

National Strategy for Service User Involvement in the Irish Health Service 2008-2013





Produced by the Department of Health and Children, the Health Service Executive
and in consultation with the Health Services National Partnership Forum.

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MINISTER FOR HEALTH AND CHILDREN'S FOREWORD



Service User Involvement in the Irish Health Services

I am very pleased to launch this important strategy document that will drive service user involvement in our health services. The role of the service user has been central to government health policy and while much good work has been done to build the voice of the service user into decisions in health care we need to ensure that best practice in this area is disseminated to all parts of the health service.

Service users should be able to articulate their views and be listened to in their individual interactions with health care professionals and as key stakeholders where decisions are taken about future health service development. The key for service users is that they get clear feedback and that they feel their contribution has been valued.

With the successful implementation of this strategy primary care teams will be sitting down with their patients developing models of service provision that will meet their needs. Older people and their families will be engaged in discussions about the quality of their community care provision. Mental health services will be ensuring that their care packages are tailored to the needs of their service users.

I believe that this strategy can be a key driver to ensure that service user involvement enables the health services to anticipate problems, avoid complaints, develop appropriate and effective service provision and it guarantees that service users will be at the centre of efforts to drive up the quality and safety of service provision.

A handwritten signature in black ink, which appears to read 'Mary Harney'.

Mary Harney T.D.
Minister for Health and Children.

CEO'S FOREWORD



Easy access and public confidence are two key objectives of our health transformation programme.

Members of the public can bring great clarity, practicality and transparency to the development of truly patient-centred services. They can act as a valuable reference point to ensure that the decisions and actions of executives and clinicians always put the needs of people who use our health services first.

This strategy document represents a significant step forward in actively involving the public in this programme of change. Working in partnership with other statutory and voluntary organisations, and staff representative bodies, the HSE is taking a lead role in overseeing the implementation of this strategy.

It will build on the existing work by the HSE in engaging with people who use or may have reason to use its services such as the *Your Service Your Say Compliments and Complaints Policy*.

Implementing this strategy will revolve around three levels of engagement:

- ❑ Individual service users: *involvement in their own care*
- ❑ Community: *involvement in local service delivery and development*
- ❑ National: *strategic policy informed through involvement of service user organisations in partnership with health care professionals.*

I would like to acknowledge all who contributed to the development of this strategy and the members of the Steering Group for sharing their knowledge and experience during its preparation.

We should always enthusiastically welcome the involvement of those who use our health services and are willing to give up their time to do so. I would encourage all staff therefore to endorse and support this strategy and consider it a valuable resource.

Brendan Drumm.

Professor Brendan Drumm
CEO Health Service Executive.

DEFINITION OF KEY TERMS

We use the term 'service user' to include:

- ❑ People who use health and social care services as patients
- ❑ Carers, parents and guardians
- ❑ Organisations and communities that represent the interests of people who use health and social care services
- ❑ Members of the public and communities who are potential users of health services and social care interventions.

The term service user also takes account of the rich diversity of people in our society whether defined by age, colour, race, ethnicity or nationality, religion, disability, gender or sexual orientation, and may have different needs and concerns.

We use the term service user in general, but occasionally use the term patient where it is most appropriate.

By 'involvement' we mean:

'A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change...' (HeBE 2002).

We would also see a role for service users in monitoring health service performance.

ABBREVIATIONS

CEO	Chief Executive Officer
DoHC	Department of Health and Children
EAG	Expert Advisory Group
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
LHMs	Local Health Managers
OMC	Office of the Minister for Children
PCCC	Primary Community and Continuing Care
RHO	Regional Health Office
RHF	Regional Health Forum
NCF	National Consultative Forum

INTRODUCTION

The service user should be central to their own care and to the design and delivery of health and personal social services. This will result in more appropriate services of a higher quality with increased service user compliance and satisfaction. This strategy will build on the existing work undertaken and documented on service user involvement in health. This strategy has been developed to ensure a systematic and consistent approach to service user involvement across the health and social services. It will build upon the current good practice in involving service users across the country. The strategy has the support of the Minister for Health and Children and the Board and the Chief Executive Officer of the Health Service Executive (HSE) and it represents a significant step forward in developing strong service user involvement in health in Ireland. The strategy comprises a statement of principles and specific goals together with relevant actions.

LEGISLATIVE, POLICY AND STRATEGY CONTEXT

This strategy has been produced in the context of the following key Department of Health and Children (DoHC) and HSE strategies:

❑ A Vision for Change (2006): Report of the Expert Group on Mental Health Policy

"Involvement of service users and their carers should be a feature of every aspect of service development and delivery".

❑ The HSE Corporate Plan (2005-08)

Objective 4 states that: *'we will develop the HSE as a dynamic, effective and learning organisation in partnership with service users, patients, staff, not for profit/voluntary/community sector and other stakeholders. This means that we are committed to learning from the experience of our service users, partner service providers, staff and other stakeholders. We will actively consult around the planning, delivery and evaluation of our services'.*

❑ The Health Act (2004)

States that: *'The Executive may take such steps as it considers appropriate to consult with local communities or other groups about health and personal social services'.*

The Act also allows for the establishment of the National Consultative Forum, Regional Health Fora and Advisory Panels.

In January 1, 2007, 'Your Service Your Say' a national Comments, Compliments and Complaints Policy came in to effect to ensure that the people using services provided by the HSE have every opportunity to comment on their experiences, both positive and negative. The HSE, in accordance with Part 9 of the Health Act 2004 and the Health Act 2004 (Complaints) Regulations 2006, is committed to providing a system for the management of complaints that facilitates effective feedback from and communication to all service users. The HSE will ensure that the results of complaints and service user comments on health and social services will be integrated with the service user involvement process outlined in this strategy.

❑ The National Health Strategy (2001): Quality and Fairness – A Health System for you
National Goal No. 3: Response and Appropriate Care Delivery.

Objective 1 states that: *'The Patient is at the centre in the delivery of care'*. Action 52: *'Provision will be made for the participation of the community in decisions about the delivery of health and personal social services'*.

❑ Primary Care – A New Direction (2001)

Action 19 outlines that: *'Mechanisms for active community involvement in primary care teams will be established. Community participation in primary care will be strengthened by encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of primary care services. Consumer panels will be convened at regular intervals in each health board. At local level, primary care teams will be encouraged to ensure user participation in service planning and delivery. Consumers will also have an input to needs assessments initiated by individual health boards. A greater input from the community and voluntary sector will enhance the advocacy of primary care teams in ensuring that local and national social environmental health issues, which influence health, are identified and addressed'*.

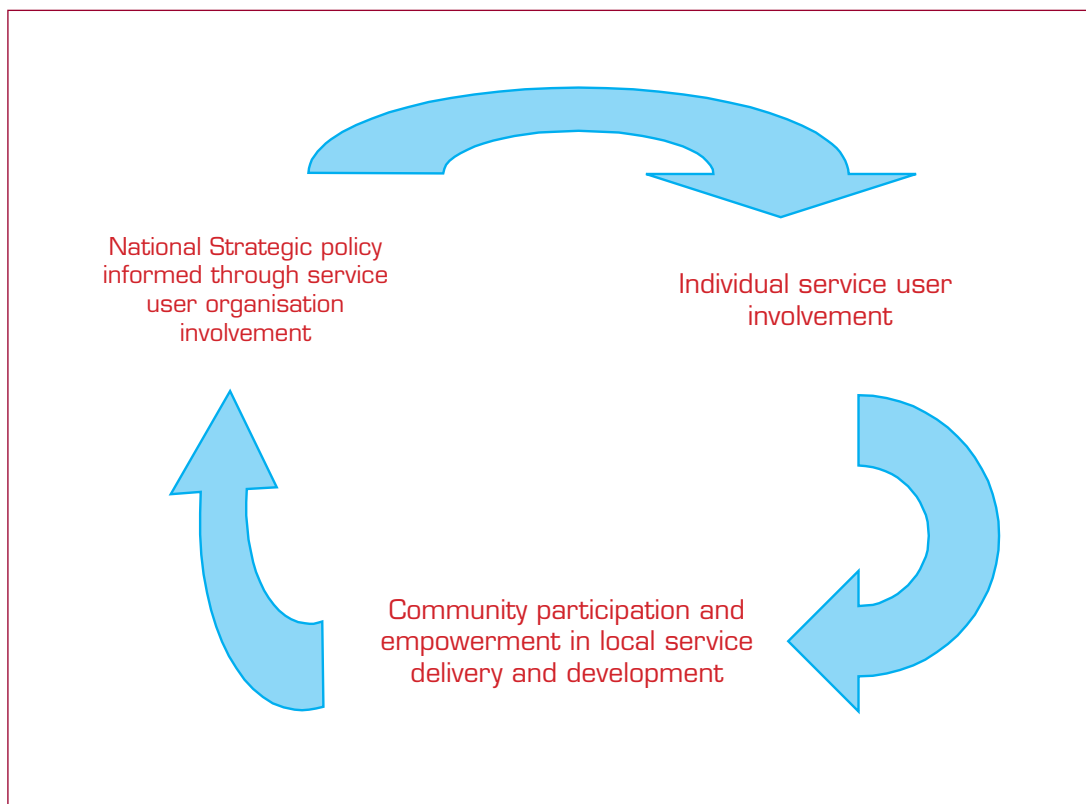
❑ National Children's Strategy (2000)

Goal 1 states that: *'Children and young people will have a voice in matters that affect their lives and their views will be given due weight in accordance with their age and maturity'*.

THE APPROACH

The approach to the strategy is based on three levels of involvement. These are categorised as follows:

- ❑ Individual service users: involvement in their own care
- ❑ Community: involvement in local service delivery and development
- ❑ National: strategic policy informed through involvement of service user organisations in partnership with health care professionals.



WHY INVOLVE SERVICE USERS?

The literature in this area suggests that promoting greater service user involvement will result in:

Individual

On a patient-clinician level:

- ☐ Better health and treatment outcomes
- ☐ Increased patient satisfaction with care
- ☐ Increased sense of dignity and self-worth
- ☐ Empowerment of the patient, leading to greater responsibility for care
- ☐ Improvements in staff and patient relationships and increased trust
- ☐ Reduced level of complaints and safer care.

Community

On a community level:

- ☐ Improved policies to address inequalities in health
- ☐ Services that respond better to the needs of the community
- ☐ More equitable and inclusive services that help to address social exclusion
- ☐ Reduced complaints and increased trust.

National

On an organisational level:

- ☐ Ensures policies and service plans are informed, relevant, appropriate and targeted
- ☐ Cost-effectiveness promoted by delivering better service outcomes
- ☐ Improved public perception and confidence in the health services
- ☐ Greater understanding of the links between health, lifestyle and the circumstances in which people live their lives.

The Department of Health and Children hold a National Consultative Forum (NCF), the HSE Regional Health Office (RHO) supports the Regional Health Forums (RHF), and a number of Expert Advisory Groups (EAGs) have also been established by the HSE. All of the input from the approaches laid out in this strategy will be fed back and linked with the proposals from the NCF, the RHF's and the EAGs into the planning, development and service evaluation processes.

GUIDING PRINCIPLES FOR SERVICE USER INVOLVEMENT

- ❑ Service users, especially those whose voices are seldom heard, have a right to be involved in the development of the health and social services that they use and this is a key element in the delivery of patient-centred care.
- ❑ Commitment of management at all levels is essential to ensure leadership and delivery on this strategy.
- ❑ Service users should be centrally involved in their own care.
- ❑ Open dialogue, trust and mutual respect are key ingredients of successful service user involvement.
- ❑ Involvement must be based on inclusion, diversity and equity – health services must engage socially excluded groups including those who are socio-economically disadvantaged, ethnic minorities and Travellers, people with disabilities, lesbian, gay, bisexual and transgendered people, children, young people and older people and users of mental health services.
- ❑ Clear channels of communication with the health service for service users are essential to effective involvement.
- ❑ Accurate and timely feedback and information to service users are key elements of successful user involvement.
- ❑ Service user involvement initiatives must be systematically evaluated and learning from service user involvement initiatives must be disseminated across the health and social services.

WHO IS THIS STRATEGY INTENDED FOR?

The principles of this strategy apply to all who use the health and social services, participate in health service programmes and/or who work with the health service as employees. This also includes carers, parents, guardians and associations of service users, and contractors and suppliers of services.

DEVELOPING THE STRATEGY

This strategy provides a unified framework for service user involvement in the health services. It builds on and incorporates much work and consultation that has been conducted in the past, including reports on patient and community involvement.

A number of meetings were held with community and patient representatives and their views remain consistent with past consultation exercises and research findings.

In addition to the meetings with community and patient representatives, staff within the HSE were invited to complete an online questionnaire capturing their views and experiences of involving the service user in the planning, design, delivery and evaluation of health services.

In developing this strategy seven key goals and the actions required to achieve them have been identified.

GOALS

The strategy consists of seven goals and a number of actions under each goal. Each action is accompanied by a lead organisation and a description of what should result from the actions.

Action: refers to the necessary steps required to achieve each of the following seven goals:

1. Commitment and leadership
2. A systematic approach to effective service user involvement
3. Patient involvement in their own care
4. A Patients Charter
5. Specific work will ensure the involvement of children, young people and socially excluded groups
6. Develop existing service user structures
7. Performance and development.

Year: within each goal there are a number of actions which will be delivered upon within the given timeframe of one to five years.

Lead: refers to the organisations identified as leading on the implementation of each of the actions outlined. During the implementation process, however, individual roles and responsibilities will also be highlighted, thus ensuring accountability.

Deliverables: refers to the proposed outcomes that should result from the actions taken throughout the five year process.

Goal 1: Commitment and leadership

Managers and Clinicians at all levels of the organisation will demonstrate their commitment to the development of service user involvement in the planning, development, delivery and evaluation of the health services.

Year	Action	Lead	Deliverables
1-5	1.1 Wide consultation will be ensured in the preparation of legislation and policy.	DoHC.	Involvement of service users in policy and legislation development.
1	1.2 Management and clinical leadership at all levels will seek to create the environment, the structures and related processes for service user involvement to work effectively.	HSE.	Part of business plans, staff appraisals and the annual service plan.
1-5	1.3 Major health service developments will involve service users when they are being planned.	HSE, service users.	Service user involvement and influence over service planning.
1-5	1.4 The effectiveness of the implementation of the strategy will be monitored and reviewed by local management with service users and be submitted to the Head of Consumer Affairs on an annual basis.	HSE, service users.	Annual report of progress presented to HSE senior management team.

Goal 2: A systematic approach to effective service user involvement

The planning of service user involvement will be carried out in a systematic manner in which strategy development and methods of involvement are based on a clear understanding of desired outcomes.

Year	Action	Lead	Deliverables
1-2	2.1 A range of mechanisms will be designed, and implemented to facilitate involvement of service users.	HSE, service users.	Guidance made available to local services and PCTs on best approaches to user involvement.
1	2.2 Build a commitment to service user involvement into the HSE annual service plan for all services.	HSE.	The HSE service plan will include commitments to service user involvement and reports on the plan will detail progress in meeting those commitments.
1-2	2.3 Build an obligation to user participation into contracts with non-HSE providers of health services.	HSE.	All contracts to contain a commitment to user involvement.

Year	Action	Lead	Deliverables
1-2	2.4 Health Service providers will build on collaboration with other organisations engaging users to prevent duplication and overlap.	HSE, HIQA, Local authorities.	Joint consultation exercises developed.
1-5	2.5 Service user involvement will be integrated within customer service initiatives and be linked to Regional Fora, EAGs, complaints and quality assurance initiatives.	HSE.	The output of different customer service initiatives will be fed into other service user involvement processes.
1	2.6 Each service area will be required to complete a service user self-assessment tool.	HSE.	Assessments completed and plans developed.
1-2	2.7 Evaluation will be planned from the beginning and costed into any service user involvement initiative.	HSE, service users.	Published evaluation reports disseminated throughout the health system.

Goal 3: Patient involvement in their own care

Models of patient care delivery must continue to develop the role of the “expert patient”, especially those with long-term illnesses, in developing their own care plan and in looking after their own condition.

Year	Action	Lead	Deliverables
1	3.1 The HSE will promote patient involvement in their own care as partners with health professionals.	HSE, service users.	Clear strategic plans developed to promote and encourage service users to get involved in their own health care.
2	3.2 The HSE will educate staff in the importance of patient involvement in their care.	HSE.	Education programmes delivered and integrated into existing staff development programmes.
2	3.3 Service provision to service users with long-term illness will be specifically targeted to promote user involvement in care.	DoHC, HSE, service users.	Chronic disease management policy and practice will explicitly commit to service user involvement in care.

Goal 4: A Patients Charter

A rolling programme setting out what patients should expect from the health services will be developed with service quality standards for service users.

Year	Action	Lead	Deliverables
1	4.1 A patients' charter will be developed, based on previous commitments to patients and models of charters from other countries.	HSE, DoHC, service users.	A patient charter, distributed widely to service users.
2	4.2 Service user involvement will be central to efforts to guarantee patient safety in healthcare settings.	HIQA, DoHC, HSE, service users.	Processes to improve patient safety will enable service users to promote the minimisation of risk.
2	4.3 Guarantees of service quality that service users can expect will be developed in an incremental fashion.	HSE, HIQA, DoHC.	Service standards published and available to service users.

Goal 5: Specific work will ensure the involvement of children, young people and socially excluded groups

All involvement work must make specific efforts to ensure the participation of children, young people and socially excluded groups.

Year	Action	Lead	Deliverables
1-5	5.1 All involvement work will prioritise the participation of socially excluded groups and those whose voices are seldom heard.	HSE, DoHC, service users.	Participation of socially excluded groups in involvement initiatives including targeted work to guarantee participation. Evaluation will assess this.
2-5	5.2 Children and young people will be engaged in the planning, design, development, delivery and evaluation of services, in accordance with the <i>Operational Policy on Children & Young People's participation</i> .	OMC, DoHC, HSE, HIQA.	Children and young people are effectively involved in health service planning. Goals, aims and objectives, targets, training needs and resources for participation are identified, with progress measured and monitored.

Goal 6: Develop existing service user structures

There are a number of existing structures for user involvement which need to be examined to ensure best practice is implemented throughout.

Year	Action	Lead	Deliverables
1	6.1 Work with PCCC in the development of community participation on primary care teams.	HSE, service users.	Increased involvement of service users in primary care teams.
1	6.2 Work with PCCC to develop the voice of older people and their families who use HSE and independently provided community care services.	HSE, HIQA, service users.	Mechanisms established for users of older people's community services to comment on the quality of care.
1	6.3 Work with hospital and network managers to develop service user involvement through panels and other methods.	HSE, Service users.	Consistent involvement of service users across the country in advising on the quality of hospital care.
1	6.4 Development of best practice guidelines for setting up and running a consumer panel.	HSE, service users.	Guidelines completed, agreed and disseminated.
1	6.5 Review consumer panels for their effectiveness in influencing service decisions and in involving socially excluded groups.	HSE, service users.	Consumer panels reviewed and recommendations made on building on best practice.
1-2	6.6 Develop approaches to promote advocacy in line with proposals from the HSE Older Persons Forum.	HSE, service users.	System of advocacy developed to support those who need it in dealing with the health services.

Goal 7: Performance and development

Learning and development programmes, aimed at meeting the development needs of service users and of health service staff, will be an integral part of HSE training programmes.

Year	Action	Lead	Deliverables
1-2	7.1 Provide training to develop the capacity of individuals and groups to engage effectively with health service providers.	HSE, service users.	Service user education programme delivered.
1-2	7.2 Develop a service user involvement module to be formally incorporated into HSE staff training. Involve training and development officers.	HSE, service users.	Inclusion in staff training for all relevant service providers.
2	7.3 Provision of support and mentoring for service users and providers on involvement.	HSE, service users.	Increased confidence of service users and providers and increased involvement.
2-5	7.4 Provide feedback to service users on the outcomes of their involvement.	HSE	Published reports of local involvement and benefits to the service.
2-5	7.5 Develop effective processes for the learning and sharing of information on good practice in service user involvement.	HSE, HIQA, service users.	International, national and local experience in service user involvement will be shared across the system.

CONCLUSIONS

Service user involvement promotes health and personal social services that are safer, more accessible and of a higher quality. This strategy proposes to further develop the many good initiatives in involving service users in a systematic way so that best practice is applied in all service settings. The service planning process will ensure that progress in involving service users is assessed and acted upon.

With the support of the Minister for Health and Children and the CEO of the HSE, service user involvement will be given significant emphasis over the next five years.

This strategy will be widely disseminated with a particular emphasis on staff representative organisations and the partnership process to promote staff support for the strategy. An implementation group with broad community and user involvement will monitor its implementation.

Progress on the implementation of this report will be evaluated by the HSE on an annual basis and fed back to the Department of Health and Children, the implementation group and the senior management team in the HSE.

For further information about the work of 'Your Service Your Say' and a review of the literature supporting this strategy document log onto:

http://www.hse.ie/portal/eng/Your_Service_Your_Say/

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