

**Informing Healthier Choices:  
Information and Intelligence for  
Healthy Populations**

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## Introduction

### The Context

In 2004, we set out our plans for tackling some of the most important health problems affecting people in England. Six key areas were highlighted for action in the White Paper *Choosing Health: Making Healthy Choices Easier*.

Tackling health inequalities;

Reducing the numbers of people who smoke;

Tackling obesity, including promoting exercise;

Improving sexual health;

Improving mental health and wellbeing;

Reducing harm from alcohol and encouraging sensible drinking.

Other elements of this national health improvement strategy were published in earlier documents such as *Saving Lives: Our Healthier Nation* (1999), *Getting Ahead of the Curve* (2002), and *Tackling Health Inequalities* (2003).

This new strategy sets out proposals to provide comprehensive and innovative information systems that can make a real difference to delivery of these plans in a cost effective fashion. The ultimate aim is health improvement but these proposals would also underpin evidence-based commissioning of services, as well as providing more precise and meaningful monitoring of performance of public service activities.

Work to improve the health of the population is by no means the preserve of the health services. Increasingly, local responsibility for the health of communities will be shared between the agencies that make up Local Strategic Partnerships (LSPs) and with the communities themselves. Information and knowledge relevant to health is generated by and should be used by a wide range of agencies and individuals. Information systems need to work across these settings in an integrated way in order to provide a fully informed picture of health and its determinants. This strategy aims to support that approach.

Health is a significant element of local Public Service Agreements (PSAs) and their related targets. The Office of the Deputy Prime Minister (ODPM) has published plans for Local Area Agreements (LAAs), which are currently being developed in a series of pilot sites. These agreements will include multi-agency plans to promote healthier communities and narrow health inequalities through effective combinations of key local services (such as health, education, housing, crime and accident prevention). This approach is reinforced by the White Paper *Our health, our care, our say: a new direction for community services* which states “The main responsibility for developing services that improve health and wellbeing lies with local

bodies: PCTs and local authorities.” The LAAs will require information systems to support them.

*Public health without information is like pathology without a laboratory”*

Michael Goldacre

## **The Role and Scope of this Strategy**

The focus of this strategy is on the areas covered in *Choosing Health*. However, its measures will also support wider health priorities such as action on health inequalities, health protection and effective commissioning of health and wellbeing.

It provides the required vision, leadership and plans for delivering health information and intelligence nationally and also a framework to harmonise the work of different agencies. It includes measures to improve the availability of relevant data, strengthen organisations, support the skilled workforce in this area, and develop innovative information systems. The strategy calls for cultural, organisational and technical developments. *Choosing Health* and *Our health, our care, our say* provide a rare opportunity to initiate these important changes.

## **Aim**

To improve the availability and quality of health information and intelligence across England and to increase its use to support population health improvement, health protection and work on care standards and quality.

## **Objectives**

1. To support delivery of *Choosing Health* and *Our health, our care, our say* by making information and knowledge available to local communities to inform their decisions.
2. To meet the information and intelligence needs of key Department of Health and wider health-related Government policy objectives such as commissioning for health and wellbeing, reducing inequalities in health, monitoring the public health function, achieving health literacy, and tracking relevant PSA targets locally and nationally
3. To support the work of professionals engaged in improving the health of the population. This includes helping Directors of Public Health (DPHs) to prepare reports for local authority overview and scrutiny committees and joint reviews of the health status, wellbeing and health needs of their population, as proposed in *Our health, our care, our say*.

## Benefits

The strategy will provide consistent reliable information on levels of health in communities, trends over time and patterns within communities. This will be available in an accessible form alongside information on the major causes of ill health, together with evidence of what can be done to help.

Better information on health needs and on the effectiveness of interventions will lead to more effective commissioning of services for health improvement and care, and better value for money in the procurement of public services aimed at tackling the causes of ill health.

The strategy provides a framework for information collection and analysis that will enhance and refine our knowledge of inequalities in health and provide a mechanism for much closer monitoring of progress in tackling them.

The development of comprehensive real-time linked data systems, including data from primary care as well as other sources, will enhance surveillance of a wide variety of health threats and improve our ability to react quickly and effectively to protect the health of the population.

Better use of existing data, data sharing between organisations and centralisation of some systems should reduce the burden of information collection on care services.

The information availability and communication to the public will help inform their decisions and choices about their own health and wellbeing and help realise “the public’s priorities” as defined in the consultation on *Our health, our care, our say*.

More strategic decisions will be made on the basis of a common understanding of health priorities, the impact of public and private sector programmes on health, and the likely value for money of efforts to improve health.

Co-ordinated action across agencies will be more likely and will be more effective, because all agencies will have shared knowledge of the health challenges in their local communities.

Public awareness and understanding of population health issues will be greater.

Public action and support for health improvement initiatives is likely to increase.

**Information and intelligence systems should be able to answer basic questions such as:**

- ❖ How many teenagers smoke in my local area and how can we, as a school, have an impact on this?
- ❖ What are the main health problems for materially deprived communities in my town?
- ❖ What is happening to rates of sexually transmitted diseases in my area, compared with the national average and what should we as a Primary Care Trust be doing about it?
- ❖ How big a problem is alcohol-related domestic violence in this area and which localities need most help?
- ❖ How effectively have new vaccines been introduced in this region and which communities need additional attention to improve coverage?
- ❖ What are the health effects of living in areas with high levels of radon in the ground?
- ❖ What are the long term effects of taking medicines that have only been followed for five years in clinical trials before being licensed?
- ❖ How effective was our recent campaign to reduce alcohol-related road traffic accidents and has the benefit been sustained over time?
- ❖ Is specialist health care being provided equitably in this region?
- ❖ What are the health care needs of ethnic minorities in inner city areas?
- ❖ Where in this town should a new mental health clinic be sited to maximise its impact?
- ❖ What are the most pressing unmet health needs among patients in this practice?
- ❖ What can I as a mother do about my child's weight problem?

## Lessons from the second Wanless Report

In his second report, entitled *Securing Good Health for the Whole Population*, Derek Wanless concluded that good information is needed to identify health problems early. It helps people and organisations decide what to do, how to do it and then to track progress. Adequate information is essential when making the case for change and for investment in health. If the public are to engage in a dialogue on health, people need access to meaningful information about local health issues. This basic knowledge allows them to express their preferences from an informed position.

Wanless concluded that “little comprehensive information is collected on the health status of the population or on the prevalence of important behavioural factors such as smoking, drinking, diet and exercise”. He also found that “there is no regular mechanism by which a Primary Care Trust (PCT) or Local Authority (LA) can gather reliable information on its own population”, and that “given the multi-sectored nature of public health, the current lack of effective mechanisms for data-sharing between organisations at local and national levels, is a major potential impediment to more targeted and responsive public health actions”.

The issues raised in the Wanless report with regards to information use in public health can be summarised as follows:

- Gaps in existing information data flows and systems inhibit data capture, sharing and dissemination.
- Links are not sufficiently well made between numerical data on population health, research evidence and information on the cost-effectiveness of interventions.
- Public health capabilities and capacities need to be developed to make other resources more effective and to promote health literacy.
- More evidence is needed on cost-effective interventions and that evidence needs to be rapidly disseminated to drive local action.

There was further criticism in the report of performance monitoring processes which did not, at the time, properly recognise the importance of public health objectives:

*“Objectives to improve health outcomes and tackle key risk factors, such as smoking and obesity, need to be given equal weight in the NHS performance management and inspection systems to waiting times. These need to impact both on PCT managers and, through the new opportunities created by PMS and the GMS contract, on front line professionals... The Department of Health should reinforce the role of SHAs in relation to the performance management of the public health function within PCTs,” ...*

Securing Good Health for the Whole Population

## Drivers for change and improvement

The problems identified in the Wanless report are a cause for concern and need to be addressed. However, there are reasons for optimism.

- The UK benefits from universal provision of health care and a system of registration in General Practice that provides an excellent basis for collecting population-based information.
- A number of long standing surveillance systems are in place and have delivered good results in the past, for example on cancer and infectious diseases. Several SHAs have already developed local frameworks to plan and monitor in-year delivery of the Health of the Population Local Delivery Plan (HoP LDP) targets.
- The Government has invested heavily in providing a first class IT infrastructure for the NHS which is now being implemented. This will provide unparalleled access to large scale data sets on health care activity in hospitals, General Practice and the community.
- *Choosing Health* has focussed attention on health improvement issues across Government and between agencies locally. It has also provided for the expansion of the role of the National Institute for Health and Clinical Excellence (NIHCE) into public health and health improvement.
- *Our health, our care, our say* has emphasised the need for better, more accessible information available to the public and for a stronger, better defined role for DPHs in their work with LA overview and scrutiny committees and in contributing to joint reviews of the health and wellbeing of their populations. It also emphasises the need for better information and intelligence sharing between PCTs and LAs in order to support the commissioning process.
- The latest Government policy for *Commissioning a Patient Led NHS* places considerable emphasis on the use of population data to inform choices as does the general programme for reform of the NHS set out most recently in *Health reform in England: update and next steps*.
- There is cross Government support for data-sharing between public agencies with appropriate safeguards to protect privacy.
- The need to strengthen the evidence base in public health is being addressed by the UK Clinical Research Collaboration (UK CRC), which is developing a comprehensive public health research strategy.
- The new NHS Research and Development strategy, *Best Research for Best Health*, confirms the Department of Health's commitment to using the new comprehensive NHS IT system to support research. It also identifies as a priority the use of routinely



collected data for research on the health of the population, the natural history of disease and the effectiveness of interventions.

## A vision for the future

Problem-based health information and intelligence systems at national and local level will be designed around the needs of users. These systems will hold real-time data of sufficient scope and validity to be of real value and will provide easy access to high quality evidence and know-how. The systems will deliver information through easy to use portals configured by users to become their “public health desktops”.

Users of the systems will be able to get the training they need. The expert information and intelligence workforce will be supported and developed. Attractive careers should be available to those who want to work in health information and intelligence at all levels.

Information from multiple sources on individuals or areas will be linked within a limited number of secure confidential systems. These will then report suitably aggregated or anonymised results to users. This approach reduces the need to disclose identifiable data but greatly increases the potential value of individual data sets. Linkage is a powerful technique that allows the non-health causes of health problems to be assessed and monitored directly alongside their health consequences.

The information systems will be accessible to the public as well as to professionals in order that we can approach the “fully-engaged” scenario envisaged by Derek Wanless. There will be multiple integrated points of access (most likely web-based interfaces) that will guide users to the material that they require (data, information, evidence, know-how, policy and links to further resources).

*During the consultation on Our health, our care, our say, respondents over-whelming wanted better access to better information to help them make choices and take control of their health and wellbeing.*

There will be a programme of active communication of health messages to local communities in line with other Government policies.

Organisations involved in collecting, managing and analysing the information at regional and national level will work within a clear framework that defines their roles, provides a governance structure and secures their funding. They will work together to build and maintain the systems, to monitor and improve the quality of the underlying data, and to support users.

Communities of practice will be actively supported through integrated knowledge management resources which easily identify local sources of relevant experience and know-how. Well catalogued repositories of useful data, knowledge and other resources will also be available that can be easily and systematically searched.

Information on the effectiveness of interventions will be integrated with other data to monitor and predict trajectories in health outcomes against realistic targets. This will show which interventions (in which populations) are required to achieve targets such as reduction of inequalities in life expectancy.

The proposed National Settlement System (NSS) and Financial Resource Management Systems (FRMS) being implemented as part of *Commissioning a Patient Led NHS* will provide financial data which will allow for cost information to be attributed to health interventions. This will assist in the modelling of commissioning decisions by PCTs and LAs and support their partnerships.

## A national framework for health information and intelligence

Data collection	<p>Data should be collected as a by product of routine public (or private) sector activity as far as possible.</p> <p>Data should be of known validity and completeness.</p> <p>Available data should cover the causes of health and illness including wider determinants as well as health outcomes and information on levels and quality of services provided.</p> <p>Sources of data should include: primary, secondary and community NHS care, local public sector sources, private sector, and voluntary sector sources.</p>
Data management	<p>Data should be efficiently shared, collated, validated, linked, anonymised, and archived as appropriate using secure systems.</p> <p>Person-level data should be handled in such a way that the rights and interests of the individuals concerned are acknowledged and respected while striking a proportionate balance with the public benefit.</p>
Analysis	<p>The systems involved should allow a range of approaches to analysis, including:</p> <ul style="list-style-type: none"> <li>• Ad hoc, query-based analysis</li> <li>• The regular production of specified indicators</li> <li>• Surveillance for unexpected trends and outcomes</li> <li>• Modelling of health outcomes against targets</li> <li>• Data feeds for disease registers including cancer registries</li> <li>• Area based analyses from national to small-area with comparisons</li> </ul>
Interpretation in context	<p>The results of the analyses must be interpreted in the context of:</p> <ul style="list-style-type: none"> <li>• Statistical and methodological issues including data quality</li> <li>• Evidence from research</li> <li>• Experience of practice</li> <li>• Local knowledge.</li> </ul>
Communication of messages	<p>The messages derived from the interpretation of the information and evidence must be communicated to relevant audiences using a range of media appropriate to the target audience or audiences.</p>

In due course, we envisage a national Health Information and Intelligence System (HIIS) supported by NHS Connecting for Health and its Secondary Uses Service (SUS). An overview of this system is given in Appendix 1. The same principles can be applied at local level with the development of integrated local information systems based on explicit data-sharing protocols between agencies. These will be supported where appropriate by common national information governance and informatics resources.

In addition to technical developments such as these, there are a number of other important pre-requisites for the success of the strategy. These include:

- gaining a better picture of users' requirements for information and intelligence;
- attention to the quality and completeness of the primary data;
- development of IT systems and supporting informatics as tools to support the manipulation and analysis of large scale datasets in a secure environment;
- development of modelling approaches that combine information on effectiveness with demographic, risk factor and outcome data to predict trends in key indicators under different assumptions;
- clarification and development of the roles of different bodies and better joint working, between information providers at regional and national level;
- substantial attention to the need for skilled staff in organisations using, developing and maintaining the system, and to their training and career development;
- establishment of training resources for public health information, intelligence and knowledge skills, accessible via a central on-line repository;
- establishment of data-sharing agreements between contributing agencies as envisaged by the Cabinet Office in its report *Privacy and Data-sharing: the Way Forward for Public Services* (April 2002) and more recently promoted by the Council for Science and Technology in their report *Better Use of Personal Information: Opportunities and Risks* (November 2005);
- willingness among potential users to apply the outputs of the system to policy and public health practice, or in the case of the public to their personal choices.

*“Information is like water. It must be gathered from where it falls, channelled cleaned, treated and tested before being stored in reservoirs. It must then be made available on tap to those who need it, wherever and whenever they need it.”*

Adapted from a metaphor coined by Sir Muir Gray

### How might things be different in future: the professional perspective?

“I am a health professional working in local government and am involved in coordinating and commissioning publicly funded services to the local population. We use providers from the state, independent and non-statutory sectors and work closely with local general practices. My job includes identifying important health issues early in case the local population need protection of some sort, providing expert input into assessing local health care standards, and ensuring all public services contribute to improving health and reducing health inequities.”

“To do this effectively, I work with a team of information analysts, research officers, service commissioners, and policy officers. We are in turn served by an integrated information and intelligence system. At any time, the system is likely to warn us that one of our health and welfare indicators has crept outside the acceptable limit in to an area of concern. These alerts are based on regular automatic data feeds from many different government departments, but also from agencies such as the Met Office. In the past we somehow survived whilst having no idea when important parts of the health and welfare system were performing badly or if some important health indicator such as life expectancy in part of our district was static or falling.”

“The information system links all the routine data sources automatically so, whether we are involved in health surveillance or working with commissioners, we spend negligible time finding the data, and nearly all our time ensuring that we understand what the data are telling us about the health of the population we serve and what we should be doing about it. The system will also automatically flag up the latest evidence on cost effective interventions relevant to our population.”

## **What is the current situation?**

A great deal of relevant information on the health of communities in England is at least potentially available. However, we recognise a number of problems and challenges in using these data:

- Some important data are still missing such as local smoking rates or local child height and weight information.
- The data that are available are not always accessible, of adequate quality or in a usable format. A particular problem that PCTs and LAs face is obtaining access to health and non-health data about populations that can be linked together in a meaningful way, to add value to its practical application.
- Few of the data available are consistently benchmarked and validated across the country, making comparisons on a national or local basis difficult to interpret and potentially misleading.
- Access to and interpretation of important data sources relies on skilled analytical staff and many organisations, especially smaller PCTs and LAs, currently do not have sufficient resources to do this.
- The diverse nature of the data collections, and the lack of accessible common portals, means that collation of the data and application of results to real population health issues remains a huge challenge even for well resourced departments.

## **Availability of health datasets**

A summary of the health and healthcare datasets potentially available in 2005 in a PCT is given in Appendix 2. Although they all have their limitations, these resources represent a solid foundation from which to build.

## **Availability of non-health data sets**

Information on the underlying causes of ill-health and health-damaging behaviour, such as poverty, violence or an otherwise poor quality physical or social environment, is essential to an understanding of the health of populations. Access to non-health data sets such as those on housing or levels of income support is possible at national level but is often better at local level.

Some jointly appointed (LA and PCT) Directors of Public Health have made these data available alongside health data (see for example [www.mkiobservatory.org.uk/](http://www.mkiobservatory.org.uk/)). Other data are being made available nationally through the ODPM's Neighbourhood Statistics project and the Audit Commission's Area Profiles.

**Categories of available non-health data relevant to the health of populations, with examples of data sets in each category**

<u>Domain</u>	<u>Examples</u>
Crime	All crimes, burglaries, violent crimes, robbery, domestic crime and domestic incidents, neighbour complaints.
Economy	Business formation rate, business survival rate, youth unemployment, long term unemployment, average weekly earnings, Regional Productivity Index.
Education	Exam results, NVQ levels in the labour market, school performance and standards, school attendance.
Fire	Accidental dwelling fires, arson fires.
Housing	Council tax bands, housing tenure, development forecasts, housing affordability index.
Local Authority Performance	Best Value Performance Indicators, Comprehensive Performance Assessments.
Social Indicators	Attendance Allowance, Disability Living Allowance, Incapacity Benefit, Index of Multiple Deprivation, Income Support, Estimates of Income.
Environment	Gas and electricity consumption, Audit Commission Quality of Life Indicators (community cohesion, culture and leisure, transport and access etc.)



## Access to data

There is currently no single portal where a good range of the most useful population data, information and knowledge is presented in an accessible and easily understandable fashion.

Further difficulties include:

- Comparing public health data across time and place is sometimes difficult because of changes in boundaries and indicator sets over time, or restrictions on access to the data.
- Accurate denominator data may be difficult to obtain for specific populations or may be inconsistent between sets of statistics.
- Data-sharing between organisations is currently impeded by the absence of appropriate protocols, incompatible systems and confusion over confidentiality and disclosure regulation.
- Some datasets are only available at a cost to the user.
- Capacity within the public health information and intelligence workforce is limited and training and development opportunities in this area are sparse and currently not well co-ordinated at national level.

## Data quality issues

Underlying data quality is fundamental to the value of any derived statistics. Data quality has a number of components, including completeness, accuracy and timeliness. The picture in England is currently mixed with some areas of generally high quality data for example on registrations of death, cancer registration or prescribing in general practice. Other areas may be very incomplete and variably collected, for example information on operative procedures from hospital systems or on diagnosis from general practice.

One area of particular concern is ethnicity data. Despite the statutory duty of public bodies to promote race equality, routinely available ethnicity data across the health service is limited and often incomplete. Overall, for example, 24% of HES data entries remained incomplete – not known or not stated - for ethnicity in 2004/5. Ethnicity data is particularly weak in primary care. This situation was highlighted in a recent report on ethnicity and health produced by the London Health Observatory on behalf of the Association of Public Health Observatories (APHO).

Special problems for population health uses are as follows:

- The health of populations is often assessed using data collected by others for other purposes: the classifications and coding systems used during data capture may not suit this additional purpose.

- Standardisation and interoperability of the systems used to collect data is crucially important in a real time information system in which computer systems need to be able to interrogate each others' databases without the need for a human interface.

## **Delivering the Vision: How do we get there?**

### *Short and long term benefits*

Creating a fully integrated system will take time and some of the benefits of this strategy will not be apparent until additional infrastructure and capacity is established. We have taken a long term view, as recommended by Derek Wanless. However, within the strategy there will be a number of substantial early benefits such as the community profiles and the reports derived from them, workforce support initiatives, public health data safe-havens, and the National Library for Public Health (NLPH).

### *Building on existing roles across agencies*

The strategy depends on the work of groups such as NHS Connecting for Health, the Health and Social Care Information Centre (HSCIC), NIHC, the Public Health Observatories, the Health Protection Agency, Cancer Registries, the Healthcare Commission, individual PCTs and many others with established roles in health improvement. In addition, we need to engage across organisational boundaries to involve all agencies whose work contributes indirectly to population health outcomes. This needs to happen at national, regional and local levels. The implementation of the strategy as a whole will require central co-ordination and monitoring and arrangements for this are set out later in this document.

### *Linking with other strategies*

It is essential that this strategy is not seen in isolation and that work to support it is closely linked with and supports complementary work on other initiatives. The relationships will vary for different areas of the strategy, but within the Department of Health, for example, the strategy needs to be linked with *Standards for Better Health, Better Information, Better Choices, Better Health*, the information strategies that support each of the National Service Frameworks, *Agenda for Change, Best Research for Best Health* and the *National Social Marketing Strategy*. It is also important that the strategy can deliver the population health information required for *Commissioning a Patient-led NHS* and *Our health, our care, our say*.

### *Working across Organisations*

More widely, the strategy needs to be closely aligned with the work of the Office of the Deputy Prime Minister and Government Office Regional Relationship Teams in building safer and stronger communities and specifically to support the information needs of Local Area Agreements, and the monitoring of Public Service Agreements at local and national levels. Other areas of overlap include with Department for Education and Skills on information from schools and *Every Child Matters*, with the Audit Commission on the production of Area Profiles, and with the Healthcare Commission and the Commission for Social Care Inspection on indicators of performance in public health. The strategy depends on effective methods for confidential data-sharing between Government agencies and this will be a major theme in its implementation.

*Responding to the needs of users*

The strategy should be responsive to the needs of users and for that reason we will set up two new groups to specify those needs more fully (1) a public health user group for NHS Connecting for Health's Secondary Uses Service and (2) a new national forum for information analysts working in PCTs and Local Government. These groups will complement existing support networks, for example those provided by the APHO technical group and the Faculty of Public Health.

The main elements of the strategy are summarised in the following four boxes:

### 1. Improved data and information provision

- Collecting national child height & weight data
- Obtain & collate GP data on lifestyle nationally
- Improve the quality & completeness of NHS ethnicity data
- Further develop public mental health intelligence
- Produce and publish comprehensive Community Profiles for all Local Authorities and for England as a whole
- Model key health outcome indicators using information on the effectiveness of interventions
- Implement a social marketing communication strategy based on messages from the Community Profiles
- Create an accessible population health web portal for professional and public users

### 3. Workforce training and support

- Collate existing and develop new curricula and training courses in health information and intelligence
- Set up an on-line repository of training materials and resources in information and intelligence
- Create a Health Information and Intelligence Workforce Steering Group and implement a workforce development strategy for information and intelligence
- Develop models for information and intelligence roles in different organisations
- Develop and support career pathways for specialist information and intelligence staff
- Set up a national PCT/LA information analysts forum

### 2. Stronger organisations

- Strengthen the PHOs & APHO
- Confirm role of Cancer Intelligence Units
- Integrate regional information functions
- Develop the population health role of NIHCE
- Commission a National Library for Public Health
- Create population health “safe-havens” for linkage of personal data in a secure and confidential environment

### 4. Development of a national Health Information and Intelligence System (HIIS)

- Data warehouse and data mart
- Accessible and flexible interface
- Population health indicators
- Surveillance systems
- Disease registers
- Knowledge management systems
- Research and central statistics

### How might things be different in future: the public perspective?

A mother has become increasingly concerned that her eleven year old son, Tom, has been putting on weight, and is worried that this may have implications for his health in the future. There seem to be many pressures on Tom to eat unhealthily. Also he does not seem to be as active as she was at his age, his favourite pastimes being television and computer games. She accepts that she has a joint responsibility with her local health services and Tom's school to help him make healthier choices. She feels she needs more information to do this effectively.

Tom's mother attends her GP surgery and finds leaflets there on a range of topics, including one on child obesity and exercise. This contains links to further sources of information.

When she returns home, she looks at an NHS internet site mentioned in the leaflet. This contains a comprehensive description of the health of her local community and the nation as a whole. It shows her that although where she lives there is a higher than average rate of child obesity, the rates are falling. The site summarises current health improvement programmes aimed at reducing child obesity. There are links to practical sources of information based on sound evidence that she feels will help her manage her son's weight.

Tom's mother feels reassured that health issues that are of concern to her are being taken seriously at local and national levels, and that effective action is being taken. She is better informed and is empowered by that knowledge to take more effective action herself to improve her son's health.

People said they want services that are based around their needs and that

- help them to make choices and take control of their health and wellbeing by understanding their own health and lifestyle better, with more support on prevention and promoting their independence;
- offer easy access to help when they need it, in a way that fits their lives. To get the service they need, people want more information about where it is best for them to go;
- meet the whole of their needs, particularly if these are ongoing, and support their wellbeing and health, not just focusing on sickness or an immediate crisis.

*Our health, our care, our say - Figure 1.2 The Public's Priorities*

## Outline delivery plans

The following sections briefly describe current plans to address the identified needs. Detailed plans will be elaborated by the Strategy Implementation Team following further consultation.

### 1. Improved data and information provision

The strategy will initially focus on bringing together information which is already available however one of its key aims is to increase the availability of a much wider range of information relevant to public health and to drive up underlying data quality.

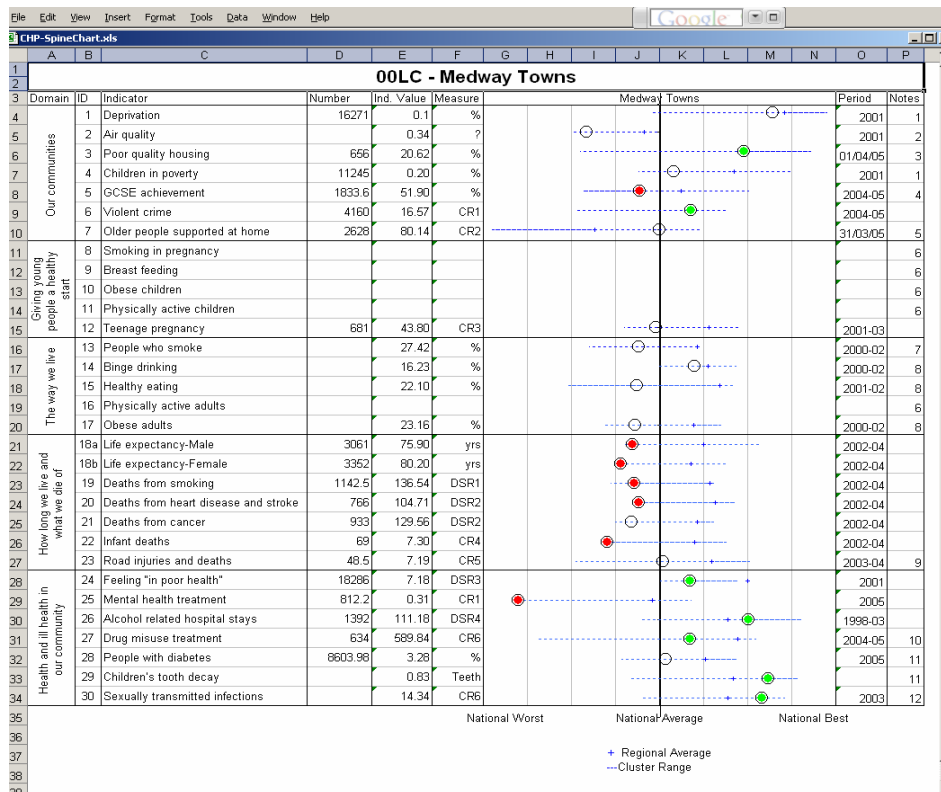
#### *Local Authority Community Profiles*

APHO has been commissioned in consultation with potential users, and in collaboration with the National Centre for Health Outcomes Development (NCHOD), to identify a core set of public health indicators available at Local Authority level to be reported each year. These indicators will consist of data that is comparative, validated and benchmarked both locally and nationally and will provide a unique picture of health and wellbeing for an area. This set will be gradually expanded as new data sources become available (for example child obesity and GP smoking data). The PHOs have compiled data on these indicators and will make analyses available in the form of Community Profiles. The first Community Profiles will be available in April 2006.

#### *National and Local reports*

The Department of Health will produce a national report each year based on the messages derived from a national view of the Community Profile data set. The first report will be produced by the summer of 2006. The PHOs will produce reports to each Local Authority in England based on information and messages from the Community Profiles. These will be produced from April 2006 onwards and will provide basic analysis of important indicator values for each population relative to other areas (see example). In this format the reports are primarily intended to support joint efforts between local government and the NHS to improve health and reduce health inequalities, such as with the DPH reports for LA overview and scrutiny committees and the joint reviews of health and wellbeing on their populations.

### Example of a Local Authority Community Profile



### Communication Strategy

The Department of Health is developing a communication strategy to deliver appropriate messages derived from the public health information system to professionals and policy makers (and co-ordinate these messages with other Government policy initiatives) and very importantly, to members of the public. These messages, when made available to the public, will help inform their decisions as part of patient choice, including decisions on health, lifestyle and wellbeing in order to help realise “the public’s priorities” as described in *Our health, our care, our say*. The Central Office of Information (<http://www.coi.gov.uk/>) has provided a brief report on methods for communicating public health messages direct to the public. Design work will be commissioned to provide a high quality and consistent look and feel to the local and national reports, which would carry through to the associated web portal.

### Interactive web-site

The PHOs will establish a web-based portal that gives access to the information used to generate the Community Profiles. This will allow users with the necessary competence to further analyse the patterns present in local reports by undertaking additional queries. This web portal will be progressively developed, following an assessment of users’ needs, to become one possible entry point to the full range of public health information and intelligence resources as envisaged in the strategy (a public health “desktop”).



### *Modelling health indicators*

Work will be commissioned to help SHAs set up information systems that integrate health outcome information with information on the effectiveness of interventions. These systems will allow realistic targets to be set for population health improvement in local areas. Such targets will be based on estimates of the likely impact of local action over and above background trends in demography, risk factors and the natural history of the conditions concerned. A relatively easy although still not straightforward case would be the assessment of the likely impact of a new vaccination schedule (for example pneumococcal meningitis) or a screening programme (for example colo-rectal cancer) on numbers of cases of the condition. More complicated but essentially the same approach would be a model of the effect of improved secondary prevention of cardiovascular disease on inequalities in life expectancy.

### *Joint work with the Audit Commission*

The Department of Health is working with the Audit Commission to pilot local communication exercises based on the first Community Profiles, in 2006. These may include the use of leaflets and other techniques aimed at empowering the general public and their representatives through the provision of meaningful information, as well as methods directed at professionals working in Local Authorities and their partner organisations. The outcome of these pilot exercises will be assessed with a view to designing a national communication strategy to ensure that the general public are aware as soon as possible of important public health messages. This work will be undertaken in consultation with the Local Government Association and the Neighbourhood Statistics project.

### *Child obesity data*

The Department has issued guidance to PCTs on the measurement of height and weight of all primary school children in Reception (ages 4-5 years) and Year 6 (ages 10-11 years). The data will be collated locally and used for population monitoring purposes. Parents will be able to opt out of the programme of measurements if they wish.

### *GP data on smoking and obesity*

The Department of Health has commissioned PRIMIS to develop a set of MIQUEST queries that will extract person-level data from practice systems on smoking and on height and weight. The validity of the results will also be assessed. If data quality is acceptable, these queries can then be used by PCTs to extract data from local practices. The Health and Social Care Information Centre is also working with the four main providers of GP data to derive data on lifestyle and obesity that can be used at national and local level.

In aggregated form these data can describe local patterns of smoking and obesity in relation to area of residence, social class, ethnicity, age and sex. They will also provide important guidance for the planning and evaluation of local services and public health initiatives.

### *Ethnicity*

The Department of Health considers that improving the quality of ethnicity data is an important objective and a necessary step to addressing any health inequalities in relation to ethnicity. The Department published in July 2005 the document entitled *A practical guide to ethnic monitoring in the NHS and Social Care*. The Healthcare Commission is now assessing the collection of ethnicity data by hospitals, efforts are underway to collect ethnicity data from users of mental health services and new primary care registration forms are intended to facilitate the collection of ethnicity data (at least for new registrations).

In addition, the Health and Social Care Information Centre has established a high level project on data quality intended to drive up data quality across a wide range of data sources. The need for better ethnicity data will be taken account of in that project.

### *Mental Health*

It is recognised in *Making it possible: a good practice guide to improving people's mental health and wellbeing*, that mental health promotion strategies would benefit greatly from adopting good practice, which includes evidence-based interventions and further developing public mental health intelligence. This recognition is carried forward in *Our health, our care, our say* and is an area on which the Strategy will provide expert advice and guidance on. Public mental health intelligence will be incorporated into the national Health Information and Intelligence System (HIIS) proposed as part of the Strategy.

## **2. Stronger organisations**

### *Strengthening the Public Health Observatories*

Funding for the PHOs in England has already been increased by £1million per annum from 2005. The role of APHO in managing work undertaken collectively by the PHOs will be strengthened. The Governance arrangements for the PHOs will be reviewed to ensure effective use of these and other resources.

### *Cancer Registries*

The important role of cancer registries / cancer intelligence units will be confirmed and supported. Information flows to cancer registries from NHS sources should continue until equivalent replacements are available from SUS. The roles of other regional information providers will be clarified and strengthened where necessary.

### *Integrate regional information functions*

The new Directors of Public Health for the SHA's/GOR's will ensure that all regional bodies with an information and intelligence function work together to provide a co-ordinated function in support of public health and other Government priorities.

### *NIHCE and the evidence base*

The Department has commissioned NIHCE to undertake a full review of evidence for the effectiveness of methods of achieving behaviour change at population and community level. The results will be available in 2007.

(<http://www.publichealth.nice.org.uk/page.aspx?o=BehaviourChangeGID>).

The accessibility and use of the evidence base for interventions that support health and wellbeing will be overseen through a new National Reference Group for Health and Wellbeing. The National Institute for Health and Clinical Excellence (NIHCE) and the Social Care Institute for Excellence (SCIE) will play key roles. Building on this information and intelligence strategy, a central database will also be developed as a resource for commissioners.

The Department will also:

- contribute to the Clinical Research Collaboration's strategy on public health research ensuring that the new joint strategy for public health research includes research on information and intelligence issues;
- commission the Campbell Collaboration (<http://www.campbellcollaboration.org/>) to provide syntheses of relevant evidence on the effectiveness of policy interventions in the social, behavioural and educational fields.

### *National Library for Public Health*

A new National Library for Public Health will be commissioned to replace the current Public Health Electronic Library (<http://www.phel.gov.uk/>). This will be part of the National Library for Health (NLH) funded by NHS Connecting for Health. As part of this exercise the Taskforce will commission the further development and promulgation of the Public Health Language (<http://www.nphl.nhs.uk/>).

The National Library for Public Health will work with the PHOs, NCHOD and others to provide an integrated knowledge management service accessible through a web-based portal. It will also develop and support "communities of practice" in public health. This service will gradually build up its resources to meet the needs of public health users. It will be explicitly linked to other Department of Health initiatives intended to provide information to the public in line with *Better Communication, Better Choices, Better Health*.

### *Data-sharing between agencies for public health*

The Department of Health will develop an information governance specification for the creation of public health "safe-havens" and will, if necessary, apply to the Patient Information Advisory Group (PIAG) for Section 60 support. The "safe-havens" will be secure data-management environments set up to receive identifiable data from a number of agencies for the purpose of linking and anonymising the data. Analyses of the linked files would then generate aggregated statistics for users that would not themselves contain confidential information. The safe-havens will have explicit data security policies, data-sharing agreements

and Cauldicott Guardians. The Department will seek the endorsement of the Information Commissioner and others to ensure that privacy is fully protected. The Department of Health will commission the production of toolkits to support local application these approaches with model versions of the necessary documents.

*Working with NHS Connecting for Health*

A public health user group has been established to advise NHS Connecting for Health and its Secondary Uses Service on the design and specification of parts of the Service still to be delivered within the existing contract, and to suggest any additional requirements for the public health user-defined data-mart. The Health and Social Care Information Centre will be asked to undertake the detailed design and commissioning of the public health data-mart (advised by the public health user group). This group will also be asked to raise any issues relating to data quality that are of concern to public health users and fall within the remit of NHS Connecting for Health.

### 3. Workforce training and support

#### *Information workforce skills and capacity*

A Public Health Intelligence Workforce Steering Group has been established by the Department of Health in order to recommend workforce developments within the wider *NHS Agenda for Change Knowledge and Skills Framework*. The group will assess and recommend the information skills required in all organisations, work to improve the availability of training in this area, and develop career pathways for information staff.

Together with the Improvement and Development Agency for Local Government (<http://www.idea-knowledge.gov.uk/>), the Group will develop a model that describes the information and intelligence skills required in different organisations to support the implementation of *Choosing Health* and *Our health, our care, our say*, and health improvement objectives more generally.

The Workforce Steering Group will work with SHAs and Workforce Development Directorates to develop information and intelligence modules and training courses for formal undergraduate and post graduate curricula, as well as products that can be made more widely available in NHS Trusts and Local Government for all staff.

An on-line repository will be set up to contain toolkits and courses to support those aiming to improve their skills and knowledge in public health information and intelligence. This will probably be within the new National Library for Public Health and will include a wide range of health information skills (such as critical appraisal, health equity audits, health scrutiny work, and health impact assessments etc.). Training the trainer programmes will be developed to cascade these skills throughout the workforce.

The Department of Health will, through its wider NHS Knowledge and Skills Framework, implement the recommended workforce development strategy, ensuring that funded training programmes and other resources are available to ensure the availability of a well-trained information and intelligence workforce of adequate size. Together with the workforce planning directorate, career pathways will be developed for current and future specialist information staff in the NHS.

#### *Ensuring responsiveness to user requirements*

The DH will invite a relevant organisation to set up a national public health analysts forum intended to bring together and support analysts from PCTs and Local Authorities in order to establish their operational needs and inform the further development of the strategy. The forum will also be asked to raise any issues of data quality that are of concern to users. The new Forum will complement other groups already able to canvass the needs of those working in PHOs and more senior public health specialists.

#### **4. Developing a national Health Information and Intelligence System (HIIS)**

In addition to the actions described above, work will start on developing the long term vision of a central public health information system built around the NHS Connecting for Health Secondary Uses Service (see Appendix 1). This provides a unique opportunity to bring together a wide range of data in a single secure environment with very flexible potential to provide data for public health practice and research. The work will draw on the best available expertise in health informatics and will include:

- Agree, define and secure access to the key components of a national core population health data set which is collected routinely, indexed appropriately and made available through the health information system.
- Identify relevant additional data sets which could be useful and negotiate access to them.
- Ensure that data management protocols are in place so that data can be incorporated into the data warehouse in real-time and in a format that allows linkage and analysis.
- Agree a transition plan with CfH and SUS to ensure that existing data flows (e.g. to cancer registries, HPA and universities for research) are not interrupted before SUS is able to provide equivalent access.
- Agree and negotiate the implementation of data standards in relation to the core data sources so that data collection processes deliver data sets that are fit for purpose.

Once the public health data-mart is beginning to operate a number of further steps will be required:

- Design and specify analytical tools that can be used for ad hoc queries of the system with an interface linked to them by existing public health “desktops”.
- Design and specify additional tools for purposes that support population health improvement (such as cohort management, disease registers and certain research designs).
- Design and specify surveillance systems which would make structured routine analyses of the data in order to generate standard outputs of various kinds. Access to the system for surveillance will be provided for a range of organisations with legitimate purposes including the PHOs (e.g. for Community Profiles), HSCIC, cancer registries, the Health Protection Agency, Medicines and Healthcare products Regulatory Agency (MHRA), Healthcare Commission and CSCI, and NIHC.

- Design tools to ensure that knowledge is actively managed and presented within the system. The PHOs, NCHOD, NIHCE and NLPH will work together to specify an approach to knowledge management within the HIIS. This will be progressively implemented in consultation with users.

The system should be continuously reviewed to ensure that it is meeting the needs of its users but the overall approach should remain consistent to allow the processes to be consolidated. The following actions will be needed:

- Undertake regular evaluation and audit of all elements of the national HIIS to ensure its quality (including whether it continues to meet user requirements) and consistency.
- Commission independent evaluations of certain important elements of the strategy, for example the communication strategy and the analytical tools.
- Hold workshops with stakeholders, including the national public health analysts forum, and other users to discuss progress and ensure that the outputs meet their needs and are fit for purpose.
- Review from time to time the implementation of the strategy as a whole to ensure that it continues to provide value for money for the NHS.



## **Delivering the Strategy: Programme Management**

### **Bringing it all together**

The Department of Health will set up a Strategy Implementation Steering Group and a Strategy Implementation Team to develop detailed plans, to take forward the work streams outlined in this strategy and to evaluate their impact.

A comprehensive programme of governance will be established and maintained by the Strategy Implementation Team. This will include detailed project and programme plans, an ongoing risk register, cost-benefit analyses where applicable, a detailed change management plan reflecting the needs of the PH I&I workforce, a structured approach to receiving feedback, comments and suggestions and a formal change control process.

### **Strategy Implementation Steering Group**

The steering group will have representatives from the following

- Department of Health sponsors and policy leads
- Strategy Implementation Team Members
- Organisations who have a key role in the delivery of the strategy (e.g. PHOs, HSCIC, CfH, HPA, NLH, Office of National Statistics, NIHCE, relevant academic groups)
- Key users of the outputs from the strategy (e.g. Commissioners, Healthcare Commission, user involvement group nominations)

### **Quality Assurance**

Each year the developing national HIIS will be audited to determine to what degree it is meeting its objectives and user requirements and to recommend changes for further development.

Advice will be sought from existing groups, such as the Scientific Reference Group on Health Inequalities, Information Standards Board, Faculty of Public Health Information Committee and others.

### **Further work in 2006**

The programme of activities will be commissioned or implemented by the Strategy Implementation Team and will form the basis for the delivery of the strategy. In order to fully promote the strategy and vision, the Steering Group and Implementation Team will engage with various interested agencies and stakeholders at local, regional and national level. Throughout the process, the delivery teams will need to continuously assess and respond to the needs of public health users in what will be a changing environment as reforms in the NHS are implemented.



### Success criteria for the strategy as a whole

	<b>Criterion</b>	<b>Assessment method</b>
1	Real-time, flexible, access to the public health information and intelligence system, which reflect user requirements.	Usage statistics and reviews of satisfaction among a random stratified sample of users
2	A system which makes the work of Public Health practitioners more effective at local level.	Regular feedback from Directors of Public Health and the Public Health Analysts Forum
3	A system which is demonstrably continually improving	Rising levels of use of the ad hoc enquiry system and improving user satisfaction levels.
4	Data-sharing between agencies is improved.	Number of data-sharing agreements in place between health and non-health agencies
5	Reduced burden of data collection.	Reduced number of data items directly entered by front-line staff that would not otherwise be recorded as part of clinical care
6	Improving data quality	As shown by regular data quality audits
7	Providing on-line training resources	Increased number of high quality national on-line training resources in a central repository
8	Developing an I&I training strategy	Increased information and intelligence training cascaded through SHAs, WDDs, Acute and Primary Trusts
9	Identifying career pathways for information and intelligence staff	Retention and recruitment of high quality specialist staff
10	Consistent application of the strategy	Programme reviews commissioned by the Department of Health

## Risk Management

<b>Risk</b>	<b>Likelihood</b>	<b>Impact</b>	<b>Contingency</b>
Lack of stakeholder engagement and ownership	L	Strategy is not widely accepted or endorsed	Ensure local stakeholders are consulted via the PHOs and national stakeholders via a workshop Wide communication and consultation
Strategy is not linked into the wider context of health, social care and public health NHS strategy	L	Strategy does not build upon and support existing and wider health, social care initiatives and strategies	Undertake systematic review of wider strategies and initiatives, also consult with relevant stakeholders
Strategy is not as detailed and proactive as planned	L	Strategy lacks authority and is not widely accepted	Ensure that consultation is focussed and gathers views and ideas about specific questions/areas rather than general attitudes
It is not possible to achieve a common understanding and consensus of requirements and actions within the public health stakeholder community	M	Strategy lacks coherence and is not widely accepted	Development of a coherent and inclusive framework for the strategy combined with wide consultation and engagement on the draft document
Lack of Programme Board and ministerial approval	M	Strategy not published on set date	Engage and communicate ongoing work/ideas to the Programme Board and ministers throughout the project, to ensure expectations are met
Failure to obtain Department Gateway Review approval	M	Strategy cannot be published	Notify and engage with Gateway Review personnel immediately and ensure Gateway actions are scheduled into project plans

## The Public Consultation and Thereafter

During the consultation, members of the Taskforce will be working to achieve a high level of engagement across Government and in Regions. The consultation will provide an opportunity to publicise the thinking behind the draft strategy, as well as to ensure that the needs of stakeholders will be adequately addressed in the final draft and in the delivery of the strategy. Views will be sought particularly on how the strategy can best support delivery on the ground of *Choosing Health, Commissioning a Patient Led NHS* and *Our health, our care, our say*.

After the three month consultation period, the Taskforce will oversee the refinement and incorporation of feedback into the strategy. It will then stand down once the strategy is complete. A new, smaller, Strategy Implementation Steering Group will be established, along with a Strategy Implementation Team.

Following the end of the consultation period, a summary of responses will be prepared and made available on the Department of Health website. Please note that information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes (these are primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004). If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department. The Department will process your personal data in accordance with the DPA and in the majority of circumstances; this will mean that your personal data will not be disclosed to third parties.

### Contact Details

The consultation document is available at [www.dh.gov.uk/consultations](http://www.dh.gov.uk/consultations) and comments are welcome from all interested parties. A form is attached for your reply. Please complete this response form and attach your comments to it.

The deadline for responses to this consultation is **Monday 5<sup>th</sup> May 2006**.

**Contact:** Robert Jack  
**Address:** 5<sup>th</sup> Floor  
Skipton House  
80 London Road  
London SE1 6LH  
**Email:** [robert.jack@dh.gsi.gov.uk](mailto:robert.jack@dh.gsi.gov.uk)  
**Telephone:** 020 7972 3727

## Consultation Code of Practice

Department of Health written, public consultations follow the Cabinet Office code of practice. The code includes the following criteria:

1. Consult widely throughout the process, allowing a minimum of 12 weeks for written consultation at least once during the development of the policy.
2. Be clear about what your proposals are, who may be affected, what questions are being asked and the time-scale for responses.
3. Ensure that your consultation is clear, concise and widely accessible.
4. Give feedback regarding the responses received and how the consultation process influenced the policy.
5. Monitor your department's effectiveness at consultation, including through the use of a designated consultation co-ordinator.
6. Ensure your consultation follows better regulation practice, including carrying out a Regulatory Impact Assessment if appropriate.

Respondents are also invited to comment on the extent to which the criteria have been adhered to and to suggest ways of further improving the consultation process. If you have any comments or complaints about the consultation process, these should be directed to:

Steve Wells  
Consultations Coordinator  
Department of Health  
Skipton House  
80 London Road  
London SE1 6LH

Email: [steve.wells@dh.gsi.gov.uk](mailto:steve.wells@dh.gsi.gov.uk)

### Questions for Consultation

1. Have we presented a fair view of the current position, and have we identified the main problems that need to be addressed?
2. Apart from this consultation, what is the best way for us to ensure user input shapes the strategy and its implementation? Is the National Analysts Forum a good idea?
3. Does the overall strategy and vision for the future cover the right areas? Are there any that in your view require particular emphasis?
4. Are the principles set out in the vision the right ones? If not what changes would you suggest?
5. Taking the delivery plans as a whole, are these the right areas in which to work? Are we taking the right approach to individual issues – please comment on any particular plans that you think need to change or would benefit from a different approach? Are there any additional initiatives that you would like to see included in the strategy (either existing or new)?
6. Of the outline delivery plans, what are the priorities for early delivery and what would be an appropriate timescale for these?
7. Is the balance between developing new data sources and using existing ones about right?
8. It is clear where responsibility lies for the developments described in the strategy? If not, which areas need clarification?
9. What obstacles do you foresee to the delivery of the strategy and how best do you think these could be overcome?
10. Can you suggest ways in which you or your organisation could contribute to further development or implementation of the strategy?

**Consultation Response Form**

To: Robert Jack  
5<sup>th</sup> Floor  
Skipton House  
80 London Road  
London  
SE1 6LH

From: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please indicate clearly if you are replying on behalf of a group or an organisation.

On behalf of: \_\_\_\_\_

**Informing Healthier Choices: Information and Intelligence for Healthy Populations**

- \* I support the content of the public health information and intelligence strategy and have no comments to make.
- \* My comments on the public health information and intelligence strategy are attached.

\* My reply may be made freely available.

\* My reply is confidential (please supply an explanation as to why you regard the information you have provided as confidential).

\* My reply is partially confidential (indicate clearly in the text any confidential elements and supply explanation as above).

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 1: How could a National Health Information and Intelligence System work in practice?

A fully functional and integrated national health information and intelligence system would consist of the following elements:

1. A **flexible interface for ad hoc enquiries** that allows users to interrogate the underlying data sets and generate outputs of various forms. The flexible interface would be linked to a knowledge management system (see below) and to individual health information systems such as Health Space.
  - Users of different backgrounds and skill levels would require different forms of access from the sophisticated analytical programmer who would need detailed information on data structures in order to frame queries to the non-technical person who would require a “point and click” approach.
  - The interface would be a set of programmes that provide output in a variety of formats from data tables to graphs and maps. The specification of the outputs would be determined by the user within certain limits. Standard reports would provide explanations of the methods used, comments on data quality and aids to interpretation.
  - Users without specialist skills would be strongly encouraged to take advice on the interpretation of the outputs of these queries before acting on them.
2. A system to generate standard outputs from the underlying data on a range of **Population Health indicators** that relate for example to particular PSA targets.
  - The indicators would be generated at varying population levels down to small areas (e.g. census super output areas).
  - Organisations with a performance management function (e.g. Healthcare Commission) would specify some indicators for that purpose.
  - Other indicators would be used to contribute to “area profiles” produced by the Audit Commission.
  - Further indicators would generate community profiles for Local Authority areas.
3. The data sets would be regularly interrogated by a range of **surveillance systems** linked to reporting mechanisms that automatically detect unusual patterns and trends.
  - Information on infectious diseases would be monitored by the Health Protection Agency.
  - Information on adverse events related to specific treatments would be monitored by the Medicines and Healthcare Products Agency.
  - The effectiveness of screening programmes would be monitored by the National Screening Committee.
4. Special queries of the data (and in some cases special data feeds to the data repository) would be set up to generate subsets of data that constitute **national disease registers**. These would use agreed case definitions and validation procedures (for example using additional clinical data from images, or pathology reports).

- Registers would be set up to cover conditions such as diabetes, congenital abnormalities and coronary heart disease.
  - Other registers would be set up for procedures such as joint replacements, cardiac interventions and innovative health-care products such as stents, prostheses and implants.
  - There would be a single national data source for cancer registers although the need for regional cancer intelligence functions would continue.
5. A centrally managed national data repository or **“data warehouse”** that would hold the underlying individual level data obtained from a range of routine sources.
- The repository would be very secure and would operate in a strictly controlled and audited fashion. Access to the repository would be limited to those who need access in order to build and maintain the files and generate extracts.
  - The repository could be part of the NHS Connecting for Health Secondary Uses Service (CfH SUS) and would therefore receive data from health service sources in real-time (GP clinical systems, community pharmacy, hospital out-patients and inpatients, and the patient demographic system as a real-time continuously updated denominator).
  - Another option would be a set of fully interoperable distributed (federated) data warehouses receiving data from SUS and other sources.
  - In addition the warehouse could receive other individual level data of relevance to health (e.g. routine data collected in the community by social services or education services) results of special surveys (such as Health Survey for England) and special clinical data sets (for example laboratory data on cancers from laboratory systems) or indeed any other data set that is available with personal identifiers. These data would be linked at individual patient level within the repository (using the same techniques used for the rest of SUS).
  - The data within the repository would be refreshed frequently in order to provide close to real-time outputs.
6. A set of data derived from the main repository which is designed to be particularly useful for population health improvement purposes, a **public health “data mart”**.
- The data mart would contain pseudonymised data derived from the underlying linked files in the repository.
  - The data mart would also contain other non-person-based information that can be used to perform analyses (such as area-referenced outputs from the census, housing data, crime data or other information on social and economic status).
  - The data mart would be continually refreshed but would also contain frozen extracts from previous time points for trend analysis (or could construct them synthetically).
  - The data mart could be interrogated by a wide range of users or could produce standard outputs (see above).
  - The data mart would have a “public” entrance which would allow flexible access to derived or aggregated data without risk of disclosure of personal data (privacy protection software would constantly monitor outputs and suppress any potential disclosures).



- There would also be a “trade” entrance for those who need access to more sensitive data in order to fulfil a public or statutory function and this would be controlled through the SUS Role-Based Access procedures (RBAC).
7. A **knowledge management system** would be integrated with the flexible interface. This would be linked to the **National Library for Public Health** and would use material produced by the National Institute of Health and Clinical Excellence among other sources. All material in the system would be indexed using the **National Public Health Language** with its supporting **thesaurus**.
    - Users who specify queries would be offered information about the interpretation of those data including common pitfalls.
    - Information on the effectiveness of interventions would be made available in a tailored fashion which matches the query as closely as possible.
    - The system would act as a portal to other sources of data and knowledge that would be tailored to the user and the query. The system would learn which resources are popular and would use this information to refine its specificity (like Google).
    - On-line learning materials would be provided on Public Health concepts and on the use and interpretation of information.
  8. The data mart would be the main source of pseudonymised health care data sets for **health research and central statistics**. Research groups would apply for access to patient level data which would normally be provided with an inconsistent SUS pseudonym (i.e. an individual’s id would be different for each set of data). Research groups can ask for specific groups of patients to be flagged as a cohort of interest within the data warehouse and would receive regular outputs for that cohort as events occur. When the patients’ consent has been obtained or other approval has been obtained (e.g. from PIAG) identifiable data could be provided.
  9. The **Public Health Observatories** would be special users of the data mart. They would extract regional subsets and would undertake a range of analyses based on those subsets. They would continue to act as a single port of call for those who need access to health information at regional level and increasingly for those who need advice on use and interpretation of data (since direct access would be much more readily available). The Public Health Observatories would continue to act as advocates for users of health information. They would help to define the requirements for the public health data mart.
  10. The **Health and Social Care Information Centre** would also be a special user of the data mart, as well as being responsible for setting up of the data mart itself. It would operate at national level to provide access to health data and information for Government agencies and arms-length public bodies. The **National Centre for Health Outcomes Development** would provide methodological advice to users, would help to design the analyses available in the responsive interface for ad hoc enquiries and would continue to produce standard outputs in the form of a compendium of health statistics.
  11. At local level there would still be a need for sharing of sensitive data in a secure environment. **Local data warehouses and marts** would be set up by PCTs with strict data security policies to handle smaller scale identifiable data sets from local organisations such as the police, drug treatment centres, local authorities and local health care providers. The identifiable data would be linked and held in a secure warehouse with recognised “safe haven” status. These safe-havens would need PIAG approval. Pseudonymised extracts would be available to local organisations through the local data mart.
  12. **Members of the public** would have access to a wide range of material from the data mart and would be able to undertake their own analyses using tools developed for ad hoc analysis. They would be able

to store the results in Health Space along with information about their own health and health care. The Public Health information system would be integrated with other public-facing exercises such as the Audit Commission's Area Profiles project.

13. **Healthcare providers** would be able to use the system to assess the need for health-care in the communities that they serve. **Healthcare commissioners** would be able to use the system to monitor patterns of health and health care provision in the communities for whom they are responsible. This would be in addition to information from systems designed to track the provision of care ("Payment by Results"). Those responsible for performance management of **health care and public services** would be able to use the system to track appropriately defined health indicators at different population levels.
14. There would be **active communication** of important messages derived from the new health information system. A communication strategy would cover various methods to be used to communicate with policy makers, health professionals, communities and individuals. Links would be made to groups with skills and experience in marketing and mass communication and to other DH strategies such as *Better Information, Better Choices, Better Health*. Wherever possible a dialogue with users would be established so that the system can adapt to meet the needs of its users (two-way communication).

To summarise, the information system would be used by:

**The Public** - who would have access to a wide range of material such as the population health profile of their local community and would be able to undertake their own analyses should they wish. They should be able to store their results in Health Space along with information about their own health and health care. The health information system would be integrated with other public-facing exercises such as the Audit Commission's Area Profiles project.

**Policy-makers** – who would have easy access to real-time health data tailored to support Government agencies and arms-length public bodies, often provided via the Health and Social Care Information Centre.

**Public health and other professionals** – who would be able to find better more accurate and up-to-date data more easily and analyse them in real-time as well as being automatically alerted about unusual patterns and trends.

**Commissioners** – who would have improved access to accurate population health profiles enabling more patient needs based, cost effective and equitable commissioning of services and resource allocation.

## Appendix 2: Health and healthcare data sources relevant to public health available in a PCT with a well developed information function

Data source and contents	Smallest geographic area	Location of data
Exeter system: patients registered with general practices. Also includes information on transfers of registration, immigrant status and cervical and breast screening.	Postcode	Held at PCT's
NHS Strategic Tracing Service and Open Exeter: web-based access to the Exeter patient register.	Postcode	Access restricted via NHSnet
MIQUEST: complete download of data from general practice computer systems in PCT population on a six month rolling basis.	Postcode	PCT population only
QMAS: extract of data from general practice computer systems for GMS contract indicators.	PCT/GP practice	Access restricted via NHSnet
GPAQ patient survey: annual survey of 10% PCT population. GPAQ questionnaire on patient experience with lifestyle indicators appended.	Postcode	PCT population only
Hospital Episode Statistics (HES): final cleaned dataset of inpatient and outpatient data for NHS Trusts.	Postcode (disclosure rules apply).	Access restricted via DH. Borough and electoral ward analyses produced by PHOs.
Inpatient, outpatient and A&E data (CDS): inpatient and outpatient dataset for NHS Trusts, more timely than HES but subject to less cleaning processes. A&E data also included but of limited quality.	Postcode	Held at PCT's
A&E file from Local Hospital: database of all A&E attendances for Local Acute NHS Trust.	Postcode	PCT population only
Public Health Births and Mortality Files (PHBF/PHMF): births registrations and deaths registrations for PCT area.	Postcode	ONS, Held at PCT's.
Birth notifications: births dataset received from local hospitals.	Postcode	PCT population only. Statutory but not used by most PH departments.
Family health needs assessment (FHNA): forms completed by health visitors at the new	Postcode	PCT population

<b>Data source and contents</b>	<b>Smallest geographic area</b>	<b>Location of data</b>
birth visit. Linked to the birth notifications dataset.		only
NHS terminations of pregnancy: terminations data received from local NHS agency.	Postcode	PCT population only
Confidential Enquiry into Maternal and Child Health database: infant mortality data collected on CEMACH forms.	Postcode	PCT population only, CEMACH
Epex: patients having contact with community services in PCT population and activity data for community services.	Postcode	PCT population only
Smoking cessation: database of clients of smoking cessation services and vouchers issued.	Postcode	Held at PCT's, dataset may vary.
Census of population: data from the decennial Census.	Output area/electoral ward	Open access, ONS website
Indices of multiple deprivation	Super output area	Open access, ODPM website
Compendium of Clinical and Health Indicators: national set of public health related indicators.	PCT/LA	Compiled by NCHOD available nationally via website
Cancer registrations: data from Regional Cancer Registry.	Postcode	On request from cancer registry
Population estimates and projections for PCTs/LAs	PCT/LA	Open access, ONS website
Population estimates and projections for electoral wards and ethnic groups	Electoral ward	Access restricted through County Council
ONS vital statistics and estimates of conceptions: statistics on births, deaths, infant mortality and conceptions.	PCT/LA/Electoral ward	ONS, Held at PCTs.
Statistical reports from Department of Health and ONS	PCT/LA or region	DH and ONS websites
Health survey for England	England	Open access, DH website
Prescribing toolkit and ePACT.net from the Prescription Pricing Authority: indicators by general practice and data on all general	PCT/GP practice	Access restricted via PPA website

<b>Data source and contents</b>	<b>Smallest geographic area</b>	<b>Location of data</b>
practice prescriptions.		
Biochemistry, haematology, microbiology and radiology data: from databases held at Local Hospital.	Postcode/GP practice	PCT population only
Regional Ambulance Service data	Postcode	On request from Ambulance Service