
INVOLVE

Public Health Strategy & Action Plan 2004/2005

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1. Introduction

This strategy and action plan is intended to inform members of INVOLVE, the Support Unit and other interested stakeholders about INVOLVE's priorities, aims and activities in relation to public health research during 2004/05. The action plan operates in conjunction with INVOLVE's "Strategic Plan: 2003 – 2006: Creating the Expert Resource" and "Operational Plan 2004/05".

Sections 1 – 5 outline the context in which the action plan was drawn up. Section 6 is INVOLVE's action plan for the current year. At the beginning of 2004, a consultation exercise was carried out by the Support Unit with a small number of stakeholders in public health research and this provided INVOLVE with many recommendations as to how it could carry its work forward. The action plan has responded to the key messages that emerged from the consultation process. It is however necessary to acknowledge that the response has also been shaped by the existing commitments and the resource limitations of INVOLVE.

2. What is public health research?

Probably for most people it is not easy to identify a 'public health' research project as such. This is perhaps because there are genuine overlaps with NHS and social care research but also because the definitions of the terms 'public health' and 'public health research' are less well understood and somewhat contested. There are however a few pointers that sometimes make public health research somewhat easier to recognise. Public health is about improving the health of populations and communities rather than individuals and its remit goes beyond just being concerned with people who use health or social services to encompass the topics of health protection, promotion and prevention. This means that for example, public health research might be looking at screening or immunisation programmes or perhaps at the links between health and the physical environment or health and employment.

3. The current national context

INVOLVE's intention to develop a public health strategy is timely in that the subject of public health is currently receiving an unprecedented amount of positive attention from the Government. In the past, government attention and resources have been focused disproportionately on the demands of service provision rather than health promotion and illness prevention.

Securing Our Future Health: Taking A Long Term View

In 2002, the first Wanless review for the Treasury (Wanless, 2002) looked ahead to the health service of 2022 to make an assessment of what resources would be required to provide high quality health services. The Wanless report identified the need to substantially increase spending to catch up with the health systems of other 'developed'

nations. It then described and costed three possible scenarios – ‘solid progress’, ‘slow uptake’ and ‘fully engaged’ - over the twenty year period and estimated that if the ‘fully engaged’ scenario were achieved it could not only deliver better health outcomes but also potentially save the government an investment of £30 billion. The key factors in the ‘fully engaged’ scenario are that there is a dramatic improvement in public engagement, life expectancy goes beyond current forecasts, health status improves dramatically, use of resources is more efficient and the health service is responsive with high rates of technology uptake. The report went on to look at key factors that impacted on service demand, one of which was that of health promotion and disease prevention:

“Improved public health, through health promotion and disease prevention, could therefore have a significant impact on health status and ultimately the demand for health services and the resulting cost.... The scale of the impact of promotion and prevention will depend on two principal factors: the level of public engagement; and the success of public policy in promoting such engagement through, for example, ensuring wide access to the latest evidence on risk factors or specific interventions.” (Wanless, 2002, p.46)

Securing Good Health for the Whole Population

In 2003, the Government asked Derek Wanless to undertake another review (Wanless, 2004) but this time focusing on public health. In particular, on prevention, the wider determinants of health and the challenges of implementing the ‘fully engaged’ scenario. Both Wanless reports drew attention to the fact that the public health evidence base was inadequate and that there had been a lack of investment in public health research. One of the recommendations of the second Wanless report was for the development of a public health research strategy that would look at the “roles of the various research bodies in relation to public health, and how they best work together to identify and address gaps in public health research, to ensure the structured and coherent development of the public health research requirements of England” (Wanless, 2004, p.185). Significantly for INVOLVE, the report made no mention of the value of public involvement in research despite the fact that INVOLVE had contributed to the consultation. Shortly before the second Wanless report was published further Government public health initiatives were implemented.

Public Health Research Consortium

The Department of Health’s Policy Research Programme (PRP) has put out a tender for bids to create a Public Health Research Consortium. There is initial funding for this project of approximately £3.5 million over five years. A lead academic institution will take responsibility for overall management of the consortium whilst collaborating with other groups and institutions to offer a broad range of appropriate experience and skills. The consortium will negotiate its programme of research with the Department of Health and focus on strengthening the evidence base for health improvement and on narrowing health inequalities. INVOLVE will be represented on the commissioning board of this project.

Choosing Health?

“Choosing Health?” is a Government consultation on action to improve people’s health. It concluded at the end of May 2004. Submissions to the consultation will feed in to a White Paper on public health due for publication before the end of the year and which, according to a speech made by Secretary of State for Health, John Reid, addressing the NHS Trust Chief Executives’ Conference, “will set out a clear strategy for future action”. As part of the consultation exercise eight topic based Task Groups were created, bringing together a

mixture of key stakeholders to look at specified areas. None of the task groups focused on research although two – the ‘Working With and For Communities Task Group’ and the ‘Consumers and Markets Task Group’ – had a public engagement remit. At the beginning of May, Melanie Johnson, the Minister for Public Health, announced two further “Choosing Health?” consultations focusing on diet and physical activity. INVOLVE has contributed to the “Choosing Health?” consultation.

Public Health Sciences: Challenges and Opportunities

In March 2004, the Wellcome Trust (2004) published a report by their Public Health Sciences Working Group. The report considered the current state of public health sciences and made recommendations for improvement. Amongst their recommendations was the need to establish a national academic public health strategy group that would involve all the relevant governmental and non-governmental funding agencies. A further suggestion, echoing the second Wanless report, was for the creation of a time limited working group that would develop a national strategy for public health research. As with the Wanless reports, the Wellcome Trust report does not raise the issue of actively engaging the public in the research process.

Strengthening the public health evidence base will be an essential part of the Government’s public health strategy. INVOLVE needs to ensure that the issue of public involvement does not get omitted from any future research and development strategy and that it is acted upon.

4. INVOLVE’s public health work to date

In 2001 the PRP funded INVOLVE to broaden its remit from focusing purely on NHS research to include public health and social care research. In the same year the Department of Health published “A Research and Development Strategy for Public Health”. This document made several references to the importance of public involvement in research. One of the action points in the document was that:

“Main funders will develop the involvement of practitioners and the public in all parts of the public health R&D research process. DH will do this by extending the role of *Consumers in NHS Research* to R&D for public health.”
(Department of Health, 2001, p.18)

From June 2001 until March 2002, Jane Royle, on behalf of INVOLVE, undertook a consultation exercise with PRP Liaison Officers and a small number of people within the public health research community to find out what were the prevailing attitudes and practices of some public health institutions to public involvement in research.

In May 2002 INVOLVE hosted a seminar at the Royal Institute of Public Health which aimed to explore how to involve members of the public effectively in public health research. It was attended by researchers, members of the public, voluntary sector organisations, research commissioners and public health practitioners.

The role of Public Health Development Worker was only funded until the end of March 2002 (although Jane Royle has stayed with INVOLVE in another capacity, and continues to offer INVOLVE the benefit of her public health expertise). However the Group has

continued to benefit from the advice and guidance of Dr Catherine Law, a public health researcher who represents the PRP in the Group and has been tasked with pump-priming INVOLVE's public health work.

The Group has responded to a number of the recommendations that emerged both from the consultation process and the seminar:

- The Group's name was changed from 'Consumers in NHS Research' to 'INVOLVE', with the strap line, 'promoting public involvement in NHS, public health and social care research'
- The Group identified that use of the term 'consumer involvement' was no longer appropriate and adopted the term 'public involvement' with a broader definition
- Two of INVOLVE's three key publications have been revised to reflect the change in terminology and include a balanced mix of examples of good practice from NHS, public health and social care research
- INVOLVE's newsletter has regularly included articles relating to public health research
- Articles on public involvement in research have been published in public health newsletters
- A brief information sheet for public health researchers has been developed
- The Support Unit has attended, exhibited and presented at public health conferences
- The Group has responded to Government consultations
- The Group has worked to find new members with a background in public health

Although both Group members and the Support Unit have endeavoured to integrate public health research into their work it has been more difficult to achieve than the integration of social care research. One of the reasons for this may be that social care research has more or less led the way in public involvement in research and therefore there is a higher base level of awareness and a growing culture of public involvement in both research and practice. Another reason may be that the terms 'public health' and 'public health research' are poorly understood and contested in a way that the terms 'social care' and 'social care research' are not. Whilst the Group has ring fenced funding for public health work, it has struggled to identify how best to deploy it.

It is against this background that in 2004 the Support Unit has undertaken a further consultation exercise with key stakeholders in public health research. The reasons for doing so were:

- To exchange information
- To develop a better understanding of specific barriers to public involvement in public health research
- To identify organisations that are interested in working more closely with INVOLVE
- To develop a public health strategy for INVOLVE

Appendix 1 lists the people that have contributed to this consultation to date. It is by no means a representative sample but the approach taken was to begin by making contact with non governmental organisations, government agencies, public health networks, community researchers, local government researchers, epidemiological researchers, Directors of Public Health at Primary Care Trust, Strategic Health Authority and regional Government Office level. These initial contacts have gone on to suggest other individuals or organisations who they felt would be valuable contacts.

5. Messages from the consultation process

There are three key messages that have emerged from the consultation process:

- It is necessary to understand and acknowledge that there are barriers that are specific to public health research and they should be given proportionate attention. However, almost all of the barriers to public involvement in public health research described by interviewees are shared in common with NHS and social care research.
- Interviewees were not asking INVOLVE to provide them with different or new services. They want access to existing services, and it is interesting to note that a number (6) of interviewees had not previously known of the work of INVOLVE - or 'Consumers in NHS Research'.
- For many interviewees, public involvement in research was not a subject that they had spent much time considering. Promoting awareness of the relevance of public involvement to public health research is a priority.

A semi structured questionnaire was used as the basis for discussion with interviewees. Answers to the following three questions were crucial to the development of INVOLVE's public health strategy:

Q. What do you see are the challenges of incorporating public involvement in public health research?

Almost all of the issues that were raised by people as being challenges particular to public health research are in fact challenges that are also faced by NHS and social care research. For example, interviewees identified the difficulty in finding people, the lack of resources, the lack of skills to work with the public, the perceived lack of interest on either side and the difficulty of trying to work with 'hard to reach' groups. Some of the problems raised seemed at first glance to be purely public health related but when studied further are also issues common to other types of research:

- A lot of public health research is secondary research – i.e. number crunching data collected by others, or synthesis of research – e.g. systematic reviews. There is no role for the public in such research.
- Some areas of public health research deal with areas that are inherently controversial and may have major political, social and economic implications – e.g. water fluoridation, childhood vaccinations. Involving the public in this research could be 'counterproductive'
- Who to involve? When you are not dealing with chronic conditions it is difficult to know who should be involved and what 'expertise' they are bringing. For example a person who has arthritis sits as a lay member on an advisory group for a research project looking at an intervention for arthritis and offers a perspective from the view point of someone with long term experience of arthritis. Who should be the lay member on an advisory group for a research project evaluating the '5 a day' healthy eating campaign?
- Public health research is under funded and lacks infrastructure. It doesn't have the resources to support public involvement

- Difficulty of rooting public health research in the community. There is no sense of 'constituency'.

Some research has to respond very rapidly and looks for answers to 'hard' science questions. It is difficult to imagine where/how public involvement could add value to the research process. E.g. SARS. 6 weeks work of 11 labs worldwide.

This left a small number of issues that related specifically to public health research and were mentioned by interviewees with regularity:

- Lack of agreement amongst public health researchers in defining the boundaries of what is 'public health' and what is 'public health research'
- The public don't know what 'public health' and 'public health research' are
- Lack of examples of good practice in public health research

Q. How might INVOLVE be able to assist you?

A small number of organisations felt that INVOLVE was not in a position to be of any assistance to them but they were glad to have a better understanding of what INVOLVE does. Each meeting was an invaluable opportunity to exchange information. Different organisations were clearly at different stages in dealing with the issue of public involvement in research. Some organisations, such as the Health Development Agency and the Health Protection Agency, expressed interest to work with INVOLVE in the future. The assistance that interviewees wanted from INVOLVE included:

- Keeping in contact and sharing information (x 9)
- More contact. For example, presentations, conferences, offering advice on specific projects, writing articles for a newsletter (x 7)
- Providing written materials with basic 'how to' information and examples of good practice relevant to public health (x 3)
- Offering advice and ideas on how to address the topic of public involvement in research in general (x 3)
- Generating and facilitating a debate about why community research is often disregarded on the basis that the methodologies used are not 'scientifically rigorous'.
- Finding out what the public want from public health research. What are their priorities?

Q. INVOLVE has limited resources at its disposal. What would you advise INVOLVE to do, in order to make the best use of its resources in developing its work in the field of public health research?

Again, a small number of organisations didn't feel they were in a position to respond to this question. Those who did suggested the following:

- Generally work to raise awareness and promote debate on the issue of public involvement in research - meet people, write articles, attend conferences, host seminars/workshops, give talks etc (x 5)
- Work with local groups and communities to get a sense of what is going on at 'grassroots' level and pass that information on to government agencies and larger organisations (x 3)

- Make inroads on the training of public health researchers (x 2)
 - INVOLVE should be working in small ways at different levels – e.g. some work with national agencies, some with education/capacity building, public health networks, research networks and consortia
 - Work with research funders to get them to incorporate the public into the process of identifying and prioritising research topics as this will have most effect on the research agenda.
 - Widen the audience that INVOLVE is addressing by writing more articles for publication in newsletters and journals
 - Promote more widely in the public health community the work of INVOLVE and the services that it can offer
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6. INVOLVE’s Public Health Action Plan 2004/2005

6.1 Priorities, Aims & Activities

INVOLVE’s public health strategy 2004/05 has four distinct but overlapping priorities:

- Raising awareness
- Partnership working
- Capacity development
- Building the evidence base

6.2 Raising Awareness

Aims:

INVOLVE needs to raise awareness of:

- The relevance of public involvement to public health research
- The work of INVOLVE, the services and support that it has to offer

Activities:

Target	Responsibility	Action	Budget
Submit papers to and exhibit at appropriate public health conferences	Support Unit	Support Unit	Support Unit
Continue meetings with public health stakeholders (1 meeting per month)	Support Unit	Support Unit but could also be Group members with public health background?	Support Unit
Writing articles for publication in journals and newsletters	Support Unit	Group members with public health background? Freelance writer?	Support Unit

			Strategic Alliances
Responding to public health consultations	Group	Support Unit with appropriate support	Support Unit

6.3 Partnership Working

Aims:

- To develop and promote examples of good practice through working in partnership with others
- To work with at least one national organisation to support and promote public involvement in its public health research programme
- To build relationships with community based organisations

Activities:

Target	Responsibility	Action	Budget
Support the development of public involvement in the Public Health Research Consortium	Support Unit	INVOLVE (Support Unit) is already committed to take part in the commissioning process. Once the contract has been awarded INVOLVE will support and advise the consortium on public involvement in their programme.	Support Unit
Pursue initial contact made with Health Development Agency (NICE) and Health Protection Agency	Support Unit	Support Unit to establish from both agencies how INVOLVE can practically assist them in addressing the issue of public involvement in their research work.	Support Unit
Make links with community based organisations – carried out as part of meetings with public health stakeholders (see Raising Awareness table)	Support Unit	Support Unit but could also be Group members with public health background?	Support Unit
Maintaining public involvement in research as an integral part of the national public health research strategy	Group	Ensuring that INVOLVE contributes to any further development of the national strategy arising from the Government White Paper on Public Health (expected later in 2004)	Support Unit

6.4 Capacity Development

Aim:

- To increase INVOLVE's knowledge and understanding of public health research

Activities:

Target	Responsibility	Action	Budget
To increase INVOLVE's knowledge and understanding of public health research	Support Unit and Public Health Mentor	To provide the Support Unit with a public health mentor. (This could possibly be someone from the Group or PRP?) For the Support Unit to have a quarterly meeting with their mentor.	Support Unit
To increase INVOLVE's knowledge and understanding of public health research	Support Unit	To undertake appropriate training opportunities	Support Unit
To enable the delivery of INVOLVE's public health strategy	Group	For INVOLVE to ring fence one member of Support Unit staff for one day per week to deliver the public health strategy	Support Unit

6.5 Building the evidence base

Aims:

- To support the development of the evidence base for public involvement in public health research
- To encourage monitoring of public involvement in public health research

Activities:

Target	Responsibility	Action	Budget
To support the development of the evidence base for public involvement in public health research	Group	Actively encourage relevant researchers to provide project details for the INVOLVE database	Support Unit
To encourage monitoring of public involvement in DH/NHS public health research	Group and Support Unit	Identify opportunities for routine data monitoring of public involvement in public health research	Support Unit

6.6 Looking ahead to 2005/06

Whilst INVOLVE is developing its own capacity and understanding of public health research it is useful to have a stand alone public health strategy that acts both as a framework defining working boundaries and is an action plan.

In March 2005 the Support Unit will submit a report to the members of INVOLVE that highlights how INVOLVE has performed over the previous nine months in relation to its public health strategy. The Support Unit will also submit to INVOLVE a draft strategy for 2005/06. Both these documents will be written with the advice of the Support Unit's public health mentor.

**Philippa Yeeles, Research Involvement Officer, INVOLVE Support Unit
June 2004**

7. References:

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http://www.wellcome.ac.uk/en/images/pub_health_sci_7867.pdf

8. Appendix – Contributors to the consultation

Name	Post and Organisation
Karen Bollan	Development Manager National NGO Forum
Peter Borriello	Director of Research & Development Health Protection Agency
Victoria Combe	Consumer Branch Food Standards Agency
Anna Coote	Public Health Programme Director King's Fund
Paul Dornan	Policy and Research Officer Child Poverty Action Group
Paul Edmondson-Jones	Director of Improving Health and Quality Portsmouth City Primary Care Trust Member Hampshire & Isle of Wight Public Health Network & Wessex Primary Care Research Network
Steve Fairman	Head of Public Health & Research Governance Framework Lead Thames Valley Strategic Health Authority
Mike Gill	Regional Director of Public Health Government Office for the South East
Tonya Gillis	Communications Officer Health Development Agency
Sian Griffiths	President Faculty of Public Health
Annette Hackett	Clinical & Research Governance Support Officer Thames Valley Strategic Health Authority
Alison Hill	Programme Director South East Public Health Observatory
Louis Levy	Nutrition Division Food Standards Agency
Heidi Livingstone	Knowledge Information Management Health Development Agency
Angela Mawle	Chief Executive UK Public Health Association
Caroline Mulvihill	Acting Director of Research Health Development Agency
Stephen Peckham	Head of Department of Sociology and Social Policy Oxford Brookes University
Mike Rayner	Director British Heart Foundation Health Promotion Research Group
Robert Sherriff	Director of Public Health Thames Valley Strategic Health Authority
Juliet Whitworth	Researcher Local Government Association