

PROPOSALS
for a
POPULATION HEALTH OBSERVATORY
for
IRELAND AND NORTHERN IRELAND

BACKGROUND PAPER

October 2004



PART ONE: BACKGROUND

1.1 INTRODUCTION

The need for reliable intelligence to support public health action has been highlighted in the health research strategies and the health/public health strategies of both Ireland and Northern Ireland (1,2,3,4).

Around the world, public health observatories have been developed to help meet these growing information requirements for effective public health policy and practice. The Institute of Public Health in Ireland is exploring how the population health observatory function might be developed on the island, and a broad-based advisory group has been established to oversee this work.

There is no universal model of what a population health observatory should look like or what it should do. Existing observatories have developed according to local/regional/national needs and circumstances.

While the experiences of existing observatories provide useful insights, the advisory group is keen to bring together potential stakeholders on the island to discuss their information requirements and how an observatory might best add value to efforts to improve health and reduce health inequalities.

This paper describes the background for an observatory for Ireland and Northern Ireland, and outlines the advisory group's current thinking about the population health observatory function. This, it hopes, will provide an appropriate framework for the discussion of its development on the island.

1.2 EXISTING PUBLIC HEALTH OBSERVATORIES

The oldest public health observatories in Europe are the 26 regional health observatories (observatoires regionaux de la sante (ORS)) in France that were created in the early 1980s in the context of decentralisation. They are funded from national as well as local and regional sources and co-ordinate their activities through a national federation (<http://www.fnors.org>). Regional health observatories also exist in the French speaking part of Belgium.

Academic professionals and 'competent authorities' in public health from the twenty Italian regions co-operate to form the National Observatory in the Italian Regions (Osservasalute) (www.osservasalute.it) in Italy.

In 2000, nine regional public health observatories were established throughout England because "many agencies are involved in collecting and using information about health and disease in the population. Yet in some cases information may not be available or may be unreliable ...; at local level data may be even patchier" (5). More recently, a public health observatory has been established within the Wales Centre for Health. Scotland is currently exploring how the population observatory function might support health information developments there.

The national association of English and Welsh observatories, the Association of Public Health Observatories (APHO), recently identified six areas where observatories could support local, regional and national bodies. These were:

- To continue to provide high-quality information to support decision-making aimed at improving health and reducing health inequalities;
- To establish a cost-effective infrastructure for monitoring and surveillance of the public's health;
- To work with partner organisations and agencies to develop a systematic and usable evidence base of interventions covering the whole spectrum of public health activity, focusing particularly on evidence of cost-effective public health interventions;
- To provide methodological advice and support to ensure that local data collection and modelling methods are as robust and valid as possible;
- To make efficient use of information and communications technologies in support of decision-making across the spectrum of public health activity;
- To build public health capacity by supporting public health professionals in developing their skills in health surveillance and information management.

The APHO's website (www.apho.org.uk) includes links to the nine English observatories and the Welsh observatory, and gives an overview of the range of work that has been undertaken. The APHO publication *Progress and prospects 2003/04* documents the significant contributions that these observatories have made to public health in the short time since they were established (6).

To strengthen and co-ordinate the work of these regional observatories, a Regional Health Observatory Network in Europe (RHONE) has emerged.

A somewhat different type of observatory is the European Observatory on Health Care Systems which aims "to support and promote evidence-based policy making through comprehensive and rigorous analysis of health care systems in Europe" (<http://www.euro.int/observatory/toppage>).

1.3 THE IRISH CONTEXT

In Ireland, the national health information strategy was recently published and significant health services reforms are being implemented. In Northern Ireland, a review of public health will soon be issued. Across the island many agencies and individuals already have key responsibilities for providing research and information support for public health.

The Institute of Public Health is an all-island body that works to combat health inequalities and influence public policy in favour of health. Two of its strategic objectives are to "promote co-operation for public health between the Republic of Ireland and Northern Ireland" and to "strengthen the information and skills people need to work for improvements in the health of society" (<http://www.publichealth.ie>).

Investing for Health, Northern Ireland's public health strategy, calls on the Institute of Public Health "to develop plans for comparative monitoring of trends in health, the

determinants of health and health inequalities, North and South and relative to the other EU countries" (3).

It is now Department of Health and Children policy to establish a national population health observatory in Ireland. *Health Information: A National Strategy*, Ireland's national health information strategy, emphasises that the observatory should have a North/South as well as an international dimension, be developed within existing infrastructure, and identifies the Health Information and Quality Authority as the responsible agency (7).

The Institute is exploring, with support from both Ireland and Northern Ireland, how the population health observatory function might be developed across the island.

1.4 FIRST STEPS TO DEVELOP AN ALL-ISLAND OBSERVATORY

In late 2003 the Institute launched two demonstration websites (a Public Health Data Inventory website (<http://datainventory.publichealth.ie>) and a mortality website (<http://mortality.publichealth.ie>) to illustrate the potential of web-based technologies. Both websites were well received.

In early 2004 the Institute received seeding funds from the Health Research Board in Ireland and the Department of Health, Social Services and Public Safety in Northern Ireland to integrate these websites and build some tools and other resources for an all-island population health observatory.

A broad-based advisory group has been established to oversee the longer term planning for the observatory. The advisory group includes members from the departments of health, the (current) health boards and their departments of public health, the leading statistical agencies on the island, the community and voluntary sector and academia. Its Terms of Reference are to:

- Develop a vision for an all-Ireland population health observatory;
- Develop a five-year plan that builds on the seeding projects; and
- Build support for the vision and secure funding for the plan.

It is expected that the advisory group will complete its initial work in March 2005. The Stakeholders' Meeting is a key element of its work.

PART TWO: PROGRESS TO DATE

This section contains a brief progress report on the seeding projects that are being undertaken by the Institute of Public Health. These projects include:

- The construction of web-based tools and resources;
- Other developments to underpin their use; and
- Engaging with potential stakeholders.

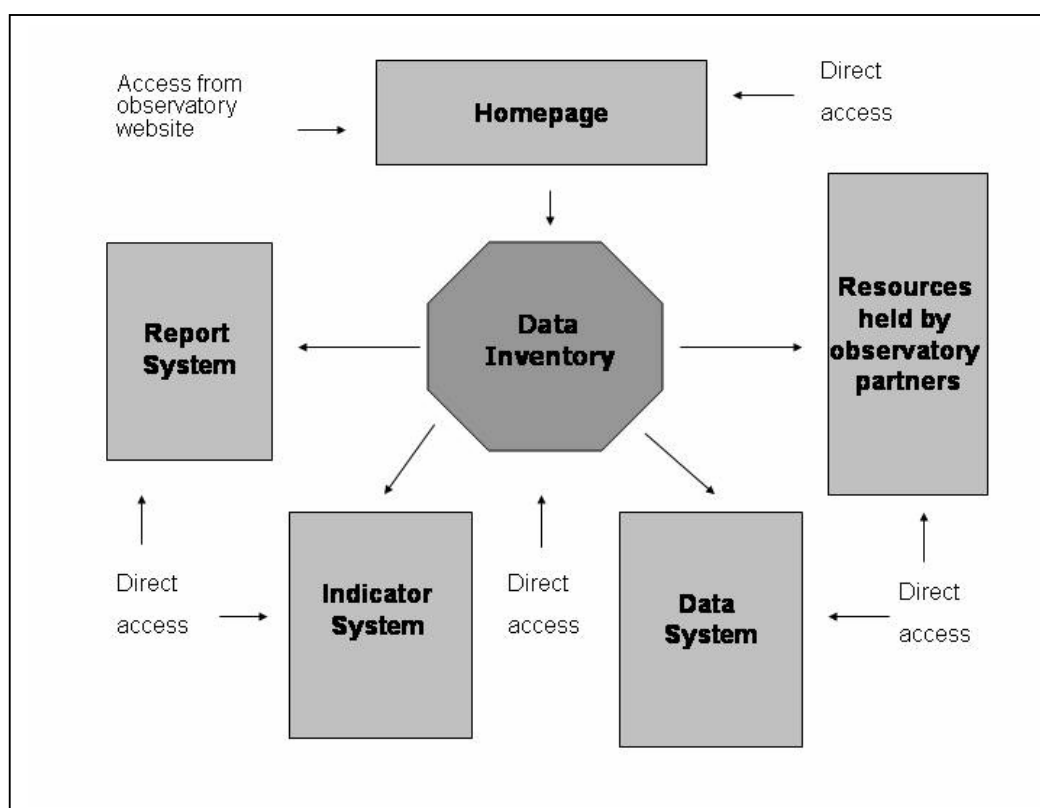
The outputs of this work have been designed so that they can support the emerging observatory.

2.1 WEB-BASED TOOLS AND RESOURCES

Population Health Information System (PHIS (Online))

The 'Population Health Information System (PHIS (Online))' website is designed to be a 'first port of call' for population health information that aims to increase awareness, access and use of existing information. In the future it will contain published reports, pre-defined indicators and aggregated data. It is envisaged that the website will hold core information on the wide range of topics relevant to population health and include online tools to support users with limited local analytical capacity.

Figure 1. The main components of the PHIS (Online) website



The main components of PHIS (Online) will be:

- A Population Health Data Inventory – a searchable catalogue of relevant information resources together with standard details ('metadata') about each.

- A Report System – a searchable collection of key policies, strategies and programme documents as well as published reports.
- An Indicator System – a searchable collection of pre-defined indicator sets together with online presentation tools.
- A Data System – a searchable collection of aggregated data sets together with online data aggregation, analysis and presentation tools.

If a visitor to the website is seeking resources that are not stored internally, or wants to better understand the internal resources on the Indicator System or Data System, they will be referred to the observatory's partners and their websites.

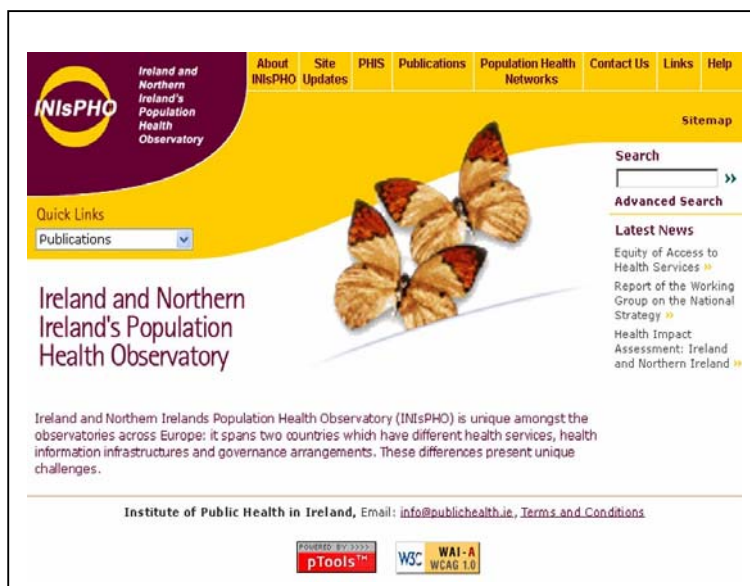
Visitors to the Indicator System and Data System will be able to bring together and compare variables from different information resources; giving them a more comprehensive understanding of their topic.

The Department of Health and Children in Ireland produces a CD-based collection (PHIS (CD)) of selected data tables that is distributed chiefly to public health departments. PHIS (Online)'s Indicator System will extend PHIS (CD) by including a larger collection of tables and making them available more widely through the web. The Data System will include the aggregated data underlying the pre-defined indicators on the Indicator System (including those in the PHIS (CD) tables) and these will be used to update the indicators when new data become available. The PHIS (Online) website and PHIS (CD) will develop as complementary resources.

A holding website for the observatory

As a 'shopfront' for the emerging observatory, a holding website is also being developed.

Figure 2. Draft homepage of the holding website for the observatory



As well as incorporating the PHIS (Online) website, this website will:

- Serve as a vehicle for gaining input from stakeholders, informing them of new developments and getting feedback;
- Include tools to support the proposed population health networks; and
- Provide a focus point for those interested in the development and use of population health intelligence on the island.

2.2 OTHER SUPPORTING DEVELOPMENTS

These websites are being constructed so that they can expand to meet the growing needs of stakeholders:

- A data model that supports data warehousing techniques underpins the management of the information resources stored on the PHIS (Online) website.
- Metadata standards to catalogue information resources and facilitate access and sharing have been developed.
- Content management software has been installed so that the content of the websites can be easily updated.
- Both websites include extensive administrator functionality so that other information resources can be easily added.

The information resources (published reports, pre-defined indicator sets and aggregated data sets) that would be included in the PHIS (Online) website are currently being compiled, and links to potential partners' websites are being negotiated.

2.3 ENGAGING WITH POTENTIAL STAKEHOLDERS

During 2004 the Institute of Public Health has been seeking support for the observatory and building the network of stakeholders that is critical to its success:

- A series of informal meetings with the two health departments and statistical agencies was held earlier in the year.
- The advisory group was established to oversee the longer term development of the observatory; it has met twice so far this year.
- A seminar entitled 'Public Health Observatories in England and Wales' was held in Dublin in September to give people on the island an opportunity to meet the Directors of the English and Welsh observatories.
- An overview of the observatory was given at the 3rd Population Health Summer School in Cork in a session entitled 'Public health observatories: democratising information'. A brief questionnaire was also distributed to attendees.
- The island's emerging observatory participates in the Association of Public Health Observatories (APHO). It has been represented at meetings of the association during the year as well at its strategic planning day.

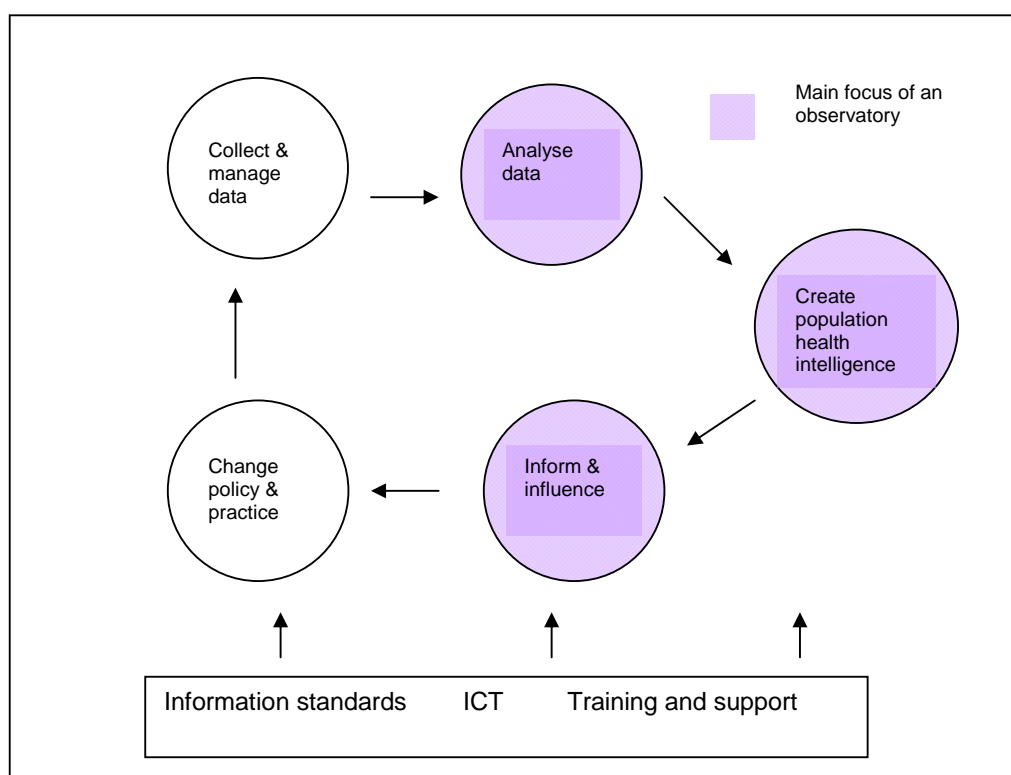
PART THREE: A SKETCH OF AN OBSERVATORY FOR THE ISLAND

This section provides a sketch of what an observatory might look like, what it might do and how it might operate. It is presented to help frame discussion of the key issues regarding the observatory's development.

3.1 SIMPLE FRAMEWORK FOR INFORMATION-BASED POLICY AND PRACTICE

To understand how an observatory might achieve its aims, it is useful to outline the broad steps involved in the development of population health intelligence and its efficient translation into effective public health policy and practice (see Figure 3).

Figure 3. Development and translation of intelligence into policy and practice



Population health observatories tend to focus on the steps that are shaded in Figure 3. They tend not to collect data, develop policy or deliver programmes. Rather, they provide information support to others who do.

3.2 WHAT IS A POPULATION HEALTH OBSERVATORY?

A population health observatory is a partnership of organisations and networks involved in producing, interpreting and disseminating information about the population's health.

It aims to provide information support for those working to improve health and reduce health inequalities.

It provides leadership and adds value by

- bringing together relevant information on the population's health and well-being, the health services, lifestyle behaviours and the wider determinants of health;
- making this information more accessible and available for use in improving health and reducing health inequalities;
- facilitating early identification of emerging issues.

It supports the activities of its partners, undertakes particular pieces of work to fill gaps and helps to meet the needs of users of population health intelligence.

North-South issues

An all-island observatory would be unique amongst public health observatories because it would span two jurisdictions that have different health services, different health information infrastructures and different governance arrangements. From these differences would arise unique benefits and challenges.

An all-island observatory would aim to fully support the population health function in both jurisdictions while maximising the benefits from working across the island. This may mean that the observatory develops at a different pace and in slightly different ways in Ireland and Northern Ireland according to their needs and circumstances.

3.3 WHO ARE ITS PARTNERS?

The observatory's partners are those agencies and individuals who are involved in the development and dissemination of population health intelligence.

Some partners will have broad remits such as:

- Leading statistical agencies (Central Statistical Office in Ireland and the Northern Ireland Statistical and Research Agency);
- Leading research agencies (Health Research Board in Ireland and the Research and Development Office for the Health and Personal Social Services in Northern Ireland);
- Health services agencies such as the Health Services Executive in Ireland, the departments of health, the (current) health boards in Ireland and health and social services boards in Northern Ireland; and
- Academic departments and other established research organisations such as the Recognised Research Groups in Northern Ireland.

- Information agencies such as the Health Information and Quality Authority in Ireland;
- Health and social service providers such as hospitals, general practitioners, dental services, etc.

Others may have more specific remits that cover:

- Specialist topics (such as the cancer registries, communicable disease surveillance units, cardiovascular information systems and other disease registries and systems);
- Particular geographical areas (such as the Investing for Health Partnerships and the Health Action Zones in Northern Ireland, the community development boards in Ireland and local government); and
- Particular population groups (such as Travellers support groups and child health reference centres).

Users of population health intelligence also have a key role in an observatory. These include policy makers, health and social service managers and providers, community workers, the general public, the media and politicians.

Different models for the partnership underpinning the observatory could be used. For example, a co-ordinated 'hub and spoke' model may be appropriate. In such a model the hub might focus on issues at the broad level with the spokes, made up of the key partners, covering specialist topics, particular localities or population groups. This is somewhat akin to the model used in the UK where the APHO has a national co-ordination role and the regional observatories, as well as contributing to national projects and supporting regional needs, also take a lead agency role for particular topics.

3.4 WHAT MIGHT AN OBSERVATORY DO?

The work that an observatory might do can be grouped into four main functions:

- Strengthening population health data;
- Developing public health intelligence;
- Translating intelligence into policy and practice; and
- Supporting population health networks.

Many agencies and individuals already make significant contributions and the key question is how an observatory can best support their efforts. The sections below list some examples of how an observatory might do this.

Strengthening population health data

Suggestions about how an observatory might help fall into three broad headings:

- Bringing together in one place, core information on the wide range of topics relevant to population health;
- Supporting the particular information systems/data collections; and
- Contributing to information standards, data quality and ICT.

As examples suggested to the advisory group:

- The core information held by an observatory could be captured in an all-Ireland Public Health Common Data Set (PHCDS). An observatory could help define the indicators and compile and disseminate them. These indicators could form the basis of local, regional and national population health profiles.
- An observatory could help develop socio-economic indicators for inclusion in particular information systems.
- An observatory could contribute to population health aspects in the development and implementation of information and ICT standards. For example, the PHIS (Online) website is based on a comprehensive data model, the data inventory, data dictionary and metadata standards; all of which will need to be regularly reviewed and updated. An observatory could help strengthen interoperability between information-based websites on the island.

Creating population health intelligence

To create population health intelligence, the results of data analyses have to be interpreted in the context of other relevant research and the experiences of individuals and organisations.

Suggestions of how an observatory might help fall into three broad headings

- Filling gaps in routine monitoring and surveillance (particularly as it relates to non-communicable diseases);
- Undertaking specific information/research projects; and
- Making data and analysis tools more widely available.

As examples suggested to the advisory group:

- An observatory might co-ordinate production of routine reports such as monitors of population health and well being, health inequalities, the broader determinants of health, regional population health profiles and inter-regional comparisons.
- An observatory might undertake information/research projects looking at:
 - Data collection, management and analysis methods;
 - The burden of illness and demand for health services;
 - The possible impact of ageing and lifestyle changes may have; and
 - Programme evaluations.
- The PHIS (online) website with its links to the observatory's partners' websites is a key resource to help increase awareness, access and use of existing information. It also includes online data aggregation, data analysis and presentation tools to support users who have limited local analytical capacity.

Translating intelligence into policy and practice

If an observatory is to contribute to efforts to improve health and reduce health inequalities, population health intelligence must be translated into effective policy and practice.

Suggestions about how it might help fall into three broad headings:

- Increasing awareness, access and use of existing public health intelligence;
- Directly supporting particular population health initiatives; and
- Supporting public health advocacy.

As examples suggested to the advisory group:

- The PHIS (online) website with its links to the observatory's partners' websites is a key resource to help increase awareness, access and use of existing public health intelligence.
- An observatory could directly support health impact assessment. "Advising on HIA" is a required function of the population health observatory to be established in Ireland (7). "Advising on the methodology and implementation of HIA in the North, while making links with parallel developments in the South" is identified as part of the Institute's contribution to the implementation of the Investing for Health Strategy in Northern Ireland (3).
- An observatory could provide information support for population health aspects of all-of-government strategies such as New Targeting Social Need in Northern Ireland and the National Anti Poverty Strategy in Ireland.

Supporting population health networks

Underlying these functions, population health networks need to be supported through sponsorship of professional meetings and other opportunities for knowledge sharing, training and mentoring, etc.

Suggestions about how an observatory might help include:

- Support for existing networks such as the two public health alliances on the island and existing networks; and
- Establishing new networks such as the observatory's partners, a Population Health Information Users Forum and a network of health information analysts.

The need to provide support at the local/regional/national level was emphasised. Participation in initiatives such as Public Health Electronic Networks (PHeNET) in the UK (<http://www/PHeNet.org.uk>) could greatly strengthen the reach and contribution of these networks.

3.5 HOW MIGHT AN OBSERVATORY OPERATE?

The advisory group believes that the development and operation of the observatory should be guided by agreed principles.

It is difficult to discuss how the observatory should be managed when it is at such an embryonic stage. The role of partners and how it arranges its external relationships, management and information governance, and funding are all key issues. It might also be useful to establish specific groups such as technical groups.

The advisory group would like to see these principles, and details of how an observatory might operate, developed through discussion with key stakeholders and the departments of health on the island.

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APPENDIX 1. ADVISORY GROUP MEMBERSHIP

Paula Kilbane	Chief Executive, Eastern Health & Social Services Board (Chair).
John Devlin	Deputy Chief Medical Officer, Dept of Health & Children.
Kevin Kelleher	Director of Public Health, Mid-Western Health Board.
Marie Laffoy	Director of Public Health, Eastern Regional Health Authority
Anna Lee	Manager, Tallaght Partnership.
Hugh Magee	Senior Statistician, Dept of Health & Children.
Bill McConnell	Director of Public Health, Western Health & Social Services Board.
Liz McWhirter	Director, Information and Analysis Directorate, Dept of Health Social Services & Public Safety.
Liz Mitchell	Principal Medical Officer, Dept of Health, Social Services & Public Safety.
Liam Murray	Dept of Epidemiology & Public Health, Queens University Belfast.
Ivan Perry	Dept Epidemiology & Public Health, University College Cork.
Sheelah Ryan	Chief Executive Officer, Western Health Board.
John Wilkinson	Chair, Association of Public Health Observatories.
Jane Wilde	Director, Institute of Public Health.
Kevin Balanda	Associate Director, Institute of Public Health.