

IMPROVING HEALTH IN WALES



NHS  
WALES  
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CYMRU

# Informing Healthcare

Transforming healthcare using  
information and IT

Intranet: <http://howis.wales.nhs.uk/ihc>  
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Llywodraeth Cynulliad Cymru  
Welsh Assembly Government

ONE PATIENT ONE RECORD • ONE PATIENT ONE RECORD

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# FOREWORD

## by the Minister for Health and Social Services

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This document sets out a vision for transforming healthcare in Wales through the introduction of tools and techniques appropriate to the Information Age. Its implementation will put Wales at the forefront of innovative care delivery for the generations of the 21st century.

More than 50 years after the inception of the NHS, it is clear that the recording, collection, sharing and use of high quality, accurate and complete information falls well below publicly and professionally acceptable standards. Shortcomings have been identified in all the recently published major reports of care failures: Bristol Royal Infirmary, Alder Hey, the Shipman case, the Victoria Climbié Inquiry and ongoing concerns have been raised by the Commission for Health Improvement and the Audit Commission. These failures in communication and dissemination of information are endemic in all sectors of care – in primary, community, secondary and tertiary sectors. They affect all management levels, from individual care practitioners to Chief Executives, who must now formally exercise a 'duty of care' to patients. At a time when we are trying to develop closer working between health and social care agencies in the interests of seamless care, this too is frustrated by inadequacies in our records and information systems.


The findings of these reports and the accompanying public outcry has focused attention on the vital importance of information and electronic support systems to care professionals, patients and patients' representatives alike. All of the reports are consistent in pinpointing poor information-keeping and communication between care professionals at the heart of the problems. The best outcome for individual patients cannot successfully be achieved or subsequently audited without an accurate and complete care record, accessible by the health and social professionals looking after them. In turn, this detracts from the ability of public health practitioners to assess and review the effectiveness of treatments and procedures within the population as a whole.

This has all served to tarnish the reputation of the NHS and its partner organisations in the eyes of the public. At the same time, the public is increasingly able to access information for itself, whether through official government publications, or via the media or directly via the Internet. The spotlight on comparative information about organisational performance and individual care professionals' success rates will remain firmly fixed in the years to come.

The need for a dramatic change in the prevailing information culture is now recognised. As the outgoing President of the General Medical Council, Sir Donald Irvine said in his farewell address in November 2001:

*"We live in the Information Age. For the first time in history any of us can interrogate the database of medicine directly through the Internet rather than through doctors. That technical innovation has itself created the conditions for profound social change. It has altered the balance of power between doctor and patient - in favour of the patient - forever."*

This strategy shows how the interests of the public, patients, professionals and political leaders in Wales can be integrated to deliver better informed and better quality care for the people of Wales. It focuses on health and healthcare, but the repeated references in the document to the increasingly close relationship with social care partners reflects the Welsh Assembly Government's determination to develop care services which are seamless. Later this year, I expect to release a companion document *Informing Social Care* which will complete the vision of information developments and sharing to support our ambitions for the people of Wales.



**Jane Hutt**

Minister for Health and Social Services

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# 1. EXECUTIVE SUMMARY

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## INTRODUCTION

1.1. The health service in Wales is massive and complex. It manages over 10 million face-to-face healthcare events every year. The majority of these transactions are problem-free and successful. However, a minority fall below the required standard. This is rarely the fault of the health professionals delivering the care, but relates to a systemic failure in the NHS to capture patient-centred and clinically relevant information in a structured, accessible and re-usable way.

1.2. Without such information, every transaction for a patient can feel like starting again. Progress made in one consultation might be lost in the next as required records and test results cannot be found, or they are not fully and accurately communicated to other health professionals in the care process. This is not a rare occurrence – it happens to an estimated 1 in 4 outpatients<sup>1</sup>. Once in hospital, the risks of fragmented information persist. Decisions sometimes have to be taken in the absence of all the facts, because results or records cannot be found. Usually this is not a major problem because safety is built in to the care process. However, it has been estimated that 1 in 10 inpatients is harmed in some way by the care they

receive<sup>2</sup>. Many of these 'adverse events' can be traced to poor availability and use of information in the care setting. Others can be attributed to a system-wide failure to learn from mistakes.

1.3. The health service has not invested adequately over many years in proper information support for healthcare delivery. There are many complex reasons for this, including:

- Lack of financial resources to commit to information and IT tools and developments.
- A focus on management information rather than clinical information.
- Risk aversion in the face of 'IT disasters' in the public sector and elsewhere.
- The separation of information and IT staff from core healthcare delivery.
- Failure to integrate technology with new ways of working.

1.4. The results are a health service that is unable to cope under the burden of its own information mountain and a poorer service for patients.

1.5. *Informing Healthcare* presents a fundamental re-assessment of the

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<sup>1</sup>Blendon R.J. et al. Common concerns amid diverse systems: Healthcare experiences in five countries. *Health Affairs*. 22 3 106-121.

<sup>2</sup>Department of Health (2000): *An Organisation With A Memory*. London, Department of Health. Available online at <http://www.doh.gov.uk/orgmemreport/orgmemexecsum.htm>

problem and a coherent approach to its solution. It describes how the new methods, tools and technologies of the Information Age can transform health services for the benefit of this and successive generations in Wales. It is the fruition of Welsh Assembly Government commitments made in *Improving Health in Wales – A Plan for the NHS with its partners*. It is a significant and strategic approach to investing in information and communications technologies infrastructure, and to modernising service delivery by supporting new ways of working with better information support and access to knowledge in the care process.

## THE CASE FOR CHANGE

### STRATEGIC CONTEXT

- 1.6. It is generally accepted that the NHS in Wales and the wider health service require modernisation. However, it is not enough just to look at the way things are today in formulating answers to problems. The context for health and healthcare is changing rapidly. The Welsh Assembly Government is responding to those changes with new policies and ideas. These include:

*A Winning Wales*, which sets out broader economic policy for Wales over the period up to 2010, and provides the context for NHS contribution to the economy both in terms of health improvement and healthcare provision and as the largest employer in Wales.

*Cymru Ar-lein (Wales Online)*, which describes how Wales will embrace information and communications technologies to support individuals, communities and businesses, enhancing local democracy, supporting greater productivity and promoting achievements in Wales on the world stage.

*Dyfodol Dwyieithog: A Bilingual Future*, which acknowledges the importance of being able to deliver services in people's language of choice in areas such as health and social care, and sets out plans to work with service delivery organisations to help them achieve this aim.

*Well Being in Wales*, which makes a positive link between the health and well being of the population of Wales and its future prosperity. It describes a far more integrated approach to health across government policy areas, and focuses on reducing poverty, social exclusion and health inequalities, while encouraging sustainable development. In doing so, it re-defines the role of health and social care services as positive investments in future prosperity as opposed to seeing them as a cost to the country.

*Improving Health in Wales*, which sets out a broad ten-year development framework. It describes a patient-focused health service, delivering high quality, evidence-based and integrated care to patients and carers; health improvement to the population of Wales and its local communities; and a reduction in health inequalities in the

population of Wales. Foremost among its objectives are the management and oversight of healthcare quality through clinical governance and the development of truly integrated health and social care services for patients.

1.7. It is vital that this strategic context is well understood, and that *Informing Healthcare* is grounded within it, if technology-assisted change is to be successful. Healthcare is facing significant challenges worldwide as demand increases while supply is under pressure. This is happening at the same time as governments are recognising the need to invest heavily both in healthcare and in new information technologies as means to support long-term prosperity. The need to understand the impact of this increased investment, by evaluating the cost effectiveness of the care provided, is also beginning to be recognised.

1.8. Within healthcare, through the delivery of high quality, rapid and integrated care, the goal is to return patients to health as quickly as possible, and to maintain them in good health. Achievement of this goal is often hindered by a legacy of fragmentation between health sectors, organisations and services. While service reconfiguration may reduce fragmentation over time, it cannot be done quickly because of the scale and complexity of health infrastructure and it cannot solve the problem completely as health professionals will always be distributed widely.

1.9. The advent of new information and communications technologies (ICT) provides an opportunity to support service improvement and integration around the patient by developing a seamless and shared information base. From the patient perspective, services will be integrated when health professionals are able to work with them supported by common information. If we can integrate patient information then we can integrate patient care.

### OPERATIONAL ISSUES IN THE NHS

1.10. While change is needed to support future models of care, it is important not to overlook problems with the current health service. A stream of high profile enquiries has shown that it is often under-mined by long-standing and systemic information problems. Poor record-keeping undermines the quality of care. Antiquated paper-based systems are used to carry out sophisticated processes such as prescribing, putting patients at risk as avoidable mistakes are made.

1.11. These enquiry reports are powerful documents, but the problems they describe will remain part of the day-to-day experience of patients and carers, health professionals and management decision-makers until fundamental and decisive action is taken to solve them. This strategy provides the basis for that to happen. There is much good work being done by NHS staff in Wales in improving patient care, and this will provide important impetus for the

implementation of *Informing Healthcare*.

## THE INFORMING HEALTHCARE VISION

- 1.12 *Informing Healthcare* is based on a vision of patients, carers and professionals working together, supported by the latest evidence, to reach agreement on appropriate and cost effective healthcare for the patient. It states that the resulting decisions and actions – referrals, tests, treatments, discharge – should be transparent and open to evaluation, that outcomes should be recorded and used to improve services and that the whole health transaction should be carried out in a secure and confidential way.
- 1.13 Achievement of this vision will require long-term commitment, and the learning of lessons – good and bad – from previous technology-assisted change programmes. Principles have been set down for *Informing Healthcare* implementation to help avoid the pitfalls.
- 1.14. The strategy focuses on five key benefit areas.

### A SINGLE RECORD

- 1.15. The most significant cause of current information problems in the NHS is the lack of a holistic patient record that is accessible to those who require the information, including patients and carers. Fragments are held by many professionals in many settings but none have access to the whole record.

Patients rarely get to see even the fragments of the record. The impact of this is both pervasive and damaging to integrated health and social care.

- 1.16. The concept of the Single Record is designed to overcome these problems. It does not mean that all information will be held in one place, but it does mean that health professionals will be able to access all the information they need, and only the information they need, about a patient whenever and wherever they need it. This access will take place in a secure environment, and profiling of users will ensure that it is limited to what any given professional needs to know.
- 1.17. The benefits of the Single Record will be seen directly in healthcare delivery. Less time will be taken up in searching for information or paper-based administration; more time will be available for patients. Greater sharing of information across health sectors will provide many opportunities for service improvement, and patients accessing their own record will be able to play a greater role in their own health maintenance and improvement.
- 1.18. The eventual goal is the development of a fully integrated approach to health and social care records, although total integration of these records is currently beyond the scope of this strategy. Meanwhile, all steps will be taken to ensure that developments in healthcare records and social care records are strategically convergent.

## WORKFORCE EMPOWERMENT

- 1.19. The implementation of *Informing Healthcare* will involve significant changes for the workforce, both in developing new skills and finding new ways of working. The exploitation of high quality information is likely to become more central to clinical culture and to consultations with patients.
- 1.20. The new skills required will range from basic IT and information management skills through to sophisticated critical appraisal techniques and statistical analysis, depending on the requirements of the individual. *Informing Healthcare* will ensure that the right balance exists between the core skills that all health professionals should have and the availability of specialist health informaticians to undertake more complex tasks.
- 1.21. The benefits from Workforce Empowerment will be manifold. Staff will be able to take advantage of new productivity tools, and computerised business support services, to improve their working life. They will be able to communicate much more efficiently through e-mail. The new Human Resources system will provide NHS employees with access to their own staff record. Patients will benefit as staff are able to use automated tools to facilitate patient transfer between clinicians and to provide services such as prescribing which will have in-built safety checks. Most importantly, evidence-based healthcare will become a reality as health professionals are able to access and

use the latest evidence and best practice routinely.

## PATIENT AND CARER EMPOWERMENT

- 1.22. Healthcare delivery has a history of paternalism with health professionals making decisions on behalf of patients, sometimes without explaining why. This must now change, both because of growing consumer awareness in healthcare and because recent enquiries have highlighted the problems associated with paternalistic culture.
- 1.23. The change of culture towards shared decision-making, with the patient and carer becoming part of the healthcare team, will be long-term and will require careful thought in its development. Nevertheless, there are practical steps that can be taken in the short-term and good practice exists in Wales in this area. This should be evaluated and encouraged more widely.
- 1.24. The long-term benefits of shared decision-making will be significant, with far more interest being shown by people in their own health status and in more considered access to health services. In the short-term, patient satisfaction with services will be increased through the provision of better information about treatments, risks and benefits. Patient anxiety could be reduced significantly if health professionals are able to provide a clearer schedule of the next steps in

the care process and the likely duration of the patient journey.

## SERVICE IMPROVEMENT

- 1.25. In recent years, modernisation and ICT programmes in healthcare have not been well integrated. This strategy argues that they must be closely aligned both strategically and in practice if benefits to patients are to be maximised. The introduction of technology without changed working practices will have little impact. Changed working practices without new technology will be harder to sustain in the long term, and may miss important effectiveness and efficiency gains. Most importantly, new technology makes possible new ways of working that could not otherwise succeed.
- 1.26. A range of applications exist which have – properly implemented – been proven to bring benefit in healthcare and these should be early candidates for investment across Wales. They include: electronic communications; requesting and reporting of tests; Picture Archiving and Communication Systems (PACS); e-prescribing and scheduling.
- 1.27. The benefits from such applications are likely to be significant, and will particularly improve:
- Patients' safety, through a more controlled clinical environment.
  - Patients' experience, with less inconvenience and anxiety during the care process.

- Responsiveness of care, by speeding up day-to-day activities.
- Efficiency of care, by reducing the administrative burden on health professionals.

## KNOWLEDGE AND INFORMATION MANAGEMENT

- 1.28. In common with many healthcare systems, NHS Wales has a large amount of data but is often unable to use it to good purpose, either at the front-line of care or in support of management and planning. This situation often arises because of a misalignment between the goals of the health service and the measures within it. For example, the goals are mainly about clinical outcome, yet most data collected is administrative in nature. This means that performance management can often seem remote to health professionals.
- 1.29. A re-assessment of the measures needed to assess whether goals are being met is likely to lead to a combination of new measures being developed and some old measures and data collection processes being stopped. New measures will be supported by the introduction of the Single Record, as it will augment clinical data capture. Better use of the information collected will be supported by the education and training planned in the Workforce Empowerment stream of *Informing Healthcare*.

1.30. The benefits from improved Knowledge and Information Management will manifest themselves throughout the health service. For health commissioners, there is a clear need to understand how resources have been used to deliver healthcare and to identify where health needs are not being met. At the front-line, health professionals will be able to analyse clinical performance and caseload and to plan services to best meet patient needs. Service managers will be able to monitor progress on National Service Frameworks across the health economy. Public health professionals, whether in the National Public Health Service or the Wales Centre for Health, will have comprehensive and accurate data with which to analyse population and community health trends. Politicians will be able to account for the health service in a more detailed and positive way.

## NEXT STEPS – ORGANISING TO DELIVER

### STRATEGY IMPLEMENTATION PROGRAMME

1.31. *Informing Healthcare* requires a long-term programme of technology-assisted change in the Welsh health service. It will require significant organisation and resources in order to deliver its vision. The *Informing Healthcare* Strategy Implementation Programme ('the Programme') is designed to ensure that the strategy is properly managed to meet its objectives.

1.32. *Informing Healthcare* will be a project-based strategy. The Programme will identify individual projects and products and ensure that they are delivered in a coherent way in support of the overall change programme. The Programme will not undertake ongoing information or IT service provision. Such provision will be the domain of national and local health organisations in Wales and, where appropriate, private sector suppliers.

1.33. While the Programme will be responsible for delivering strategic products and overseeing health service-wide projects – enabling, supporting and monitoring progress on the strategy – it will not take responsibility for organisational and professional change. This responsibility will continue to rest with Chief Executives and Boards of health organisations.

### STRATEGY IMPLEMENTATION PROGRAMME BOARD

1.34. Over time, *Informing Healthcare* will affect everybody in Wales, whether as a member of the health service workforce or as a patient, carer or citizen. Therefore, the proper engagement of stakeholders to oversee and engage with the strategy is vital. This will be achieved primarily through the innovation of Benefits Groups.

1.35. The creation of a Strategy Implementation Programme Board ('the Board') will ensure clear and transparent accountability. The Board will be chaired by a public appointee,

who will be accountable to the Minister and the NHS Wales Director, supported by a full-time Programme Director and Programme Support Office. The Board will be accountable for the successful development and running of the programme, and for supporting and monitoring the delivery of the strategy and its corresponding benefits. It will derive its authority from its Programme Mandate, agreed with the Welsh Assembly Government.

### **STRATEGY IMPLEMENTATION PLAN 2003/04**

- 1.36. Visible *Informing Healthcare* activity in 2003/04 will focus upon the areas identified already as early priorities – Legacy Management and Readiness. Work will also begin on establishing work programmes to deliver early objectives within each of the five key benefit areas. The complete Strategy Implementation Plan 2003/04, including fully resourced plans for all of the national and local projects which are being initiated during the next twelve months, will be published following its approval by the Board and will be annually updated thereafter.

## 2. INTRODUCTION AND BACKGROUND

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- 2.1. *Informing Healthcare* describes how the new methods, tools and technologies of the Information Age can transform health services for the benefit of this and successive generations in Wales. It is the fruition of Welsh Assembly Government commitments made in *Improving Health in Wales – A Plan for the NHS with its partners*. It is a significant and strategic approach to investing in information and communications technologies infrastructure, and to modernising service delivery by supporting new ways of working with better information support and access to knowledge in the care process.
- 2.2. The NHS in Wales has also made a commitment to improved business systems, with 12 NHS Trusts having invested in a common state of the art financial system that will integrate with the Electronic Staff Record, a project to provide one database for all employee records in the NHS.
- 2.3. The Welsh Assembly Government's integrated approach to improving health and reducing health inequalities – *Well Being in Wales*<sup>1</sup> – describes the health service as an investment in the future prosperity of Wales. In doing so, it rejects the notion of the NHS as an 'illness service' or as a cost to society. Instead, the NHS is seen as a partner in the collective effort of bringing greater equality, social inclusion and sustainable development to the people of Wales.
- 2.4. The NHS is just one contributor to health, and *Well Being in Wales* sets out clearly the importance of other social and cultural factors such as education, living conditions and income. It also stresses the central role of communities and individuals in improving their own health and in making best use of health services.
- 2.5. In this context, the goals of the health service<sup>2</sup> can be summarised as helping people, to the greatest extent possible, to be:
- Free from pain and disability.
  - Independent.
  - Productive and creative.
- 2.6. The achievement of these goals often requires a contribution from a wide range of stakeholders, starting with the patient and their family and carers, moving through the whole range of primary, secondary and community health services, and often also including social care staff and support from the voluntary sector. This means that the whole health service must be well co-ordinated to ensure that the patient returns to health as quickly as possible.
- 2.7. While there are many daily examples of excellence in health and social care interventions in Wales, it is clear that there is much work to do before we can claim that the health service is able to return people as quickly as possible to

their daily lives, having provided them with high quality care.

2.8. Therefore, the NHS and the wider health service need to change. As this document will illustrate, they need to become:

- More patient-focused: providing continuous and integrated care for patients throughout their journey through the health service.
- More responsive: providing care closer to home for patients and keeping them informed about the progress of their care.
- More co-ordinated: ensuring that all contributors in the health service are working together for the benefit of the patient.

2.9. In analysing the gap between the ideal situation and the current reality, common threads for both patients and professionals are access to better information and access to better tools to support the care process. The fragmentation which patients experience every day in today's health services is often caused by poor flow and sharing of information.

2.10. The opportunities for improvement in NHS services are often most sharply presented in the formal and informal feedback received from patients. Praise should be used to inform best practice. Criticism should provide lessons to be learned. However, the scale of the challenge to improve should not be under-estimated. As the NHS Ombudsman said in 2001:

*"Poor communication and inefficient record keeping are at the root of many of the problems we come across in our investigations. Regrettably, the cases that appear here suggest that some of the problems I have commented on in the past continue to arise."*

2.11. *Informing Healthcare* is designed to show how the co-ordinated application of work in five benefit areas, described in the Vision chapters of this document, can tackle the clinical information and communication problems that often lie at the heart of health services shortcomings and thereby bring about the transformation of health services in Wales for the benefit of patients, staff and the population as a whole.

2.12. The strategy is presented in the following order, though each of its chapters is designed to stand alone as far as possible:

- Executive Summary.
- Introduction and Background.
- The Case for Change.
  - Strategic Context.
  - Operational issues in the NHS.
- The *Informing Healthcare* vision.
  - A Vision for the Future.
  - A Single Record.
  - Workforce Empowerment.
  - Patient and Carer Empowerment.
  - Service Improvement.

## Knowledge and Information Management.

- Next Steps.

- 2.13. Each main chapter is headed by a summary section, so that the strategy can be scanned quickly just by reading these summaries.
- 2.14. *Informing Healthcare* is the result of much hard work by NHS and Welsh Assembly Government staff, and owes much to the many organisations and individuals who contributed to its development. It began with the work of the Information Task and Finish Group, set up to support implementation of *Improving Health in Wales*. This work was then published in summary form to support widespread consultation, both written and through 'Roadshow' meetings. The consultation process, while overwhelmingly supportive, raised important questions, which have been addressed as fully as possible in this refreshed document<sup>3</sup>.
- 2.15. To the greatest extent possible, this strategy has been developed to meet the needs of its stakeholders. The challenge now is to implement it for the benefit of patients, carers and health professionals and in support of the well-being and prosperity of Wales. The final chapter – Next Steps – outlines the ways in which this will be done.



# THE CASE FOR CHANGE



## 3. STRATEGIC CONTEXT

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### SUMMARY

*Healthcare is facing significant challenges worldwide as demand increases while supply is under pressure. This is happening at the same time as governments are recognising the need to invest heavily both in healthcare and in new information technologies as means to support long-term prosperity. The need to understand the impact of increased investment, by evaluating the cost effectiveness of the care provided, is beginning to be recognised.*

*Within healthcare, the goals are to prevent ill-health where possible and to return patients to health through the delivery of high quality, rapid and integrated care. Achievement of this goal is often hindered by a legacy of fragmentation between health sectors, organisations and services. While service reconfiguration may reduce fragmentation over time, it cannot be done quickly because of the scale and complexity of health infrastructure and it cannot solve the problem completely as health professionals will always be distributed widely.*

*The advent of new information technologies provides an opportunity to support service improvement and integration around the patient by developing a seamless and shared information base. From the patient perspective, services will be integrated when health professionals are able to work with them supported by common information. If we can integrate patient information then we can integrate patient care.*

### INTRODUCTION

3.1. It is generally accepted that the NHS in Wales and the wider health service require modernisation. However, it is not enough just to look at the way things are today in formulating answers to problems. The context for health and healthcare is changing rapidly, and the Welsh Assembly Government is responding to those changes with new policies and ideas. It is vital that this strategic context is well understood, and that *Informing Healthcare* is grounded within it, if technology-assisted change is to be successful.

3.2. Health and healthcare services are under increasing pressure across the world. Within many European countries, including Wales, a mixture of demographic, economic, scientific and technological changes is leading to increased demand and decreased supply.

3.3. Factors affecting demand include:

- Changes in birth and death rates leading to an older population, with a far greater proportion of over-65s and much longer lifespan for people.
- Greater public awareness of possible new treatments and demand for them to be universally available.
- Greater consumer expectations about availability and quality of

services, especially in the public sector.

3.4. Factors affecting supply include:

- A reducing working age population from which to recruit and train health professionals.
- The introduction of the European Working Times Directive and its impact, especially on the hours worked by junior doctors.
- Greater economic competition for healthcare staff.
- Rising costs in healthcare due to new health technologies and drugs.
- Decades of under-investment in health facilities and IT, hampering efficiency when compared with the wider economy.

3.5. Set in this context it is vitally important to understand how the limited resources available are being utilised.

3.6. Health and healthcare has traditionally been seen as a separate activity from other welfare services, and more so from broader economic activities. This separation has been counter-productive in many ways, and has left a legacy of isolation and fragmentation both at an economic level – where healthcare has been seen as a necessary cost rather than an economic investment – and at an NHS organisational level – where particular healthcare providers have been tasked with managing specific phases or

episodes of care rather than providing elements of an integrated service to support people to recover and maintain good health.

3.7. The following sections provide an overview of the strategic context for *Informing Healthcare*, considering both broader Welsh Assembly Government policy as well as policy developments relating to the NHS and the health service. These policies have been chosen for discussion because *Informing Healthcare* is a practical expression of policies designed to:

- Bring economic prosperity to Wales.
- Modernise Wales through the use of ICT.
- Provide information about services in patients' first language.
- Improve health and well being in Wales.
- Modernise health services in Wales.

## WELSH ASSEMBLY GOVERNMENT POLICIES

3.8. Government policy in Wales is based upon the achievement of greater and sustainable prosperity for all in a society which is based on community values, co-operation and equality of opportunity and outcome for individuals. This means that local accountability for public services is vital, as is the active participation of the population in the design of services.

## A WINNING WALES<sup>4</sup>

3.9. The Welsh National Economic Development Strategy – *A Winning Wales* – sets a range of targets for development by 2010. These include:

- Increasing GDP per head from 80% to 90% of UK average by 2010.
- Creating a net additional 135,000 jobs by 2010.
- Reducing number of working age adults without qualifications from 25% to 10%.
- Increasing the proportion of Welsh business using e-commerce to the UK average.

3.10. The role of the health service in supporting economic development is clear. People will have more opportunities to work and to progress if they benefit from good health. Economic inactivity in the working-age population of Wales is much greater than the UK average, as is the number of claimants of incapacity benefits<sup>5</sup>.

3.11. *Informing Healthcare* cannot contribute directly to the improvement of this situation, but better provision of information in the health service will contribute to ensuring that its resources are deployed as effectively as possible, and hence to solving wider economic problems.

3.12. It is also important to recognise the NHS as the largest employer in Wales, both directly and through associated bodies and industries. In addition to its status as a purchaser of goods and

services, it can contribute directly to economic growth by:

- Developing new services and new jobs.
- Supporting its staff in developing new skills that are useful both at work and at home.
- Implementing e-commerce to encourage electronic transactions in the wider economy.

3.13. *Informing Healthcare* will ensure that all of these activities are supported, and that health service staff are equipped with modern information tools and the skills to use them.

## CYMRU AR-LEIN (ONLINE FOR A BETTER WALES)<sup>6</sup>

3.14. *Cymru Ar-lein* is the element of the national economic development strategy that relates to the use of Information and Communications Technology by the population of Wales. Its aims can be summarised as wanting Wales to be:

- United through its use of ICT, confident in promoting achievements on the world stage and creative in exploiting ICT for the benefits of individuals, communities and businesses.
- Committed to fostering, through the effective use of ICT, its unique and diverse identity, and the benefits of bilingualism.
- Using ICT to become more prosperous, well-educated, skilled, healthy, environmentally and culturally rich.

- Served by modern, effective, efficient and accessible public services that use ICT to enhance their services.
- Active in its use of ICT in local communities, where the voice of local people is heard.
- Fairer – a place where everyone is valued and ICT is used to give everyone an opportunity to play a full part.

3.15. The goals of *Informing Healthcare* are aligned with the goals of *Cymru Ar-lein*, pursuing similar outcomes specific to the Welsh health service and thus contributing to the wider community. The strategy is intended to bring about technology-assisted change within the Welsh health economy, and ensure where possible that the NHS is able to take a leading role in national economic development through the use of ICT.

### WELSH LANGUAGE

3.16. The Welsh Assembly Government is committed to improving the provision of services through the medium of Welsh, and ensuring that the specific care needs and experiences of Welsh speakers are adequately reflected in general activities such as formulating strategies and collecting information about patients' experiences. In its policy statement on the Welsh language, *Dyfodol Dwyieithog: A Bilingual Future*<sup>7</sup>, the Welsh Assembly Government acknowledged the importance of being able to deliver services in the service users' language of choice in areas such as health and

social care, and agreed it would work with service delivery organisations to help them achieve this aim.

3.17. In 2002, NHS Wales formed an All Wales Task Group for Welsh Language Services to provide greater impetus towards a bilingual service, and ensure that users can receive their services in their preferred language wherever possible. In particular, *Informing Healthcare* will play a significant role in promoting the availability of patient information and services in the Welsh language.

### NHS AND WIDER HEALTH SERVICE POLICY DEVELOPMENTS

3.18. Within the health service, there are two key strategies that provide the context for *Informing Healthcare*. *Well Being in Wales* provides the key linkage between the health service and the wider prosperity of Wales. *Improving Health in Wales* sets out the strategic direction for the NHS for the next ten years, and contains the initial Welsh Assembly Government commitment to deliver technology-assisted change in health services, based on a robust IT infrastructure and better use of health information.

### WELL BEING IN WALES

3.19. The *Well Being in Wales* strategy builds upon *Better Health, Better Wales*<sup>8</sup>. It makes a positive link between the health and well being of the population of Wales and its future prosperity. In particular:

- It describes a far more integrated approach to health that covers a

wide range of government policy areas, and focuses on reducing poverty, social exclusion and health inequalities, while encouraging sustainable development.

- It re-defines the role of health and social care services as positive investments in future prosperity as opposed to seeing them as a cost to the country. This is especially important with regard to family services, and with services that enable people to stay in work, return to work or live longer and more independent lives.
- The role of health and social care services as large employers and purchasers of goods and services that contribute directly to economic prosperity is highlighted.

3.20. All of these developments are fundamentally dependent on the availability of high quality information – to public and patients, health professionals and managers – and on the availability of tools to rapidly access, communicate and analyse that information. *Informing Healthcare* will develop the provision of such information in a sustainable and co-ordinated way.

### IMPROVING HEALTH IN WALES<sup>9</sup>

3.21. *Improving Health in Wales* is the Welsh NHS Plan. Published in 2001, it sets out a broad ten-year development

framework. It describes a patient-focused health service, delivering:

- High quality, evidence-based and integrated care to patients and their carers.
- Health improvement to the population of Wales and its local communities.
- Reduction in health inequalities in the population of Wales.

3.22. Among its recommendations, *Improving Health in Wales* commits the NHS to significantly increasing investment in new information and communications technology (ICT) to ensure that new policies and new ways of working can be supported by high quality information. *Informing Healthcare* is the product of the Information Task & Finish Group – one of the groups set up to consider how best to deliver the *Improving Health in Wales* vision in practice.

3.23. *Informing Healthcare* is, however, not just about the ICT elements of *Improving Health in Wales*. It has a fundamental role in facilitating the whole range of structural and process changes that are required to deliver a modern NHS in Wales. The impact of new policy developments is now considered under three headings:

- Organisational change.
- Clinical Governance.
- Changing approaches to healthcare.

## Organisational Change

3.24. Healthcare in Wales is changing because the strategic vision for the country demands far greater accessibility of health and healthcare services and far greater integration of those services with broader economic policies that impact upon health and well being.

3.25. In addition to these macro changes, there is also significant change within healthcare, and within the NHS in particular. This change has been driven by a number of factors, including:

- The need for greater democratic and professional accountability in health services delivery.
- The need to focus more directly on the quality as well as volume of care.
- The need to reduce unnecessary variation in the nature and quality of health services across Wales.
- The need to enable health and social care teams to work in a more integrated way across disciplines and organisations to provide patient-centred care.
- Maximising the contribution of all health professional groups and minimising the legacy of fragmentation from the internal market reforms of the 1990s.

3.26. All of these factors have led to major strategic programmes, which are vital, but which also place the health service

under pressure as health professionals and managers strive to continue to deliver day-to-day services while responding to the need for systemic change. This has brought into sharp perspective the need for better information tools and supporting technology to facilitate change and to support continuity of patient services during periods of change.

3.27. Key developments include:

- The restructuring of NHS Wales in 2003 to introduce new, more locally accountable, Local Health Boards, as well as two new population health-focused bodies – the Wales Centre for Health and the National Public Health Service.
- The introduction of new recruitment and retention policies to ensure the availability and quality of health professionals in the NHS in Wales.
- Innovative approaches to service configuration to help balance the increased specialisation of healthcare with the need to deliver healthcare as close to the patient's home as possible.

3.28. Each of these developments needs to be underpinned by high quality information, available when needed and suitably presented, and by systems to support the generation, analysis and sharing of such information.

## Clinical Governance

3.29. Clinical governance is a vital component in modernising the NHS in Wales. The process of establishing clinical policy and then monitoring compliance with it is the foundation for delivering safe and high quality services now and in the future. It represents a significant culture change within the NHS – with a far greater focus on the outcome of care – and the start of a new relationship with citizens as partners as well as patients.

3.30. There are many dependencies for the successful implementation and delivery of true clinical governance. One necessary, albeit not sufficient, condition is to have comprehensive and timely access to clinical information about patients. In fact, staff often have too little ready access to clinical information. Where it exists it is in paper form which is easy to collect but very hard to collate and analyse to support audit and to justify clinical performance.

3.31. The Commission for Healthcare Improvement concluded in its November 2002 overview of 175 clinical governance reviews in England and Wales to date that:

*"Doctors and nurses do not always have ready access to information ... which could help them treat patients more effectively. There is poor use of information and complaints data and there are too many breaches of confidentiality guidelines<sup>10</sup>".*

3.32. Until health professionals have secure access to all relevant information about their patients, and patients can be assured that their information is treated confidentially, any claim that we have moved to a truly clinically governed environment will ring hollow.

## Changing Approaches to Healthcare

3.33. The following sections describe some of the new models of care which are developing in response to *Improving Health in Wales* or to external factors such as new legislation. The key themes that underpin them are the need for more integrated service delivery; the need for more effective team-working and the need for better information sharing. The areas covered are:

- Continuity of Care in Hospitals.
- Managed clinical networks.
- Primary Care team working.
- Integration of primary and secondary care.
- National Service Frameworks for the delivery of healthcare services.
- Unified assessments by health and social care staff.
- Multi-disciplinary working.

### *Continuity of Care in Hospitals*

3.34. The introduction of the European Working Times Directive, and the subsequent reduction in hours worked by junior doctors, has led to new shift patterns in hospital treatment. Where previously the very long hours worked

by junior doctors provided continuity of care, there is now a need to facilitate handover of patients and their active problems between clinical teams as shifts change during the 24-hour day. Current information systems are too often inadequate or at least inflexible in managing this relatively new requirement, leading to problems as care is transferred. *Informing Healthcare* must ensure that suitable clinical systems are put in place to support continuity of care.

### *Managed Clinical Networks*

3.35. Managed clinical networks have developed in response to the need for hospitals to specialise more and more while retaining a sufficient catchment of patients to ensure that the quality of treatment remains high. This has led to a blurring of traditional team and organisational boundaries, and greater co-operation between health and social care teams whose members may be spread across many locations and a wide geographical area. As patients increasingly move outside the traditional single-hospital pathways of care, so it is necessary to ensure that information about them is able to move more freely and securely between professionals involved in their care. Existing ICT infrastructure and tools fall short of being able to support this, and *Informing Healthcare* must ensure that these shortcomings are rectified.

### *Primary Care Team Working*

3.36. Healthcare that takes place outside the hospital setting – delivered by GPs, community nurses, dentists, pharmacists, opticians and allied health professionals – must be co-ordinated around the patient as a seamless service if it is to be most effective. The historical development of community-based health services has led to organisational barriers as staff have been based in practices, hospitals and high street settings, each with their own set of clinical notes and patient records.

3.37. The introduction of Local Health Boards will support and develop closer working between these elements of community health services, and will facilitate greater co-operation between health and social care staff. However, true integration will require shared contribution and shared access to a common information base. The first step in modernising primary care information systems in Wales is well advanced through the ICT Foundation Project in General Practice. The challenge for the medium and long-term will be to ensure that all healthcare professionals operating in the community have access to good information, and that they are fully able to share information with each other to support better care for patients.

## *Integration Of Primary And Secondary Care*

- 3.38. While the challenges of providing integrated information within primary and secondary care services are immense, the problem of sharing information across health sectors must not be ignored. From a patient perspective, the journey from primary to secondary care and back is often fraught with frustration, poor communication and delay.
- 3.39. A root cause of these problems is that they involve a 'handover' of the patient between services. Currently, this is based solely on a summary – in referral and discharge correspondence – rather than on the basis of ongoing access to records. The quality of the information summary is then a constraint on the subsequent quality and efficiency of care. While improvements in the quality and speed of such correspondence would help immensely in the short-term, a long-term solution must facilitate the ongoing sharing of information between all professionals involved in caring for a patient, regardless of their health sector or organisation.

## *National Service Frameworks*

- 3.40. National Service Frameworks (NSFs) set standards for healthcare throughout a patient's journey, from initial primary care contact through hospital services and potentially community or social care services. The focus of each NSF is different – some are based on care groups (such as

Children or Older People), while others are condition-specific (such as Coronary Heart Disease). However, they all require the safe and appropriate transfer of information between teams of professionals in many disciplines across a range of healthcare settings. This transfer of information has historically been done on paper as a 'handover'. Now it is needed on a shared basis, electronically and in real time.

## *Unified Assessments*

- 3.41. Unified assessments take the integration of care a step further – bringing together professionals across health and social care to support patients and carers. Unified assessment thus requires co-operation not just across NHS settings but also across health and social services. Such joint activities are increasingly common, requiring the controlled sharing of patient information outside the NHS (and reciprocal sharing of social care data with the NHS). Current information systems have not, in general, been designed to support unified assessments, and problems often arise because of information incompatibility between systems. Access to NHS systems by social care staff (and vice versa) also raises issues relating to data protection and patient consent. These issues must be addressed quickly to ensure the efficient delivery of health and social care services in Wales.

## *Multi-Disciplinary Working*

3.42. A common feature of all of these new approaches is that they rely not just on organisations coming together but also on close co-operation and more flexible working between professionals from different disciplines. Where different professions may previously have kept their own records about a patient's care, it is increasingly necessary for many professionals to be able to access parts of a patient's record and share their findings with each other. This is especially important in fields such as Children's and Older People's Services where it is critical that a wide range of professional staff, often geographically dispersed, are able to share information quickly to make the best decisions for patients. The modernisation of information systems and processes is essential if such models of care are to be supported.

## 4. OPERATIONAL ISSUES IN THE NHS

### SUMMARY

*While change is needed to support future models of care, it is important not to overlook issues with the current health service. A stream of high profile enquiries has shown that it is often under-mined by long-standing and systemic problems. Many of these relate to the poor availability and use of information. Patients and carers can feel they are not fully informed about planned treatments. The current environment of fragmented information and confusion over the rules about who can share what with whom are putting health and well being at risk. Poor record-keeping undermines the quality of care. Antiquated paper-based systems are used to carry out sophisticated processes such as prescribing, putting patients at risk of avoidable mistakes.*

*The enquiry reports are powerful documents, but the informational problems they describe remain part of the day-to-day experience of patients and carers, health professionals and management decision-makers. For patients and carers, the experience may range from minor irritation through to actual harm as mistakes are made. For health professionals, care is often compromised by missing information or by the need to carry out laborious and paper-based administrative duties to support the care process. Management decision makers – both NHS managers and public health professionals – sometimes find that data currently abstracted from frontline care is often insufficient to support fully the judgements they need to make.*

*A long-term, sustained investment is required to tackle these problems and transform the health service into an information-rich environment in which high quality and responsive care can be delivered.*

### INTRODUCTION

- 4.1. Many current policy developments have resulted directly or indirectly from historical problems in UK healthcare. While these have often had much wider social and cultural implications, they serve to exemplify the deep-seated information problems faced by NHS staff and patients everywhere.
- 4.2. The following examples are designed to show the scale of the challenge but also the scale of ambition in *Informing Healthcare* to support the transformation of the health service. They are all concerned with specific enquiries and studies, but all have wider implications, especially regarding the use of information. They are:
  - *Learning from Bristol*; the Bristol Royal Infirmary Inquiry.
  - *Too Serious a Thing*; the review of children's services in Wales.
  - *A Spoonful of Sugar*; the Audit Commission report on medicines management.
  - National Confidential Enquiry into Perioperative Deaths (NCEPOD).

## LEARNING FROM BRISTOL<sup>11</sup>

- 4.3. The Bristol Royal Infirmary ('Bristol') Inquiry was set up in response to concerns about the unusually high number of deaths of children receiving cardiac care at the hospital. It uncovered an appalling sequence of events that meant that a number of children may have died unnecessarily because of shortcomings in their clinical care.
- 4.4. Alongside many recommendations about clinical accountability and service monitoring, the Inquiry made recommendations about the availability and use of information in clinical encounters across the NHS. Specifically:
- Care professionals must see patients as partners in clinical decision-making.
  - Patients and the public must be given timely, appropriate and tailored information about treatment and care in a way which is sensitive to their needs.
  - Patients must be given support to make informed decisions about consenting to treatment.
  - The NHS should ensure that it routinely seeks and acts upon feedback from patients about the quality of its services.
  - Investment should be made in high quality IT systems to ensure that NHS information is of the highest quality to support care delivery, clinical audit and

performance management of the NHS.

- 4.5. The UK government response to the Bristol Inquiry, *Learning from Bristol*, directly recommends significant investment in new information systems and skills, noting that:

*"Information and IT underpins delivery of the NHS Plan"<sup>12</sup>*

- 4.6. *Informing Healthcare* is designed to address these recommendations in Wales.

## TOO SERIOUS A THING

- 4.7. *Too Serious A Thing – the Review of Safeguards for Children and Young People Treated and Cared for by the NHS in Wales*<sup>13</sup> – complements the Bristol Inquiry in that it considers the whole span of health services across all settings for children in Wales in establishing how children can best be protected from abuse.
- 4.8. As with Bristol, it makes many significant recommendations about the organisation and management of children's services. It also makes many sharp observations and recommendations about issues relating to common standards and the availability and sharing of information between care staff.
- 4.9. In particular:
- The report expresses concern about the variation in policies and procedures for child protection across Wales, and recommends the adoption of a

common national set of policies and procedures, noting that such a standard would facilitate both clearer communication with the public and more straightforward clinical audit.

- It stresses the importance of joint working across organisational boundaries in support of the child, and the availability of relevant information to staff who need it.
- It notes that laws on confidentiality and data protection are not well understood, leading professionals to err on the side of caution. It concludes that:

*"It is no use holding large amounts of potentially useful information if it cannot be shared in order to protect the child's health."*<sup>14</sup>
- It draws attention to shortcomings in current information systems, partly through lack of investment and partly through a lack of standardisation in the use of codes between different organisations using the same child health system.
- It recommends that systems should be explored that support controlled sharing of information between health and social services staff.

4.10. Many of the wider issues raised can only be resolved by government policy

on children's services or by professionals working in the field. However, *Informing Healthcare* has a vital role to play in ensuring that information standards are set and deployed, that the rules for accessing information are clear and appropriate and that modern and corporate systems are maintained and/or developed in support of children's healthcare in Wales.

## A SPOONFUL OF SUGAR

4.11. This report examines the management of medicines in NHS hospitals in England and Wales, and concludes that the combination of greater patient throughput and availability of many more effective drug treatments means that current manual information and dispensing systems are no longer adequate. The report cites examples of prescribing and dispensing errors:

*"Most errors are caused by the prescriber not having immediate access to accurate information about either the medicine or the patient."*

(Audit Commission, *Spoonful of Sugar*, p23).

4.12. The report estimates that adverse drug events might cost the NHS in the UK £1.1 billion per year. It also cites evidence to suggest that improved information systems could avoid 78% of transcription errors that lead to such adverse drug events<sup>15</sup>.

4.13. The report recommends the following measures to overcome the shortcomings in current practice:

- The introduction of a standard nation-wide automated dispensary system.
- A national system for medicines coding and bar-coding.
- Introduction of Electronic Patient Record systems.
- Better co-ordination of primary and secondary care prescribing.

4.14. In effect, this report recognises that medicines management in the NHS is still reliant on paper or limited IT systems and human intervention, and that this reliance leads to errors. Its recommendations are important in that they aim to move the NHS to a culture of IT-based automated services, releasing staff to undertake more direct patient care and audit duties.

#### THE NATIONAL CONFIDENTIAL ENQUIRY INTO PERIOPERATIVE DEATHS (NCEPOD)

4.15. NCEPOD, which now operates within the National Institute for Clinical Excellence, aims to review clinical practice and identify potentially remediable factors in the practice of anaesthesia, surgery and other invasive medical procedures. Although focusing on patient deaths in hospital, it looks at quality of care rather than cause of death.

4.16. In its recent reports, NCEPOD makes a number of observations and recommendations that are important in considering the future of NHS information:

- Trusts and hospitals must establish systems to ensure that

all patients' medical records are always available to care professionals.

- There should be a uniform casenote system in the NHS.
- All Trusts in the NHS should use information systems with a nationally agreed specification.

4.17. NCEPOD is highly critical of current records management, 'deploring' the lack of a standard format for patient records and commenting:

*"It is with some trepidation that NCEPOD imagines how Electronic Patient Records will progress if the problems with the content and retrieval of manual casenotes are anything to go by."*

(NCEPOD 2001, p23).<sup>16</sup>

4.18. It is clear that the strategic development of the health service in Wales will require the introduction of electronic records for patients – paper records simply cannot sustain a service which is multi-disciplinary team based, geographically dispersed and driven by the need for quality and reliability of care. *Informing Healthcare* must respond to the challenge set by NCEPOD to ensure that electronic records can be introduced that improve significantly upon the paper-based status quo.

## DAY-TO-DAY ISSUES WITHIN THE NHS

- 4.19. While large-scale inquiries into NHS problems are valuable in highlighting the need for investment and change, there is also a need to consider carefully the shortcomings in day-to-day processes in the health service.
- 4.20. The health service in Wales is both huge and complex. It is constituted from a wide range of national, local, statutory, contractor and voluntary organisations, with intricate networks that span a wide range of welfare services. It is supported by over 70,000 staff, operating from hundreds of locations. It spends over £3.5 billion per annum to provide a wide range of services for the 3 million residents of Wales.
- 4.21. In spite of this complexity, its goal is relatively straightforward – to help individuals with health problems to be free from pain and disability, to be independent, creative and productive and thereby support the prosperity of Wales. It is important to recognise the scale of its activities and achievements in doing this every year.
- 4.22. In spite of its successes, problems still exist within the health service. They are caused by fragmentation, by processes that have evolved rather than being designed, and by a chronic lack of timely and relevant information. Solutions to problems in one part of the health service can often amplify problems elsewhere as unintended consequences develop. Some of the daily issues that occur in

this massive and complex system are described below from the perspective of patients and carers, health professionals, managers and public health professionals.

### PATIENTS AND THEIR CARERS

- 4.23. Notwithstanding the best efforts of staff, there is a lack of good and accessible information for patients and their carers to enable them to:
- Know what is wrong with them.
  - Know the options for treatment.
  - Have the evidence to make the right choice.
  - Know what will happen next and in future.
- 4.24. Patient journeys can go wrong because standards and processes are not in place to ensure that the NHS and its partner organisations get things right first time. This can cause problems ranging from irritation about delays through to risks to their safety through clinical errors. Some examples include:
- Wasted journeys because records are mislaid.
  - Frustration as the same information is requested again and again.
  - Inconvenience and discomfort through repeat tests when results are lost.
  - Anxiety through lack of continuity and clear explanation.
  - Incorrect treatment due to misidentification or misdiagnosis.

4.25. Recent research has also confirmed that patients sometimes have very little time with doctors once they gain access to them. The UK average length for GP consultations is less than ten minutes<sup>17</sup> and has been estimated to be similar for outpatient appointments. Research in UK outpatient clinics<sup>18</sup> has suggested that over 40% of the appointment time can be taken up on administration, disturbances from outside such as phone calls, or simply trying to find records or results.

4.26. Thus, the patient journey through the system can be lengthy, disjointed and confusing. Each step through the care process can be subject to administrative delay, repetition of information requests, loss of information, human error and other adverse events. To put this in stark context, the Department of Health has estimated that 1 in 10 hospital admissions leads to harm to patients in the UK, and costs an estimated £2 billion per year<sup>19</sup> in extra care, in addition to the costs of any subsequent litigation by patients. No estimates are available for harm caused to patients outside the hospital setting.

## HEALTH PROFESSIONALS

4.27. The current health service is not only responsible for poor experiences for some patients. Staff also suffer the frustration of missing information, missing results and missing records. They have to chase up appointments that appear not to have been made and correspondence that seems not to have arrived. While the situation is often

bad for primary care and hospital doctors, it can be even worse for nursing, therapies and peripatetic staff who may have no access to a patient's history and records at all other than from their own note-taking. Staff who have trained for many years to be clinicians often find themselves doing administrative tasks for a third of their working day<sup>20</sup>.

4.28. Thus, the biggest information issue for health professionals is simply to gain access to what they need to know to support their day-to-day work. In this respect, healthcare has fallen behind the rest of the economy over the last twenty years by failing to provide information technology tools in the workplace fast enough.

4.29. For health professionals who do have access, they often have information systems which, though they were and are perfectly adequate for their original purposes, are now unsuited to help them work in the more integrated and team-based environment that is required in modern healthcare.

4.30. There is continued reliance on multiple paper and, sometimes, electronic patient records which:

- Fragment information about the patient.
- Can often only be used by one person at a time.
- Are prone to errors and misreading.
- May even refer to a different patient with the same name.

4.31. Such problems are demoralising and time wasting, and they detract from the time and quality of care that health professionals can offer patients. Implementation of *Informing Healthcare* must seize opportunities to tackle problems such as:

- Laborious paper-based ordering processes for tests and X-rays (which can consume a third of the working day for some junior doctors).
- Delays in getting results because they are paper-based.
- Time-consuming recording by hand in patient notes.
- Errors caused by poor access to timely information.
- Difficulty in managing and auditing their individual and team caseload.

#### **PUBLIC HEALTH PROFESSIONALS**

4.32. It is of equal concern that high quality clinical data is not accessible to public health specialists. Provision of rich clinical data would support a range of epidemiological activities including:

- Early spotting of health trends in the population (e.g. any increase in the prevalence of asthma or diabetes).
- Monitoring of geographical patterns in hospital admissions that might suggest the existence of new or localised health hazards.

- Local analysis where particular health concerns have been raised by local communities (e.g. siting of mobile phone masts, incinerators and waste tips).

#### **MANAGERS**

4.33. Information and system problems in operational healthcare affect patients and health professionals in their immediate interactions. However, they also have a much wider impact as information derived from individual patient care is used for a wide range of purposes.

4.34. Currently, there are several problems with the flow of information from delivery of care to individual patients through departmental and organisational management and outwards to the commissioners of care (e.g. Local Health Boards, Health Commission Wales), to watchdog organisations (e.g. Commission for Healthcare Improvement, Community Health Councils) and to national government level.

- Most clinicians record information in paper records. The coding of this information into computer datasets is undertaken by skilled coders, but there is often no ownership or quality assurance of this data by the clinicians who generate it.
- Information is largely generated from inpatient episodes of care. There is little flow of information from outpatient, community or primary care for wider planning use.

- There is significant local variation in the use of definitions and codes for particular activities and conditions, making accurate comparison difficult.
- Most of the 'healthcare' information available tends to be administrative rather than care focused.

4.35. Poor availability of information for managers is serious. It hinders the ability of a range of organisations to carry out their statutory duties. The NHS in Wales has received considerable additional investment over the past few years and yet managers are often unable to state what the outcome of that extra investment has been. It constrains performance management and the benchmarking of NHS organisations as any information is often not collected on a consistent basis and is therefore not comparable. Planning in the NHS requires information about where investment is required to meet health needs and should be based on an evidence-based case for appropriate resources to meet growing population healthcare needs. It is also necessary to demonstrate that care is cost effective.

## CONCLUSION

4.36. There is clear evidence of day-to-day information and communication problems in the health service for patients and carers, health professionals and managers. It is important to recognise that these

problems are largely systemic – related to the nature of the system – rather than due to failings on the part of those who work within the system. Solutions to such problems require sustained investment and effort over the long-term. This strategy provides the framework within which this work can begin.

# THE VISION AND WAY FORWARD



## 5. A VISION FOR THE FUTURE

### SUMMARY

*Informing Healthcare is based on a vision of patients, carers and professionals working together, supported by the latest evidence, to reach agreement on appropriate and cost effective healthcare for the patient. It states that the resulting decisions and actions – referrals, tests, treatments, discharge – should be transparent and open to evaluation, that outcomes should be recorded and used to improve services and that the whole health transaction should be carried out in a secure and confidential way.*

*Achievement of this vision will require long-term commitment, and the learning of lessons from previous technology-assisted change programmes which have often faltered. Principles have been set down for Informing Healthcare implementation to help avoid such pitfalls. In particular, the strategy will pursue a corporate and health economy-wide approach and will seek to achieve benefits quickly and incrementally. It will be underpinned by strong project management, will make best use of existing systems and resources, and will adopt a robust approach to ensuring that organisations are ready for ICT investment.*

The strategy will be focused on five key benefit areas:

- *A single integrated electronic health record for every patient.*
- *The empowerment of the workforce through information literacy and IT tools.*

- *The empowerment of patients and carers through shared decision-making about care.*
- *Service improvement, supported by technology.*
- *High quality knowledge and information management.*

5.1. This chapter sets out the basis of *Informing Healthcare* in four sections:

- Introducing the vision.
- Principles.
- Scope and relationship to other strategies and initiatives.
- Benefit areas.

### INTRODUCING THE VISION

5.2. The vision at the heart of this strategy is simple. It is about enabling health professionals and patients and their carers to come together to deliver the best possible care for the patient, and the best possible health-related quality of life thereafter. The decision-making process should be informed by:

- Shared knowledge of the patient's expectations and circumstances.
- Shared knowledge of the patient's condition and care history to date.
- Shared knowledge of the treatment options and their risks and benefits.
- The experience and knowledge which each party brings to the discussion.

- 5.3. It will be vital to ensure that the processes of care are centred around the patient, and that they are carried out as efficiently and safely as possible. There is growing recognition among care professionals that new approaches to healthcare have the potential to increase care quality and effectiveness, as discussed in Chapter 3.
- 5.4. *Informing Healthcare* aspires to ensure that:
- Health decisions are evidence-based, with proper patient involvement, and open to scrutiny.
  - Health actions are recorded and open to evaluation.
  - Health outcomes are recorded and used to inform better practice.
  - Health information is held securely and confidentially, in line with the patient's wishes.
  - Health information is available when and where it is needed to support the practical delivery of healthcare to patients and the improvement of health.
  - Health information supports investment planning.
- 5.5. Information collected as part of the care process will, in a suitably aggregated or anonymised form, provide the foundation for many activities in the health service from clinical audit through to national service planning and population health improvement.
- 5.6. Achieving the vision described here will enable the NHS and its partner organisations to operate within a fully supported evidence-based culture. Patients will be assured that they are receiving treatment that is informed by up-to-date best practice. Health professionals will know that they have state-of-the-art information tools at their disposal, and that these tools genuinely support modern and multi-disciplinary models of care. Healthcare managers will be able to work more closely with clinical colleagues, sharing a common set of information about clinical practice.

## PRINCIPLES

- 5.7. *Informing Healthcare* is being introduced into a health service in which everybody has some experience – whether as a patient or a member of staff – and therefore legitimate preconceptions about the value of strategies for technology-assisted change. They will therefore rightly expect that problems from the past have been considered and lessons learned.
- 5.8. The initial draft of *Informing Healthcare* – produced by the Information Task and Finish Group – set out a vision and a series of actions to achieve that vision. Subsequent consultation suggested that people would like to see explicit reference to the principles underlying the strategy to demonstrate the learning process. We have done that and provided additional material to show the

thinking behind the approach being adopted.

5.9. The principles are set out here, together with an indication of how they will affect strategy implementation. More detailed points are addressed in later chapters on specific benefit areas.

- A whole health economy approach.
- A corporate approach.
- A long-term investment strategy.
- An incremental approach to implementation.
- Building from strength.
- Building on standards.
- A strong project management culture.
- Ensuring readiness.
- Providing access for all.
- A secure and confidential service.

### **A WHOLE HEALTH ECONOMY APPROACH**

5.10. *Informing Healthcare* is intended to support the health and healthcare community in its work across the whole health economy of Wales. This includes patients and carers as well as staff working in primary, secondary, community, social care and voluntary settings. Furthermore, it is not organisation-focused. Organisational boundaries are increasingly irrelevant in healthcare delivery in Wales, and the strategy seeks to support new models of care and ways of working rather than perpetuating outdated approaches. In particular, the strategy

will seek to support the integration of healthcare teams working across multiple settings for the benefit of patients.

5.11. This does not mean that sector and organisation-specific developments will be discouraged. On the contrary, there are many vital developments in primary care ICT that are either ongoing – for example, the ICT Foundation Programme in General Practice – or which require significant attention – for example, the provision of access to other primary care practitioners such as nurses, dentists, pharmacists and opticians. Equally, there are many urgent requirements in secondary care, and in links between health and social care, that must be developed.

5.12. It does mean that the long-term strategic focus must be on delivering an integrated approach across the whole health community, and that investments will be scrutinised to ensure that they are working towards this goal.

### **A CORPORATE APPROACH**

5.13. *Informing Healthcare* is a corporate strategy. This means that it will be undertaken by the Welsh Assembly Government, the NHS in Wales and partner organisations acting together collectively to achieve the best outcome for health and healthcare in Wales. The reasons for behaving in this way are both healthcare-related – the need to ensure that high quality services exist across Wales – and economic – the need to deploy

resources to get the maximum return on investment in terms of healthcare benefits.

- 5.14. A corporate approach means that health professional stakeholders across Wales can gain proper oversight of and engagement with the strategy, and can in turn be empowered by it. It also means that the NHS and its partners can act more effectively and efficiently in relation to suppliers<sup>21</sup> and can organise human and technical resources efficiently to maximise delivery and job satisfaction.
- 5.15. 'Corporate' does not mean 'centralist', but rather 'collectively, as one body'. Solutions to problems should be found by stakeholders from across Wales working together. The governance arrangements for planning and managing the implementation of *Informing Healthcare* – the Strategy Implementation Programme – have been crafted to enable this. These solutions will then be deployed in common across Wales using corporate resources. Local research and innovation will be encouraged and supported within the corporate framework, provided that it is designed with the long-term goal of delivering benefits to all stakeholders across Wales.

#### **A LONG-TERM INVESTMENT STRATEGY**

- 5.16. As noted above, change strategies supported by technology have often run into problems due to affordability. The scale of investment required to

deliver change is often more than health service stakeholders are prepared or able to make. Alternatively, investment is made but then interest and belief wanes in the medium term as benefits prove harder to achieve than originally envisaged.

- 5.17. *Informing Healthcare* will require a long-term financial commitment, but this commitment will need to grow in an incremental way over time to ensure sustainability. The strategy sets out five areas where change is needed and it is vital that these are developed in a balanced way. Large-scale investment before the health service is ready will just lead to disillusion and doubt, and will not bring about sustainable change.
- 5.18. Funding has been made available in 2003/04 to initiate *Informing Healthcare* and ensure that urgent projects can get under way. Longer term funding for the strategy will be reviewed annually on a rolling basis through the annual Budget Planning Round.

#### **AN INCREMENTAL APPROACH TO IMPLEMENTATION**

- 5.19. *Informing Healthcare* and its implementation are designed on the basis of lessons learned from a decade or more of attempts to introduce new information technology into the NHS. A strong message in the consultation process was that a grand and expensive vision, where benefits are delivered only after many years of cost, should be avoided. The implementation

of *Informing Healthcare* will follow an incremental path, whereby the cycles of investment and benefit delivery will be much shorter than in previous strategies. Projects which can deliver strategic benefit without massive up-front investment will be prioritised so that widespread commitment to the strategy is gained through results rather than faith. This will facilitate the building of confidence in key stakeholders and, just as importantly, deliver early benefits to health professionals.

5.20. Previous technology-related strategies have often promised massive benefits in return for massive investments. Usually, the massive investment is needed first and the expected benefits are delivered later. This has led, on the whole, to three main outcomes:

- Stakeholders who have been asked to make a leap of faith and a huge investment conclude that the risk is too great and fail to provide adequate funding, causing the strategy to fail.
- Stakeholders fail to sustain funding or even reduce it, leading to patchy or incomplete implementation where some organisations and staff groups gain benefits and others do not.
- Stakeholders persist with the investment but then fail to get the promised benefits, causing disillusion in the potential of new technologies to improve health services.

5.21. There have been many significant project successes in health, where benefit has been delivered. The fact that many health organisations could no longer run without information systems support is indicative of this. However, the widespread perception remains that technology-assisted change in healthcare fails far more often than it succeeds.

### **BUILDING FROM STRENGTH**

5.22. Although the strategy makes clear that there are systemic information problems in the NHS in Wales, there are also many examples of good practice and developments that support the implementation of *Informing Healthcare* both nationally and locally. These include: the ICT Foundation Programme for GPs; the Health Of Wales Information Service (HOWIS); the Information Quality Programme and the EDICT programme for education and training in ICT.

5.23. In addition, NHS Wales has a long track record of delivering information systems on a corporate all-Wales basis. In recent years, the ICT Foundation Programme for GPs has dramatically reduced the variety of systems in use in general practice from twenty six down to ten, which are all now accredited to national standards. There are many healthcare services in Wales where corporately procured information systems are in common or universal use. These include :

- Audiology.
- Child Health.

- Finance.
- DAWN telecommunications network.
- Human Resources (Electronic Staff Records).
- Pathology.
- Pharmacy.
- Primary Care – screening, registration and contractor payments.
- Radiology.
- Wales Administrative Register.

5.24. It will be important to secure these systems and build upon them, and also to seek out other more local initiatives that might have potential to be expanded across Wales as the *Informing Healthcare Strategy Implementation Programme* is developed. The solid base provided by such systems will give Wales a head start in moving towards a common ICT platform for healthcare. Careful management of this legacy will ensure that systems are retained where they continue to provide value and are replaced – corporately – when it is appropriate to do so.

### **BUILDING ON STANDARDS**

5.25. Adherence to corporate information standards in Wales has been patchy in the past. This is partly because organisations have focused on their own information needs and have therefore developed 'local' standards and definitions and partly because the performance management of new and developing standards has been compromised by lack of investment

funds to support changes in underlying information systems. This has led to continuing problems with the assessment of the performance of the health service and the organisations within it.<sup>22</sup>

5.26. In future, it will be vital both that information standards keep up with modernised services and new ways of working and that all organisations comply and keep up with published information standards. In the long-term, information standards in Wales will be managed within the UK Information Standards Board (ISB) framework. Wales will be an active participant in and adherent to developing UK-wide standards in all but exceptional cases where divergence of wider health policy requires a different approach in Wales.

5.27. Below the umbrella of ISB sign-up, it is vital that health organisations in Wales adhere to nationally agreed standards in a number of complex technical and information areas. These include:

- Interoperability.
- Security.
- Data definitions.
- Clinical coding.
- Record management (manual and electronic).

### **A STRONG PROJECT MANAGEMENT CULTURE**

5.28. Good project management is vital to strategic success. There are three fundamental reasons for this. Firstly, the discipline imposed by the PRINCE<sup>23</sup> project management methodology

ensures that proper stakeholder oversight and involvement is initiated and maintained. Secondly, clear and agreed project briefs support clear expectations in the customer community. Thirdly, strategic credibility rests upon the ability to deliver projects on time and within budget

- 5.29. It is generally accepted that there are too few qualified project managers available to the health service in Wales, and it will therefore be imperative to 'grow' a project management culture. The first step towards such a culture will be the establishment of a Programme Support Office to act as a collective resource for strategy implementation and as a centre for the development of project management excellence in NHS Wales.

### ENSURING READINESS

- 5.30. The most commonly cited cause of technology-related project failure is the failure to prepare the ground in an organisation before implementing the change process and introducing new technology. *Informing Healthcare* has acknowledged this by introducing a Readiness Framework as part of the overall Strategic and Financial Framework for Wales. Organisations in NHS Wales will be tasked with ensuring that a broad range of issues are addressed – usually in areas where best-practice already exists in Wales – before they undertake significant investment in support of *Informing Healthcare*.

- 5.31. The Readiness Framework is published as part of the *Informing Healthcare Strategy Implementation Plan*.

### PROVIDING ACCESS FOR ALL

- 5.32. *Informing Healthcare* is committed to ensuring as quickly as possible that all healthcare staff who need access to patient information to provide care will be able to get it whenever and wherever they need it. They should also be able to do so through an interface which is manifestly an NHS Wales standard, and integrated across applications, reducing the need for organisation or department specific training each time an individual moves to a different job or service location. In moving incrementally to this vision, priorities for staff access can be set according to delivery of healthcare benefit. Previous strategies have left a legacy of uneven access to ICT resources. This is partly a consequence of approaches to infrastructure being fragmented by organisation-based initiatives and partly a reflection of the differing priorities that have been afforded to different healthcare sectors historically. In particular, peripatetic and junior staff have often found it difficult to gain access to resources.

### A SECURE AND CONFIDENTIAL SERVICE

- 5.33. Both public and professionals are concerned that the introduction of electronic health records across Wales might lead to inappropriate access to records by so-called 'hackers' or by

overly curious staff. They are equally concerned that electronic records, on which they will grow to depend, might be rendered temporarily unavailable by power cuts or system failures.

- 5.34. *Informing Healthcare* applications will be implemented according to the best available practice in the protection of healthcare information. All users – whether healthcare professionals or patients – will be individually identified, authenticated and profiled to establish what rights of access they have to patient records and how much they are able to see within any given record. All actions will be audit trailed and any breaches of confidentiality will be notified to senior clinical guardians.
- 5.35. Patient information will be stored securely in externally audited data centres, which will have appropriate back-up and disaster recovery facilities. All organisations providing staff access to patient records will be audited to ensure that they comply with latest best practice on information access.
- 5.36. All staff accessing *Informing Healthcare* applications will receive full training in the implications of confidentiality law and best practice in implementing it. A full code of conduct for staff will be introduced, with disciplinary penalties where this code is not followed.
- 5.37. All NHS 'legacy'<sup>24</sup> information systems will also be reviewed to ensure that they meet best possible practice in the

proper protection of patient information.

- 5.38. Breaches of confidentiality and security will be the greatest risk to the credibility of the *Informing Healthcare* programme, and all reasonable steps will be taken to ensure that they do not occur.

## SCOPE AND RELATIONSHIPS WITH OTHER STRATEGIES

- 5.39. The scope of *Informing Healthcare* is necessarily broad as it will underpin the transformation of working practices that are at the heart of health and healthcare provision. In moving forward it will be vital to ensure that there is close integration between developments stemming from *Informing Healthcare* and wider strategic developments in the five benefit areas. It will also be important to establish clear lines of responsibility where interdependencies between *Informing Healthcare* and other strategic activities and projects exist. The following sections set out the key interfaces.

## INTERFACE WITH FOUR COUNTRIES ICT STRATEGY

- 5.40. ICT strategy in England and the other UK countries is developing in parallel with *Informing Healthcare*. Close links are maintained through the UK Countries IM&T Forum. While there are different priorities and approaches between the four countries, there is a clear imperative to ensure common information standards and interoperability between ICT systems so

that the free flow of patients across borders is not affected. This will primarily be achieved through common information standards. From time to time, it may also involve common systems procurements where these are seen to be advantageous to more than one country without compromising strategic objectives and timetables. The Electronic Staff Record and other shared service initiatives are good examples of this.

### INTERFACE WITH SOCIAL CARE INFORMATION STRATEGY IN WALES

5.41. The long-term goal in Wales is to develop the effective integration of health and social care records, and *Informing Healthcare* is designed to support that goal. The Welsh Assembly Government has concluded that while it is appropriate now to align ICT strategy across health and social care services in Wales, full integration of a single health and social care record should remain a longer-term vision. There are many reasons for this, but first amongst them is the requirement for professionals in both domains to debate the issues and agree the process and timescales by which such an integration should take place.

5.42. Instead, the relationship will be developed along the following lines:

- All developments in relation to electronic records in Wales in either health or social care will be undertaken in such a way as to be consistent with eventual

convergence between health and social care records.

- ICT leads for health and social care will meet regularly to discuss options for greater joint working wherever it is appropriate.
- Strategies in both domains will seek to ensure inter-operability between systems and a parallel strategy to *Informing Healthcare* will be developed for social care in full partnership.
- Where appropriate, staff from health and social care will be granted access to each other's systems on a controlled and 'need to know' basis where this is necessary for the proper management of patient or client care. Protocols to determine the rules of information sharing are being set in place as a first step towards a fully integrated security and confidentiality model.

### INNOVATIONS IN CARE

5.43. Innovations in Care has undertaken significant recent work in the improvement of care processes in Wales. In practical terms, there is much that can be learned from close alignment between *Informing Healthcare* and Innovations in Care. This theme is pursued further in the chapter on Service Improvement. Ongoing discussions will ensure that activities are fully integrated where appropriate.

## DIAGNOSTIC SERVICES STRATEGY

- 5.44. The Diagnostic Services Strategy in Wales is responsible for developing the most appropriate future configuration of services such as, but not limited to, pathology, radiology and tele-diagnostics on an all-Wales basis. As the strategy is still under development, its recommendations and timescales are not known at the time of writing.
- 5.45. *Informing Healthcare* has within its scope the maintenance and development of information systems to support diagnostic services, and its plans are therefore dependent on the outcome of the Diagnostic Services Strategy. It will be important to ensure that there is full alignment between any planned service reconfiguration and any systems procurements that are required either to achieve strategic goals or to overcome legacy management problems.
- 5.46. For the avoidance of doubt, it is now accepted that strategic decisions in the following areas of activity will fall to the Diagnostic Services Strategy, with *Informing Healthcare* responsibility being limited to ICT support for the implementation of those decisions:
- Pathology services configuration.
  - Radiology services configuration.
  - Picture Archiving and Communications Systems strategy.
  - Telemedical diagnostic services.

## BUSINESS INFORMATION SYSTEMS

- 5.47. In addition to information systems to support direct care, the NHS in Wales is developing systems for business support information. Twelve of the NHS Trusts have procured the same financial system sharing a common chart of accounts. This system will be further developed, for example, to add electronic procurement across each of the Trusts.
- 5.48. NHS Wales will also introduce a unified Human Resources system that will include Electronic Staff Records (ESR) for all NHS staff over the next three years. This implementation is part of a joint project with NHS England. This system will eventually be integrated with the financial system to create a common business platform for the NHS. The advantage of having common and familiar screens across the NHS to access purchasing and personnel data will empower staff working in the NHS. It will be important for these to integrate with the clinical systems developed through *Informing Healthcare*.

## BENEFIT AREAS

- 5.49. In order to realise the vision of *Informing Healthcare* and the benefits associated with it, investment and change management will be required across a wide range of NHS activities. This strategy will focus on the achievement of goals in five key 'benefit areas':
- A single integrated electronic health record for every patient.

- Empowerment of the workforce through information literacy and tools.
- Empowerment of patients and carers through shared decision-making about care.
- Service improvement, supported by technology.
- High quality knowledge and information management.

5.50. In the following chapters, each of these is now discussed in more detail to show how *Informing Healthcare* will support transformation of the health service in Wales. Each chapter sets out the reason that the benefit area is important ('Why?'), the methods by which it will be approached ('How?'), and the benefits that will result.



## 6. A SINGLE RECORD

### SUMMARY

*The most significant cause of current information problems in the NHS is the lack of a holistic patient record that is accessible to those who require the information, including patients and carers. Fragments are held by many professionals in many settings but none have access to the whole record. Patients rarely get to see even the fragments of the record. The impact of this is both pervasive and damaging to integrated health and social care.*

*The concept of the Single Record is designed to overcome these problems. It does not mean that all information will be held in one place, but it does mean that health professionals will be able to access all the information they need, but only the information they need, about a patient whenever and wherever they need it. This access will take place in a secure environment, and profiling of users will ensure that it is limited to what any given professional needs to know.*

*The benefits of the Single Record will be seen directly in healthcare delivery. Less time will be taken up in searching for information or paper-based administration; more time will be available for patients. Greater sharing of information across health sectors will provide many opportunities for service improvement, and patients accessing their own record will be able to play a greater role in their own health maintenance and improvement.*

*The eventual goal is the development of an integrated approach to health and social care records, and Informing Healthcare is designed to be consistent with that goal.*

### WHY 'A SINGLE RECORD'?

- 6.1. *Informing Healthcare* is based upon a holistic view of the health service. Its goals are not achieved until patients are able to return to the best possible daily life, having received speedy and high quality treatment within the system. Patient records, which act as both the driver for activities in the system and as a medico-legal record of those activities, should be comprehensive and should reflect both the whole patient journey for an episode of care and relevant information from previous episodes.
- 6.2. Record-keeping in the NHS today suffers from two main shortcomings. Firstly, it is based around fragments of the patient experience within a given healthcare organisation or even a given discipline within an organisation. Secondly, it is largely paper-based and thus suffers from all of the practical difficulties associated with paper records in any walk of life. In health, these problems are made worse by the complex, multi-disciplinary and geographically dispersed nature of the care process.
- 6.3. From a patient perspective, the difficulties of the current approach to records are obvious:
  - The constant need to repeat even the most basic information to each new professional they meet.
  - Situations where the record is not available and professionals

have to rely on patients for information.

- In a recent international survey, which included the UK<sup>25</sup>, in up to 1 in 4 outpatient consultations important information such as records or results had not arrived on time.
- This research also suggests that around a quarter of patients report that they have received conflicting advice from different professionals in their care process. Around 1 in 10 patients think they have been sent for duplicate tests, either because results are missing or because of administrative deficiencies.

6.4. Whilst these problems are most acute and discomfiting for patients and carers, they are also reflections of problems faced by health professionals, who have developed coping mechanisms because of the limitations of available clinical information.

6.5. In short, a new approach to record-keeping is needed in Wales because the current system is simply no longer appropriate to support current and developing models of healthcare and inconsistent with a commitment to high quality and responsive patient care. It is increasingly unacceptable that healthcare decisions have to be made in the absence of relevant information, simply because that information is not in the right place at the right time.

## HOW?

6.6. The vision in Wales is that health professionals and patients and carers will be able to access all of the information relevant to healthcare decisions whenever and wherever it is needed. This vision has been expressed in the phrase 'Single Integrated Electronic Health Record' or 'Single Record' in common use. Each of these five words has a purpose, and each is further explained below:

### 'SINGLE'

6.7. 'Single' means that patients should be uniquely and correctly identified. It is quite possible in current health information systems for a patient to have multiple identities and multiple records which are not linked in any way. This may be because they have been treated in several places or because they have changed address or because their details have been inaccurately entered. Their records may even be confused with those of another patient with the same or similar name. In order to provide the highest quality healthcare, it will be important to identify everybody uniquely. This will be done using the NHS number as the master index.

### 'INTEGRATED'

6.8. 'Integrated' means that all relevant health information about patients, subject to stringent safeguards, should be accessible to health professionals treating them. The same facility should be available to patients themselves, or their carers if they wish it. All should

have access wherever and whenever the information is needed. It is currently not possible for parties to any given health record to know that they have all relevant information. This can sometimes lead to problems and on rare occasions has had tragic outcomes, where, for example, co-morbidities have not been recognised or key test results have not been seen. 'Integrated' does not mean that the whole patient record will be held in one place, but it does mean that the whole record should be available (subject to access rights and rules on sensitive information) to a health professional, a patient or carer from one place.

#### **'ELECTRONIC'**

- 6.9. 'Electronic' is self explanatory to an extent, and covers a variety of electronic media, including digital images, audio and video clips. It is vital to point out that new models of care and approaches to monitoring the quality of care will simply not be possible unless information is held electronically. It is not feasible to have paper-based information instantly available to a range of health professionals in a range of settings.

#### **'HEALTH'**

- 6.10. The purpose of health services is to improve, maintain or restore good health. It is therefore important to focus the record on the outcome of care and key indicators of progress as much as on the care process itself. In future, people may use their health

record to self-monitor key indicators such as weight or blood pressure over time or even to help them to reduce risky behaviours relating to drug or alcohol consumption or smoking.

- 6.11. Although the integrated 'health and social care' record is beyond the current scope of *Informing Healthcare*, the strategy will aim to maximise operational sharing of information across health and social care and will actively support convergence towards a fully integrated record. In particular, the Single Record in health will enable electronic sharing of information between health and social care systems (subject to information sharing protocols), which will enable patient/client information exchange during the Unified Assessment Process.

#### **'RECORD'**

- 6.12. Existing health records have two main purposes – they act as an information base for health professionals and they act as a medico-legal record of the care provided. While many new applications may develop as citizen access to health records is developed, it is imperative that both of the current applications of the record are properly maintained and supported in future.

- 6.13. When it is completely implemented, the Single Record will be:

- An electronic and structured set of health information based around an individual's health and care status and encounters across

all healthcare sectors and settings.

- Accessible from a wide variety of locations by the patient or care professional, given appropriate security and access rights.
- Organised primarily to support continuing, efficient and quality care across the complete patient journey.
- Protected by secure profiles which will ensure that access is on a 'need' basis and that the patient is aware of who can see what information.
- Secure, with an audit trail of all individuals who have accessed the record and their interactions with it.
- Added to both by health professionals and patients themselves.
- A replacement for existing paper records and used as a medico-legal record as well as a health record.

## BENEFITS

6.14. The benefits that will derive from the introduction of the Single Integrated Electronic Health Record in Wales are far-reaching, and include the following:

- Patients can enter the NHS and its partner organisations at any time and in any location and be assured that necessary

information about them will be available to those caring for them.

- Patients will be confident that both their current health circumstances and their beliefs, wishes and expectations about their care are available to those health professionals currently treating them, without the need for constant and frustrating reiteration.
- Care can be fully integrated between health professionals; all members of the care team in primary, community and secondary settings will know precisely where the patient is in their journey through the NHS and its partner organisations regardless of whether the patient is in hospital, in the GP practice or community based.
- Patients will be able to access their record and ensure that any errors or misunderstandings are corrected quickly.
- New models of care – integrated care pathways, managed clinical networks, changing organisational and professional roles – can be properly supported in a way which is impractical or impossible with a fragmented record base.
- It will be more straightforward for health professionals to more actively manage practice and caseload populations to prevent

future illness or to ensure that chronic disease is appropriately managed.

- The outcome(s) of care can be recorded in a consistent way, signalling when a care intervention has ended; what kind of ongoing support is needed; and whether the intervention worked or not.
- In governance terms, healthcare teams will be able to satisfy themselves that they have access to all relevant information about their patients. Clinical audit is currently hampered by the need to track down paper records and extract relevant information. This can be especially difficult on a multi-site basis. The provision of good quality information will enable audit to focus on analysis rather than collection of information.
- There will be a 'common look and feel' to health record systems across Wales, making it much easier for the increasing number of health professionals who operate across multiple organisations and for those changing jobs. Preparedness to use electronic systems, as opposed to personal paper notes, will increase.
- Information systems training costs will be reduced as all health professionals will be learning similar tools and techniques.



## 7. WORKFORCE EMPOWERMENT

### SUMMARY

The implementation of *Informing Healthcare* will involve significant changes for the workforce, both in developing new skills and finding new ways of working. The exploitation of high quality information is likely to become more central to clinical culture and to consultations with patients.

The new skills required will range from basic IT and information management skills through to sophisticated critical appraisal techniques and statistical analysis. *Informing Healthcare* will ensure that the right balance exists between the core skills that all health professionals should have and the availability of specialist health informaticians to undertake more complex tasks.

The benefits from Workforce Empowerment will be manifold. Staff will be able to take advantage of new productivity tools to improve their working life. They will be able to communicate much more efficiently through e-mail. Patients will benefit as staff are able to use automated tools to facilitate patient transfer between clinicians and to provide services such as prescribing which will have in-built safety checks. Most importantly, evidence-based healthcare will become a reality as health professionals are able to access and use the latest evidence and best practice routinely.

### WHY 'WORKFORCE EMPOWERMENT'?

7.1. There are three inescapable truths about the response needed to alleviate the existing problems and developing

pressures facing the Welsh health service, and indeed many health systems around the world:

- Comprehensive cultural change is required.
- The necessary change can only be brought about in a sustainable way by the staff operating at the frontline of patient care.
- In order to bring about change, staff will need time to step back from day-to-day activities and reflect upon the opportunities for service improvement and may then need to develop new skills to implement it.

7.2. Thus, *Informing Healthcare* talks about Workforce Empowerment because it is based on the belief that staff will need both time for reflection and the new skills and new tools associated with the Information Age to help them to deliver service improvements to patients and carers and service-wide improvements for the people of Wales.

7.3. Elwyn and Charles (2001)<sup>26</sup> provide an insight into the growing importance of technology assisted change in clinical culture when they say:

*"It is highly likely that obtaining access, appraising, and explaining data using well honed interpersonal skills to arrive at negotiated and comfortably accepted decisions will be the*

*bedrock of future clinical practice."*

7.4. In other words, skills which have previously been provided by support services – libraries, information and IT – and often treated as outside core clinical competences are now moving to the centre of clinical practice. Elwyn and Charles are stark about the consequences for those who ignore this new requirement: *"They will be left behind."*

7.5. The requirement for all health professionals to gain access to computers and to develop new skills is evident in a range of new approaches and policies in healthcare. These include:

- The introduction of clinical governance, where clinical data needs to be collected and analysed to support risk management and audit.
- The introduction of National Service Frameworks, where data about patient management will be collected to support national audit.
- The development of evidence-based healthcare, meaning that health professionals are expected to stay up-to-date with developments in their field and be able to justify their clinical decisions in light of best practice.
- The introduction of clinical appraisal and re-validation, where clinicians will be required

to demonstrate good practice through presentation of information about their caseload and performance.

- The appraisal of the cost effectiveness of care.

7.6. Health professionals already use information constantly in their day-to-day work. It is essential to their safe and efficient practice of healthcare. To the extent that we limit its availability, we constrain their ability to practice professionally. Various studies have suggested that they may spend on average a quarter to a third of their time in seeking, interpreting and analysing information<sup>27</sup>. It is less clear how much of this time is productive work and how much is a frustrating search for relatively simple facts, such as a test result, or an attempt to interpret someone else's handwriting. It is also unclear how often health professionals have to make decisions in the absence of information that should be available to them.

## HOW?

7.7. At the most basic level, *Informing Healthcare* will increase the availability of computing devices to healthcare professionals to ensure that they have access to core applications, communications tools such as e-mail and access to knowledge through specialist databases and via Internet.

7.8. However, the provision of systems alone does not facilitate better healthcare. Health professionals need to have access to such systems *and* the

skills to exploit them. They also need to have time to reflect on how these new systems and skills can best be utilised to improve patient care. In spite of the obvious benefits, computerisation in healthcare is lower than in most other industries<sup>28</sup> and the availability of tools for electronic communication and knowledge management is limited. Lack of access to information and communication technologies is a contributing factor to a parallel lack of information management and analysis skills in the NHS and its partner organisations.

7.9. Therefore, it will be necessary to equip health professionals with new skills before they are truly able to exploit the potential of information technology and new ways of working.

7.10. *Informing Healthcare* will expand education and training provision for all staff who need it in the following areas:

- Computer use and applications, through the introduction of the European Computer Driving Licence as a recognised standard in healthcare.
- Information management, to support staff in the collection, analysis and presentation of data in all disciplines.
- Critical appraisal, to support staff who require access to evidence to find, appraise and store latest evidence about best practice in their field.

- Health informatics, to provide expert support to clinical staff who require deeper statistical analysis of their caseload and treatments to find and develop service improvements for patients.

7.11. Many of these areas will be supported by the development of materials and courses based on the *Learning to Manage Health Information*<sup>29</sup> curriculum. This will also form the basis for discussions with providers of clinical higher education to introduce a much more structured and significant health informatics element into the education process for future health professionals.

## BENEFITS

7.12. The benefits that will flow from Workforce Empowerment include:

- Ability to undertake tasks that are currently slow, time-consuming and paper-based, in a faster and more efficient way. These might include: test orders; clinical correspondence; management returns, travel and subsistence claims.
- Access to computer-based efficiency tools such as electronic diaries and meeting schedulers to support daily planning.
- Ability to undertake basic information analysis personally to achieve a much faster result than sending data for analysis to expert but in-demand information specialists.

- Ability to undertake rapid and frequent caseload analysis and audit as information becomes available electronically. Currently audit is often slowed down considerably as paper records have to be found and analysed.
- Ability to communicate and share information electronically to seek guidance or second opinions.
- Access to knowledge bases, guidelines and protocols from the workplace and in real time.
- Support for service improvement techniques as new processes become possible through the ability to share data across the health team in real-time.
- The development of a critical mass of staff who are comfortable with and skilled in the use of computers in the health workplace.

7.13. It is also important to remember that many benefits are currently 'unknown' as they will derive from the innovative ideas of staff who have been given new tools and skills to support their daily work.

7.14. The principle underpinning Workforce Empowerment in *Informing Healthcare* is the creation of a virtuous circle. Staff with access to technology can work more efficiently by removing wasteful and time-consuming paper based processes. This will free up more time for reflection on the possibilities for service improvements. Service improvements will facilitate greater throughput and support greater quality of patient care, as well as generating commitment and enthusiasm for further investment in skills, technology and time for reflection.

## 8. PATIENT AND CARER EMPOWERMENT

### SUMMARY

*Healthcare delivery has a history of paternalism with health professionals making decisions on behalf of patients, sometimes without explaining why. This must now change, both because of growing consumer awareness in healthcare and because recent enquiries have highlighted the problems associated with paternalistic culture.*

*The change of culture towards shared decision-making, with the patient and carer becoming part of the healthcare team, will be long-term and will require careful thought in its development. Nevertheless, there are practical steps that can be taken in the short-term and good practice exists in Wales in this area. This should be evaluated and encouraged more widely.*

*The long-term benefits of shared decision-making will be significant, with far more interest being shown by people in their own health status and in more considered access to health services. In the short-term, patient satisfaction with services will be increased through the provision of better information about treatments, risks and benefits. Patient anxiety could be reduced significantly if health professionals are able to provide a clearer schedule of the next steps in the care process and the likely duration of the patient journey.*

### WHY 'PATIENT AND CARER EMPOWERMENT'?

8.1. Clinical decisions about care are either visible to patients or not. If they are not visible or not discussed, they are

based on the care professional's view of what is good for the patient and not the patient's view or that of their carers – this is often referred to as 'paternalistic'.

8.2. Growing consumerism and social awareness have seen this culture eroding in recent years – often in a confrontational rather than co-operative way. Large-scale inquiries such as at Bristol Royal Infirmary and Alder Hey have shown how outdated and unacceptable 'paternalism' has become. The continued increase in complaints and litigation shows that a successful alternative is still needed.

8.3. At the same time, there is evidence that the development of a consumer society has led to inappropriate demands on health services and staff by some patients. A number of examples have been cited in recent campaigns by Ambulance and Out of Hours Services to reduce trivial calls, which by tying up resources may put lives at risk. These include requests for ambulances to taxi people to visit friends in hospital and emergency calls for conditions such as hiccups<sup>30</sup>.

8.4. Thus, there is a need to consider new ways of perceiving the relationship between health professionals and patients and carers, which will support the rights and responsibilities of all parties in a mutually acceptable way and lead to a more equal and co-operative approach to decision-making.

- 8.5. The search for alternative approaches is made complex by the wider legislative agenda around human rights, data protection and confidentiality. For example, the appropriate balance between continuity of care and the individual's right to privacy has not yet been found, and confusion abounds about what is and what is not permissible in many situations<sup>31</sup>. A much greater focus on shared – and transparent – decision-making provides a positive first step to overcoming such confusion.
- 8.6. Modern care must not only be based on the best healthcare evidence available but also on the beliefs, wishes and expectations of the patient. This means that health professionals will need the time to discuss diagnoses and planned treatments with patients and agree with them on the best way forward. They will also need the time to evaluate and record the wider impact of illness and disability on the patient's quality of life to better inform future care decisions.
- 8.7. The complexity of care means that there are often choices in the nature and timing of treatment, and in the costs, risks and benefits of particular approaches. Where they wish it, patients should be helped to understand these choices and their individual wishes should be taken into account by care professionals. Equally importantly, these wishes should be recorded so that they can inform future care and so that patients do not need to reiterate them at every encounter.
- 8.8. However, even at the most basic level, patients are not often enough provided with information that helps them to navigate their journey through the health service. They are quite often unsure about the best way to access health services, and may waste their own and health professionals' time if they choose the wrong entry point. They are often referred from one service to another and asked to undergo tests and procedures without clear and advanced warning about what is going to happen to them and why. They often wait for significant periods between health activities, unsure whether the delay is planned or unplanned or resource not treatment related.

## HOW?

- 8.9. From the outset, it is important to acknowledge that Patient and Carer Empowerment is a long-term process. While shared decision-making is intellectually attractive, health professionals have to work with a wide range of patients, some of whom may explicitly choose to defer all decisions to the professionals. Equally, any process which requires more time to be spent with patients must be realistic about the associated resource requirements.
- 8.10. Having said this, there are many examples of good practice across the Welsh health service that can be implemented more widely without incurring very much additional time and cost:
- Few health professionals receive feedback on their communication

skills, and yet good feedback is the best way for people to improve such skills. At least one trust in Wales<sup>32</sup> has developed a scheme to support such feedback routinely.

- Patient leaflets that explain patient journeys for particular conditions are in use in several places, but they are not available everywhere, they are not available for all conditions, they are sometimes not available bilingually or multilingually and they are often not standardised across Wales or even across a particular health organisation. It is both best practice and efficient to reduce unnecessary variation in information supplied to patients across Wales. Early steps will be taken to ensure that a standard and multilingual electronic library of patient information leaflets is available to all health professionals and citizens in Wales using Internet and World Wide Web technology to facilitate easy access. This will require close working with organisations in the voluntary and charitable sectors.
- Information about the risks and options associated with particular treatments is often provided verbally in a consultation but rarely followed up by a written explanation and/or copies of subsequent clinical correspondence.

- Good information for patients on possible post-treatment issues and the most appropriate response to them could reduce the stress on both patients and services that they might contact when such problems arise yet it is rarely made available.
- For patients with chronic conditions and their carers, links to voluntary and other support organisations are often provided in a haphazard way. Furthermore, the huge domain knowledge possessed by many patients with long-term conditions is rarely exploited for the benefit of either health professionals or other patients.

## BENEFITS

8.11. The benefits of empowering patients with better information and more opportunities to share in decision-making could be significant. They include:

- Greater patient satisfaction as people are better informed and better able to move quickly through the health service.
- Less inappropriate access to services as patients are better informed about the best way to get rapid and effective healthcare.
- Greater compliance with treatment as patients gain a better understanding of the rationale for treatment and the consequences of not pursuing it.

- Reduced stress on healthcare staff as patients take more responsibility for their own health and place less burden on professionals to make decisions for them.
- Fewer complaints, and possibly less litigation as patients are better informed about why treatment options have been pursued and what the risks are, and so less likely to blame the health service if outcomes are disappointing.

## 9. SERVICE IMPROVEMENT

### SUMMARY

*In recent years, modernisation and ICT programmes in UK healthcare have not been well integrated. This strategy argues that they must be closely aligned both strategically and in practice if benefits to patients are to be maximised. The introduction of technology without changed working practices will have little impact. Changed working practices without new technology are likely to be inefficient and unsustainable in the long-term. Most importantly, new technology makes possible new ways of working that could not otherwise succeed.*

*A range of applications exist which have – properly implemented – been proven to bring benefit in healthcare and these should be early candidates for investment across Wales. They include: electronic communications; requesting and reporting of tests; PACS; e-prescribing and scheduling.*

*The benefits from such applications are likely to be significant, and will particularly improve:*

- *Patient safety through a more controlled clinical environment.*
- *Patient experience through less inconvenience and anxiety during the care process.*
- *Responsiveness of care by speeding up day-to-day activities.*
- *Efficiency of care by reducing the administrative burden on health professionals.*

### WHY 'SERVICE IMPROVEMENT'?

9.1. Many of the issues raised earlier indicate that the NHS has historical systems and processes that are no longer well suited to the way in which care needs to be delivered. Two approaches to resolving these problems have grown up in UK healthcare. On the one hand, the Modernisation Agency in England and Innovations in Care in Wales have developed tools and techniques to support process analysis and change. On the other hand, the National IT Programme in England and Welsh Assembly Government IT initiatives in Wales have developed technology-based solutions to such problems.

9.2. *Informing Healthcare* is based upon the view that modernisation and technology need to be fully integrated if benefits are to be achieved. There are five key reasons why this is important:

- Evidence from other industries shows that process change works best when it is supported by good data about what is actually happening within a system or process. Thus, process change without access to good information may not be effective.
- Information and communication technologies make changes possible that could not be achieved by manual approaches. This is particularly the case in a complex, multi-disciplinary and

geographically dispersed system like health.

- The modernisation of information systems is necessary, but it will not bring benefits unless it is properly integrated with changes to current working practices across the whole health economy, which must be led by health professionals themselves.
- New approaches to healthcare delivery must be kept aligned with information standards. For example, the benefits of new staff roles such as nurse practitioner and new approaches such as one-stop clinics and medical assessment units are diminished if the activity cannot be properly recorded (and therefore attract funding) because it no longer fits traditional definitions<sup>33</sup>.
- Service Improvement ideas which are not captured and disseminated widely are missed opportunities. *Informing Healthcare* will ensure that mechanisms are put in place to support the sharing of ideas and best practice across Wales and beyond.

9.3. The approach to technology-assisted change put forward in *Informing Healthcare* has been designed to be consistent with the most commonly used Service Improvement techniques in the following ways:

- It focuses on delivering best service to the patient.
- It engages directly with front-line staff and activities.
- It adopts a whole systems approach to process change.
- It offers an incremental way forward based on shared learning.

9.4. From the perspective of patients and carers, change will centre around the management of the patient journey. Every patient undertakes a journey of sorts when they come into contact with health and social services. These journeys might be straightforward – a visit to the GP and then the pharmacist, and the taking of medication for a week – or they might be immensely complex. A cancer patient may be treated by tens of health professionals in a range of healthcare settings during their treatment.

9.5. At any one time, as many as 1 in 10 of the population of Wales might be undergoing some kind of patient journey. Thus we have perhaps 300,000 people following one of several hundred paths through the health and social care system. Good management of these journeys will enable patients to have a positive experience of the system as things are done in the right order and in an efficient and sympathetic way. Poor management, on the other hand, leads to delay, frustration and discomfort.

9.6. The goal of technology-assisted Service Improvement is to ensure that health services are designed and delivered in such a way as to provide a good experience for patients while maximising the quality and efficiency of healthcare delivered. This is a massive undertaking because the current health service has developed by making particular services efficient and effective in themselves, rather than focusing on the patient's journey and the best possible team-based management of their care. Re-design of patient journeys, supported by integrated information systems, will bring major benefits to patients and professionals.

## HOW?

9.7. Advances in clinical technology have made available applications that can facilitate improved working practices in a number of clinical domains, leading to service improvement. The following examples are technologies which are in actual use in at least some places in the UK health service. All of them require the combination of new technology applications and work to improve processes and change working practices to be successful.

### ELECTRONIC COMMUNICATIONS

9.8. Electronic mail is now pervasive in society, and yet take-up in health services has been slow. This is partly due to under-investment but is also a reflection of the complexity of health organisations and the constraints on sharing patient information without a

fully-formed security infrastructure. These issues are now being addressed in Wales, and the rollout of e-mail in primary care is progressing rapidly. The provision of e-mail and directory services to all health professionals in Wales will be an early priority. Care will be needed to ensure that e-mail is used appropriately in support of patient care and national guidance on acceptable use will be issued.

9.9. NHS Wales is also well advanced in the provision of video conferencing facilities which is already enabling geographically dispersed staff to take part in virtual meetings and case conferences without the need to travel long distances. Given the development of clinical networks and closer integration between primary and secondary care, it is expected that the requirement for these facilities will increase significantly over the next few years.

### TEST REQUESTING AND RESULTS REPORTING

9.10. It is now possible to support the requesting of tests and the reporting of results electronically, whether from within a hospital or from primary care. Paper-based approaches, which are hugely time-consuming and inefficient, can be replaced in a coherent way across the health service. However, as with e-mail, close attention must be paid to parallel changes in working practices if benefits are to be maximised.

## PICTURE ARCHIVING AND COMMUNICATION SYSTEMS (PACS)

- 9.11. PACS facilities have been introduced in a number of hospitals and departments across Wales already. They have the potential to enable health professionals to order and store images such as X-rays electronically so that they can be viewed by authorised staff whenever and wherever they need to. PACS has the potential to save large amounts of time that is now spent hunting for images, and will reduce the inconvenience faced by patients who have to have duplicate tests because images are unavailable or lost when needed.
- 9.12. The provision of PACS facilities is expensive, especially if access is provided across the community as opposed to limited rollout either within the radiology department or in high-use areas such as fracture clinics and outpatients. It will therefore be important to have a co-ordinated approach in Wales that ensures that organisations co-operate to deliver the most cost-effective PACS infrastructure for the Welsh health service as a whole. The forthcoming Diagnostic Services Strategy will set out the key principles for future PACS investment in Wales.

## PROTOCOLS AND GUIDELINES

- 9.13. Several organisations in Wales have now produced standard protocols and guidelines and made them available on local Intranets. This has brought benefit to both hospital and primary

care users. The next step will be to support the 'pull' of patients into appropriate specialist services by integrating protocols into record technology. This will be especially important as traditional routes into specialist care are replaced by a plurality of nurse-led clinics, rapid assessment centres and one-stop clinics. Patients will need to be scheduled quickly to attend the right service for their particular condition and severity.

- 9.14. Similarly, the HOWIS service has made the knowledge base of healthcare available widely in NHS Wales, providing access to a range of evidence-based materials. The next steps will be to increase the range of materials available and then to begin the integration of these materials into interactions with the patient record. This will provide health professionals with context-specific guidance during the patient consultation.

## ELECTRONIC PRESCRIBING

- 9.15. Electronic prescribing has been identified as one of the key technologies to improve patient safety in the health service. It can reduce human errors by challenging improbable prescriptions and incorrect dosages and alerting for contra-indications. It can also eradicate errors made due to the misinterpretation of handwriting. The Audit Commission has shown that the estimated costs of prescribing problems, and therefore savings if they are resolved, are considerable<sup>34</sup>.

9.16. However, take-up of electronic prescribing in the UK health system has been mixed. In primary care, most GPs now produce prescriptions electronically. However, secondary care development has yet to begin in earnest. There are many reasons for this<sup>35</sup>, including lack of resources, but the main cause seems to be that paper-based prescribing and medicines management processes are enshrined in 'custom and practice', and therefore hard to replace. Thus, progress to improve prescribing outcomes for patients will require close working between those responsible for introducing the new technology and health professionals tasked with changing working practices.

9.17. It is vital that the development of electronic prescribing is undertaken corporately so that the Welsh health service can converge on a standard approach to e-prescribing. It is also vital that it is undertaken on a whole economy basis. Patient safety will continue to be undermined if separate and often partial primary and secondary care versions of patient drug records persist.

### **ELECTRONIC SCHEDULING**

9.18. From a patient perspective, the health service can often seem like a hurdle race where each new transaction requires that they explain their problem and their history to each new health professional. The Single Record approach will help to overcome such problems. However, the ultimate aspiration for patients is to have a full

itinerary of booked activities across health and social care as soon as possible in the patient journey. The elderly patient requiring a new hip would therefore know in advance not only about their likely admission, operation and discharge dates but also about plans for community-based care and even the date when new handrails will be fitted in their bathroom to facilitate their safe return home.

9.19. Routine end-to-end scheduling of the patient journey is some years away, and will require far better planning information than is currently available, shorter waiting times to make it practicable, and integrated working across health and social care services. Early steps are being taken in Wales through the piloting of partial booking and the introduction of unified assessments to identify needs. Subject to evaluation, further electronic booking facilities will be developed and rolled out. The ultimate goal, however, must be the end-to-end scheduling of services for the patient.

### **BENEFITS**

9.20. Examples of the many benefits that such service improvements will bring include:

- A reduction in patient inconvenience and anxiety through electronic resource scheduling throughout the patient journey. This will ensure that services are patient-centred and that activities such as tests, procedures and follow-ups are

booked to take place in the right order in the right way and that fewer operations and clinics are cancelled.

- More efficient care resulting from a reduction in wasted clinical time due to process problems and delay (e.g. GPs will spend less time on chasing outpatient appointments; hospital doctors on chasing test results; community nurses on filling in contact forms). This will be especially important in the hospital environment where the availability of junior doctor time is under significant pressure.
- More responsive care resulting from rapid transmission of clinical communications across the care team for a particular patient (e.g. outpatient referrals and discharge summaries). The current paper process can take weeks, whereas it can be done electronically in minutes.
- A more controlled environment for clinical care leading to reduced clinical risk and improved patient safety, especially through the systematic removal of human error in both clinical and administrative procedures.

# 10. KNOWLEDGE AND INFORMATION MANAGEMENT

## SUMMARY

*In common with many healthcare systems, NHS Wales has a large amount of data but is often unable to use it to good purpose, either at the front-line of care or in support of management and planning. This situation often arises because of a mis-alignment between the goals of the health service and the measures within it. For example, the goals are mainly clinical and yet most data collected is administrative in nature. This means that performance management can often seem remote to health professionals.*

*A re-assessment of the measures needed to assess whether goals are being met is likely to lead to a combination of new measures being developed and some old measures and data collection processes being stopped. New measures will be supported by the introduction of the Single Record, as it will augment clinical data capture. Better use of the information collected will be supported by the education and training planned in the Workforce Empowerment stream of Informing Healthcare.*

*The benefits from improved Knowledge and Information Management will manifest themselves throughout the health service. For health commissioners, there is a clear need to understand how resources have been used to deliver healthcare and to identify where health needs are not being met. At the front-line, health professionals will be able to analyse caseload and plan services to best meet patient needs. Service managers will be able to monitor progress on National Service Frameworks across the health economy. Public*

*health professionals will have comprehensive and accurate data with which to analyse population health trends. Politicians will be able to account for the health service in a more detailed and positive way.*

## WHY 'KNOWLEDGE AND INFORMATION MANAGEMENT'?

- 10.1. Knowledge and Information Management is concerned with marshalling the information available within a system and its environment to optimise the performance of that system. The application of knowledge in this way can occur at all levels within the system, from services to a specific patient through the work of particular teams and organisations up to the level of the overall system itself.
- 10.2. The true optimisation of performance can only be done with measures relating to the explicit goals set out for the system. Behaviours in systems are profoundly affected by what is measured. If these measures are implicit, or worse if they are different depending on particular departments or organisations inside the system, then outcomes will be sub-optimal for patients and for the wider economy.
- 10.3. In reality, and in spite of the masses of data collected every day in the health service, it is often very difficult to get answers to questions that focus either on an individual patient or on the performance of the system as a whole. There seem to be four main reasons for this:

- There has not traditionally been an overall patient focus in health information, which means that data is collected to measure the efficiency of inputs rather than quality of outputs for a given patient.
- The historical focus of computerised information has been on the processing of patients through the system and not on the capture of clinically rich information.
- Measures of quality and outcome are still developmental and are therefore applied either in a limited and experimental way or in the form of proxies such as 'time taken to treat'.
- Most information is collected at the level of organisation and is used to measure the internal and comparative performance of organisations rather than the performance of the overall health service in delivering its goals for patients and the economy.

10.4. As these barriers are overcome, either through the developing cultural change of perspective to 'patient focus', the introduction of the Single Record, or else through a more sophisticated ability to measure what matters, then knowledge management will be needed to assess the efficacy and impact of new forms of measurement.

10.5. In particular, it must be remembered that measures affect behaviour. If people's performance and remuneration is to be judged on particular measures, then it is only fair that they are able to improve those measures to the best of their ability. Unfortunately, if measures are not aligned to the overall goals of the health service then this may cause people to behave in a way which optimises their local performance at the expense of overall service delivery to patients.

10.6. In global terms, Knowledge and Information Management is needed in the health service to ensure that:

- There is information about how resources are utilised.
- Measures are available to assess the achievement of the goals of the service.
- Care processes are informed by the best available evidence and practice.
- Inappropriate variation in system performance is highlighted and managed.
- Service improvement is supported both by best practice and by regular feedback on progress.
- Service planning is informed by accurate analysis of bottlenecks and gaps in supply.

- Resources are not wasted on collecting that which can be measured as opposed to that which should be measured.
- A careful distinction is established between measures of the impact of the system, e.g. in meeting demand or improving health, and measures of the performance of the people in the system, e.g. in increasing throughput or improving care quality.
- The democratic accountability of the health system is strengthened and maintained.

## HOW?

10.7. The development of Knowledge and Information Management in the health service will rely on delivering three key elements:

- Commitment from key stakeholders to seek to manage knowledge more actively in support of patient-focused care and the overall achievement of health service goals.
- The development of knowledge, information and data management skills in people throughout the health service.
- The routine availability of knowledge and knowledge management tools in the workplace.

10.8. The first of these requirements is increasingly evident in Welsh Assembly

Government policies and strategies. There is a positive commitment to see the health service as an investment and to manage it in order to deliver the best possible health, and ultimately prosperity, outcomes. In parallel, there should be a reduction in the burden of information collection that is not relevant to these goals and which does not add value in seeking their achievement. The planned introduction of the 'Balanced Scorecard' approach to performance management in the health service in Wales will provide the foundation for a re-evaluation of appropriate measures of health service performance from the perspectives of key stakeholders.

10.9. The second requirement will be delivered through Workforce Empowerment initiatives in *Informing Healthcare*. The motivation for staff to develop such skills will be significantly enhanced if they are able to see the benefits and opportunities presented through a more sophisticated approach to Knowledge and Information Management.

10.10. The third requirement will be a key short-term goal for the Single Record and Service Improvement areas of *Informing Healthcare*. The long term goal is the provision of a high quality electronic record supported by sophisticated applications. In the short term, the goal must be to increase the availability of relevant information to frontline health professionals to support direct care, the governance of care and opportunities to undertake early service improvements.

## BENEFITS

10.11. The following examples show areas where significant service benefits will be gained through better Knowledge and Information Management:

- Performance management will be improved as targets can be set in a more sophisticated way, focusing directly on clinical performance and patient experience.
- National Service Frameworks implementation will be facilitated by the ability of healthcare staff to share access to patient records across several professional disciplines and organisations.
- Chronic disease management: the sharing of information between primary and secondary care services is essential if patients with chronic diseases are to be treated early and close to home. Evidence from London hospitals<sup>43</sup> suggests that greater resources to support the management of respiratory diseases in primary care could significantly reduce the impact of winter pressures on hospitals.
- Caseload management: caseload analysis identifies patterns of patient presentation and demand that can lead to significant changes in care delivery. For example, analysis of general practice caseload might lead to the setting up of regular nurse-

led clinics for the management of particular conditions.

- Clinical re-validation will be facilitated by the availability of straightforward electronic access to historical caseload and outcomes.
- Patient complaints: analysis of patient complaints enables identification of 'common cause' issues such as the unavailability of the patient record or poor communications within the healthcare team.

10.12. Better quality clinical information will also flow through to provide benefits to population-level analysis:

- Communicable disease control will be better supported as it will be far easier to trace patients who have been treated in particular locations or in contact with particular staff or equipment if problems arise.
- Screening for specific diseases can be better targeted and patient groups with chronic conditions can be better managed.
- There will no longer be a need to develop separate and fragmented disease registers in Wales, as these will be easily derivable.
- Population health information can be extracted in a comprehensive and structured way across Wales, facilitating both small-scale local and large-scale national epidemiological studies.

- The democratic process in Wales will be better supported as detailed and specific information will be available to assess whether the NHS is achieving its overall goals.



## NEXT STEPS



# 11. STRATEGY IMPLEMENTATION PROGRAMME

## ORGANISING TO DELIVER

### STRATEGY IMPLEMENTATION PROGRAMME

- 11.1. *Informing Healthcare* requires a massive and long-term programme of technology-assisted change in the Welsh health service. It will need significant organisation and resources in order to deliver its vision. The *Informing Healthcare Strategy Implementation Programme* ('Programme') is designed to ensure that the strategy is properly managed to meet its objectives.
- 11.2. *Informing Healthcare* will be a project-based strategy. The Programme will identify the necessary individual projects and products and ensure that they are delivered in a coherent way in support of the overall change programme. The Programme will not undertake ongoing information or IT service provision. Such provision will be the domain of national and local health organisations in Wales and, where appropriate, private sector suppliers.
- 11.3. While the Programme will be responsible for delivering strategic products and overseeing health service-wide projects – enabling, supporting and monitoring progress on the strategy – it will not take responsibility for organisational and professional change. This responsibility will continue to rest with Chief Executives and Boards of health organisations.

## STRATEGY IMPLEMENTATION PROGRAMME BOARD

- 11.4. Over time, *Informing Healthcare* will affect everybody in Wales, whether as a member of the health service workforce or as a patient, carer or citizen. Therefore, the proper engagement of stakeholders to oversee and engage with the strategy is vital. This will be achieved primarily through the innovation of Benefits Groups, as described below.
- 11.5. The creation of a Strategy Implementation Programme Board ('the Board') will ensure that clear and transparent accountability is achieved. The Board will be chaired by a public appointee, whose accountability to the Minister and the NHS Director will mirror that of an NHS Trust or Local Health Board Chair. The Chair will be supported by a full-time Programme Director.
- 11.6. The Board will be accountable for the successful running of the programme, and for supporting and monitoring the delivery of the strategy and its corresponding benefits. It will derive its authority from its Programme Mandate, agreed with the Welsh Assembly Government.
- 11.7. Membership of the Board will be based upon proper representation of all of the stakeholders in the Welsh health service, and will include:
  - Patient and carer representatives.

- Voluntary staff.
- Health professional staff – doctors, nurses, allied health professionals, scientists.
- Social Care staff.
- Senior management staff.
- Staff side representation.
- NHS Wales Department staff.
- Directors of Benefit Groups (described below).
- Key observers.
- Contribute to the development of project briefs.
- Support local delivery and the realisation of benefits in implementation.
- Take a programme-wide view of their benefit area.
- Provide quality review and user support to projects.

## **STRATEGY IMPLEMENTATION PROGRAMME – PLAN AND PROJECTS**

### **STRATEGY IMPLEMENTATION PROGRAMME – BENEFIT AREAS AND BENEFIT GROUPS**

11.8. The strategy identifies five benefit areas in which incremental and balanced progress must be made in order to bring about the eventual modernisation and transformation of health services. In order to ensure stakeholder engagement in every area, five Benefit Groups will be established. These will act as a key mechanism for ensuring robust stakeholder involvement in the shaping and monitoring of strategy implementation. Each Group will be chaired by a Director, highly experienced in that benefit area, who will sit on the Board. These Groups will provide an efficient and effective forum for individual experts and users in each benefit area to shape, support and monitor the strategy.

11.9. In particular, the Benefit Groups will:

- Work with the Board to shape the detail of putting the vision into practice.

11.10. The strategy will be project-driven. Thus, the Board will oversee a number of projects. Each project will be run in accordance with the PRINCE methodology to ensure the right mix of accountability, responsiveness to customers and cost-efficient delivery.

11.11. The Board will agree its programme of projects on an annual basis, based on its funding allocation from the Welsh Assembly Government. This will form the basis of an annual Strategy Implementation Programme Plan ('the Plan').

### **STRATEGY IMPLEMENTATION – PROGRAMME SUPPORT OFFICE**

11.12. A Programme Support Office (PSO) will be established to act as the resource pool for the strategy, and in particular will provide or co-ordinate:

- Project management support to the Programme.

- Legal, technical and procurement support to the Programme.
- Resource coordination across project staff, NHS secondees and contractors.
- Change management support to the Programme and to local organisations.
- Publicity and communications services.

## EARLY PRIORITIES

### LEGACY MANAGEMENT

11.13. *Informing Healthcare* is an incremental strategy – its Programme will not undertake 'big bang' solutions. For this reason, it is vital that the functional, legal and contractual status of existing information systems is reviewed and appropriate action taken to ensure that operational continuity is maintained and that user development continues to take place.

11.14. The Legacy Management programme has already started in Wales, and has generated a baseline database of existing information systems. Where significant problems have been identified, projects have been initiated either to replace, develop or re-negotiate contractual terms with suppliers of the information systems concerned. Where development requirements have been identified, business case support has been provided to ensure that the right balance between investment in legacy solutions and investment in strategic replacements is maintained.

11.15. The Legacy Management programme will continue to play a significant role until such time as strategic solutions developed or procured under *Informing Healthcare* have been fully implemented, and the transition from existing systems is completed.

### READINESS

11.16. The Readiness Programme is designed to ensure that local organisations identify and manage local dependencies for progress in implementing *Informing Healthcare* in a range of areas. These include:

- Local oversight and organisation of *Informing Healthcare* implementation.
- The management of unique patient identification and demographic information.
- The management of staff identification to support authorised access.
- The management of paper health records according to best practice.
- The management of security and confidentiality according to best practice.
- Adherence to NHS information standards.
- The availability of access devices (e.g. PCs) for health professionals.
- Training and development in priority areas identified in *Informing Healthcare*.

11.17. The need for Readiness has been signalled to NHS organisations through the Strategic and Financial Framework 2003/04.

### **STRATEGY IMPLEMENTATION PLAN 2003/04**

11.18. Visible *Informing Healthcare* activity in 2003/04 will focus upon the areas identified above. Work will also begin on establishing work programmes to deliver early objectives within each of the key benefit areas. The complete Strategy Implementation Plan 2003/04, including fully resourced plans for all of the national and local projects which are being initiated during the next twelve months, will be published following its approval by the Board and will be refreshed annually thereafter.

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- <sup>2</sup> The term 'health service' is used in this document inclusively to refer to those organisations and individuals who contribute professionally or voluntarily to health outcomes for patients and populations. It includes the NHS but it is often used instead of 'NHS' because many contributors are not formally part of the NHS, though they are often seen as part of the 'NHS family'.
- <sup>3</sup> A summary is available at <http://www.wales.nhs.uk/sites/documents/365/ihc-consult-feedback.pdf>
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