system, piloted at Cwm Taf NHS Trust with positive results, will improve patient safety by reducing the possibility of error, incorrect interpretation of data and delays in the availability of information.

Next steps are to make CHIRP available across Wales.

Palliative Care

Sometimes in healthcare, treating the illness isn’t enough. For many patients confronting chronic life-threatening problems, managing pain or other symptoms of the illness is paramount. The goal of specialist palliative care is to provide that relief holistically, to integrate psychological and spiritual aspects into patient care, and to offer support to chronically ill patients and their families.
Initiated in late 2008, Informing Healthcare’s Palliative Care Project will ensure all hospices can access CANISC, allowing a smooth continuation of care to the patient without duplicating previous treatment and improving the quality of life for patients with chronic illnesses. The project is scheduled for completion by 2011.

**Medicines Management**

All hospitals in Wales are now using an upgraded hospital pharmacy system, which was rolled out as part of Informing Healthcare’s medicines management programme.

The upgrade included a rewrite of the system software and new centrally-managed servers. The improvements deliver faster reports, better back-up, security and hardware resilience, and provide a stable platform for further improvements to medicines management.

Informing Healthcare is also working closely with pharmacists, doctors and nurses to design and develop an all-Wales medication transcribing system, which will be available via the Welsh Clinical Portal.

Information about any medication taken by the patient before admission is obtained by the pharmacist from a patient’s notes, phone calls to the patient’s GP or from the medication the patient has brought with them into hospital.

All this information is copied (‘transcribed’) by the pharmacist and then keyed into the pharmacy computer system in a time-consuming process that can sometimes involve keying errors.

In time, a Wales wide medication transcribing system connected to the Welsh Clinical Portal will improve efficiency and patient safety by introducing a standard electronic process across Wales to support the prescribing, supply and administration of medicines in hospital. It will also supply the drug details required as part of the patient discharge process.
Supporting best practice

Map of Medicine

Health professionals in NHS Wales using The Map of Medicine say it is helping to deliver best practice and evidence-based care for patients.

The map is a clinical information resource developed by clinicians and provides a web-based visual representation of over 400 evidence-based patient-care pathways covering 28 clinical specialties, and is designed to present the most up to date information about care and for specific conditions.

Informing Healthcare procured the Map of Medicine on behalf of NHS Wales in early 2006. The map now has around 6000 registered users across NHS Wales. The Map’s pathways are being integrated into clinical systems and used to remodel patient pathways across the country to improve patient care.

A study on a Map of Medicine-based patient care pathway in South East Wales highlighted that use of the tool has dramatically improved the referral process for chronic kidney disease. According to the research an introduction of the pathway was associated with a fall in both the number of inadequate and total new referrals received.

Overall 62% of all primary care practices registered with the Map of Medicine in Gwent sent a higher proportion of appropriate referrals and were less likely to generate referrals with inadequate information.

The study suggests that early detection has beneficial effects for both patient and healthcare staff and the Map of Medicine tool is helping to achieve this by providing the information and criteria for referral in one easy to access area.

The initiative also enabled managed discharges from secondary to primary care settings, freeing up outpatient capacity.

The chronic kidney disease pathway has been based on the current agreed guidelines prepared by the UK Renal Association and the work of the Welsh Assembly Government national service framework programme.

The study was undertaken by the Institute of Nephrology, Cardiff University School of Medicine using GP practices in Gwent.

Other pathways developed for national use in NHS Wales include

- New Born Hearing Screening Wales (NBHSW) Pathway; adapted from the English (NBHS) Pathway to include Welsh specific information
Female Urinary Incontinence Pathway was developed by the North and South Wales Incontinence Groups, Consultant Urologists and GPs to improve management of patients with incontinence.

All areas in Wales have access to the Map of Medicine and several health communities have developed localised pathways.

Nurses get involved

Nurses and midwives in Wales have the opportunity to affect the design, testing and evaluation of new technological methods through the Informing Healthcare engagement programme.

A number of regional nursing and midwifery reference groups have been established across Wales. Their role is to involve the nursing profession, raise awareness of the use of information and technology within the workplace and influence change. They also have a role to play in clinical governance, the quality assurance of initiatives and a remit to share good practice.

During the past 12 months Informing Healthcare has recruited two nursing and one allied health professional to work within the programme and ensure the nursing and midwifery input is at the forefront of design and delivery.

Patient Safety

New computer and information systems for use in health care must be safe and avoid any potential risks to patients. Testing out the safety of new systems is built into the design and development of all products and services being introduced to NHS Wales.

Clinicians and technical experts work together in hazard risk workshops to carry out risk assessments, where hazards (‘a potential source of harm to a patient’) are identified and then assessed for their clinical risk (is this likely to occur and harm a patient and the severity of that harm). Once the risk is scored, then necessary action takes place to remove the risk.

Examples of potential hazards and their associated risk are:

- Inadvertent accidental prescribing of dangerous drugs – a consequence that high risk drugs may be prescribed by mistake and the wrong treatment given
- Incorrect patient or patient details may be retrieved from an IT system – risk that wrong patient treated, wrong dosages given, or test results sent to wrong person and subsequent consequences to health
- Computer Programming error – risk that wrong treatment given over a period of time, such as radiotherapy
- Slack Security – unauthorised access to clinical (e.g. hospital) system may mean that incorrect role/person provides incorrect or inappropriate treatment to patient with health consequences
- Decision support system not alerting the clinician of dangers of treatment. Risk that ‘alert’ not produced and or not clear to clinician and wrong treatment given
Before any new products are released they will have been tested and piloted in a limited number of sites to ensure that the product is ready for the live clinical environment.

The patient safety process is backed by the Patient Safety Advisory Board, which was set up in spring 2007, to provide advice to Informing Healthcare about patient safety within its programme of work.

The Board ensures strong links with quality improvement work in Wales (such as the Welsh Assembly Government’s Healthcare Quality Improvement Plan) and pays due regard to the work of other professional regulatory bodies.

The Board feeds into the National Architecture and Design Board (NADB), where its advice can be discussed in the context of approvals of design and is accountable directly to Informing Healthcare’s chief executive officer, through its Chair.

**Welsh Language**

A Welsh Language Reference Group has been set up to consider how the Welsh language is integrated into new and improved healthcare systems, such as GP information systems and My Health Online.

Consideration has been given to how the Welsh language can be included within the Welsh Clinical Communications Gateway project, which enables electronic referrals between a GP and secondary care. For instance, the referral could include an option to record the patient’s language preference or need. This would be particularly relevant when a referral is made to an area such as speech and language therapy.

The citizen website, My Health Online, is another planned service that could include a practical inclusion of the Welsh language. It could also include a feature which tells people which staff at their local practice speak Welsh.

---

**Case study**

A four year old Welsh speaker in need of speech therapy

Tomos has been brought up in a Welsh language household, he currently only speaks and understands Welsh.

He has already met with a Welsh-speaking Health Visitor, and his parents use an online system to book an appointment with a GP.

The system shows his parents which of the doctors at his surgery are Welsh speaking.

At the appointment a referral is made from the GP to his local hospital using an electronic referral system and the GP is able to indicate on the referral that the speech and language therapy needs to take place in the Welsh language.
Supporting independent living

Chronic Care Demonstrators

People with long-term conditions often have complex care needs and can face multiple and frequent admissions to hospital, particularly as they get older. According to a recent study, two out of three people in Wales over 65 suffer at least one chronic condition, and one third have multiple chronic conditions. Many more people have care needs but are undiagnosed. Besides being distressing to the patient, it places enormous pressure on health and social services. And that pressure is growing as the population rises and people are living longer. In fact, it is estimated that 78% of all health services expenditure is linked to chronic conditions.3

One answer is to make sure the resources are available to support patients and maintain independent living in their own home. Informing Healthcare is coordinating with multiple health, governmental and community services committed to tackling the issues involving chronic care, specifically those regarding information, management and technology (IM&T) solutions.

Informing Healthcare’s role has been to develop, on behalf of the National Chronic Conditions Management (CCM) Implementation Group, a business case to secure investment to join up existing systems or purchase new technology where necessary.

So far, three “demonstrator” sites in Wales (Cardiff, North Wales and Carmarthenshire) had been set up to test out generic CCM service models and infrastructures that support people’s needs locally and promote independent living within the community.

Doctors, nurses and patients from the Carmarthenshire health and care community will be using Informing Healthcare Laboratories at Swansea University to try out the technology in simulated settings that represent the patient’s home, the GP practice, outpatient clinic, acute and community hospitals, residential home, sheltered housing, pharmacy and emergency care services. This vision of Carmarthenshire ‘in a room’ is intended to identify priorities to support new pathways of care, including access to summary information and the need to communicate with colleagues.

PRISM (Predictive Risk Stratification Model)

Informing Healthcare has worked with health professionals and data analysis experts to develop a predictive risk stratification algorithm and web-based tool to help identify people at increased risk of an emergency admission to hospital or in need of additional care. The Predictive Risk Stratification Model (PRISM) uses health data from GP practices and hospitals to band the population according to their level of risk.

The potential use of the information is in the process of being tested and evaluated by the Chronic Care Demonstrators. For example, information could be used by GPs, community nurses and social services to provide additional care, increased support or preventative treatments to help avoid deterioration in an individual’s health and keep people out of hospital.

In Spring 2009 the Prism project pilot took its first steps towards becoming an all-Wales system when the Welsh Assembly Government approved the creation of a stage plan that defined the resources required to implement the web-based tool nationally.

3 “Designed to Improve Health and the Management of Chronic Conditions in Wales
Developing the right skills

A new version of the Health Informatics Careers Framework (HICF) containing double the content and over 100 job titles was launched in summer 2009.

Available from www.hicf.org.uk it offers a comprehensive route map for careers in health information within NHS Wales. It brings together competencies, underpinning knowledge, training and qualification routes and a database of job descriptions across nine career levels in a user friendly format.

Informing Healthcare has lead the development with collaborative input from Connecting for Health (the English health IT programme) and Skills for Health to create the first career framework for health informatics in the UK.

The framework is for people who work in:

- Knowledge Management
- Information Management
- Health Information as senior managers and directors
- ICT staff
- Health records and patient administration
- Clinical informatics staff
- Health information educators and trainers

The framework is one just one aspect of a highly successful period for the Health Informatics Professional Development Programme (Hi-Profile).

In June over 200 staff attended the annual Hi-Profile conference, which focused on the role of health informatics staff in shaping the future of healthcare in NHS Wales.

A wide range of courses were also made available through Hi-Profile including project and programme management, ITIL the IT Infrastructure Library, statistical analysis, benefits management, facilitation skills, presentation and assertiveness skills.
Working with educational partners
Now underpinned by the Career Framework, Hi-Profile is working in partnership with the Careers Service in Wales and NLIAH (National Leadership and Innovation Agency for Healthcare) to promote health informatics as a career option to school children and young adults. The programme often visits school to work with children promoting informatics in the NHS and has been a frequent visitor to a number of careers fairs in Wales.

Health Informatics virtual community
The Health Informatics Virtual Community is becoming the first portal of call for all informatics news in NHS Wales. It is an online one stop shop for informatics staff to find out information on learning, news and events. Since its launch in 2007 the sites continue to grow in functionality and content and now has 600 members registered. Registered members enjoy up to the minute alerts on current news and learning items.

Health Informatics physical community
The Health Informatics Physical Community provides physical events for informatics staff throughout NHS Wales to come together, network and meet colleagues face to. Now in its third year the 2009 community conference will highlight how informatics is a core requirement to the delivery of services in a modernizing NHS.

Developing basic IT skills
This year, the programme completed a pilot on Elite, a solution for basic IT skills development. The pilot highlighted that basic IT were still lacking amongst a number of staff groups in NHS Wales. Now that the pilot is complete the programme is currently considering the options for future delivery of basic IT skills in NHS Wales.

Case study
Clinical coder Marie Seward works behind the scenes, but her job is essential to NHS Wales. She works at University Hospital in Cardiff, taking a doctor’s case notes and translating often complicated medical terminology into special codes for entry into a medical database. Without coders like Marie, who are responsible for medical statistics, trends analysed, financial plans implemented and trusts to be paid, the nation’s healthcare system couldn’t work.

“A lot of people don’t know what we do,” she says.

Health informatics staff like Marie make up the professionals dedicated to the collection, management and sharing of information and knowledge supporting the efficient delivery of patient care. They include people who manage health records, information governance, IT, knowledge management and dozens of various other professions.
Service Management

Making best use of information and technology relies on excellent IT support services. Health professionals need to know that problems with essential computer systems and networks will be resolved quickly and efficiently whenever they occur, whether it is late at night or early in the morning.

Introduction of national systems and an increasingly mobile work force also require integrated support solutions.

Informing Healthcare is working with the Business Service Centre and Health Solutions Wales to develop service management that is consistent across Wales and supports the increasing number of national services, such as RADIS2, The Map of Medicine and NADEX.

The aim is use of existing resources and IT support to create virtual centres of excellence based on the IT Infrastructure Library (ITIL), which is a best practice methodology for the delivery of IT services.

The service management tool ‘Service Point’ developed by Health Solutions Wales is being introduced as a national helpdesk software solution and has been piloted successfully at Hywel Dda trust.