SECTION NINE

INTELLIGENT INFORMATION AND CLINICAL GOVERNANCE

This section considers the need for 'intelligent information to:

- underpin all aspects of the Board and PECs discharge of their integrated governance duties and responsibilities
- enable the Board/PEC to identify the priority health needs of the local community
- enable the Board/PEC to assure the safety and quality of current clinical provision made directly by the PCT and its constituent practices
- enable the Board/PEC to assure the safety and quality of current clinical provision made by the dentistry, pharmacy and optometry services for which the PCT is responsible
- enable the Board/PEC to assure the safety and quality of the services commissioned by the PCT.

The new Commission for Health Audit and Inspection has made it clear that they will:

'make information, "intelligent information", central to CHAI's activities'

CHI, 2003

They will therefore:

'ensure that organisations providing healthcare are aware from the outset that one of the most important criteria against which they will be assessed is their capacity to collect, analyse, respond to and learn from information about their own organisation. This, after all, is one of the elements of any successful organisation. If an organisation cannot be adequately assessed because some of the necessary information is not there, the assessment, instead, will be made on the basis of the extent to which the organisation is (or is not) collecting information and using it to improve the care it provides'

CHI. 2003

Their expectation is that 'intelligent information' (that is, robust data that has been analysed and made comprehensible and fit for purpose in relation to the audience and the use to which it is to be put) should underpin all decisions made by the Boards of NHS organisations and thus provide the foundation for 'integrated governance'.

So far as clinical governance in particular is concerned intelligent clinical and other information has a vital role to play.

'A health organisation establishing a culture of clinical governance must develop excellence in the selection, management, and effective use of information and data to support policy decisions and processes'.

Halligan and Donaldson, 2001

Accurate and appropriate clinical and public health information is vital to Boards and PECs. Armed with this information, together with fiscal and corporate information, they will be able to discharge safely and imaginatively the statutory duties placed upon them in relation to the organisation's controls assurance and its clinical and integrated governance.

Key learning from the pilot programme

Given the legacy of partial, unco-ordinated and incompatible data systems that they have inherited, most PCTs are confronted by a significant challenge, and will require significant national and SHA leadership and support if they are to generate and base their clinical and corporate actions upon the 'intelligent information' that will be sought by CHAI.

Equally importantly, given the unique and complex governance arrangements of PCTs, many need to develop 'smarter' ways of handling the information flow between and within the Board and the PEC in order to ensure the coherence, alignment and effective overall strategic leadership of the PCT.

When the original pilot questions and materials were developed this section was called Data, Information and IMET. Across all the PCTs in the pilot programme the section on Data, Information and IMET was in the middle of the range of overall section scores scoring 5.1 on the progress scale (range 3.3 to 7.1).

The 25 PCTs that were under a year old when they completed the questions predictably found this to be even more challenging, scoring an average of 4.7 whilst the remainder scored an average of 5.5.

The issue was particularly difficult for recently constituted PCTs that had inherited a fragmented data set or a poorly resourced IMET infrastructure from their predecessor organisations.

Almost all PCTs felt that they lacked robust information and evidence in relation to vital aspects of their core responsibilities for the safety and quality of services with specific questions relating to the robustness of the information available to the Board and PEC, scoring only:

- 5.5 in relation to Public Health
- 5.2 in relation to the safety of the PCT's own provision
- 4.6 in relation to the safety of commissioned provision.

Equally it was clear that in many PCTs much needed to be done to improve the flow of 'intelligent information' between and within Boards and PECs. Given the unique governance arrangements of PCTs, the flow of information between these two groups needs to be pro-actively and skilfully managed. Hitherto, this issue has received little attention and, as a result, on many occasions important 'work in progress' (in relation both to the generation and the implementation of key clinical and other strategies) was invisible to everyone other than the individuals carrying it out.

On the other hand, the majority of PCTs were satisfied that their 'Guardian' had taken active steps to implement the Caldicott requirements and to keep them abreast of progress.

At the time of completion of the process almost all PCTs felt that they, their SHA and local health communities were constrained by the need to await the outcome of the national strategy on information technology and investment. As a result a significant number had not developed a costed and timelined strategy for IT, knowledge and information management.

The breadth and depth of IM&T expertise available to individual PCTs varied widely, with a number reliant upon the energy and commitment of local clinicians with a passion for new technology. Overall there was an identified need to establish networks for primary care IM&T specialists so that best practice could be shared and common solutions sought to system-wide difficulties and problems.

At the time of the first feedback workshops, the vision for the new CHAI had not been published. Even after its publication it had received little direct attention from Boards and PECs. A vital part of the current follow-up process with all participating PCTs is, therefore, to draw to their attention the foci of the new Inspection and Audit regime and, in particular, the emphasis that it places upon the generation and use of 'intelligent information'.

The importance of appropriate and timely information

As long ago as 1998, the Audit Commission identified that

'nearly every NHS trust in England needs to take steps to ensure that it is capturing accurate information about its patients.'

More recently, the Commission for Health Improvement concluded that 'analysis of recurrent themes suggests that use of information is an indication of an organisation's commitment to clinical governance.'

CHI, 2002

CHI has noted that in almost half of the organisations it has reviewed, including PCTs, the Trust Board did not receive the information concerning clinical governance and service activities that enabled them to be pro-active and strategic. It has called for action to improve the collection of data and/or the use of information in almost all cases.

As the new CHAI Vision points out:

'Although there is a considerable amount of data in the NHS, collected at the local and national levels, the data have not traditionally been used to provide systematic information on the quality of care that patients are receiving. Yet, the ability to improve care depends, critically, on having access to the necessary information'

CHI, 2003

The longer term benefits of sustained NHS investment in information technology-based electronic patient records, and other technology-assisted analytic and modelling tools, are set out in the '*Information for Health*' White Paper. However, data is already being collected (often in a variety of different forms and formats) across the constituent practices of PCTs and across local health economies. Pragmatism and imagination must be employed to make the best use of this data.

'While Information for Health ...emphasises the importance of systems to support the clinical governance agenda, it will be some years before their implementation is complete. Organisations in the primary and secondary care sectors must therefore make use of what is available.'

Clinical Governance Bulletin. June 2001

Encouraging evidence exists that, in at least one priority clinical area - coronary heart disease - a positive start has been made - even in the face of significant difficulties.

'PCG/Ts have made progress in achieving connectivity, increasing the use of information management tools, implementing data quality standards and collecting data to support implementation of the National Service Framework for coronary heart disease. However, information to support the core functions of PCG/Ts continues to be perceived as inadequate, shortages of staff and funding remain problems.'

National Primary Care Resource and Development Centre, 2002

long-term strategy to define and meet the data, information and

REFLECTION

Is there evidence of a

intelligence needs of the PCT?

Information needs of Boards and PECs

In order to discharge their many and complex functions, the Boards and PECs of PCTs need:

- robust and reliable local public health information so they can plan provision on
 the basis of an accurate and informed understanding of the nature and the needs of
 their patient community and identify the gap that may exist between real need and
 current provision and service usage
- reliable and robust comparative national data so they can locate the local picture
 within an appropriate context
- reliable quantitative clinical and fiscal information about the PCT itself so they

can measure their own activities against explicit performance targets

- robust clinical information so they can assure the quality of current provision made directly by the staff of the PCT or its constituent practices and in the dentistry, pharmacy and optometry services for which the PCT is responsible
- quantitative and qualitative information about the performance of organisations
 from which they commission services so they can monitor current value for money
 and quality and so that they can make informed commissioning choices in the future
- comparative and illuminating information derived from regional, national and other sources to inform the Local Delivery Planning process.
- 'PCTs will be responsible for planning and securing the provision of the totality of care and services that their population needs, either by direct management or through agreement with other organisations they will need to consider their information needs and plan to support these either individually or in collaboration. In addition they will need to play an intelligent customer role with the NHS Trusts providing services to their patients.'

Department of Health, 2001

Moving from data to 'intelligent information'

'What use do NHS trusts make of clinical data and information? Sadly, the short answer to this question seems to be 'not much.'

Clinical Governance Bulletin, June 2001

Most NHS organisations collect vast quantities of data locally, as an integral part of their procedures and systems. Some of this is essential; much replicates data which already exists somewhere else in the organisation's own system (or in other parts of the NHS) and some is without current purpose.

'To measure NHS progress in making best use of information, Sir Richard Doll cited Finagle's Laws:

The information you have is not what you want.

The information you want is not what you need.

The information you need is not available!'

Clinical Governance Bulletin, June 2001

The presentation to a Board or a PEC of quantities of locally derived raw clinical or other data may illustrate the difficulty that the organisation faces — it does not, of itself, support informed debate.

'Healthcare is supersaturated with data. Few industries gather as much data as is gathered in health: The challenge is to turn it into information.'

Cullen et al, 2001

This challenge is particularly acute when the data itself has been gathered and recorded in characteristically different ways. In this situation, aggregation is not a simple mathematical task, but demands the exercise of complex extrapolation and judgement. Inevitably, given the different histories, traditions and systems infrastructures of GP

practices, many PCTs have inherited a back-log of data — and data collection systems — which are neither readily compatible nor comparable.

The new Commission for Health Audit and Inspection has recognised the burden that the proliferation of external demands for information imposes upon health care providers:

'At present, too many bodies are engaged in collecting what is, in fact, largely similar information, in different ways, at different times, thereby imposing considerable burdens on staff.'

CHI, 2003

It summarises two of its key aims as:

'to create an information-led system of assessment and to reduce the burden of regulation.'

CHI, 2003

To this end it will:

'promote the co-ordination of the process whereby information is obtained. CHAI will work with other bodies including the Department of Health, the Medical Royal Colleges, NHS Information Authority, NHS Litigation Authority, the Health and Safety Executive, the NHS Confederation, the Commission for Patient and Public Involvement in Health, and others, including the private sector, to agree a template of common data required by all of these bodies and the form in which the data are to be collected'

CHI, 2003

Critically it recognises that:

'the data sought should be data of use to and already known to and used by clinical staff and managers in their delivery of services.'

CHI, 2003

It is helpful to consider information as data that has been processed in some logical way so that the results are useful to those involved in the operation of the organisation.

Specifying the Board and PEC's minimum information needs

Every Board and PEC needs to gather evidence of its own performance against standards specified in the NHS Performance Assessment Framework — or defined regionally. Initially, the Board and PEC must specify the minimum intelligent information that needs to be extracted and presented to them from the range of existing data sets relating to each core PCT function and statutory responsibility.

This information must also be sufficient to enable them to make safe and defensible evidence-based decisions and judgements about current and future patterns of provision.

'Twenty percent of chief executives reported inadequate information to support needs assessment.'

National Primary Care Resource and Development Centre, 2002

The depth and the texture of such information is likely to go significantly beyond the information which Boards and PECs are routinely required to provide merely to satisfy

REFLECTION

To what extent are the Board and PEC aware of CHAI's emphasis upon the generation and use of 'intelligent information'

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external performance measurement demands. The more complex this information is, the more important it will be to ensure that it is available ahead of Board/PEC meetings. All too often, time pressure results in the most important papers being tabled at meetings. The result is that members feel compelled to make decisions having had little time for reflection or informed debate.

Although the overall average score for the question on the timeliness of information presented to Boards and PECS scored 5.8 (well above the overall average for the whole section) a significant number of the 1200+ Board and PEC members who completed the pilot questionnaire did not feel that the information presented to them in relation to Board or PEC agenda items was sufficiently timely or comprehensible, with non-Executives and PEC clinicians ivoicing particular concern.

Important information should always be available in advance so that all members (not least the Non Executive Board Members) have the opportunity to digest and analyse it—and to ask informed questions during the meeting.

'One key output of clinical governance ought to be demands for clinical data that are timely, complete, comprehensive and accurate.'

Clinical Governance Bulletin, June 2001

The need for such data will inevitably place a considerable burden on management and administrative systems within the PCT and its constituent practices.

'To transform data into information, effort and intelligence are required.'

Clinical Governance Bulletin, June 2001

Used wisely, this information can:

- · support the most effective targeting and use of resources
- · assist management processes
- facilitate accountability and the delivery of effective and overtly clinically governed care
- shape future service reconfiguration and the investment of time and other resource that this demands.

In the absence of such information, it is difficult to see how a Board or a PEC can function in a way that is consistent with the discharge of their statutory responsibilities and the duties of either corporate or clinical governance.

Prioritising action to improve data collection and intelligent information generation

In focussing energy and resources upon improvements in data collection, analysis and information generation, it is essential to pay due regard to national and regional clinical priorities. The information generation task confronting PCTs, within any timescale, can be eased if explicit clinical priorities have been identified, explicitly owned within and across the PCT the SHA and (where possible) across the local health economy (this issue is explored more fully in Section 8).

REFLECTION

Do Board and PEC members routinely receive appropriate information in sufficient time to enable them to read, reflect and contribute fully to discussion and debate within the Board/PEC?

REFLECTION

What evidence is there of clear prioritisation of information strategies that derive from the PCT's clinical governance priorities? Efforts to systematise and improve data collection and information generation can then be co-ordinated around concrete priority issues. The Board and PEC can then

- · support and monitor change management actions
- · evaluate impact and progress

through repeat audit of data quality and information usage.

Information needs of the PCT's clinical and management community

It is clear that Boards and PECs must have the requisite level and quality of information that will enable them to fulfil their own statutory duties and functions. They also have a broader clinical governance duty: to develop strategies and initiate actions which meet the information needs of management and clinical staff who organise, deliver or commission care for the patient population.

'CHI asked at least two-thirds of organisations to act because clinicians and managers did not have ready access to information that helped them to provide effective health care. This information includes:

- patient information, including test results, and systems which staff can analyse and act upon for quality improvement
- · trust policies.'

Commission for Health Improvement, 2002

The White Paper Better Information, Better Health identifies the key role of information management and technology strategy and operational systems in producing the evidence that enables clinicians and managers to base decisions upon robust clinical and operational evidence.

'Effective health care requires an information infrastructure to extend the human mind's limited capacity to recall and process large numbers of relevant variables; this knowledge should be held in tools that are kept up-to-date and used routinely, rather than in people's heads, which are expensive to load and faulty in the retention and processing of knowledge.'

Clinical Governance Development Plan, Barnet

Notwithstanding the historically disparate nature of the PCT clinical community, some significant progress has been achieved.

'Almost all PCG/Ts (95%) had at least half of their practices using Read codes, 60% data entry and extraction protocols, and 56% disease management guidelines.'

National Primary Care Resource and Development Centre, 2002

The work of the Primary Care Collaboratives has underlined the importance of local and focussed analysis of clinical data as a springboard to improvement — and evidence of its achievement.

'Rigorous, regular measurement has been central to the improvement work in Collaborative practices. The discipline of examining and understanding the data at practice level each month enables practices to target their ongoing care effectively.'

The National Primary Care Development Team, 2002

Although much can be achieved at the clinical coal-face, the gradual development of a complex data set that covers the entire diverse range of a PCTs responsibilities and actions will demand persistent investment over time. The inherited resource base, both in personnel and in hardware and software, continues to present major difficulties.

'Major obstacles to progress were a lack of staff (80%), a lack of money (75%), and too many priorities (71%). Many IM&T leads were not confident of meeting national targets for IM&T development.'

National Primary Care Resource and Development Centre, 2002

A PCT must adequately support its own IMET staff so that they can work closely with partners in the local health economy to construct a business case which will, in line with the national strategy, enable the SHA to:

- agree costed implementation plans from PCTs and other members of the health communities
- · allocate funds
- approve IM&T business cases
- · monitor progress using nationally consistent performance criteria
- broker IM&T solutions across networks
- · interpret national policy locally
- provide leadership for health informatics
- ensure data flow and quality across their patch and to the centre.
- 'The need to invest in world-class IT must be recognised so that the fundamental principles of data collection, validation and management can be observed.'

Bristol Royal Infirmary Inquiry, 2002

In order to help NHSTs and PCTs respond to the extent of the challenge posed by the demand for system-wide 'intelligent information', the *Vision for the new CHAI* envisages:

'the development of 'Information Units' within organisations providing healthcare, dedicated to collecting, reporting, disseminating, analysing and learning from the data originating in their organisation and from information fed back to them. Such Units already exist in one form or another in many organisations. Our aim is that they come to be seen as an essential part of the organisation; properly staffed and funded.'

CHI, 2003

Such units would be welcomed by, and of massive assistance to, PCTs, as will the CHAI commitment to a 'local presence' designed to:

'meet the needs of staff at the "frontline", management and regulators. Its principal purposes will be: to assist in the collection and interpretation of information in its local context; to coordinate assessment and visits by local peers and the local community; and to coordinate, locally, the reduction in the burden of visits of one sort or another from inspectorates.'

CHI, 2003

Information needs of individual patients

PCT Boards and PECs are responsible for ensuring that they have strategies and monitored implementation plans to deliver appropriate clinical information to individual health professionals and other paid carers. They must also have parallel strategies and implementation plans enabling them to provide comprehensible and useful clinical (and other) information to individual patients and their informal carers.

Excellent progress has been made in generating literature that gives patients a more informed understanding of their own condition; this, in turn, enables patients to take greater responsibility for and control of their own treatment and recovery, or illness management. This information needs to be actively disseminated and appraised to ensure that is accessible to

- · people with learning disabilities
- members of minority ethnic communities whose first language may not be English
- people with visual or auditory impairments.

Halligan and Donaldson, 2001

Information needs of the wider local community

The Patient Forum, the OSC and other formal and informal mechanisms of consultation have been established to ensure that local communities are able to make the strongest and most informed contribution to:

- · the evaluation of the quality of current provision
- the development of new and innovative ways of identifying and responding to current and emergent need.

A PCT has a duty to generate and disseminate information in a format that is clear, comprehensible and effective in reaching this target audience.

The Patient Prospectus is the prime example of such information; and will need to reach the widest possible local audience. Where possible, this should be with the support of local broadcast media.

^{&#}x27;Empowering patients with information, and increasing their contribution to planning services, can greatly influence the development of clinical governance.'

'A central tenet of *The NHS Plan* was that services should be shaped around patients, so we need to find out what they think. Having established that, trusts need to act on it. Patient prospectuses will say 'this is what we have done on the basis of what you have told us'. They will also cover how organisations respond to complaints and what the Commission for Health Improvement (CHI) has said about them. This will allow patients to be more informed about the services they receive and eventually allow them to make choices about where they have their care.'

Sarah Mullally, chief nursing officer and lead director for public and patient involvement at the Department of Health

Developing an IM&T strategy to support clinical transformation

Current data must be routinely translated into intelligent information, not just within the boundary of any one health care organisation, but across a local health system and/or economy. Each PCT needs to develop a local strategy to support national and regional initiatives designed to streamline and co-ordinate data gathering and data processing. Information and intelligence can then serve planning, monitoring, evaluation and transformation initiatives.

'Transformational change' requires more sophisticated information systems that facilitate rapid acquisition, processing and sharing of rich, complex information that enables effective knowledge management.'

NCCSDO, 2001

This is particularly true in the light of the growing emphasis upon information to inform proactive approaches to health care planning and provision, or:

'the need to move away from management by reaction to management by anticipation'

CEO Bulletin

To give impetus to this change, the Healthcare Operational Intelligence Project has produced a guide: Information for Action: a Good Practice Guide on Anticipatory Management in Health Care.

All of these strategies and actions will require active collaboration with the SHA. There will also have to be a commitment to investment in IMET actions that demand co-ordination:

- · across the boundaries of health care organisations
- across the frontier which historically has separated health care information systems from those in social care.

'PCTs will:

- collaborate with their local NHS Trusts and Social Services in the formulation of integrated and costed local implementation plans;
- ensure that IMET for the care networks providing their services are fully integrated and supported around the needs of their patients;
- resource collaborative implementations as part of the wider commissioning of services.'

Department of Health, 2001

Responding to the Caldicott requirements

In gathering, processing and managing patient data and the information that proceeds from it, the Boards of all NHS bodies have a statutory responsibility to comply with the standards of confidentiality and ethical organisational practice laid down in the Caldicott Committee's Report on the Review of Patient-Identifiable Information. To this end, they must ensure that they have appointed a Caldicott Guardian who reports regularly to the Clinical Governance Committee or PEC on compliance and related issues.

CALDICOTT EXEMPLAR

North East Lincolnshire Primary Care Group

PROTECTING AND USING PATIENT INFORMATION

ACTION PLAN 2001/2002

Background

At a Caldicott Overview and Local Implementation meeting held during October 1999 discussions took place as to how the recommendations of the Caldicott Committee's Report on the Review of Patient-Identifiable Information could be implemented effectively across North East Lincolnshire Primary Care Group.

The group identified key areas to take forward including Contracts, Code of Conduct, Training, Induction Procedures, Information Flows, Information to Patients and Safe Haven Procedures.

During February 2000, all Practices, the Central Management Team and Grimsby Area Primary Care Emergency Centre were asked to complete a Management Audit Organisational Profile based on the areas previously identified. The main purpose of the baseline assessment was to take stock of existing activities and to raise awareness across the locality.

The results were collated and realistic targets were set to raise performance levels.

It was acknowledged that Practices will need support in achieving the targets which have been set at a pace that is both challenging and locally sustainable

Priorities for action

Now that you have finished reading through this section, please identify three priority actions for the PCT in relation to data collection and information management.

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References

Bristol Royal Infirmary Inquiry 2001. Learning from
Bristol: The Report of the Public Inquiry into Children's
Heart Surgery at the Bristol Royal Infirmary 1984-1995,
BRI Inquiry Final Report, Bristol: BRI Inquiry

Clinical Governance Bulletin, June 2001, vol. 2, no. 2

CEO Bulletin 2002. Issue 146 November. www.doh.gov.uk

CHI, 2003. Vision for the New CHAI
www.chi.nhs.uk/eng/about/chai_vision.pdf

Commission for Health Improvement 2002. *Emerging Themes.* www.chi.nhs.uk

Cullen, R., Nicholls, S. and Halligan, A. 2001. NHS
Support Team: Measurement to demonstrate success.

British Journal of Clinical Governance, 6, 4, 273-278

Halligan, A. and Donaldson, L. 2001. Implementing Clinical Governance: turning vision into reality (Education and Debate). *British Medical Journal*, 322, IAI3-IAI7

Department of Health 2001. Shifting the Balance of Power within the NHS: Securing delivery, London: DH

Sarah Mullally, chief nursing officer and lead director for public and patient involvement at the Department of Health

National Primary Care Resource and Development Centre 2002. National Tracker Survey of Primary Care Groups and Trusts 2001/2002: Taking Responsibility?

Manchester: NPCRDC

National Primary Care Development Team 2002. The National Primary Care Collaborative: The First Two Years,

Manchester: NPCDT

NCCSDO 2001. Making informed decisions on change. Key points for Healthcare Managers and Professionals

London: NCCSDO

CG Development Plan, Barnet.

Resources

 $\label{eq:decomposition} \mbox{Department of Health} - \mbox{access to all Department of} \\ \mbox{Health information is through their website:}$

www.doh.gov.uk

The Modernisation Agency is a valuable source of information. You can access the different strands of the Agency through the website at:

www.modern.nhs.uk

National Clinical Governance Support Team — the CGST runs a series of programme to support the implementation of clinical governance 'on the ground' www.cgsupport.org

The National Primary and Care Trust Development Programme — the NatPaCT team helps PCTs with organisational development

www.natpact.nhs.uk

Information for Action: a good practice guide on anticipatory management in health care is available at: www.doh.nhsweb.nhs.uk/nhs/hoip/index.htm

Weed, L. L. 1997. New connections between medical knowledge and patient care. *British Medical Journal*, 315, 231-235 www.bmj.com/cgi/content/full/315/7102/231

Rating the PCT's current stage of development

Please rate the PCT's current stage of development in relation to the following questions. Remember to use the Response Sheet provided for your answers.

- 9.1 To what extent do the Board and PEC have a strategy to develop 'intelligent information' systems?
- 9.2 To what extent is the information available to the Board and PEC sufficiently robust for them to discharge their public health functions in relation to the current and future needs of their communities?
- 9.3 To what extent is the information available to the Board and PEC sufficiently robust to assure the safety and quality of current provision made by the PCT?
- 9.4 To what extent is the information available to the Board and PEC sufficiently robust to assure the safety and quality of the services commissioned by the PCT?
- 9.5 To what extent is the PCT currently meeting the Caldicott Standards?
- 9.6 To what extent have strategies to generate 'intelligent information' been agreed across the local health economy?