



*Ireland and  
Northern  
Ireland's  
Population  
Health  
Observatory*



## Framework for Ireland and Northern Ireland's Population Health Observatory (INIsPHO)

The Institute of Public Health in Ireland

**Better intelligence, better decisions, better health**



**THE INSTITUTE OF  
PUBLIC HEALTH IN IRELAND**



# Framework for Ireland and Northern Ireland's Population Health Observatory (INIsPHO)

Prepared by Kevin P Balanda with assistance from Cynthia McMahon

January 2006



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January 2006



## FOREWORD

Around the world, population health observatories have developed to help meet the growing research and information requirements for evidence-based policy and practice.

This framework for the all-Ireland population health observatory was developed by an Advisory Group chaired by Dr Paula Kilbane, Chief Executive Officer, Eastern Health and Social Services Board, Northern Ireland. It is the result of a year-long process of engagement including a very successful stakeholders' meeting held at the Royal Hospital Kilmainham, Dublin in October 2004.

I believe that, working closely with others who produce, disseminate and use health intelligence, the observatory will contribute significantly to improving health and reducing health inequalities on the island.

Its location within the Institute of Public Health in Ireland, with its remit to promote North-South co-operation in public health and primary focus on health inequalities, will greatly strengthen this contribution.

I would like to thank Dr Kilbane and the members of her Advisory Group for their tireless efforts; they have made a valuable contribution to the health intelligence function on the island.



Dr John Devlin  
*Chair, Management Board*  
Institute of Public Health in Ireland

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# PART A. BACKGROUND AND RATIONALE

## 1. BACKGROUND

### 1.1 INTRODUCTION

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

Around the world, population health observatories have developed to help meet growing information requirements. They develop according to local, regional and national needs and circumstances, and there is no universal model of what a population health observatory does or how it goes about its work.

Following earlier work, the Institute of Public Health in Ireland was asked to develop a number of web-based tools for an all-Ireland observatory, and to explore how the population health observatory function might be developed on the island. A broad-based Advisory Group was established to oversee this work, and this chapter gives some background to its work.

### 1.2 EXISTING PUBLIC HEALTH OBSERVATORIES

The first public health observatories in Europe were the 26 health observatories (Observatoires regionaux de la sante (ORS)) established in the early 1980s during a period of decentralisation in France. They are funded through 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 in the 20 Italian regions co-operate to form the National Observatory in the Italian Regions (Osservasalute) ([www.osservasalute.it](http://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 was established within the Wales Centre for Health. ScotPHO, the Scottish Public Health Observatory, is co-located in ISD Scotland and NHS Health Scotland.

The Association of Public Health Observatories (APHO), recently noted that observatories could support local, regional and national bodies by:

- Providing high-quality information to support decision-making aimed at improving health and reducing health inequalities
- Establishing a cost-effective infrastructure for monitoring and surveillance of the public's health
- Working 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 cost-effective public health interventions
- Providing methodological advice and support to ensure that local data collection and modelling methods are as robust and valid as possible
- Making efficient use of information and communications technologies to support decision-making across the spectrum of public health activity
- Building public health capacity by supporting public health professionals to develop their skills in health surveillance and information management.

The APHO's website ([www.apho.org.uk](http://www.apho.org.uk)) gives an overview of its members' work. Its annual publication *Progress and Prospects 2004–2005* documents the significant contributions observatories have made in the short time since they were established (6).

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

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 HEALTH RESEARCH AND INFORMATION ENVIRONMENT ON THE ISLAND**

Ireland and Northern Ireland have different health and social care systems, different health information infrastructures and different information governance arrangements.

Organisational structures in both Ireland and Northern Ireland are changing rapidly. Major health services' reforms are underway in Ireland with the establishment of the Health Service Executive (HSE) and the Health Information Quality Authority (HIQA). In Northern Ireland changes will follow the recent Review of Public Health and broader Review of Public Administration.

The visions for the research and health information environment in the two jurisdictions are similar.





### 1.3.1 RESEARCH

The health research strategies in Ireland and Northern Ireland both highlight the need to generate new knowledge, to disseminate existing and new research findings, and to build capacity to enable these to happen.

The national health research strategy in Ireland, *Making Knowledge Work for Health: A Strategy for Health Research* states that ‘research is a key factor in promoting health, combating disease, reducing disability and improving the quality of care’. It identifies ‘two complementary but distinct pillars ...: establishment of a research and development function within the health services, and enhanced support for science for health’. This support includes developing health libraries and information services, addressing data protection issues, building research and analytical capacity on the island, and working in partnership to build a thriving research culture in the health services (1).

Northern Ireland’s research and development strategy, *Research for Health and Wellbeing* also highlights the significant contribution that research and development makes to health and social care. The strategy distinguishes ‘research’ and ‘development’ - the latter being defined as ‘the evaluation of new methodologies of care and techniques and their experimental introduction into service using scientific methods and approaches’. For this, it highlights a number of key strands including special initiatives, education and training, career development, and dissemination and uptake (2).

### 1.3.2 INFORMATION

In Ireland, *Health Information: A National Strategy* takes health information to be ‘any information used to help make an informed health-related decision or to inform oneself of health-related issues, whether at the personal, professional, managerial or political level’. The Strategy notes that ‘the type and complexity of the information will vary depending greatly on its purpose whether used by a patient deciding where to go for advice, a health professional weighing up the pros and cons of a particular intervention, a service manager deciding on a budgetary allocation or a policy maker devising a new strategy’ (7).

The vision of the National Health Information strategy in Ireland is of a ‘trusted and valued health information environment within which all stakeholder groups, namely the general public, clients/patients, carers, healthcare professionals and service staff, health service managers, public health policy makers and Government, researchers and the media are enabled and empowered to make informed choices to promote, protect, restore and maintain the health of individuals and of the population’ (7).

*The Review of the Public Health Function in Northern Ireland – Executive Summary* places Health Information and Intelligence as one of the three main elements in Managing Public



Health Knowledge; the other two being Research and Development and Building the Evidence Base (8).

In Northern Ireland, one of the main considerations for managing public health knowledge identified in its review of the public health function is to develop a high quality, accessible knowledge management system which can draw from established evidence bases and measure impact and outcomes of public health activity over a period of time. It must also provide accurate, relevant and timely information on key public health problems in order to improve public understanding and aid decision making (8).

#### **1.4 AN ALL-ISLAND OBSERVATORY**

The Institute of Public Health in Ireland is an all-island body the aim of which is to combat health inequalities and influence public policy in favour of health. Its remit is to 'promote co-operation for public health between the Republic of Ireland and Northern Ireland' including the area of monitoring and surveillance. Much of its work focuses on 'strengthening 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 '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).

Department of Health and Children policy is to establish a national population health observatory in Ireland. Action II of Health Information: A National Strategy, the national health information strategy, emphasises that the observatory should have a North/South as well as an international dimension, and be developed within existing infrastructures (7). The Health Information and Quality Authority (HIQA) has a key role in many areas of the strategy.

In October 2003 the Institute launched two demonstration websites (a public health data inventory website (<http://datainventory.publichealth.ie>) and an all-Ireland mortality website (<http://mortality.publichealth.ie>)) to illustrate the potential of web-based technologies to increase awareness, access and use of available information. Both websites were very well received.

In 2003–2004 the Institute received seeding funds from the Health Research Board (HRB) in Ireland and the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland to:

- Integrate these websites into a web-based tool for an all-Ireland population health observatory and
- Develop a longer-term plan for the observatory.





A key question for the Advisory Group was where the observatory should be located. One of the possible locations for an all-island observatory, raised and supported by many people during the Advisory Group's work, was the Institute. In early 2005 the Department of Health and Children allocated funds to establish the observatory within the Institute. This welcome funding allowed the Advisory Group to complete its work more quickly. The Institute's Management Board agreed to establish a structure to manage the Observatory.

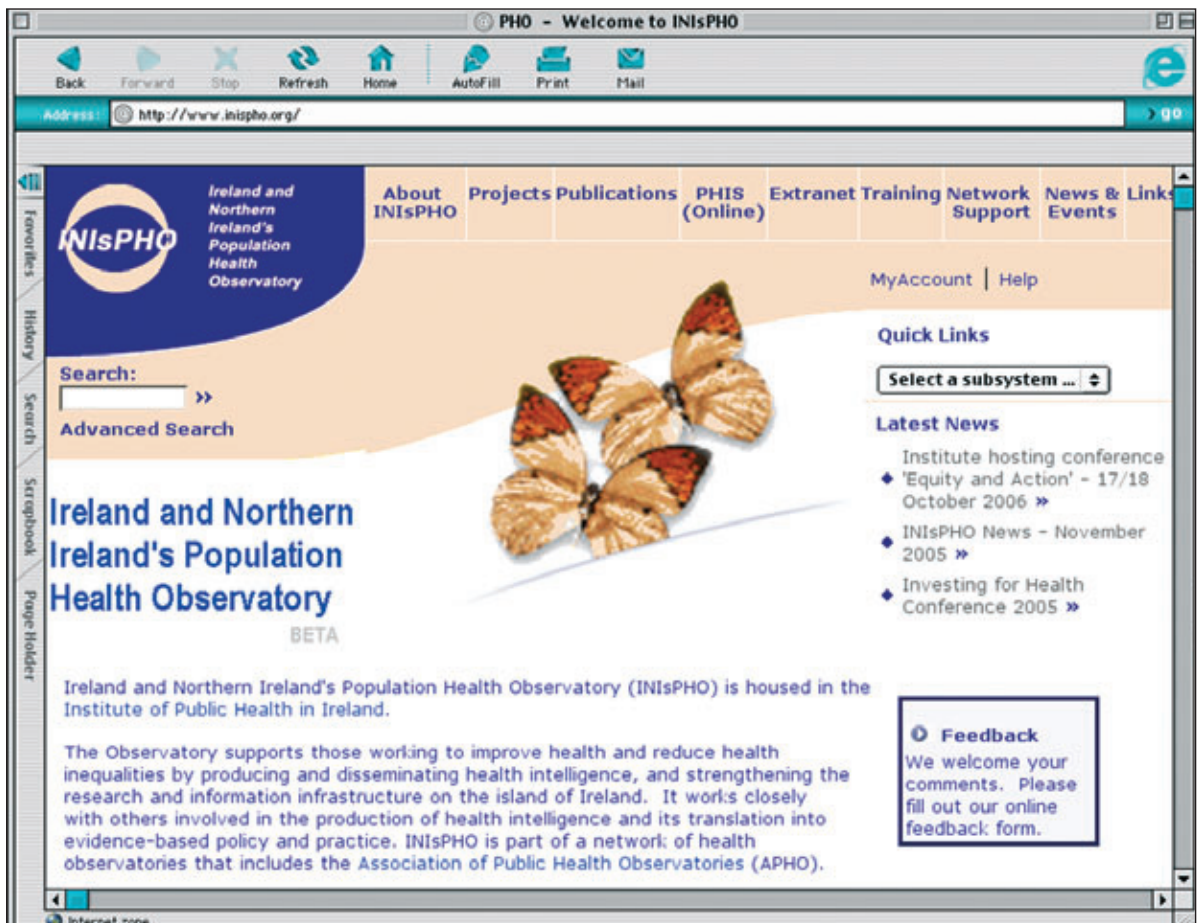
## 2. WEB-BASED TOOLS FOR THE OBSERVATORY

### 2.1 OBSERVATORY WEBSITE

This website is the 'shopfront' for the observatory.

It can be accessed using any of its three registered web addresses:  
<http://www.inispho.org>, <http://www.inispho.ie>, and <http://inispho.org.uk>.

*Figure 1: Homepage of the observatory's website*



The website:

- Provides a focus for those interested in the production and use of health intelligence on the island
- Includes tools to support the observatory's partners and other stakeholders
- Serves as a vehicle for informing stakeholders of new developments and receiving feedback.

The website incorporates the PHIS (Online) website. In time, a Public Health Advocacy website will be available on the homepage.



## 2.2 POPULATION HEALTH INTELLIGENCE SYSTEM (PHIS (Online)) WEBSITE

The Population Health Intelligence System website (PHIS (Online)), is designed to be a 'first port of call' for intelligence about health, the factors that affect it and the interventions that improve it.

It can be accessed through the INIsPHO website or directly through one of its three web addresses: <http://www.inispho.org/phis>, <http://www.inispho.ie/phis> and <http://inispho.org.uk/phis>.

The resources in the PHIS (Online) website include:

- Different sources of knowledge
- Resources with varying analytical content
- Both qualitative and quantitative data
- Online analytical and presentation tools.

*Figure 2: Homepage of the PHIS (Online) website*

**PHO - Population Health Intelligence System**

Address: <http://www.inispho.org/index.asp?locID=235.docID=1>

Search:  >>  
Advanced Search

**Population Health Intelligence System (Online)**  
BETA

The 'Population Health Intelligence System (PHIS (Online))' website is designed to be a 'first port of call' for intelligence about health, the factors that affect it and the interventions that improve it.

The main components of the PHIS (Online) website are:

- A Population Health Knowledge Resource Catalogue – searchable catalogue of knowledge resources together with standard details ('metadata') about each.
- A Reports System – searchable collection of key policies, strategies and programme documents as well as evaluation reports.
- Research & Evidence Portal (under development).
- An Indicators System – searchable collection of pre-calculated indicator sets together with online presentation tools.
- A Data System – searchable collection of aggregated data sets together with online data aggregation, indicator calculation and presentation tools.
- Media Library (under development).
- Gateway to Grey Literature (under development).

**Feedback**  
We welcome your comments. Please visit INIsPHO and fill out our online feedback form.

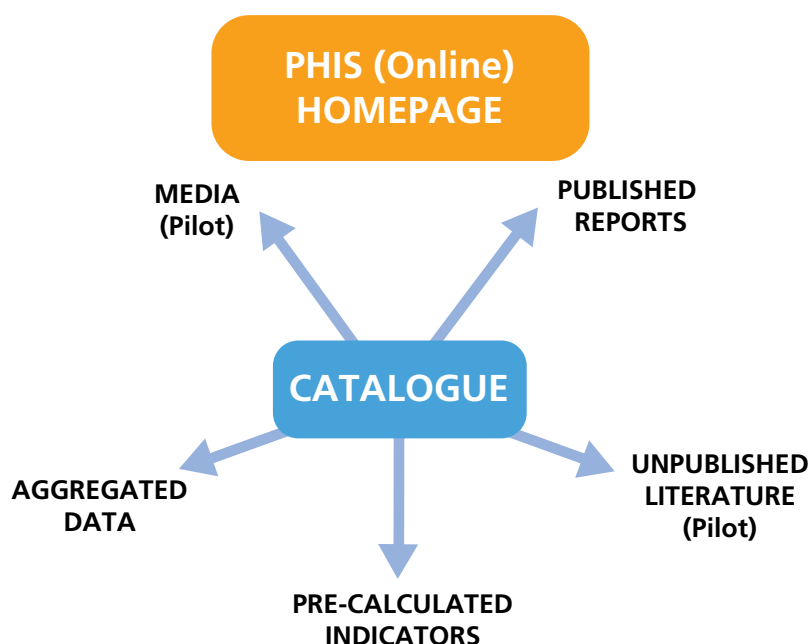
**PHIS(CD) Tables**  
Retrieve all PHIS(CD) Tables from the Indicator System.

**NI DPH Core Tables**  
Retrieve all NI DPH Core Tables from the Indicator System.

The main components of the PHIS (Online) website are:

- The Population Health Knowledge Resource Catalogue – a searchable catalogue of knowledge resources together with standard details about them
- The Reports System – a searchable collection of key policies, strategies and programme documents as well as published research
- The Indicators System – a searchable collection of pre-calculated indicator sets together with online presentation tools
- The Data System – a searchable collection of aggregated data sets together with online data aggregation, indicator calculation and presentation tools.

*Figure 3: The systems of the PHIS (Online) website*



In time, the Media Library – a searchable catalogue of other media together with standard details about them – will be added.

Visitors to the Data System can bring together variables from different data sets. The Data System will also include the aggregated data underlying the pre-calculated indicator sets in the Indicator System. Visitors will be able to explore these indicator sets using online tools in the Data System.

The Department of Health and Children in Ireland produces a CD-based collection PHIS (CD) of indicator tables that it distributes chiefly to public health departments. Indicator tables from PHIS (CD) are amongst the first resources to be included on the Indicator



System; making them widely available through the web. In the future the indicator tables will be updated on the PHIS (CD) from the PHIS (Online) website, and the PHIS (CD) and the PHIS (Online) website will be developed as complementary parts of an integrated population health information resource in Ireland.

The core tables included in the Annual Reports of the Directors of Public Health (DPHs) in Northern Ireland are also amongst the first resources included in the PHIS (Online) Indicator System, making them more widely available through the web. It is hoped that, in the future, these too will be seen as a useful complement to the Annual Reports of the DPHs in Northern Ireland.

### **2.3 OBSERVATORY EXTRANET**

In addition to the observatory's website an extranet has been established to support INIsPHO projects and activities that require a secure environment (with password-protected login). These include supporting working groups (such as the diabetes and health poverty index), and the development of pilot websites (such as the Advocacy website and Media Library).

Any number of secure areas can be established and managed.

### **2.4 ADMINISTRATION FUNCTIONALITY**

Except for the analytical components of the PHIS (Online) website, the observatory's website and extranet are written in a content management system that allows website content and structure to be easily updated and modified.

Significant administrative functionality has been incorporated into INIsPHO's website, the PHIS (Online) website and the observatory's extranet.

The administrative facilities that underpin the websites allow:

- The website administrator (or a visitor under supervision) to suggest and add new reports, indicator sets and data sets to the PHIS (Online) website
- Metadata for these resources to be easily inputted and edited
- Website visitors to store aspects of their previous visits on their own account areas
- Any number of different electronic newsletters to be emailed
- Electronic bulletin boards to be operated
- Online polls to gather input and feedback that can be processed
- Website visits and usage to be monitored.

## **2.5 INFORMATION STANDARDS**

Metadata standards (data about data) are used to systematically index and catalogue resources; a data model is required to properly manage and manipulate data.

The data model and metadata standards to underpin the observatory's websites and support their ongoing development have been defined (9, 10,11). The observatory's metadata standards are based on the Dublin (Ohio) Metadata Element Set (12) and incorporate the National Public Health Language (13). By using these standards a website visitor needs to learn only one indexing system and searching/browsing procedure. Once implemented on web-based libraries, ICT is available to link (make 'interoperable') these libraries so that a visitor to one library can search/browse the resources on any other using the same procedures. These metadata standards are vital infrastructural support for the librarian function for knowledge management.

While these metadata standards and the data model were developed for the observatory's websites, it is hoped that they will contribute to the work of the Health Information Quality Authority (HIQA) in Ireland and the equivalent agency in Northern Ireland with responsibility for national standards.

## **2.6 HARDWARE AND SOFTWARE**

Applications and database servers, an additional development server, and other hardware needed to support the observatory's websites have been purchased.

Software licenses for MS-SQL and a content management system (CMS) called pTools (both internet and extranet versions) have also been purchased.

The servers have been housed in a data centre in Dublin operated by DataElectrics P/L which also provides the connection to the world wide web.

Parallel P/L, the company that supports the CMS software, has been contracted to provide maintenance support for the servers.



## 3. LONGER-TERM PLANNING

### 3.1 METHODS

A broad-based Advisory Group was established to oversee the longer-term planning for the observatory. The Advisory Group included members from the departments of health, the (then) health boards and their departments of public health, and the lead statistical agencies on the island, as well as the community and voluntary sector and academia (see Appendix 1).

Its Terms of Reference were to:

- Engage with the observatory's potential stakeholders
- Advocate and build support for the observatory
- Develop a longer-term vision of the observatory together with its first five-year plan
- Ensure that the web-based tools being developed were aligned with these.

The Advisory Group developed this framework by:

- Running information sessions and consulting potential stakeholders
- Engaging and consulting international agencies
- Circulating a background paper
- Hosting a broad-based stakeholders' meeting.

During 2004 the Advisory Group, supported by the Institute, ran a number of information sessions on the island to inform and consult potential stakeholders. These included:

- A seminar entitled 'Public Health Observatories in England and Wales' held in Dublin in September 2004 that gave people on the island an opportunity to meet the Directors of the English and Welsh observatories.
- An overview of the observatory presented to 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.
- A series of informal meetings with the two health departments, statistical agencies and Directors of Public Health across the island.
- The Stakeholders' Meeting held in Dublin in October 2004.

Advisory Group meetings were held on 8 June 2004 (Dublin), 21 September 2004 (Belfast), 10 December 2004 (Belfast) and 18 February 2005 (Dublin).



In addition to these activities on the island, the Institute became an Associate Member of the Association of Public Health Observatories (APHO) and participated in a number of international events. These included:

- Bi-monthly APHO Executive meetings
- An APHO Strategic Planning Conference in London
- An APHO Staff Conference in Birmingham
- A presentation at the European Conference of Public Health Observatories held on 8-9 July in Durham
- APHO Technical Group meetings, NPHL meetings
- Site visits to a number of the English observatories including SWPHO (Bristol), SEPHO (Oxford), NEPHO (Durham) and NWPHO (Liverpool).

Following these activities the Advisory Group developed a background paper, distributed to over 350 people on the island, on the possible shape of an all-Ireland observatory.

This formed the basis of a Stakeholder's Meeting at Royal Hospital Kilmainham, Dublin in October 2004. The aims were to engage with potential stakeholders, obtain feedback on the background paper and discuss the future of the observatory. One hundred and ten people from a wide range of organisations and sectors attended the one-day event. After a series of keynote addresses, participants joined facilitated roundtable workshops. These were followed by a plenary discussion and the Chair's summary.

The report on the meeting was distributed to all invitees.

### **3.2 KEY FINDINGS FROM THE STAKEHOLDERS' MEETING**

The concept of a population health observatory was enthusiastically welcomed. While a number of issues needed to be clarified, none of these were seen as insurmountable and there was widespread support for moving forward with an all-island population health observatory.

Some of the key messages arising from the meeting are listed below.

#### **Information and function**

- The observatory should be action-oriented and not just a repository of data. It should have a focus on supporting action to improve health and reduce inequalities. There was some debate about how actively it should be involved in advocacy.
- As well as maximising the use of existing data the observatory should help to fill gaps in information. In particular there was strong support for including qualitative information in the observatory.





- Information needs to be disseminated to a wide audience of users in an accessible format.
- The observatory needs to avoid duplicating the efforts of other agencies.
- There was support for quick wins, projects with immediate benefits, which do not jeopardise long-term strategic development.
- A population health observatory could play a key role in supporting standards for information, and information and communication technology.

### **Local/Regional/National/All-island information needs**

- There was a strong feeling that the observatory should meet both local and regional information needs. The development of an agreed core data set was considered useful for this purpose.
- As well as the North/South dimension, the English, Scottish, Welsh and European dimensions were also important (in particular the EU Public Health Programme).

### **Partners and relationships**

- The observatory should be inclusive and participatory in its development and management.
- The observatory's relationships with its partners and other stakeholders are very important. Two-way communication was emphasised – not only should the observatory support its stakeholders, they in turn should have an input into the development and management of the observatory.
- The observatory should have clear relationships with other information agencies such as HIQA and the disease registries.
- The observatory should clearly define the value it adds and how it supports the efforts of existing agencies.

### **Management and governance**

- There are ethical issues associated with increasing access to information. Data protection issues associated with data transfer also need to be addressed.

# PART B. PROPOSED FRAMEWORK FOR THE OBSERVATORY

## 4. THE FRAMEWORK

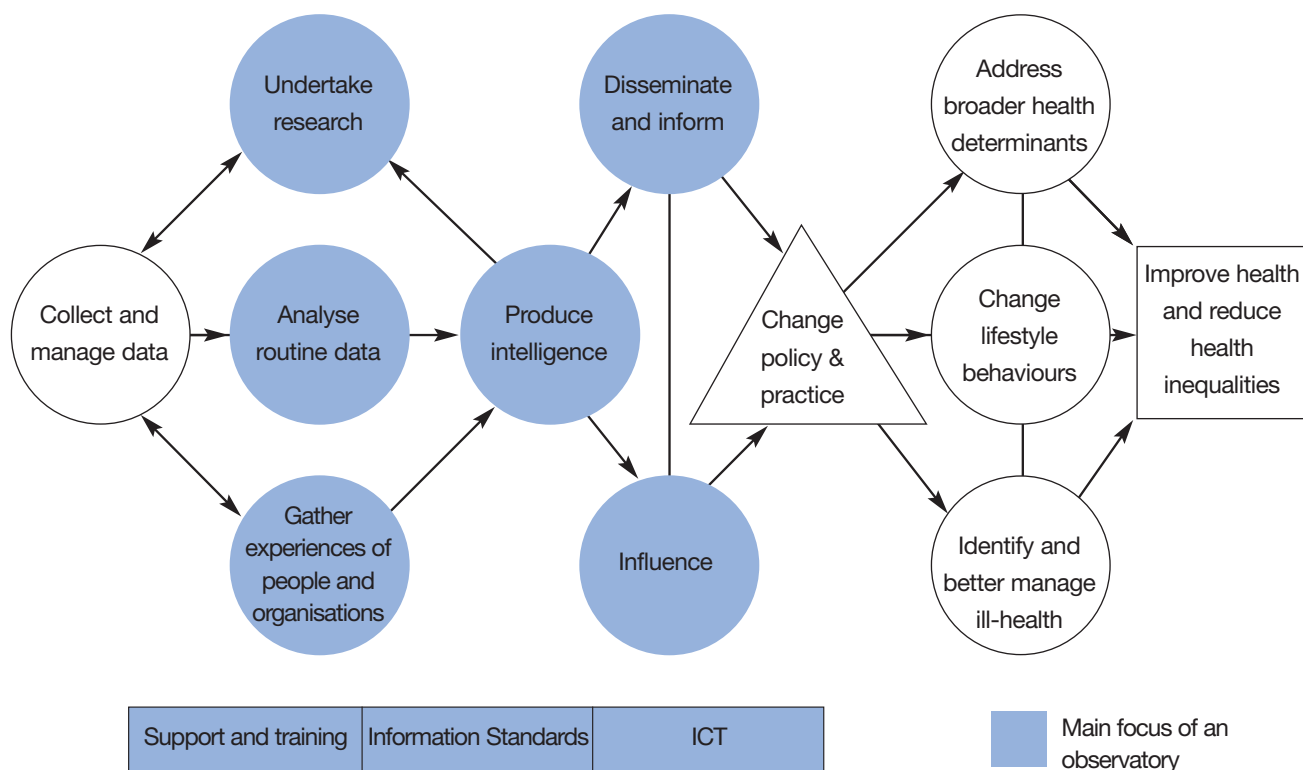
The all-Ireland observatory must contribute to improving health and reducing health inequalities in both jurisdictions, while maximising the benefits of all-island working.

### 4.1 EVIDENCE-BASED POLICY AND PRACTICE

#### 4.1.1 A CLEAR LINE OF VISION

The observatory has a clear 'line of vision' from its work to the population's health, illustrating how its work helps improve health and reduce health inequalities. This line of vision outlines the processes involved in the production of health intelligence and its translation into evidence-based policy and practice (see Figure 4 below).

*Figure 4: The production and translation of health intelligence into evidence-based policy and practice*





Monitoring and surveillance, research and evaluation, are all within this line of vision.

Population health observatories tend to focus on the shaded steps in Figure 4. They tend not to collect data, develop policy or deliver programmes; rather they provide research and information support to those who do.

Many agencies already contribute significantly to the health intelligence functions in Ireland and Northern Ireland. The challenge for the observatory is to support their activities by filling gaps and avoiding duplication.

#### **4.1.2 THE POTENTIAL CONTRIBUTION OF THE OBSERVATORY**

Observatories tend to respond to local and regional needs, and there is no one model for what they do or how they go about their work.

Nevertheless, existing observatories exhibit a number of common features that distinguish them from other agencies and highlight their unique contribution. Observatories make a unique contribution and add value by:

- Bringing together information – of different types and on different topics – in innovative ways to give a more wide-ranging understanding of public health issues
- Helping to translate intelligence into evidence-based policy and practice
- Placing inequalities at the heart of their work
- Maximising awareness, access and use of existing information
- Supporting local and regional needs within an appropriate national, all-island and international context
- Working collaboratively with others to produce, disseminate and use health intelligence
- Advocating and supporting the co-ordinated development of health research and information.

Observatories are key elements of the research and information infrastructure that supports population health. The systems, structures and resources that support an observatory's operation can also support research. For example:

- Its network of health and social care providers can facilitate cluster-randomisation trials of practice-based health and social care packages
- The infrastructure it uses to deliver local and regional support can facilitate co-ordinated community trials of community-based interventions

- Its data sets are key resources for data-analysis projects that seek to integrate different types of information on different topics in order to explore complex effects
- Its data sets, combining information of different types on different topics, are useful for hypothesis generation.

The strategic direction and day-to-day work of the observatory will be driven by the intelligence needs of the Department of Health and Children (in Ireland) and the Department of Health, Social Services and Public Safety (in Northern Ireland).

## 4.2 AIMS AND OBJECTIVES

The observatory is known as Ireland and Northern Ireland's Population Health Observatory (INIsPHO). This is a simple name that explicitly includes, in alphabetical order, the two jurisdictions. The logo of the observatory is:



### 4.2.1 AIM

The observatory aims to support those working to improve health and reduce health inequalities by producing and disseminating health intelligence, and strengthening the research and information infrastructure on the island of Ireland.

### 4.2.2 OBJECTIVES

Its objectives are to:

1. Produce health intelligence by undertaking research and information to address health priorities
2. Plan for the future by scanning the horizon for emerging issues, forecasting future trends and exploring the impact of alternative policies and strategies
3. Monitor and survey the population's health and the factors that affect it (including health and social services, lifestyle behaviours and the wider determinants) at the local, regional, national and all-island level



4. Bring together and disseminate data, research, information and experience about the population's health, the factors that affect it and the interventions that improve it at the local, regional, national and all-island level
5. Facilitate the translation of health intelligence into evidence-based policy and practice
6. Support the Department of Health and Children (in Ireland) and Department of Health, Social Services and Public Safety (in Northern Ireland)
7. Support the Health Information and Quality Authority (HIQA) and the equivalent agency in Northern Ireland, and the Health Service Executive (HSE) and the health and personal social services agencies in Northern Ireland
8. Support other organisations and individuals involved in the production, dissemination and use of health intelligence on the island
9. Advocate and support co-ordinated development (avoid duplication, reduce fragmentation, fill gaps) of health research and information infrastructure, and the health intelligence function on the island.

## **4.3 KEY STAKEHOLDERS**

### **4.3.1 PARTNERS AND OTHER STAKEHOLDERS**

The observatory works closely with its partners – those involved in the production and dissemination of health intelligence – as well as others who use this intelligence in their efforts to improve health and reduce inequalities.

Some stakeholders have broad remits such as:

- The Department of Health and Children (in Ireland) and Department of Health, Social Services and Public Safety (in Northern Ireland)
- The Health Service Executive (HSE) in Ireland and the health and personal social services boards in Northern Ireland
- Information agencies such as the Health Information and Quality Authority (HIQA) in Ireland and equivalent agencies in Northern Ireland
- Health and personal social service providers at the primary, secondary and tertiary level
- Lead statistical agencies (Central Statistical Office in Ireland and the Northern Ireland Statistical and Research Agency)
- Lead research agencies (Health Research Board in Ireland and the Research and Development Office for the health and personal social services in Northern Ireland)
- Academic departments and other established research organisations such as the Recognised Research Groups in Northern Ireland
- International agencies such as the European Union Commission, WHO and OECD.

Other stakeholders have more specialist remits that cover:

- Particular conditions (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)
- Particular population groups (such as Travellers support groups and child health reference centres).

The general public, community and voluntary sector organisations, media, politicians, and researchers and evaluators are also stakeholders.

#### **4.3.2 WORKING TOGETHER**

The observatory supports its partners by:

- More widely disseminating and promoting their outputs
- Linking their outputs to other population health work
- Supporting secondary analyses of data
- Promoting them in other ways such as providing opportunities to showcase their work
- Supporting professional meetings and other opportunities for knowledge sharing and collaborative work.

Users have different needs. They require different types of information on different topics, and have different capacities to access, analyse or interpret, and use information. The observatory seeks to help meet these varying needs.

The Management Board will develop agreed protocols to manage its relationships with its partners and other stakeholders. Memoranda of Understanding might be useful for guiding relations with data providers and specialist agencies.

In order to work collaboratively with its partners and other stakeholders, the observatory will utilise flexible working arrangements such as joint appointments, secondments, placements and consultancies.

In light of the rapid changes occurring in both Ireland and Northern Ireland, it is vital from the very beginning that the observatory maintain strong links to emerging organisations



and structures. These include the Health Service Executive (HSE) and Health Information and Quality Authority (HIQA) in Ireland, and changes in the development and delivery of the public health function outlined in the Review of Public Health and the Review of Public Administration in Northern Ireland.

#### **4.4 VALUES AND PRINCIPLES**

The Management Board is developing agreed values and principles to guide the development and operation of the observatory. These values and principles will reflect:

- A commitment to support key public health related policies, strategies and programmes
- The primacy of evidence-based policy and practice
- A commitment to improve health and reduce health inequalities
- The importance of co-ordinated development of health research and information infrastructure
- The value of existing health research and information
- The need for efficiency by filling gaps without duplicating effort
- A broad view of health and the factors that affect it (including the social determinants of health, lifestyle behaviours, the health and social services, the non-health sector, and the community and voluntary sector)
- A comprehensive definition of 'knowledge' that recognises the complementary role of quantitative and qualitative data, and the value of the experiences of people and organisations
- A strong link to other work of the Institute.

The values and principles will also reflect commitments to work in a way that is:

- Collaborative and supports its partners and all those who use health intelligence
- Appropriately inclusive and participatory.

#### **4.5 ALL-IRELAND WORKING AND THE INSTITUTE OF PUBLIC HEALTH**

An all-Ireland observatory is unique amongst public health observatories because it spans two jurisdictions with different health services, and different health information infrastructures and governance arrangements. From these differences arise unique opportunities and challenges.



Housing the observatory within the Institute helps it take advantage of these opportunities and meet these challenges:

- The Institute is an all-Ireland body with considerable experience promoting North/South co-operation in public health
- It has a strong focus on improving health and reducing health inequalities
- Its remit is to build public health capacity including health monitoring and surveillance on the island
- It has considerable expertise in developing and supporting partnership working
- It plays a key role in a number of important health related initiatives including the development of Health Impact Assessment and support for the anti-poverty strategies in the two jurisdictions
- Its core funding is provided by the two departments of health which have a strong role in the Institute's Management Board.

The observatory supports the health intelligence function in both Ireland and Northern Ireland, while maximising the benefits of working across the island. Consequently its objectives will sometimes progress at a different pace and in slightly different ways in Ireland and Northern Ireland according to the needs and circumstances in these jurisdictions.

#### **4.6 INTERNATIONAL COLLABORATION**

The observatory will work in a European and international context.

The connections the observatory has with agencies such as APHO ensures strong linkage to the developments in England, Scotland and Wales.

The observatory's involvement in the Regional Health Observatory Network in Europe (RHONE) strengthens its links to European information developments such as the EU Public Health Monitoring Programme.

Its activities are linked to the European Public Health Information Network (EUPHIN) and indicators' development will be undertaken in the context of international initiatives such as the European Community Health Indicators (ECHI) project.



## **4.7 PROJECT MANAGEMENT**

### **4.7.1 WORKPLAN DEVELOPMENT**

A stakeholder consultation, part of the Annual All-Ireland Health Intelligence Conference, will contribute to the development of INIsPHO's annual workplans.

A draft of the observatory's annual workplan will be developed by the INIsPHO Management Group in consultation with the two departments of health, and the Health Information and Quality Authority (HIQA) in Ireland and the equivalent agency in Northern Ireland. It will then be submitted to the Institute's Management Board which finalises it. Once finalised, the observatory's workplan, together with quarterly progress reports, will be placed on the observatory's website.

Agreed criteria will be used to select projects and activities for the observatory. Initial criteria should include:

- Does it duplicate any other agency's work?
- Does it support Investing for Health/Quality and Fairness?
- Does it contribute to the implementation of the National Health Information Strategy (Ireland) and equivalent strategy in Northern Ireland?
- Does it contribute to the strategic objectives of Health Information and Quality Authority (HIQA) (Ireland) and the equivalent agency in Northern Ireland?
- Does it contribute to the Institute's strategic objectives?
- Does it contribute to improving health and reducing health inequalities?
- Is it consistent with the observatory's values and principles?
- What is the potential for North/South co-operation?
- Is it consistent with EU/international standards, and will it contribute to improved monitoring of public health at these levels?
- Is the proposal realistic (time and money)?
- Is it innovative?

These will be reviewed at the end of the observatory's first year.

#### **4.7.2 PROJECT TEAMS**

Project Teams, with external participants when appropriate, will advise on the conduct of each of the observatory's major areas of work. They represent a key vehicle through which the observatory engages with its partners and other stakeholders.

#### **4.7.3 EXTERNAL REVIEW**

The observatory is committed to an ongoing quality programme to ensure its work meets the highest possible standards.

The INIsPHO Management Group will develop protocols for the review of its work. These will include:

- Regular evaluation of its websites
- External peer review of its research and information projects
- Post-publication evaluation of its reports
- Participant evaluation of all conferences, seminars and other events run by the observatory.



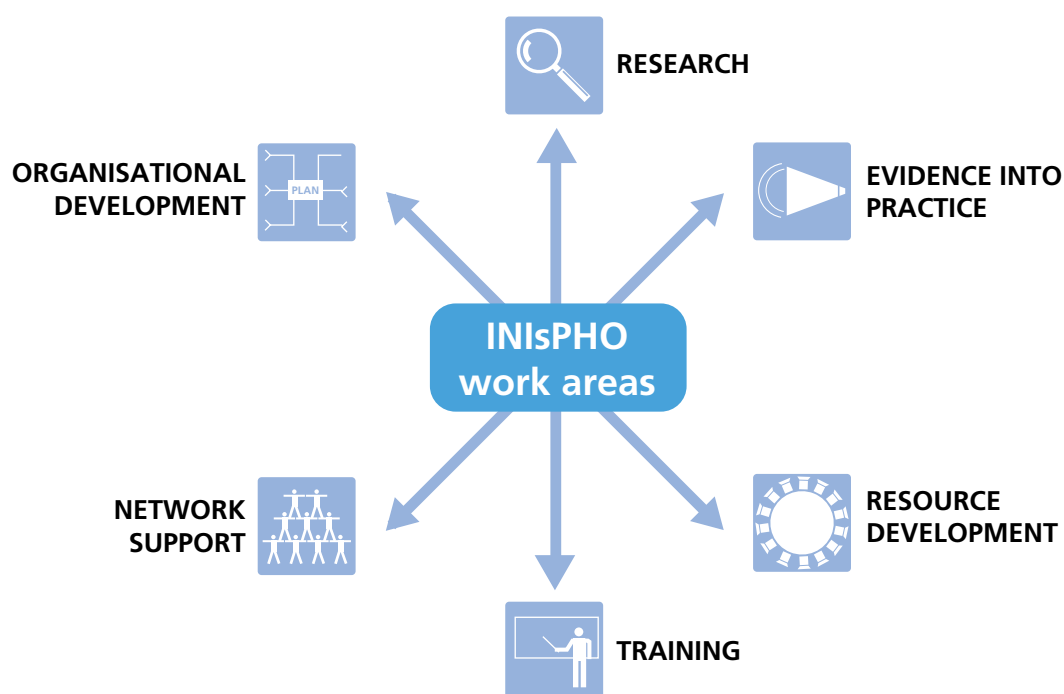
## PART C. WORK PROGRAMME

### 5. AREAS OF WORK

The observatory's projects and activities are grouped under the following headings:

1. Research
2. Evidence into practice
3. Resource development:
  - websites
  - knowledge resources
  - information standards
4. Training
5. Network support
6. Organisational development.

*Figure 5: INIsPHO Work Areas*



## 5.1 RESEARCH

The following are examples of research and information projects being undertaken by the observatory:

- Development and use of the PBS Diabetes Population Prevalence Model on the island
- Demographic and socio-economic data standards for health information systems: the National Cardiovascular Information System (NCIS) as a case study
- A study of the feasibility of developing an Irish Health Poverty Index
- The burden of disease on the island.

## 5.2 EVIDENCE INTO PRACTICE

The observatory will focus on increasing awareness, access and use of health information and intelligence available on the island and elsewhere. The observatory's websites, together with other events and publications, are the main vehicles for achieving this.

Specific activities include:

- Integrating Ireland's PHIS (CD) and the PHIS (Online) website
- Disseminating Northern Ireland DPH's core indicator tables through the internet
- Design of a 'Health of Ireland, North and South' report series
- Inaugural Annual All-Ireland Population Health Intelligence Conference
- Routine research and technical reports, seminars and newsletters
- Ongoing promotion of the observatory's websites and the resources they contain.

## 5.3 RESOURCE DEVELOPMENT

### 5.3.1 WEBSITES

To support its work the observatory must maintain and continuously enhance its websites:

- INIsPHO website:
  - i. Advocacy website (pilot)
  - ii. Media Library (pilot)
- PHIS (Online) website:
  - i. Public Health Knowledge Resources Catalogue
  - ii. Reports System
  - iii. Indicators System
  - iv. Data System
  - v. Gateway to unpublished literature (pilot)
  - vi. Policies and Strategies Compendium
- INIsPHO extranet
- Interoperability with other health knowledge websites.





### **5.3.2 KNOWLEDGE RESOURCES**

The website developments above provide a web-based vehicle for increasing awareness, access and use of available knowledge resources. These resources need to be identified, collated and documented so they can be published on the websites. On occasions this involves the development of new indicator sets:

- Collating and documenting existing knowledge resources for INIsPHO's websites
- Developing an all-island Public Health Common Data Set (PHCDS)
- Developing Local Community Profiles for the island.

### **5.3.3 INFORMATION STANDARDS**

Information standards underpin the operation and development of the observatory's websites. The observatory will continue to develop its metadata standards, data standards, and link to the National Public Health Language.

HIQA in Ireland and the equivalent agency in Northern Ireland have responsibility for national standards, and the observatory has tried to align its standards with any likely national future developments. These standards have the potential to contribute to the co-ordinated development of health information infrastructure, knowledge management and the health intelligence function on the island.

### **5.4 TRAINING**

The observatory supports individuals, organisations and networks engaged in the production and dissemination of health intelligence and its translation into evidence-based policy and practice.

Initial activities in this area include:

- Ongoing support of the Public Health Advocacy website
- Dissemination of online training materials and tools.

### **5.5 NETWORK SUPPORT**

The observatory is committed to supporting its partners and other stakeholders involved in producing, disseminating and using health intelligence.

It aims to help develop and support public health networks on the island.

Initial activities in this area include

- Development of a Health Analysts Network
- Inaugural All-Ireland Health Intelligence Conference.

## **5.6 ORGANISATIONAL DEVELOPMENT**

Organisational development involves:

- Support of the INIsPHO Management Group and Technical Working Group
- Reporting (financial management and performance monitoring)
- External relations.



## PART D. GOVERNANCE ARRANGEMENTS

### 6. GOVERNANCE

#### 6.1 OVERVIEW

The observatory is accountable to the Management Board of the Institute, which itself complies with relevant national and international conventions in the areas of research, information and corporate governance.

The observatory will comply with the relevant protocols and policies in each jurisdiction – Northern Ireland and Ireland – where they exist. On occasions, such policies and protocols differ. There are also significant differences in the data protection frameworks of Northern Ireland and the rest of the UK. In such circumstances the Management Board will deal with these on a case-by-case basis.

#### 6.2 RESEARCH GOVERNANCE

The European Science Foundation's Good Scientific Practice in Research and Scholarship as described in its Policy Briefing (December 2000) and the World Medical Association's Declaration in Helsinki: "Ethical principles for medical research involving human subjects" (last amended October 2000) are both part of the Institute's formal policy.

#### 6.3 DATA PROTECTION AND FREEDOM OF INFORMATION

Following consideration by the North-South Ministerial Council of a draft Freedom of Information Code of Practice for North-South Implementation Bodies, the Institute's Management Board will conform with the final Code of Practice.

In relation to data protection, the Institute conforms with the Data Protection (Amendment) Act 2003 (which gives effect to Directive 95/46/EC of the European Parliament) in Ireland and the Data Protection Act 1998 in Northern Ireland.

#### 6.4 CORPORATE GOVERNANCE

The Institute is a company limited by guarantee registered in Ireland, and is governed by its Memorandum and Articles of Association.

In addition, the Institute endeavours to abide by established public sector governance arrangements such as the Review of Governance and Accountability Mechanisms in the General Medical Services Schemes developed by agencies such as the Office for Health Management in Ireland.



The Director of the observatory reports to the Director of the Institute, who is accountable to its Management Board.

#### **6.4.1 INIsPHO MANAGEMENT GROUP**

The Institute's Management Board is forming a broad-based Management Group to assist it. Its membership will include representation from the Institute's Management Board, the two departments of health, the Health Information and Quality Authority (HIQA) and Health Service Executive (HSE) in Ireland, and the equivalent agencies in Northern Ireland.

The Institute's Management Board will develop the Terms of Reference for the INIsPHO Management Group which may include:

- Developing the draft annual workplan for the observatory
- Engaging with the observatory's partners and other stakeholders
- Advocating and building support for the observatory.

#### **6.4.2 FINANCIAL COMPLIANCE**

The Institute complies with Company Law in Ireland by filing annual audited accounts with the Companies Registration Office. Financial statements are prepared on a historical convention basis following International Accounting Standards.

The Institute will provide financial management services to the observatory, including quarterly income and expenditure statements and auditing of accounts.





## 7. ADVICE AND GUIDANCE

A Technical Working Group will be established to provide advice and guidance on broad technical issues to the INIsPHO Management Group.

### 7.1 INIsPHO TECHNICAL WORKING GROUP

Its membership could include representation from the Health Information and Quality Authority (HIQA), Health Research Board (HRB) and Health Service Executive (HSE) in Ireland, and equivalent agencies in Northern Ireland.

Its Terms of Reference might include advice on:

- Methodological approaches
- Information and ICT standards
- Information governance (freedom of information and data protection)
- Inclusion criteria for resources on the observatory's websites and accreditation of linked websites.

It is also proposed that regular advisory fora be held to provide a wider perspective on the long-term direction of the observatory.

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## APPENDIX: MEMBERSHIP OF THE ADVISORY GROUP

The Advisory Group was chaired by Paula Kilbane, Chief Executive Officer, Eastern Health and Social Services Board, Northern Ireland.

Its members were:

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

The Advisory Group would like to thank Robert Beatty, Head of Demography and Census, Northern Ireland's Statistical and Research Agency for his earlier contribution.



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