Exploring the Potential for Cross Border Hospital Services in the Irish Border Region

The role of community involvement in planning hospital services

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Exploring the Potential for Cross-border Hospital Services in the Irish Border Region

The role of community involvement in planning hospital services

INTRODUCTION

The research reported here on the role of community involvement in planning hospital services is one element of a larger study, Exploring the Potential for Cross-border Hospital Services in the Irish Border Region – the aim of which is to ‘identify how cross-border hospital services can provide mutual benefits for the people of the border region’. It follows and builds on two recent CCBS reports – Removing the Barriers: an Initial Report on the Potential for Cross-Border Co-operation in Hospital Services in Ireland (2007) and Surveying the Sickbeds: initial steps towards modelling all-island hospital accessibility (2008).

The key focus of the overall project is to support strategic cross-border co-operation for a more prosperous and sustainable region by exploring the potential for cross-border hospital services in the Irish border region. It is one of a package of research projects being undertaken by the Centre for Cross-border Studies under the title – the Ireland Northern Ireland Cross-border Cooperation Observatory INICCO – funded by the European Union INTERREG IVA Programme.

The primary output of this overall study, which is scheduled for completion in Spring 2011, will be a robust prototype modelling tool based on patient need (disregarding jurisdictional boundaries). This will be a tool for hospital planning on a border region and all-island basis that can take into account a range of variables such as the geographical distribution of patients; clinical factors for selected specialisms, and the transport network (accessibility based on travel time). Our initial priority is that it can be applied in the context of the Irish border region. It is our hope, however, that this tool could eventually be developed and applied to hospital planning on an all-island basis (and possibly adapted for other cross-border contexts) and additional areas of clinical care.

This report presents the findings of the second strand of the project which has concentrated on the impacts of the reorganisation of health services – and specifically the acute hospital sector – on
people living in the border region. The background to this study is the emergence, alongside the implementation of the reorganisation of the health services, of a number of local campaigns to oppose the downgrading of local acute hospitals. A reflection of the strength of community support for these campaigns has been the success of single issue – save our hospital – candidates in both Monaghan and Tyrone. Paudge Connolly, a psychiatric nurse and trade union activist, was elected to Dáil Éireann in 2002 for the constituency of Cavan Monaghan. (He lost his seat in the 2007 election.) Similarly, as part of the campaign against proposals to transfer services from Tyrone County Hospital (see Chapter 11), local GP Dr Kieran Deeny was elected as a single issue candidate to the Northern Ireland Assembly in 2003.

We report here on the experience and views of different groups of patients and service users and communities in trying to influence the decision making process around the reorganisation of acute hospital facilities and service delivery in the border region. This report also explores the attitudes of service users and health service professionals to the delivery of hospital services on a cross border basis. Finally, it offers a number of recommendations for embedding personal/patient and public involvement in planning for the future delivery of acute hospital and related services in the Irish border region.

**RATIONALE**

Health service authorities on both sides of the border are committed to a ‘patient-centred’/‘person-centred’ approach that includes engagement of patients, carers and other citizens in the planning and delivery of health and social care services. Within the NHS at UK-level in recent years and in Northern Ireland, there has been considerable discussion and development of policy and practice for the engagement of service users and the wider community. Similarly, in the Republic of Ireland, the commitment to partnership and consultation has been frequently reaffirmed. PPI is acknowledged to be an essential element of health service reform. In the words of one official of the Department of Health and Children,

> “Organisational change of itself does not generate reform. It is an instrument rather than an end product and needs to be seen in that light. It requires participation to fuel the co-operation required to get results.”

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In both jurisdictions, there PPI strategies accept that patient involvement should occur wherever decisions are being discussed that will affect patients’ healthcare or lives. The International Association of Patients’ Organisations has spelt out that this should include expert committees,

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regulatory processes, facilities design and development (e.g. hospital construction or refurbishment); design of education and training programmes for health professionals; research/clinical trials design; and care and treatment guidelines design.²

In the Republic, the terminology is ‘Patient and Public Involvement’. In the National Health Service, PPI is termed ‘Personal and Public Involvement,’ implying a more active engagement of service users than the patient, who is the perhaps more passive recipient of services. In the Republic, PPI policy for the health services is set out in the National Strategy for Service User Involvement in the Irish Health Service 2008 – 2013.³ In Northern Ireland, the DHSSPS Guidelines on Personal and Public Involvement in Health and Social Care provide the framework under which service user involvement is taking place. Both these documents are discussed in detail in the following chapters.

The recent history of a series of community campaigns against the removal or relocation of hospital services, however, reflects a disjuncture between theory and practice. The process of change in recent years has been an unhappy experience for many people who have participated in consultation processes; and also for many service users who have found that the promises for enhanced, more accessible and responsive services – both acute hospital and community and primary care services – have often not been delivered.

Some progress has been made and it is important to acknowledge this. Cooperation and Working Together (CAWT) an organisation established in 1992, brings together health authorities in the cross-border region to plan and manage cross-border health and social care activity. It is supported by the two Departments of Health and funded under the European Union Peace and INTERREG Programmes. The CAWT Acute Hospitals Services project is taking forward work to deliver cross-border Vascular and Urology and Ear Nose and Throat services. Previous work has focused on renal care and diabetes. There are also a number of other CAWT projects on areas such as support for older people, diabetes, eating disorders, alcohol harm reduction, genitor-urinary medicine, improved outcomes for children and families; support for people with disabilities; social inclusion and health inequalities; prevention and management of obesity; support for families and children with autism; and cross-border workforce mobility.

In Northern Ireland there has been progress in the establishment of the Patient Client Council, and in the Republic, consumer panels have been set up to develop engagement with service users. Most

recently, a consultation has been opened on the development of a Patients’ Charter for the Republic of Ireland.

In this time of public spending constraints, however, professionals working in the health services across the island are finding it increasingly difficult to commit resources to public and patient engagement. It can be difficult to look beyond the demands of day to day service delivery within one’s own institutional or jurisdictional boundaries and consider how services might be delivered more efficiently and effectively firstly, by consulting with patients and the public; and secondly, in a cross-border context. This report will, hopefully, provide an opportunity for reflection on how local communities can influence the decision-making process more effectively, and renewed impetus for developing a patient-centred approach that can be applied to a range of cross-border solutions to the acute health needs of people living in the border region.

**Methodology**

Fieldwork for this study was conducted during the last months of 2009 and January through March 2010. A series of focus groups and interviews across the border region with both service users and health service professionals focused on exploring the influence of patients and other citizens on decisions about hospital services in the border region. A list of people consulted is contained in Appendix II.

During January and February 2010, the Centre for Cross-border Studies organised a series of 17 focus groups throughout the Border region – in Castleblayney, Cavan, Derry, Dundalk, Dungannon, Enniskillen, Letterkenny, Manorhamilton, Newry and Omagh. Invitations were issued to community groups, elected representatives and other individuals living in the border region who are on the Centre for Cross-border Studies’ mailing list. In addition, the focus groups were publicly advertised through community newsletters, the local press and with the assistance of development workers and other community leaders who encouraged people in their areas to attend. While the bad winter weather and ‘consultation fatigue’ were deterrents in some areas, in total, over 150 people participated in these events. Two of the focus groups – both in Dungannon – were specifically targeted to ensure that the consultation was inclusive of people with disabilities and ethnic minority communities.

The focus groups were asked to address some basic questions about health service reforms, patient and public involvement in hospital and health service planning, and their attitudes towards using
cross-border health and hospital services. While the emphasis on each of these areas differed depending upon who was in attendance at each group, the themes covered were:

- awareness of / attitudes to the reasons for the reorganisation of hospital services;
- agreement or otherwise with the changes to service delivery;
- what experience of consultation by the health services they had as patients or as members of the wider community;
- how local communities can influence the decision-making process;
- what is good practice in carrying out consultation / community engagement on a public policy issue or programme;
- what hospital services or other health services could or should be delivered on a cross border basis; and
- the main barriers to accessing services on the other side of the border.

Detailed notes of the points made at each focus group were transcribed, compiled and analysed. The views of focus group participants can be found in the following chapters. While participation in the focus groups was by open invitation, it should be said that inevitably, those who took the trouble to attend were those who had a specific interest in – and were frequently critical of – many of the decisions that had been taken in their areas and the decision-making process in respect of hospitals and health service planning. It must also be stressed here that the research does reflect the opinions of service users and potential service users. The views of health professionals were sought in respect of the process and outcomes of public and patient participation. It was not, however, within the scope of this research to verify the perceptions of research participants or to seek clarification or a ‘balancing view’ from service providers or others. Nevertheless, the consistency of responses from people on both sides of the border, across the border region can be taken of indicative of at least a significant section of public opinion and hopefully, will help to inform the future decision making and practice.

The views of voluntary and community sector groups were also sought through a postal questionnaire sent out to 40 organisations in the autumn of 2009. These were mainly health advocacy groups such as the organisations working on behalf of specific groups of people with long term illnesses. The pressures of time and resources did not allow for personal contact with most of these groups, and as a result, the response to the questionnaire was poor (eight responses in total). Some groups did, however, offer their experiences and insights in response to an admittedly onerous series of questions, for which the author is grateful. These contributions are also incorporated in the findings and the views of some groups who had not responded to the questionnaire were obtained through interviews. Likewise, some questionnaire responses were
followed up through interviews. Approximately 25 face to face and telephone interviews were conducted with key community representatives, representatives of health advocacy organisations and health service professionals.

All participants were assured of confidentiality; no-one’s opinion would be attributed to them without explicit permission, and the findings would be compiled and presented in a way that would ensure no individual would be quoted in a way that allowed them to be identified. Therefore, although some people were happy to go ‘on the record’, none of the individuals who are quoted below are identified.

Approaches were also made to the health spokespersons from all political parties, asking them for their views on the reorganisation of the health services and their experience of the newly-established consultative structures. The response to these requests were disappointing, with only the Irish Labour Party, Sinn Fein and the SDLP providing information. As can be seen from the list of people consulted, however, councillors from a range of political parties attended focus groups in their areas – frequently providing critical viewpoints that were not always in line with those of their party leaderships.

Another element of the research process was the use of documentary evidence and interviews to produce case studies that illustrate three very different examples of engagement by health services with service users and communities in the border region. The campaign for cancer care in the North West is a campaign with cancer patients at its core. Over a number of years community activists in Donegal have mounted an effective lobby involving a wide spectrum of local politicians, community activists and the general public. The campaign is able to claim some significant achievements, most notably a decision by the two Departments of Health to cooperate in establishing a Radiotherapy Unit in Derry (planned to commence service in 2015) that will treat cancer patients from both sides of the border. The second case study outlines the work of the Cystic Fibrosis Trust (CF Trust) and the Cystic Fibrosis Association of Ireland (CFAI). Both the CF Trust and CFAI are well established voluntary organisations that involve medical and other CF experts alongside people with CF and their families. As organisations that bring both expertise and considerable financial resources to their engagement with the health services, these groups have been able to fundamental shape policies on CF care and how and where CF services are delivered. There is now a proposal being developed for a new CF unit in Altnagelvin Hospital that will treat CF patients from both sides of the border. The Hospital Campaign for the Rural West provides a text book case of how to organise an effective community campaign yet ultimately, it has not been successful. This campaign was initiated in 2001...
The role of community involvement in planning hospital services to challenge the proposal for a new acute hospital in the South West of Northern Ireland to be built in Enniskillen, supported by a new ‘local enhanced hospital’ in Omagh, replacing the Tyrone County Hospital. Having finally lost the battle to retain acute services in Omagh, campaigners’ focus shifted to saving existing services in Tyrone County Hospital; while attempting to ensure the optimum mix of services in the planned new Omagh hospital. Recently, however, the worst fears of community campaigners have been realised. With many services in the Tyrone County Hospital already removed, it appears unlikely that funding to build the new hospital in Omagh will be forthcoming.

CHAPTER OUTLINE

Chapters One and Two review the history and key policy documents of the reform of the health services in, respectively, the Republic of Ireland and Northern Ireland. These chapters also provide an outline of the reorganisation of health and social care bodies, and in particular chart the relationship, composition and roles of the new consultative structures in the two jurisdictions.

Chapters Three, Four and Five explain the concept of Patient / Personal and Public Involvement and look at how it has been defined and developed in the two jurisdictions and beyond the island. Chapter Three sets out the concept and principles of Patient and Public Involvement (PPI), drawing on work to promote health literacy and patient education and self-management. Service user engagement has different stages and requires different approaches for different groups of patients and other service users. The PPI policies and strategies of the health services on both sides of the border draw heavily on the theory and practice of service user engagement in other countries, in particular from the NHS in Britain, but also from Europe and the United States. Chapters Four and Five set out health service policy on Personal and Public Involvement (PPI) in Northern Ireland and Patient and Public Involvement (PPI) in the Republic of Ireland respectively.

Chapters Six, Seven and Eight present the findings of the fieldwork, including responses to questionnaires, interviews with health service personnel and other key stakeholders, including community campaigners and patient advocacy organisations; and the views of people who participated in the focus groups. Chapter Six focuses on communities’ experiences of health services reorganisation. Chapter Seven reports on the findings in respect of communities’ experiences of public and patient involvement. Chapter Eight deals with the specific cross-border issues raised in the course of the research.

Chapters Nine, Ten and Eleven offer in-depth case studies of three very different examples of engagement with patients and the public. The case study in Chapter Nine recounts the community
campaign for cancer services in the North West. Chapter Ten sets out the work of the Cystic Fibrosis Trust and the Cystic Fibrosis Association of Ireland. Chapter Eleven is a case study of the Hospital Campaign for the Rural West, based in Omagh.

Finally, Chapter Twelve brings together the conclusions and key messages of the research and offers a number of recommendations for consideration by the health services and governments on both sides of the border.

THANKS

As will be seen from the list in Appendix II, a diverse group of elected representatives, Council officials, community activists, people with disabilities and carers, professional and lay health service workers and other interested people from nationalist, unionist and ethnic minority communities on both sides of the border have assisted with this research. Their participation is sincerely appreciated. Thanks also to the members of the project Advisory Group, listed in Appendix III, for their valuable contribution in reading and discussing drafts of this report. Their comments and suggestions have been very helpful in structuring the report, clarifying the findings and sharpening the recommendations.
CHAPTER 1

HEALTH SERVICE REFORM IN THE REPUBLIC OF IRELAND: THE TRANSFORMATION PROGRAMME

This chapter sets out some of the key policies and decisions that have shaped the reform of the health services and in particular, the acute hospital sector, in the Republic of Ireland over the past decade. In particular, the Prospectus and the Hanly Reports discussed below set out the main recommendations for change. June 2003 saw the almost simultaneous publication of the report of the Commission on Financial Management and Control Systems in the Health Service (the Brennan Commission), and the Audit of Structures and Functions in the Health System (the Prospectus Report), and the announcement of the Health Service Reform Programme to implement recommendations of Prospectus and Brennan. Under the Reform Programme (later renamed the Transformation Programme), the Health Service Executive (HSE) replaced 11 health boards; the Department of Health and Children (DoHC) replaced the Department of Health; and most of the 43 semi-state health agencies were absorbed into DoHC.

While in contrast to Northern Ireland, the southern health service is more highly centralised, the rationale for health service reform in the Republic is similar to that driving health and social care reform in Northern Ireland. The Minister for Health and Children, Micheál Martin, T.D., set the context and rationale for the changes in Quality and Fairness, the National Health Strategy, launched in December 2001:

“Public health systems, worldwide, are experiencing unprecedented pressures in these, the early years of a new century. Those pressures include a quantum leap in available technology, matched by radically different expectations within the population. Our growing population and changing lifestyles create new and different needs.”

QUALITY AND FAIRNESS, A HEALTH SYSTEM FOR YOU

The 2001 Quality and Fairness strategy document sets in place the framework for organisational reform: “aimed at providing a responsive, adaptable health system which meets the needs of the population effectively and at affordable cost.” The Department of Health and Children was to be restructured and Health Boards focused on a programme of change management that would develop a single integrated system, rather than one in which the approaches taken in individual health board areas varied. This would require more co-ordination between health boards.

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5 Ibid.
particularly in areas of planning and service delivery. A comprehensive independent audit of the structures and functions of the health system would be undertaken to determine the scope for rationalisation of bodies and to improve governance. This audit – The Prospectus Report – was published in June 2003.

Quality and Fairness introduced the new principle of ‘people-centredness’ in addition to equity, quality and accountability as the governing principles of Irish healthcare provision. A number of actions to address access to services and health inequalities were planned. A programme of action was to be implemented to achieve National Anti-Poverty Strategy and health targets. Specific commitments were made in the areas of services for children, people with disabilities, older people and mental health.

Primary care was identified as the appropriate setting to meet 90-95 per cent of all health and personal social services needs. The capacity of primary care would be developed to meet the full range of health and personal social services needs, reducing demand for specialist services and the hospital system, particularly accident and emergency and outpatient services.”

The overall policy objective for the reform of acute hospitals is “improved access for public patients,” to be achieved through increasing capacity through further investment, strengthening efficiency and quality of services, and working in closer partnership with the private hospital sector.

A key difference with the provision of health care in Northern Ireland is that an approach that is based on development of co-operation between public and private hospitals is integral to the health strategy for the Republic. Public patients are treated in both public hospitals or by arrangements with private hospitals (e.g. under the National Treatment Purchase Fund). Likewise, private patients are treated in public hospitals, although the strategy states that private practice within public hospitals should not be at the expense of fair access for public patients. An extra 3,000 beds were to be provided over the period to 2011; all additional beds were to be designated solely for public patients.

All persons ordinarily resident in the Republic have full eligibility for hospital services and although Irish public hospitals treat private patients, the core purpose of the public system is to provide services for public patients. Government policy has been to ensure there is equitable access for public patients and, accordingly, that the proportion of private activity is appropriately controlled. Since 1991, beds in public hospitals have been categorised as public, private or non-designated. No

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6 Ibid.
private patient being admitted electively may be accommodated in a designated public bed. There is provision for some exceptions in the case of emergencies or to accommodate a public patient in a private bed where it is necessary to manage healthcare acquired infections. The new ‘Type A’ contract with hospital consultants introduced in 2009 provides an additional lever to improve access by public patients. Public hospitals may not raise a private accommodation charge where a patient is admitted under the care of a Type A consultant; nor may another consultant involved in the treatment of such a patient charge a fee.⁷

Since the publication of the White Paper on Private Health Insurance in 1999, Government policy has been to move towards charging the full economic costs for the use of public facilities and services for private patients, “while being sensitive to the need for continuing stability in the private health insurance market and wider inflation concerns.”⁸ A report by the Comptroller in 2008, however, indicated that 50% of private inpatients in 24 acute hospitals were not charged for their maintenance. In an address to the Dáil Committee of Public Accounts, the DoHC Secretary General stressed that the primary objective must be to avoid an excessive ratio of private practice within public hospitals and, subject to that being achieved, to recover whatever income is due in respect of that level of private practice.⁹

*Quality and Fairness* promised that out-patient and accident and emergency services would be “greatly improved” and that there would be a new focus on reducing waiting times. Hospitals would be required to ensure that all patients are treated without unnecessary delay. A significant change arising from the strategy was the establishment of the National Treatment Purchase Fund, to be used “for the sole purpose of purchasing treatment for public patients who have waited more than three months from their out-patient appointment, until the target of treatment within three months is met by the end of 2004.”¹⁰ The National Treatment Purchase Fund (NTPF) is an independent statutory agency established by Government with the primary aim of providing faster treatment for public patients. The NTPF is used to reduce the amount of time public patients are on hospital waiting lists for surgery by offering treatment in private hospitals throughout Ireland and where necessary, abroad. Three private hospitals in Northern Ireland are designated as Approved Treating Hospitals under the NTPF: Northwest Independent Hospital, Ballykelly; All Clear Clinic, Belfast; and

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⁷ Opening Statement by Secretary General of the Department of Health and Children at Dáil Committee of Public Accounts, 5 November 2009.
⁸ Ibid.
⁹ Ibid.
¹⁰ Quality and Fairness, op.cit.
the Hillsborough Clinic. By the end of 2009, the NTPF had treated over 165,000 patients. Its target for 2010 is to facilitate the treatment of another 30,000 patients.11

AUDIT OF STRUCTURES AND FUNCTIONS IN THE HEALTH SYSTEM (PROSPECTUS REPORT)

The Audit of Structures and Functions in the Health System (the Prospectus Report) was commissioned to implement Action 114 of the Quality and Fairness strategy. The central theme of the report is the need to consolidate fragmented structures and functions to enable the health system to deliver sustained value for money and a high quality of services for consumers. The findings of the Audit indicated the need for extensive reforms – that go beyond the structures in the health system – to encompass areas such as supporting processes and legislative change. “As well as dealing with fragmentation there is a need to modernize the current structures and functions to lay the foundations for the future development of the system.”12 It required a fundamental shift in thinking which moves from fragmentation to consolidation and integration of health service structures.

The Prospectus Report recommended the creation of two pillars within the HSE, consisting of the acute sector, overseen by the National Hospitals Office (NHO) within the HSE, and a second pillar comprising primary, community and continuing care. All publicly funded hospital services would be under the NHO. A network of four Regional Health Offices, supported by Local Health Offices, would deliver primary, continuing, community and other non-acute services.

While recognizing the considerable challenges associated with such large scale reform of the structures and functions of the health system, and that “sustained leadership from the highest levels and coordinated effort from all agencies involved will be required,” the Prospectus Report raised the spectre of dire consequences if the new model was not adopted.

“To continue in the current direction of development of structures and functions will lead to even greater fragmentation of critical functions, potentially resulting in an ever increasing dilution of the cost-effectiveness, performance and manageability of healthcare services in Ireland. ... Sustaining the current structure, or even modifying it to some degree, is inconsistent with the level of effort required to fundamentally reorganize and reform the acute sector on a national scale and prepare for the implementation of the Primary Care Strategy.”13

The Audit recommends an increased direct consumer involvement and representation throughout the system. It stresses that engaging consumers, the general public and their representatives is “not

13 Ibid.
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just a design feature of the future model,” but a necessity for acceptance and successful implementation of the proposed consolidated structure.

“International experience has shown that where the general public and consumer representatives support a proposed course of action it can lead to the creation of momentum and demand for change on a scale otherwise unachievable. The overall agenda set out in Quality and Fairness generated a broad degree of public and stakeholder support. The DoHC therefore has an opportunity with the publication of this and other reviews in the coming months to paint a compelling vision for the future of the Irish health system in terms of the reform and modernization agenda it envisages and to engage the general public in the achievement of this vision. Development and implementation of a communication and engagement programme for the general public and consumer groups in the proposed programme of structural reform is a must if the recommendation to increase consumer involvement throughout the health system is to be taken seriously.  

In addressing the need for a consultation and communication plan, the Prospectus Report makes clear, however, that it is proposing a consultation process focused on implementation, rather than defining the desired services.

A section of the report addresses what it identifies as “tensions between local representation, decision-making and the delivery of national and regional strategic objectives” that “hinder decision-making.” One of the negative effects identified is a reluctance to accept unpopular recommendations such as the location of acute services:

“Currently the health boards, the Eastern Regional Health Authority and the area health boards operate under a legislative requirement that public representation on the boards shall exceed the total number of other members on the board. This ensures that elected representatives form the board majority grouping and that all areas covered by the board are adequately represented through a formal democratic process. However, some of the negative effects of this arrangement which have been identified are:

- Predominance of local area concerns over regional interest;
- Competition between representatives on the basis of locality or professional background rather than objective need;
- Reluctance to accept evidence-based information or recommendation where it is locally unpopular; e.g. location of acute services;
- Focus on operational and short-term issues over strategic issues.”

“I think the model put in place over 30 years ago with 273 members of health boards in addition to 166 members of the Dail and 60 members of the Seanad is no longer relevant in terms of delivering healthcare on the ground. “This is not to say there shouldn’t and mustn’t be a role for public representatives and employees and consultative groups like yours in the new business model as we go forward. That is why in the bill we make statutory provision for regional fora and for the statutory Consultative Forum such as we have here today because feedback, interaction and engagement is essential if we are to get it right.”

MARY HARNEY, TD
Minister for Health & Children

14 Ibid.
15 Ibid.
The Prospectus Report refers to the 1989 Commission for Health Funding that found there was inadequate effective representation of the interests of individual patients and clients, and that decision-making was not underpinned by management information or process/system evaluation. It quotes the *Value for Money Audit of the Irish Health System* that comments:

“the political nature of the health boards constrains the delivery of VFM health services and can make a nonsense of some elements of decision-making within the regions.”

As will be seen in Chapter 8, the abolition of the health boards and the diminished role of local government representatives in the governance structures of the health service is still a very sore issue for politicians across the political spectrum.

The Prospectus Report notes that under the then-existing structures, the interests of individuals and communities are represented through the participation of elected representatives in health governance bodies. The Audit questions, however, the effectiveness of the governance structures, and “by extension, the capacity of public (and other) representation in governance.” The Audit, “highlights the need for a coherent system-wide infrastructure for stakeholder partnerships which will link stakeholders into the health system in a meaningful way.”

The Prospectus Report identified an absence of consistent focus on the ‘consumer’. Most health agency governance structures did not make provision for consumer representation. There were no direct means for local communities to find out what is being planned for their local health service and no consistent mechanisms for service users to feedback their views so as to influence planning decisions. Similarly, there was a lack of user-friendly performance information, which could help patients, prospective patients or their carers to make choices about the services they wish to use.

It recommended that structural mechanisms to increase consumer involvement in decision-making and service delivery should be developed:

“Stakeholder partnership, and in particular the participation of individuals and communities in the health system, should not be an ‘add on’ to service delivery but an essential means of engaging people as partners with service providers to improve population health. While interaction between individual consumers and health professionals is critical for the support and encouragement of individuals and families in the management of their own healthcare, a number of additional structural requirements will be necessary to support enhanced involvement and representation in processes such as service delivery.”

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17 Prospectus, *op.cit.*
By proposing mechanisms for this engagement, the consolidated structure aims to facilitate a core objective of Quality and Fairness:

“We recognize that one of the challenges for the consolidated structure is to strike an appropriate balance between the direct participation by citizens and consumers and their representation through their democratically elected representatives. A further challenge is to reconcile stakeholder influence with the influence and authority of management at all levels. It is our view that user and citizen participation can play an extremely powerful role in transforming our health system. We believe, in particular, that evidence of responsiveness and openness in this area should be seen as an important factor in assessing managerial and service unit performance under the new structures.”[21]

User and citizen participation should include:

- Health information and health service information design, delivery and provision;
- Active engagement in community health programmes;
- Feedback mechanisms, complaints procedures and advocacy programmes;
- Opportunities for input into evaluation and monitoring of services;
- Participation in needs identification and service planning at local and regional level; and
- Inputs to policy development.

The Report recommended a broader remit for the National Consultative Forum to include influencing all national health policy to foster increased stakeholder representation and participation in policy making; a structure through which stakeholders can influence national planning and decision-making on an ongoing basis. The Forum should include representatives of patients and clients of the health service, staff, employers, the regulatory bodies and specialist health agencies. It should not, however, interfere in any way with the executive role of the HSE.

In addition, the report proposes the development of an alternative channel for democratic input at regional level, focused on the delivery of national priorities. Improvement of the decision-to-action chain requires

“effective arrangements for direct public representative input at appropriate levels without unduly limiting the ability and responsibility of managers to act in a speedy and responsive manner.”

The Report suggests that democratic input is best represented at regional level through twice yearly meetings between Oireachtas members in their respective regions with the Regional Health Office Director and staff, together with other members of the HSE as appropriate. This would complement and reinforce the Joint Oireachtas Committee on Health and Children.

This framework should not, however, take the place or reduce the role of other consultative processes at regional level such as the Advisory Panels/Regional Coordinating Committees for learning disability services and physical and sensory disability services. Genuine partnership “must

21 Ibid.
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go well beyond consultation processes to directly engage citizens and their representatives in needs identification, planning and decision-making at appropriate levels.”\textsuperscript{22} The Report proposes that a central responsibility of the Local Health Offices should be promoting citizen and community participation through consumer panels and other mechanisms.

Specific mention is given to the importance and participation process within the acute sector. The new hospital accreditation programme – requiring that service plans and performance management systems give “real weight” to consultation and participation – “will be an important driver for responsiveness and engagement between hospitals and their patients.” The authors of the report did not, however, consider it appropriate to prescribe set structures at local level to promote user involvement and stakeholder representation, “but feel it is more effective to build on guiding principles and practices already developed which can be reflected in the varying needs of individual communities.”\textsuperscript{23}

**THE NATIONAL TASK FORCE ON MEDICAL STAFFING (THE HANLY REPORT)**

The National Task Force on Medical Staffing was established in February 2002 by the Minister for Health and Children. Its purpose was to devise an implementation plan for reducing substantially the average working hours of Non Consultant Hospital Doctors (NCHDs) to meet the requirements of the *European Working Time Directive* (EWTD),\textsuperscript{24} to plan for the implementation of a consultant-provided service, and to address the medical education and training needs associated with the EWTD and the move to a consultant-provided service. The Task Force’s terms of reference charged it with “devising, costing and promoting implementation of a new model of hospital service delivery based on appropriately trained doctors providing patients with the highest quality service, using available resources as equitably, efficiently and effectively as possible.”

In June 2003, the Task Force delivered a set of wide-ranging proposals and concluded that a consultant-provided service is the only viable means of providing safe high quality patient care while reducing the working hours of NCHDs and reorganizing medical education and training appropriately. Critically, the proposals for reducing the working hours of NCHDs, together with the case for a consultant-provided service and changes to medical education and training, have

\textsuperscript{22} Ibid.
\textsuperscript{23} Ibid.
\textsuperscript{24} The EWTD requires that, by 1 August 2004, NCHDs must no longer work for more than an average of 58 hours per week on the hospital site. By this date they cannot be required to work for more than 13 hours per day on-site, and certain other rules regarding minimum rest and break periods must also be put in place. By 1 August 2007, NCHDs cannot be required to work more than an average of 56 hours per week on-site. This limit to be reduced to an average of 48 hours by 1 August 2009.
significant consequences for the organisation of acute hospital services. Flagging what would be some of the most controversial outcomes of the report, the Minister notes in his foreword that

“It points out that capacity, workload and a critical volume of patients influence where hospital services can be safely provided, and concludes that hospital services must be organised to maximise the strengths of both large and smaller hospitals.”

Thus, the Task Force calculated that the “absolute minimum level of emergency cover” required at least five doctors to be employed to allow one to be present on the hospital site, 24 hours a day, 7 days a week. All hospitals providing emergency care must have acute medicine, surgery and anaesthesia on-site. The report argues that hospitals without sufficient volumes of patients and activity cannot sustain large numbers of consultants. Sufficient critical mass will be required to achieve expertise across a range of specialties and to provide satisfactory medical education and training.

The report’s findings were not entirely driven by the European Working Time Directive. The Task Force also argued strongly that best results in treatment are achieved by multi-disciplinary specialist teams, requiring in turn high volumes of activity and access to appropriate diagnostic and treatment facilities. Cost was also an important consideration in planning the deployment of acute hospital services. The cost of providing a full spectrum of services throughout the existing acute hospital system would be “unsustainable in terms of maintaining adequate standards of medical practice and fiscal prudence.”

The key messages contained in the Task Force Report include:

- acute hospital services should be delivered by an integrated network of hospitals, currently serving populations of about 350,000. A small number of more specialist services should continue to be provided on a supra-regional or national basis;
- Primary care services, including community care, should be an integral part of this network;
- The organisation and staffing of acute hospitals should be restructured to allow for the safe provision of emergency and elective care (requiring significant changes to service provision);
- Health professionals should work as part of a multi-disciplinary team, centred on delivering quality patient care over the full 24-hour period within an integrated network of hospitals;
- The management structure of acute hospitals should be strengthened to establish clear lines of accountability and ensure appropriate availability in the context of a 24-hour service; and
- Service integration must be ensured, in particular with primary care, community care and long term/continuing care services.

The Task Force estimated that hospitals require a certain minimum catchment population in order to provide the spectrum of acute care needed to deal with emergency and acute patients. Ideally

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hospitals providing the full range of regional services should have a catchment population of 350,000 to 500,000.

“Physical distance and actual travelling time will be important factors. The defined catchment population must generate sufficient workload to maintain safe services and support staff while meeting the requirements of the ETWD.”

The Task Force proposal for restructuring of hospital services in a national context avoids addressing issues of sharing services across the border. There is only one reference in the report to North/South cooperation. The report notes that Recommendation 36 of the report on Obstacles to Mobility published in November 2001 by the North/South Ministerial Council deals with the recognition of qualifications in the medical profession. The Council recommended that the North/South training rotations such as those developed in neurosurgery and paediatric surgery should be fostered and developed by the relevant training and other bodies and that the barriers to mutual recognition of qualifications be removed. The Task Force recommends that the relevant authorities, North and South, should discuss the further development of training programmes which would accommodate rotation between the two jurisdictions.

REPORT OF THE COMMISSION ON FINANCIAL MANAGEMENT AND CONTROL SYSTEMS IN THE HEALTH SERVICE (THE BRENNAN COMMISSION).

The Brennan Commission carried out a detailed examination and review of the financial management and control systems in the Irish health service. In January 2003, they reported that they had found problems within the existing system, including:

- The absence of any organization responsible for managing the health service as a unified national system;
- Systems not designed to develop cost consciousness among those who make decisions to commit resources and provide no incentives to manage costs effectively;
- Insufficient evaluation and analysis of existing programmes and related expenditure and
- Inadequate investment in information systems and management development.

Recognising that there were increasing demands on the health system, the Commission states that “to continue to increase the resources at the rates achieved in recent years is unsustainable; hence much greater effectiveness and efficiency will be required.” Despite a substantial increase in health spending, the Commission heard evidence that there were 3,000 additional acute beds and 1,000 additional medical consultants required to meet demand and that some of the most expensive acute beds were being used inappropriately. There was under-provision and under-utilisation of day surgery and resources were being wasted. The report contains several recommendations about the

26 Ibid.
The role of community involvement in planning hospital services

public/private mix in public hospitals. Other sections of the report address non-hospital programmes, general medical services and community drug schemes, the Medical Card scheme, employment and pay issues, information systems and auditing and reporting procedures.

**HEALTH SERVICES REFORM PROGRAMME**

June 2003 saw the announcement of the Health Services Reform Programme to implement recommendations of the Prospectus and Brennan Reports. This Programme saw the Health Service Executive replace eleven health boards; the Department of Health and Children replaced the Department of Health; and most of the 43 semi-state health agencies were absorbed into the DoHC.

The Health Act (2004) legislated for the establishment of National Consultative Forum, Regional Health Fora and Advisory Panels. Section 43(1) of the Health Act 2004 states: “The (HSE) Executive may take such steps as it considers appropriate to consult with local communities or other groups about health and personal social services.”

In January 2005, the Health Service Executive was established, incorporating the National Hospital Office. The National Treatment Purchase Fund commenced operation and in July the Minister for Health and Children, Mary Harney, issued a policy direction on co-location of private hospitals on the sites of public hospitals and the transfer of private activity to those private hospitals. The Health Act of 2006 provides for the extension of private hospital facilities.

**HSE TRANSFORMATION PROGRAMME 2007-2010**

At the end of 2006, the HSE published its Transformation Programme 2007-2010, setting out how the momentum for change in the health service would be driven forward. In preparing the Transformation Programme, HSE staff were extensively consulted; although it is not clear to what extent there was any public consultation process.

In his introduction to the document, HSE Chief Executive, Professor Brendan Drumm explains the changed terminology – designating the programme one of transformation, rather than reform:

> “I deliberately use the term transformation, as many have suggested to me that ‘reform’ has become, within the HSE, too closely associated with organisational and administrative change. Our transformation must extend much further and touch almost every aspect of our work; the way we work, the way we relate to each other, our culture and our ambitions.”

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30 Ibid.
There are six Transformation Priorities, reflecting the strategic direction set out in the HSE’s Corporate Plan 2006-2008. The HSE annual Service Plans incorporate projects from the Transformation Priorities. The Table below has been taken directly from the Transformation Programme document:

<table>
<thead>
<tr>
<th>Where we are today</th>
<th>Our Six Transformation Priorities</th>
<th>Where we will be by 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many services are fragmented, disjointed and difficult to navigate.</td>
<td>Develop integrated services across all stages of the care journey.</td>
<td>My journey into, through and out of the health and social care system will be easy to navigate.</td>
</tr>
<tr>
<td>There is inappropriate use and over reliance on acute hospital services which often creates inconvenience for patients and clients and unnecessarily overloads our hospitals.</td>
<td>Configure Primary, Community and Continuing Care services so that they deliver optimal and cost effective results.</td>
<td>I will be able to easily access a broad spectrum of care services through my local primary care team, i.e. conveniently and close to my home.</td>
</tr>
<tr>
<td>Accessing high quality acute hospital care can be difficult.</td>
<td>Configure hospital services to deliver optimal and cost effective results.</td>
<td>I will be able to easily and rapidly access high quality acute care through designated centres of excellence.</td>
</tr>
<tr>
<td>Inadequate and fragmented services for chronic illness are leading to unnecessary hospital admissions and inconvenience for clients.</td>
<td>Implement a model for the prevention and management of chronic illness.</td>
<td>I can expect high quality care and results from comprehensive and integrated care programmes which will involve my community and designated care centres.</td>
</tr>
<tr>
<td>There is limited use of performance measurement as a basis for managing and improving care delivery.</td>
<td>Implement standards based performance measurement and management throughout the HSE.</td>
<td>I will be confident that I receive high quality care measured against transparent standards.</td>
</tr>
<tr>
<td>The work of staff can be frustrated by system and process constraints.</td>
<td>Ensure all staff engage in transforming health and social care in Ireland.</td>
<td>My work will have a direct impact in delivering high quality care and contribute to the overall transformation of health and social services.</td>
</tr>
</tbody>
</table>

As will be seen by the comments of research participants in the following chapters, there is substantial dissatisfaction with the implementation of the Transformation Programme among health professionals and the wider community. The Irish College of General Practitioners, for example, issued a statement in July 2009, commenting that the reconfiguration of health services has led to a considerable degree of debate and disquiet in many circles, and that there had been little if any meaningful engagement with general practice concerning the implications or practical implementation of the changes. While supporting in principle the Transformation Programme’s drive to shift delivery of services to patients away from the hospital setting, they expressed concern that the withdrawal or transfer of acute services from some hospital facilities will have a negative impact on patient safety. There had been, the GPs stated, “virtually no transfer of resources from the hospital sector to primary care to match the enhanced demand for various services now provided in
a community setting.” As will be seen in Chapter 6, these concerns have been reflected in the bitter experiences of service users on both sides of the border.

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The role of community involvement in planning hospital services

**Republic of Ireland Structures for Stakeholder Engagement with the Health & Social Care Services**

**General Public**
- **Complaints**
- **Consultation**
- **Collaboration in Policy and Decision-making**

**Health / Hospital Campaigning Groups**
**Elected Representatives**
**Patient / Service User Advocacy Groups**
**Community & Voluntary Organisations**
**Trade Unions & Health Professional Bodies**

**Health Services Executive**
HSE is responsible for delivery of all health and social care services

**Joint Oireachtas Committee on Health and Children**
Public representatives ongoing oversight of the health services

**National Health Consultative Forum**
Convened annually by Minister 350 members representing senior public and private hospital management, a wide range of health professionals, academic institutions, voluntary and community groups, patients and user groups, professional representative bodies, trade unions and relevant Government Departments.

**HSE Consumer Panels**
Encourages service user involvement at frontline level.

**Regional Health Fora (4)**
Up to 40 members, representatives of the city and county councils in their functional area. Health Fora make representations to HSE on range and operation of HPS services in their areas.

**Expert Advisory Groups**
20 members appointed on a personal basis (i.e. not representing their organisations) by HSE CEO – health professionals, clinical experts, patients, clients and service users.

**Your Service Your Say Website**
Provides practical information for anyone wishing to make a comment, compliment or complaint about health services received in Ireland and for those working to involve people in the design, development and delivery of health and social services.

**Department of Health and Children**
Strategic and Policy issues
Accountability through the Minister to Dail Eireann

**Ombudsman**
Examines complaints about the administrative actions of DoHC and the HSE
CHAPTER 2:

HEALTH SERVICE REFORM IN NORTHERN IRELAND: THE MODERNISATION AND IMPROVEMENT PROGRAMME

In Northern Ireland, the planning of hospital services and the restructuring of consultation mechanisms and processes have been driven by the overlapping and intersecting of the Review of Public Administration (RPA) and the Department of Health and Social Services and Public Safety’s (DHSSPS) Modernisation agenda.

The Review of Public Administration (RPA) was launched by the Northern Ireland Executive in June 2002. While the implementation of the Review’s proposals for the amalgamation of local authorities has still not been completed, the streamlining and rationalisation of public bodies continued throughout the suspensions of the Northern Ireland Assembly. Five new integrated Health and Social Care Trusts were established in April 2007. The Local Health and Social Care Groups (LHSCGs) were stood down and seven Local Commissioning Groups (LCGs) established that same month. A number of other new health and social care bodies have since been established by the Health and Social Care (Reform) Bill, passed by the Northern Ireland Assembly in 2009.

The restructuring of acute hospital services in Northern Ireland has taken place under the auspices of the strategy document, Developing Better Services. Modernising Hospitals and Reforming Structures. In turn, developments in Northern Ireland are taking place within the context of the UK-level Reform Plan for the National Health Service (NHS) that commenced in 2000. The reform of the acute hospital sector is just one strand of a much wider reform agenda involving a new approach to primary care, a review of community care, and a ‘population health’ approach. Together, these form the main components of “a unified and coherent approach to improving health and social services” that comprise A Healthier Future, the 20-year regional strategy for health and social services published in 2003. Thus, it is impossible to consider the reform of acute services in isolation from the wider reconfiguration of health and social care services, because these are all interdependent strands of a comprehensive strategic approach.

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32 NIA Bill 21/07 Health and Social Care (Reform) Bill.
33 Developing Better Services, Modernising Hospitals and Reforming Structures, Department of Health, Social Services and Public Safety, Belfast, 2002.
This chapter does, however, set out some of the key policies and decisions that have shaped the acute sector over the past decade. Subsequent chapters reflect how these in turn have been experienced within communities and how communities have responded to them.

**Acute Hospitals Review Group – The Hayes Report**

The consultation period for *Developing Better Services* took place between June and October 2002, coinciding with the report of the Acute Hospitals Review Group, also known as the Hayes Report. The Hayes Report was commissioned by the then Minister for Health Social Services and Public Safety, Bairbre de Brun, in June 2001, in the context of the UK-level Reform Plan for the National Health Service (NHS).

The report of the Acute Hospitals Review Group – chaired by Senator Maurice Hayes, a former Permanent Secretary to the Northern Ireland Department of Health and Social Services – contained a number of radical and controversial recommendations for the reorganisation of the acute hospital sector. Its proposals reflect the shift in policy and clinical practice from the delivery of services in acute hospitals to delivery of treatment closer to patients’ homes – in health centres or new local hospitals. Resources were to be reallocated to reflect this restructuring and service delivery would be improved. However, it was also envisaged that some acute sector resources would need to be increased. The report recommended, for example, a doubling of the number of hospital consultants alongside a 25% increase in the number of GPs; and suggested a rotation system for doctors between the acute and local hospitals.

The Hayes Report also recommended the rationalisation of hospital administration by replacing the four health boards with one ‘strategic commissioning authority’ and merging the 18 hospital trusts into three ‘integrated health systems’, or ‘super trusts’. A rationalisation of health service administration bodies was implemented with the passage in 2009 of the Health and Social Care (Reform) Bill. The four Health and Social Services Boards have been replaced with a single Regional Health and Social Care Board and there has been a merging of a number of Trusts.

The Hayes Report’s proposals for the restructuring of the acute hospital sector were, and remain, highly controversial. The key recommendations were:

- eight existing hospitals would retain acute hospital status: Belfast City Hospital; the Royal Victoria (Belfast); the Ulster Hospital (Dundonald); Antrim Area Hospital; Altnagelvin Hospital (Derry); Craigavon Hospital; Causeway Hospital (Coleraine) and Daisy Hill Hospital (Newry);

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• a new acute hospital would be built in County Fermanagh;
• accident and emergency services to be removed from five existing smaller acute hospitals: the Mater in Belfast; Omagh; the Lagan Valley; and Whiteabbey; and the closure of acute services at the South Tyrone hospital would be permanent;
• Downe and Downpatrick hospitals would lose their maternity services.

As will be seen in Chapter 4, there has been widespread opposition in communities that have lost their local A&E and maternity services. The Omagh community’s response to the proposal to locate a new acute hospital in Enniskillen rather than Omagh, the downgrading of services at the Tyrone County hospital and a subsequent proposal for a new ‘local enhanced hospital’ in Omagh are the subject of Chapter 9.

Responding to a requirement in the Review Group’s terms of reference, the Hayes Report devotes an entire chapter to the opportunities for increased cross-border co-operation in the delivery of hospital services. The only basis for such a development, the report stated, should be the “welfare and convenience of patients.” Patients should be helped to access treatment at the most convenient locations. Cross-border co-operation offered the possibility of securing local economies of scale and a critical mass: securing sustainable rota arrangements, and more efficient use of equipment. It should also be possible to arrange for the location and disposition of ambulances so as to secure the maximum degree of emergency cover and to cut down on travelling. The sense of isolation felt by rural communities could be reduced.”

The report reviewed examples of existing co-operation, mainly in the areas of training and professional development; purchasing or commissioning services from the other jurisdiction; joint service development; and research and policy work. The report noted that most joint service development had been under the aegis of Co-operation and Working Together (CAWT) and that the overall level of cross-border take-up of hospital services was quite low, with clear scope for development.

While commenting that attitudes to health care co-operation on both sides of the border are “generally very positive”, the report referred to the obstacles that had been previously identified in a report published by the Centre for Cross Border Studies. These were policy differences, funding issues (including transaction costs), different methods of remunerating doctors, reciprocation, public acceptance, professional accreditation and insurance. While acknowledging that these constraints

36 Ibid., p. 107.
37 Ibid., p 107
are “quite significant”, the *Hayes Report* argued that “they should not be viewed as insurmountable barriers but as challenges and opportunities to be overcome.”

The Review Group’s report outlined a range of opportunities for future cross-border co-operation at both local and all-Ireland levels:

- Enhanced co-operation in the vicinity of the border. Encouragement and assistance to CAWT projects;
- Inclusion of a cross-border element in all service reviews in both jurisdictions with an immediate assessment of enhancing co-operation in emergency services close to the border and alignment of emergency and disaster planning;
- Examination of the feasibility of a joint air ambulance or helicopter ambulance service;
- Provision of services that could be sustained for the combined island population that could not be provided economically for populations of 3.5 or 1.7 million – such as treatments for rare and complex conditions in children, transplant services, paediatric cardiac surgery and treatment of rare cancers.

The report recommended a thorough assessment of the potential for co-operation and stressed the need to build on the co-operation that had taken place under the terms of the Belfast Agreement. Efforts should be made to resolve ‘barrier issues’ and economic research should be commissioned on the potential for economies of scale both locally and on an all-Ireland basis.

**Developing Better Services: Modernising Hospitals and Reforming Structures**

*Developing Better Services* was published for consultation in June 2002; the Acute Hospital Review Report was published the same month. In her foreword to *Developing Better Services*, the Minister for Health, Social Services and Public Safety, Bairbre de Brun, acknowledged that the Hayes review was “set up against a background of many years of under-funding of health services, which has undermined and weakened their capacity to deliver the quality of service demanded of a modern hospital system.”

A major modernisation of the acute hospital system was “long overdue” and while substantial additional investment was required, “extra spending alone is not the answer.” The Minister reassured readers that the proposals are not about reducing acute services but aimed to ensure that “everyone will have prompt access to high quality acute care, delivered close to their homes wherever possible.” The Minister promised to consult as widely as possible on the options paper for structural change, while taking account of the emerging principles/criteria from the Review of Public Administration.

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41 Ibid.
Changes in clinical practice are at the core of the proposals, based on the trend for ever increasing specialisation by health professionals, supported by evidence that outcomes are better where treatments and care are delivered by specialist, multi-disciplinary, teams. These teams must be large enough to work effectively. The teams need to care for sufficient numbers of patients to make best use of their skills, and to maintain those skills throughout a lifetime of practice. It is increasingly difficult for smaller hospitals to deliver services to modern standards: they do not provide sufficient opportunity for health professionals to develop necessary skills and experience, are losing their training status and having difficulties in attracting and retaining staff. “Our pattern of hospitals is based on an outmoded approach to acute care.” Hospitals must change to make best use of new technologies and support new working practices.

However, while making the case for further concentration of acute services for patients with more complex conditions, the document affirms that this concentration must be balanced against the accessibility of services for patients and their families. It notes that developments in medicine and medical technology are also opening up the way for smaller hospitals to provide high quality diagnostic services and a wider range of operations and medical procedures, often on an outpatient or day-case basis.

The document insisted that none of the existing acute hospitals would close – rather they would be adapted to support the new pattern of provision. It promises that the “vast majority” of people would be within 45 minutes – and everyone would normally be within one hour – of emergency care and consultant-led maternity services. In the future, acute services would be more strongly patient-focused and organised around population groupings rather than facilities.

*Developing Better Services* proposed the establishment of a number of new local hospitals that would network with acute hospitals and local primary and community care to provide services that do not need to be delivered in a large acute hospital:

- Mid-Ulster (Magherafelt);
- South Tyrone (Dungannon);
- Whiteabbey;
- Downe (Downpatrick);
- Lagan Valley (Lisburn);
- Mater (Belfast); and
- Tyrone County (Omagh).

It was proposed that Downe Hospital and Tyrone County Hospital should be ‘enhanced local hospitals’. As well as acting as a local hospital, Lagan Valley Hospital would become a specialist

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42 Ibid.
centre for planned (elective) surgery. A second protected elective centre would be developed in a local hospital west of the Bann.

There would be nine acute hospitals:
- the Royal Group (Belfast) – Royal Victoria, Royal Maternity and Royal Children’s Hospitals;
- Altnagelvin (Derry);
- Antrim;
- Belfast City;
- Causeway (Coleraine);
- Craigavon; and
- Daisy Hill (Newry).

Additionally, the Ulster (Dundonald), and a new hospital at Enniskillen would support a broad range of acute services, including consultant-led maternity in-patient services. The development of midwife-led maternity units would be encouraged alongside consultant-led units, and two stand-alone midwife-led units would also be piloted. The document acknowledged the need for “a significant increase in staffing” to deliver these proposals.

The document also stressed: “It is essential that the organisational structures support a partnership approach between all parts of the Health and Personal Social Services (HPSS) and reinforce the effective and efficient delivery of services.” Its proposals for the restructuring of HPSS bodies were subsequently implemented in the Health and Social Care Reform Bill in 2009:

The key provisions contained in the Bill were:
- a single Regional Health and Social Care Board to replace the existing four Health and Social Services Boards that will focus on commissioning, resource management and performance management and improvement;
- a Regional Agency for Public Health and Social Well-being that would subsume and build on the work of the Health Promotion Agency but would have much wider responsibility for health protection, health improvement and development to address existing health inequalities and public health issues for all the people of Northern Ireland;
- a Regional Support Services Organisation to provide a range of support functions for the whole of health and social care that would also subsume the majority of services currently provided by the Central Services Agency; and
- a single Patient and Client Council to replace the current Health and Social Services Councils with five local offices operating in the same geographical areas as the existing Trusts, to provide a strong voice for patients, clients and carers.

Of particular relevance to this study, the HSC (Reform) Bill places a new statutory requirement on all HSC bodies to consult and involve people.

*Developing Better Services* committed the Department and the NI Executive to developing opportunities for co-operation between the North and South on a range of healthcare issues “to their full potential.” A section of the document entitled, *Working in Partnership with the South* made reference to the Hayes review recommendation that collaborative working with health services in

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the South should be encouraged: “This is fully in keeping with work already agreed and in progress.”

One example of collaborative North South work was the establishment of the North South Regional Hospital Services Group (NSRHSG). Set up under the auspices of the North South Ministerial Council (NSMC) in 2000 (See Appendix IV),

Co-operation in the area of Accident and Emergency Services covers acute hospital services generally as well as Accident and Emergency Departments. Cross-border co-operation, covering hospital services in the border areas, and wider co-operation on a regional basis, covering specialist services which are, or could be only viable where delivered on an all-island basis have been identified as two broad areas for co-operation. A North/South Regional Hospital Services Group (NSRHSG) has been established to consider the opportunities for developing partnerships covering the wider regional services."

At that time the NSMC requested the North/South Regional Hospital Services Group to consider the report of the Acute Hospitals Review Group in the North, whose remit included the scope for co-operation in the provision of services with hospitals in the South, noting that the Hayes report “suggests that there is considerable potential to develop existing cross-border initiatives for the benefit of patients.”

Other examples of cross-border co-operation mentioned in Developing Better Services include:

- A number of local cross-border initiatives being developed by CAWT, including exploring opportunities for building greater collaboration between hospitals in border areas; and
- Collaborative work by the two health departments on A&E services, planning for major emergencies, co-operation on high technology equipment, cancer research and health promotion – e.g. commissioning a feasibility study of an all-island Helicopter Emergency Medical Service and a joint contract for the disposal of clinical waste.

“Such collaboration is in the best interests of patients North and South, and it is important that the full potential of such co-operation is realised.”

Following a period of public consultation, the Minister for Health announced in February 2003 the replacement of fifteen acute hospitals by nine acute hospitals – including a new hospital in Enniskillen – and seven local hospitals. In addition, regional specialties within the Eastern Board area would be relocated and consolidated. Fracture inpatient services would be delivered at Antrim and Craigavon and there would be consultant-led maternity services at the nine acute hospitals. Protected elective capacity was to be developed at Lagan Valley, South Tyrone, Enniskillen and elsewhere. Increasing availability and access to day surgery was to be priority.

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45 Ibid.
46 Developing Better Services Modernising Hospitals and Reforming Structures, op.cit.
THE APPLEBY REVIEW

The Independent Review of Health and Social Care Services in Northern Ireland\(^\text{47}\) by Professor John Appleby, published in July 2005, reviewed the likely future resource requirements of the health and social care (HSC) sector in Northern Ireland and considered the scope for HSC resources to be used more effectively. A particular area of concern was the lack of progress on waiting times despite significant additional resources. Professor John Appleby reported that the short-term and uncertain basis on which funds had often been allocated had hampered the strategic planning of services. Around three-fifths of the additional funding has been absorbed by increases in staff costs – most of which was absorbed by higher wages and salaries rather than in recruitment of more frontline staff. An estimated quarter of the additional funds had been spent on service delivery improvements. Looking forward, it anticipated that a much smaller share of future funds would be available for service improvements.

The Appleby Review concluded that there was a 7% higher level of need in Northern Ireland compared to England. Thus the Review’s expenditure projections for the Northern Ireland health and social care sector suggested that a significant increase in resources was required in the coming years, but with slower growth after 2012. The Review also considered the need to ensure that resources available to the health and social care sector are used as efficiently as possible. A range of efficiency and productivity indicators were taken into account. Overall, health status in Northern Ireland was found to be slightly worse than in the rest of the UK. As a result, hospital activity tends to be higher than in England. The report notes however, that “there appeared to be a number of areas where health care utilisation was substantially higher than health status would suggest, such as accident and emergency attendances, which are almost a third higher than in England.”\(^\text{48}\) Appleby recommended further investigation of reasons for very high A&E use and ways to reduce inappropriate use.

Appleby also recommended detailed analysis into hospital activity trends as part of a broader analysis of the dynamics of waiting times and lists. It found that the most obvious indication of poor performance has been the large number of people on waiting lists and waiting times for treatment. While there had been some limited progress in terms of inpatient waits, there continued to be an upward trend in the number of people waiting for outpatient appointments. Very few targets had been met; the target-setting process had been erratic with few apparent long-term goals and


\(^{48}\)Ibid.
intermediate milestones; and there were noticeable gaps in target setting, such as outpatients. Overall, the report concluded that excessive waiting is not inevitable, nor an intractable problem. It recommended a multi-pronged long term strategy to reducing waiting times, including long term targets (with milestones) backed by strong incentives.

The Review considered a range of performance indicators to monitor the extent to which services were being delivered effectively. Overall, the picture that emerged was one of fewer outputs achieved per given level of input than in England, although some aspects of poor performance were shared with Scotland and Wales. The report acknowledged that in addition to simple inefficiency, there were a number of potential explanations for these disparities – such as better quality of provision, maintaining hospitals in rural locations, and higher costs of delivering services in deprived areas.

Although there was a perception that Northern Ireland was furthest behind England in the provision of social services, the evidence examined by Appleby did not necessarily support this. Appleby did find however, that “Northern Ireland still appears to be many years behind in England in terms of achieving the policy aim of providing social services in a community rather than hospital environment wherever possible.”

Professor Appleby suggested that the Review of Public Administration’s recommendations for reconfiguring health and social care organisations – in particular, the creation of new Health and Personal Social Services agencies – was in effect reinvention of the English NHS model prior to 1990. It was not clear how performance improvements would actually be achieved or how providers would be held to account for their performance. Professor Appleby commented,

“Overall, from the point of view of performance management, it is hard to see any difference between the RPA’s recommendations and the way the current system operates.”

The report concluded that:

- the Northern Ireland health and social care sector will come under increasing pressure to replicate the improvements in health outcomes envisaged for the UK but without a significant increase in funding;
- a significant underlying reason for current problems with the Northern Ireland health and social care sector relate to the use of resources rather than the amount of resources available; and
- there is considerable scope for improvement in the provision of services recognising that more efficient delivery means more resources available for service improvements.

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49 Ibid.
50 Ibid.
As noted above, the reform of the acute hospital sector is just one strand of a much wider reform agenda set out in *A Healthier Future*, the 20-year regional strategy for health and social services published in 2003. *A Healthier Future* presents a vision of how health and social services will develop in Northern Ireland giving priority to improving the physical and mental health and social wellbeing of the people of Northern Ireland. The government’s commitment to investing for health – promoting health and wellbeing and reducing health inequalities – was reaffirmed. At the centre of the Strategy was a recognition that involving service users and communities contributes to improved health and well being outcomes and more effective and efficient services.

A key policy aim was to fully involve, and support the development of, people and caring communities who will: actively promote health and wellbeing; have a central role in managing chronic conditions; and be partners in designing and managing health and social services.

A key element of the Strategy is the determination to break down the barriers between services delivered in communities (primary and community based care) and services delivered in hospitals (secondary, acute or tertiary care). The document promised a focus on delivering effective community-based services with a special focus on managing chronic conditions and the problems associated with disadvantage. Services would be provided against clear standards of access.

"If we are to improve health and wellbeing, we will need to involve people and communities and help them to take the action they need to prevent illness and harm. Individuals feel better about themselves, and their care and treatment, when they have been listened to. They are also more likely to complete their treatment and care programmes if they feel in control.

"Working with individuals and communities is the best way of making sure we provide a service where the person is at the centre of the process. Approaching issues from the service users’ view will often result in more imaginative solutions. Involving the public effectively will also help to create a better understanding of the complexities involved in managing our services.

In 20 years people and communities will be fully involved in, and actively influence, decision-making at all levels. Our services will truly centre on the person, family and community. People will want to take control of their own care and will take an active role in promoting the improvement of their own health and wellbeing and that of their communities. Caring communities will feel that they own their services and will play a central role in designing and managing them. Individuals will use their services responsibly, contributing to their overall efficiency by doing so."

The role of community involvement in planning hospital services

The Strategy foresaw the development of multi-skilled teams based mainly in communities, supported by, and including, people working in hospitals. The role of hospitals in supporting community-based services and in providing services which cannot be provided appropriately in the community was acknowledged; and a commitment made to improvement of services.

A Healthier Future, included a brief section on Cross-border Co-operation, which we reprint here in its entirety:

“We will promote the most effective use of resources through increased working across borders on the island of Ireland, throughout the UK and across Europe. Globalisation, increased international travel and the increased use and sophistication of information and communications technology (e.g. in the form of telemedicine or telemonitoring) all represent important opportunities for us to use our health and social care resources more effectively through partnership working across-borders.

“Existing initiatives on the island of Ireland demonstrate what is possible by sharing resources and expertise across boundaries. Specifically the cross-border health and social care initiative, Co-operation and Working Together (CAWT), was established in 1992 by the four Health Boards located along the border between Northern Ireland and the Republic of Ireland to facilitate cross-border co-operation. Through CAWT, the Southern and Western Health and Social Services Boards in Northern Ireland and the North Eastern and North Western Health Boards in the Republic of Ireland agreed to co-operate in order to improve the health and social well being of their respective populations.52

Co-operation And Working Together (CAWT)53 was highlighted:

“CAWT implements its activities through cross-border sub groups. There are thirteen sub groups in total spanning the complete health and social care spectrum. Comprising senior managers and planners, these sub groups plan practical activities including research, feasibility studies, needs assessment and pilot initiatives to improve cross-border services. Examples of recent developments include projects in the area of emergency planning and pre-hospital emergency care. The recommendations contained within the publication ‘Population Health Profile’ of the CAWT region, provided the basis for a number of key cross-border projects in the areas of health impact assessment, health protection policies and health promotion, shared equipment procurement, joint training initiatives and piloting a GP Out of Hours service.”54

In its response to the consultation, the Department reported that the development of A Healthier Future used a stakeholder engagement process that had involved around 3,000 people at events, in telephone interviews and participation in focus groups. It referred to the disappointment that had been expressed because a number of excellent initiatives in 32-county and cross-border co-operation had not been highlighted.55 The Institute of Public Health, for instance, had in its response to the consultation referred to its pioneering all-Ireland leadership programme. The IPH had also welcomed “the (brief) acknowledgement of the potential for co-operation between Northern Ireland

52 Ibid.
53 See Appendices III and IV for more details about cross border collaboration in health and CAWT.
54 A Healthier Future, op.cit.
and the Republic of Ireland,” noting the huge potential in this area and that “practical benefits require strategic, sustained and systematic approach to co-operation.”

The DHSSPS responded to the criticism that many initiatives had not been included in the Strategy:

“The Department is aware of a range of excellent initiatives and the issue of cross-border co-operation, including reference to existing initiatives, is covered in section 8(xi) of A Healthier Future. To ensure that A Healthier Future remained a manageable size, it was not possible to provide details of all initiatives.”

The Department acknowledged the work of the All Ireland Public Health Forum activity, noting that this work has facilitated a joined up approach and development of practice in the North & South of Ireland supporting public health initiatives. It stated that the outcomes of this work would be linked to the implementation of the Regional Strategy.

While the issues raised in the consultation are addressed in the Department’s Response, it is not possible to identify, where any of the 76 “substantive” responses have had any influence on the Strategy. Rather, it stressed that the Strategy was “a high level, aspirational document.” A Summary document of A Healthier Future, was published in May 2006. However the Summary document made no mention whatsoever of cross-border co-operation.

INVESTING FOR HEALTH

The Northern Ireland public health strategy, Investing for Health, was published in 2002. The Strategy contained a framework for action based on multi-sectoral partnership working amongst Departments, public bodies, local communities, voluntary bodies, District Councils and social partners. The key aims of the strategy were to improve life expectancy across the population and to reduce health inequalities. The Strategy had a particular focus on the most disadvantaged in Northern Ireland.

Considerable stress is placed on the contribution of public consultation in shaping the Strategy, which seeks to shift the emphasis from treatment of ill health to its prevention. However, there was no mention in the Strategy of cross-border co-operation in healthcare or of the commitment by the two governments to co-operation within an EU context on addressing poverty and social exclusion.

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www.publichealth.ie/publications/ahealthierfuturea20yearvisionforhealthandwellbeing
57 Consultation Summary: A Healthier Future, op.cit.
58 A Healthier Future. op.cit.
BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (NORTHERN IRELAND).

The Bamford Review, an independent review of law, policy and provisions which affect people with mental health needs or a learning disability in Northern Ireland was published in August 2007. The Strategic Framework for the review provided a blueprint for reform and modernisation of services based on agreed principles and standards. It adopts a strong user and carer perspective and specifies evidence-based service models aimed at addressing the current problems and barriers to good practice. It is underpinned by programme recommendations for funding, human resources, information management, research, service evaluation and performance management.

The review recommended that,

- acute inpatient services should be based in well-designed facilities and close to the community they serve such as general hospital sites;
- the quality of inpatient services should be the subject of both regional and local review;
- services must be of high quality and provide an appropriate range of assessments, therapeutic interventions and services including intensive nursing services. They must deliver a therapeutic and safe atmosphere and be sensitive to gender and cultural needs.

In October 2009, Health Minister, Michael McGimpsey launched the *Bamford Action Plan 2009-2011* and stated that the NI Executive remained committed to seeing through the reforms for mental health and learning disability services which were recommended by the Bamford Review.

DHSSPS PRIORITIES FOR ACTION 2009-2010

The DHSSPS *Priorities for Action for 2009-2010* specify the interim milestones to be achieved and/or the associated actions to be taken by March 2010. The central aims of the 20-year Strategy, *A Healthier Future*, are encapsulated in several of the Department’s Priorities for Action targets for 2011 within the Programme for Government. Particular focus is given to addressing the continuing health inequalities in Northern Ireland.

In his foreword to the *Priorities for Action 2009-2010*, Health Minister Michael McGimpsey described the time of publication – March 2009 – as a “momentous point in the development of Health and Social Care in Northern Ireland.” The year 2009-10 marks the completion of the fundamental reform of planning, commissioning and delivery of care. The new HSC Trusts, the Public Health Agency, the new Health and Social Care Board and the Local Commissioning Groups were all established. In the last two years, the Minister wrote,

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59 Bamford Review of Mental Health and Learning Disability (Northern Ireland). http://www.rmhldni.gov.uk/
60 www.northernireland.gov.uk/news/
62 Ibid.
“we have made striking progress in the responsiveness of service – most obviously in transforming hospital waiting times, but also in access to other forms of professional treatment, in substituting for institutional care a greater reliance on community-based services, closer to people’s homes and their families.”

In a Departmental press release in June 2009, the Minister again commented on the “significant improvements” made across the health and social care service over the previous twelve months. Commenting on performance against the March 2009 targets, the Minister said that most of targets had been achieved or substantially achieved and significant improvements had been made in many areas. While information on performance for many of the targets in the action plan is not available, there are areas in which progress was not as strong and more recent data shows that in some important areas such as waiting times, the situation has since deteriorated. While the NI Ambulance Service did exceed its target, the target for April 2009 was already being met in 2008.

**Target: from April 2009, no elective care patient should wait longer than 9 weeks for a first consultant-led outpatient appointment, and 13 weeks for inpatient or day case treatment.**

- At April 2008, 8,625 patients were waiting longer than 9 weeks for a first outpatient appointment. This was reduced to 488 by March 2009. Performance against targets for outpatient assessment and for surgery was generally strong with the majority of patients now receiving their outpatient appointment within a maximum of nine weeks and surgery within a maximum of 13 weeks.

- At the end of December 2009, the number of patients waiting more than 9 weeks for a first outpatient appointment was 15,716 – 19.0% of the total waiting. Of this number, 5,955 were waiting more than 13 to 26 weeks and 424 were waiting more than 26 weeks (including 137 paediatric patients and 50 rheumatology patients).

**Target: from April 2009, no elective care patient should wait longer 9 weeks for a diagnostic test.**

- At June 2008, 1,515 patients were waiting longer than 9 weeks for a diagnostic test. By March 2009 this was reduced to 86.

- At end of December 2009, there were 2,925 patients waiting over the target for the 16 selected diagnostic services.

**Target: from April 2009, no patient should wait longer than 13 weeks from referral to commencement of elective care (AHP), reducing to 9 weeks by March 2010.**

- At April 2008, 7,481 patients were waiting longer than 13 weeks for inpatient/daycase treatment. By March 2009 this was reduced to 387.

- At the end of December 2009, there were 6,010 patients waiting more than 13 weeks for inpatient treatment, of which 1,648 were waiting more than 21 weeks. Of the 6,010 patients

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63 Ibid.
65 Ibid.
68 DHSSPS, Northern Ireland Waiting Lists, op.cit.
waiting more than 13 weeks, 2,766 (46.0%) were awaiting ordinary admission and 3,244 (54.0%) were awaiting day case procedures.  

Target: from April 2009, 95% of patients should, where clinically appropriate, wait no longer than 48 hours for inpatient fracture treatment.

- In March 2008 74% of patients with fractures were treated within 48 hours across Northern Ireland. By March 2009, this figure had improved to 86%.  

Target: from April 2009, all urgent breast cancer referrals should be seen within 14 days, 98% of cancer patients should commence treatment within 31 days of the decision to treat, and 95% of patients urgently referred with a suspected cancer should begin their first definitive treatment within 62 days.

- Waiting time targets for first cancer assessments and commencement of treatment were met in the period October – December 2009.
- Waiting times for treatment following GP referrals were between 88% - 90% in the months October – December 2009.

Target: from April 2009, 95% of patients attending any A&E department should be either treated and discharged home, or admitted within four hours of their arrival in the department.

- During March 2009, 83% of patients regionally were treated and discharged, or admitted within 4 hours of their arrival in A&E.
- In March 2010, 80% of patients attending A&E departments were treated and discharged or admitted within 4 hours. No patients waited longer than 12 hours.

Target: from April 2009, an average of 70% of Category A (life-threatening) calls should be responded to within eight minutes, increasing to an average of 72.5% by March 2010 (and not less than 65% in any LCG area).

- In 2008, the Northern Ireland Ambulance Service Trust responded to 70 per cent of life-threatening calls within eight minutes.
- The Northern Ireland Ambulance Service responded to 74% of Category A (life threatening) calls within eight minutes in March 2009.

A target date of September 2009 was set for Trusts to have adopted Client Experience Standards in relation to respect, attitude, behaviour, communication, and privacy and dignity, and to put in place arrangements to monitor and report performance against these standards. The plan sets out a

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70 DHSSPS, Northern Ireland Waiting Lists, op.cit.
72 DHSSPS, Press Release, 1 April, 2010.
73 Ibid.
number of specific targets under the priority area, ‘Improving Acute Services’ (See box). Achieving these targets, the document notes,

“will require Trusts to further embed the reform agenda, including the further improvement of hospital booking processes, reducing cancelled appointments and operations, and improving theatre utilisation.”

The priority, ‘Ensuring Fully-Integrated Care and Support in the Community’ reflects the shift of services from the acute sector to primary and community care.

“We must continue to build a continuum of integrated primary and community care services that focus on people at greatest risk, supporting them to live independent lives and reducing unnecessary and inappropriate reliance on hospitals or other institutional care.”

Assessments of longer-term care needs will normally take place outside a hospital setting. Intermediate care should be developed; promoting rehabilitation and independent living in a way that will see a shift away from traditional residential and nursing home care towards flexible and responsive domiciliary care services. Informal or family carers should be supported and the continuing implementation of the carers’ strategy, Caring for Carers, should be a priority for Commissioners and Trusts.

While statistics for the year 2009-2010 are not available, data from a survey on domiciliary care – defined as the range of services put in place to support an individual in their own home, such as routine household tasks within or outside the home, personal care of the client, and other associated domestic services necessary to maintain an individual in an acceptable level of health, hygiene, dignity, safety and ease in their home – in September 2009, would indicate that there has not been substantial progress towards this target. Compared to 2008, an estimated six percent more contact hours of domiciliary care were provided by HSC Trusts in Northern Ireland than in 2008 and contact hours per client had increased in the same period from 9.4 hours to 10.1 hours. However, almost half (49%) of all clients received less than five hours of domiciliary care, up from 43% in 2008. Furthermore, HSC Trusts provided domiciliary care for slightly fewer clients than in 2008 – down by 176, from 23,553 clients to 23,377.

Trusts will be expected to ensure that palliative care teams are put in place; with the aim of decreasing the number of inappropriate admissions to hospital for these patients and wherever possible allowing them to be cared for and die in their place of choice in the community. Person-
centred care plans should be developed for people with long term health conditions to improve the quality of care and support available to users and their carers and obviate frequent, but fundamentally avoidable, admissions to hospital. At least 5,000 people should have access to telehealth/monitoring at home by December 2011. It seems difficult to reconcile achievement of these performance targets with achievement of the required £700m in efficiency savings by the end of 2010 and the further £113m in budget cuts announced at the end of May 2010.81

NORTHERN IRELAND STRUCTURES FOR STAKEHOLDER ENGAGEMENT WITH THE HEALTH & SOCIAL CARE SERVICES

General Public

Complaints Consultation Collaboration in Policy and Decision-Making

- Health / Hospital Campaigning Groups
- Elected Representatives
- Patient / Service User Advocacy Groups
- Community & Voluntary
- Trade Unions & Health Professional Bodies

Engage e-network
For the stakeholder involvement programme in health and social care in Northern Ireland (HSC Stakeholders Discussion Forum has been temporarily suspended)

NI Assembly Health, Social Services and Public Safety Committee
Has a scrutiny, policy development and consultation role with respect to the DHSSPS and plays a key role in the consideration and development of legislation.

Patient Client Council
To provide a strong voice for patients, clients and carers.

Ombudsman
Can investigate: a) complaints re Health Services and the private health care sector (only where the HPSS is funding the treatment); b) complaints arising from both the administrative actions of Health Service organisations (e.g. Trusts, Board, etc.) and the exercise of clinical judgement by health care professionals. Generally, complainants are expected to have used and exhausted the Health Service Complaints Procedure.

Public Health Agency

HSC Trusts (5)

Health & Social Care Board
Commissioning, resource management, performance management and improvement.

Local Commissioning Groups
Assess health and social care needs; plan health and social care to meet current and emerging needs; secure the delivery of health and social care to meet assessed needs.

DEPARTMENT OF HEALTH, SOCIAL SERVICES & PUBLIC SAFETY
CHAPTER 3:
LEARNING FROM PERSONAL AND PUBLIC INVOLVEMENT THEORY AND PRACTICE IN THE UK, EUROPE AND BEYOND

In this document, we have used the generic term PPI to refer to the involvement and engagement policies and practice of both health services. The health services in both jurisdictions have drawn upon much of the same literature and definitions of Personal and Public Involvement (PPI) concepts, although there are some differences in approach that will be discussed below and in the following chapters.

There is general agreement – at least in theory – that patient involvement should occur wherever decisions are being discussed that will affect patients’ healthcare or lives including expert committees, regulatory processes, facilities design and development (e.g. hospital construction or refurbishment); design of education and training programmes for health professionals; research/clinical trials design; and care and treatment guidelines design.82

The Pacesetters Programme, within the English Department of Health, has developed a comprehensive approach to PPI that offers a model for health services in both parts of Ireland. The Pacesetters Programme stresses that community engagement is much more than community consultation. “The former is about a continuous dialogue and the development of a good working relationship. The latter is about one party seeking the views of another at occasional intervals.”83 Successful community engagement must involve a ‘dialogue of equals’.

In the context of the NHS, this dialogue is about individuals and local communities who are properly informed about their health needs and what the NHS can offer. They are also empowered to talk as equals to NHS planners and professionals, while recognising the expertise of health planners and professionals. Equally, it is about health professionals who genuinely understand the needs and circumstances of different communities, and are prepared to recognise the experience and expertise that community members can bring to any debate.84

The Pacesetters Programme has identified three main stages of engagement:

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84 Ibid., pp 4-5.
1. **Information gathering:** The collection of information and data about public attitudes and requirements through surveys, etc. There is no ongoing dialogue between the public and the organisation seeking the information. The public usually participate in this as individuals.

2. **Consultation:** Members of the public and the organisation work together for a defined period to discuss a particular policy or service issue. The methods used can range from focus groups to citizens’ juries. People are brought together as representatives of the demographic profile of a particular community.

3. **Participation:** Members of the public and the organisation work together, on an ongoing basis, on a range of policy or service issues. These tend to focus on the community rather than on individuals. Community forums are an example.85

A key difference between the different approaches to engagement outlined above is the extent of the dialogue that takes place. The views of patients and the wider community will only ever be one of a number of considerations to be taken on board when making funding and operational decisions at a local level. Ensuring that service users, patients and the wider community are aware of this and have an understanding of how the decision-making process works is an important responsibility of those engaging on behalf of the service provider. The advice of the English Pacesetters Programme is equally relevant in the Ireland/Northern Ireland context:

Another reason why transparency around decision-making processes is a vital element of effective community engagement is that a common weakness of previous mechanisms is the often reactive nature of the engagement process. In the past, communities have tended to mobilise in response to the threat of service reduction, such as the closure of a hospital department or the ending of a particular service. ... Involving the local community at appropriate points in the process, rather than once decisions have been made, is another key element of effective engagement. ... Following these steps will not only alter the often adversarial nature of the provider–user relationship, but it will ultimately help to promote higher levels of awareness around the decision-making process that underpins the allocation of finite resources.86

### Key Tasks for a Community Engagement Strategy

1. Develop systems and processes that allow communities to engage in accessible ways
2. Clearly communicate opportunities to engage and explain how systems work
3. Provide accessible, ‘fit-for-purpose’ information on partner services and the mechanisms that exist to comment on these on an ongoing basis
4. Establish and maintain structures to support engagement
5. Provide appropriate developmental and administrative support to local people involved in the process
6. Place particular emphasis on engaging excluded and minority groups
7. Establish robust systems of review and quality control of all engagement activities

*A Dialogue of Equals, Pacesetters Programme*

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There must be a commitment by all staff involved in community engagement activities to provide feedback to all those involved and affected by subsequent decisions. Meaningful community engagement also means that local communities will need to be properly supported – and, in some instances, they may need to have their capacity built – to help them understand the issues and constraints facing a modern health service.\(^{87}\)

**PPI as a Tool to Address Health Inequalities**

Some attention has been given, in particular, to the importance of successful engagement with what have been described as ‘hard to reach’ groups – perhaps more appropriately described as ‘groups who are seldom heard’.

Professionals need to look at themselves *before* they attempt to engage with seldom-involved communities. The term ‘hard to reach’ was coined by professionals with a superficial understanding of the needs of marginalised communities. It is an anathema that is unhelpful and untrue. … To avoid falling into the trap of blaming communities and groups for being hard to reach, professionals will need to develop a full understanding of the make-up of the communities with whom their trusts are seeking to work.\(^{88}\)

The Pacesetters Programme explained the importance of focusing on target groups based on age, disability, ethnicity, gender, religion, sexual orientation and gender identity because,

we believe that some of their members have at some time or other faced discrimination in services delivered by public sector service providers. It is our understanding that, as a consequence of this, some members of our target groups may appear to some service providers to be more difficult to engage with than is generally the case. We also believe that a further consequence of this is that service providers are not as confident in carrying out engagement with so-called ‘hard-to-reach communities’ as they are in engaging with the general population.\(^{89}\)

Certain communities of interest are less likely to become involved if they are not specifically targeted. These include black and minority ethnic groups, young people and those who are socially excluded for economic, social, cultural or political reasons – precisely the groups who most need...


\(^{89}\) *Ibid.*, p. 3.
service providers’ interventions. The barriers to their inclusion are higher than those for other groups and, as a consequence, they sometimes appear to be harder to reach.\(^\text{90}\)

The Pacesetter Guidelines suggest that in order to be more strategic and effective when carrying out community engagement activities with seldom-heard groups, healthcare professionals need to have a better understanding of what communities are, how they function at a neighbourhood level and the differences that exist between community aspirations and patient needs. This is an essential foundation to the creation of a meaningful ‘dialogue of equals’ between health professionals and members of seldom-heard communities/groups and the engagement of seldom heard communities as partners in the development of new policies and service changes. This will not only improve the experience of service users from the target groups but will empower local communities, support joint learning to inform future policy and service development and identify and map local unmet needs, i.e. to support marginalised communities to set their healthcare priorities.\(^\text{91}\)

**REASONS FOR PUBLIC AND PATIENT INVOLVEMENT**

The UK parliamentary Health Committee’s report on PPI makes clear the need to make a distinction between public involvement as a mechanism for accountability and as a mechanism for improving services:

“The purpose of public involvement is also often confused and conflated. Two main purposes need to be distinguished: improving the design and provision of services and increasing accountability. In a publicly funded service, patients and the public are in a sense the NHS’s shareholders as well as customers and their views on larger decisions about spending priorities and service design must also be taken into account.”\(^\text{92}\)

The Pacesetters Programme warns that the NHS has historically been more successful in consulting its users than in engaging with the wider community. This assessment has been confirmed by the experiences of participants in this research described in the chapters that follow.

“The views of patients are often given precedence over the aspirations of the community. While this may be understandable, it is also an anomaly that needs to be addressed. Healthcare professionals need to understand better the differences that exist between patient needs and

\(^{90}\) Ibid., p. 17.

\(^{91}\) Ibid., p. 18.

\(^{92}\) Government Response to the Health Committee’s Report on Patient and Public Involvement in the NHS, Presented to Parliament by the Minister of State for Health Services, June 2007.
the aspirations of the wider community so that they are better able to identify when there is a need for extending the engagement process.”

The programme suggests that service users and patients care more about the quality of their everyday interactions with health professionals than about how the service is organised. Local community members, on the other hand, often care passionately about perceived threats to services, how the service is organised and about health risks. “Therefore, engaging patients equates to tackling the clinical agenda and, where necessary, changing the culture of care. However, engaging the community equates to opening up a debate about the pattern and nature of service provision and health protection.”

This distinction has been acknowledged by the UK Government’s Health Committee. Its report stressed:

> There is an important distinction to be made between the involvement of patients and of the public which have tended to be confused. ... Current or recent NHS patients are likely to bring different perspectives to bear from those held by the general public. All these distinctions should be taken into account.”

The UK Parliamentary Health Committee acknowledged that “a truly patient led NHS”, cannot be achieved unless “people have opportunities to influence services in ways that are relevant and meaningful to them and in ways which will make a difference to services.”

Users, as well as the groups that represent them, must be involved in commissioning decisions, needs assessment, prioritization, scrutiny of services and quality assurance.

“The development of a stronger local voice needs to be understood as part of the long-term programme of culture change and service transformation for health and social care which we are working towards, as it is a fundamental foundation of the health reform process.”

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**Innovations and promising practices**

- **Attention to print materials**
  - *Reduce complexity and jargon*
  - *Pilot test*
- **Attention to language and culture**
- **Move beyond reliance on print materials**
  - *Consider innovative media (but do not assume that internet is the answer)*
  - *Expand dialogue and discussion*
  - *Combine education with entertainment*
- **Work with lay public (e.g. the expert patient)**
- **Support active patient-build efficacy**
- **Change professional attitudes and stance**

*European Patient Education and Health Literacy Conference, Barcelona, January 2008.*
LEARNING FROM THE INTERNATIONAL EXPERIENCE

Both health services on the island of Ireland have contributed to and drawn upon learning and good practice in other countries. The European Patient Education and Health Literacy Conference in 2008 that explored the scope and potential of health literacy and patient education actions considered, for instance, the UK Expert Patient Program and the Stanford Self-Management Program from Stanford University in the USA as well as learning from patient advocacy groups in Europe and health literacy projects in Italy and Switzerland.98 The Stanford Self-Management Program is a model that has been promoted by, among others, the Long Term Conditions Alliance in Northern Ireland.

Another source of learning from beyond the island is the network of patients’ organisations – brought together under the umbrella of the International Alliance of Patients’ Organisations (IAPO). The IAPO has been a critical voice, noting that patients’ voices are not valued enough in policy and practice.

“Patient involvement is often mere tokenism; its influence on policy-making can be restricted by practical and financial structures, differing knowledge bases, cultural barriers and personal attitudes. Robust mechanisms must be created and enforced so that patient involvement is not just cursory, rather that patients play appropriate roles in decision-making processes with their views listened to and acted upon.”99

The IAPO makes a number of recommendations to ensure that patient involvement is integrated into all decision-making processes, occurring from the start and on an ongoing basis. They recommend patient involvement initiatives should follow IAPO guidelines, incorporating,

- Robust and transparent mechanisms to ensure that patients’ views are acted upon, not just recorded;
- Inclusion in initiation, design, implementation, communication and evaluation of initiatives;
- Practical, psychological, financial and educational support for participants;
- Varied methods to reach under-represented groups and to gather a diversity of views.

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As will be seen in the next two chapters, the PPI policies and strategies of the health services on both sides of the border draw heavily on the theory and practice of service user engagement in other countries, in particular from the NHS in Britain, but also from other European countries and the United States. In the Republic, PPI policy for the health services is set out in the *National Strategy for Service User Involvement in the Irish Health Service 2008 – 2013*. In Northern Ireland, the DHSSPS *Guidelines on Personal and Public Involvement in Health and Social Care* provide the framework under which service user involvement is taking place. Both these documents are discussed in detail in the following chapters. It may, however, still be too early to assess how the difference in emphasis between the legislation and terminology in the two jurisdictions will play out as the policies for stakeholder involvement are developed and implemented over time.

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CHAPTER 4:

PERSONAL AND PUBLIC INVOLVEMENT IN NORTHERN IRELAND

Within the NHS at UK-level in recent years and in Northern Ireland, there has been considerable discussion and development of policy and practice for the engagement of service users and the wider community. In the National Health Service, PPI is termed ‘Personal and Public Involvement,’ implying a more active engagement of service users than the patient, who is the perhaps more passive recipient of services. The legislation, also, adopts a robust approach to consultation. In Britain and in Northern Ireland, there is a statutory duty to consult. The newly-established Patient Client Council (PCC) is an independent statutory body. All Health and Social Care (HSC) bodies must cooperate and consult with the PCC and have due regard to the PCC’s advice. The PCC has the power of entry to Health and Social Care facilities and HSC bodies must provide information to the PCC.

In Northern Ireland, the DHSSPS Guidelines on Personal and Public Involvement in Health and Social Care provide the framework under which service user involvement is taking place. Both these documents are discussed in detail below.

DHSSPS GUIDELINES ON PERSONAL AND PUBLIC INVOLVEMENT IN HEALTH AND SOCIAL CARE

In September 2007, the Northern Ireland Department of Health Social Services and Public Safety issued its own guidance on strengthening Personal and Public Involvement in Health and Social Care to support the development of a more user-centred HSC organisation as envisaged by the Modernisation and Improvement Programme. This guidance is intended to assist HSC organisation to improve the quality and effectiveness of user and public involvement as an integral part of governance arrangements. “Involvement with stakeholders is viewed by the Department of Health, Social Services and Public Safety (DHSSPS) as a key aspect of the modernisation and improvement programme.”101 On its Engage website, the DHSSPS states that stakeholder involvement refers to the involvement of key individuals and organisations in “strategic decisions” about Health and Social Care (HSC) at regional level, e.g. in influencing priorities.102

The DHSSPS’s rationale for public involvement combines recognition of the rights of service users and citizens to participate in decision-making and a recognition that service user involvement contributes to higher quality care services:

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101 www.engage.hscni.net
102 Ibid.
The role of community involvement in planning hospital services

The case for personal involvement

- To ensure appropriate care or treatment;
- To improve individual outcomes and improve the patient and user experiences of care;
- To reduce risk factors, promote health and social wellbeing, prevent disease or harm and encourage self help/care;
- To improve safety and quality of treatment and care for the individual and their family;
- To understand how, when and why care goes wrong, and to ensure an apology and redress are made, where appropriate;
- To reduce complaints and litigation.

The case for public involvement

- To improve service design;
- To improve population health and social wellbeing;
- To determine priorities for commissioning and to ensure access to safe, quality services for people living and working in Northern Ireland based on need, evidence of effectiveness and available resources;
- To raise population awareness of risk factors, promote positive health and social wellbeing, and prevent disease or harm;
- To manage demand;
- To improve safety and quality of treatment and care at community and population levels;
- To discuss public expectations and agree how these can best be met, taking account of local and regional needs, the evidence of effectiveness and the availability of resources.
- To strengthen local decision making and accountability for the safety and quality of services;
- To promote social inclusion.

DHSSPS Guidance on Strengthening Personal and Public Involvement in Health and Social Care

- Individuals and communities should be actively involved in decisions affecting their lives.
- The public should influence HSC priorities and plans.
- Individuals should contribute to decisions about their own care or treatment.
- To improve individual's personal experience as service users.
- To help ‘get it right’. To ensure alignment of rights, entitlements and responsibilities.

Strong “genuine” partnerships with key stakeholders are desirable because they can deliver:

- better quality and more responsive services;
- improved outcomes of care for the individual and the population; improvement in addressing health inequalities;
- greater local ownership of HSC services;
- a better understanding of why and how services need to change and develop.

Similarly, the benefits of involvement are a combination of greater democracy: people have a right to have a say in decisions that affect their health; transparent decision-making; ownership of the final product; and improved health and care outcomes: better services, better policy, better choices; communities have a particular knowledge about issues affecting them – valuable intelligence; shared responsibility means more successful project.  

The DHSSPS guidance on PPI, Guidance on Strengthening Personal and Public Involvement in Health and Social Care followed on from the House of Commons Select Committee

103 www.engage.hscni.net.
report on PPI in the NHS that had established a new statutory duty of public involvement and consultation and places a new requirement on all health and social care organisations. The DHSSPS guidance is intended to clarify and standardise good practice in implementing existing policy requirements and statutory responsibilities. It sets out principles of good practice and provides a framework for self-evaluation to assist HSC organisations to integrate PPI into the organisation’s governance arrangements.

The DHSSPS guidance is to assist HSC organisations to:

- Improve the quality and effectiveness of user and public involvement as an integral part of good governance arrangements and to support the development of a more patient and user-centred HSC envisaged by the reform programme;
- Support HSC organisations to maintain and strengthen the voice of service users and carers in the new arrangements for the commissioning and delivery of services under the Reform of Public Administration; and
- Strengthen and improve user and public involvement in the planning, commissioning, delivery and evaluation of services as part of their clinical and social care governance arrangements.

The guidance affirms that, “Effective service user and public involvement is central to the delivery of safe, high quality services and as such is a key element of clinical and social care governance which provides the framework for quality improvement and assurance of the quality of services commissioned or provided by HSC organisations.”

The DHSSPS Guidance notes that PPI works on different levels:

- **Personal Level**: being involved in plans, decisions or giving feedback about the individual care or treatment plan for themselves or for someone they are caring for;
- **Commissioning Level**: being involved in the planning and commissioning of services to meet agreed local and/or regional needs;
- **Delivery Level**: being involved in plans, decisions and giving feedback about the ways in which services are run;
- **Monitoring & Review Level**: being involved in monitoring and review of the quality and effectiveness of services; and
- **Policy Level**: being involved in developing local regional policies.

Some of the main benefits of PPI taken from the DHSSPS Guidance, are set out in the box on page 45.

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105 House of Commons Health Select Committee Report on PPI in the NHS, April, 2007.
ENGAGEMENT AND PPI IN PRACTICE IN NORTHERN IRELAND

DHSSPS Stakeholder Involvement Programme

The DHSSPS Stakeholder Involvement Programme aims to “lead and oversee the creation of processes at local and regional level that bring together stakeholders to work collectively to improve health and wellbeing in Northern Ireland” by “facilitating the exchange of knowledge, ideas and information to inform and influence policy and action.”

The programme has three overarching objectives:

1. Ascertain the views of service users and the public on HSC services to inform policy and actions at a strategic level, e.g. Northern Ireland Public Attitude Survey, small area-focused surveys, other patient and user experience tools.

2. Work with Trusts, LCGs and other organisations to develop effective processes that facilitate stakeholder views to inform the Programme for Government and Priorities for Action, through collective and transparent processes.

3. Develop an e-communications process to promote good practice, facilitate effective exchange of information and provide a resource for HSC organisations, other organisations, the voluntary and community sector and service user groups which wish to develop approaches that involve stakeholders.107

However, the Community Development and Health Network (CDHN) – a member-led organisation that uses a community development approach to tackling health inequalities – has suggested that the initial work of the HSC Trusts on community development, stakeholder engagement, user involvement and patient and public involvement has generated a ‘Giant’s Causeway’ effect, where different Trusts have taken different approaches to this area and given it differing levels of attention and priority. This is leading to duplication, confusion and even greater fragmentation in this field.108

CDHN propose that the Public Health Agency should lead in the development of a Regional Strategy that “would provide an opportunity to cohere these developments, to harmonise up to ‘gold standard’ community development approaches.”109 The Network argues that a community development approach offers the best way to develop the necessary relationships and infrastructure to develop a shared approach to decision-making.

“A Regional Community Development Strategy will provide a mechanism to ensure coherence within the new HSC agencies, given that responsibility for the various areas of PPI, stakeholder

107 www.engage.hscni.net.
109 Ibid.
engagement etc. are distributed across different organisations. A single Strategy will ensure that each works to a coherent set.”

**Stakeholder Involvement Network for Northern Ireland**

A ‘Stakeholder Involvement Network for Northern Ireland’ was established by the new Health and Social Care Board in Autumn 2007. This will include individuals, organisations and groups not directly involved in the provision of health and social care services, but who may represent those who use the service or who make a contribution in fields that impact on broader determinants of Health and Wellbeing, for example the Northern Ireland Housing Executive, District Councils or the Department of Social Development. The network was formally established in late autumn 2007. The DHSSPS has committed itself to work with them “to ensure there is a consistent and transparent approach to stakeholder involvement at the regional level”.

The reformed health and social care bodies now carry a statutory duty to consult with service users. The new organisations established under the Review of Public Administration (RPA) were required to submit a Draft Personal and Public Involvement (PPI) Consultation Scheme to the Department of Health, Social Services and Public Safety (DHSSPS) by 31 December 2009.

**Engage Website / e-network**

As part of its commitment to strengthening its systems for engaging stakeholders, the DHSSPS established the ‘Engage’ website to encourage wider public involvement and consultation. It is one element of a major programme of stakeholder involvement on the planned changes for health and social care: as “a focal point for stakeholders to inform and influence policy and action.” According to the Department, Engage is a key communication tool for information sharing and support among stakeholders.

To provide a regional perspective to influence planning and priorities, a key element of the DHSSPS Programme of Stakeholder Involvement is an e-network linked to the Engage website. It is intended to “promote good communications, share best practice, facilitate effective exchange of information, and help identify and prioritise regional themes that can contribute to Programme for Government and Priorities for Action.” The e-network will comprise membership from a range of organisations from the statutory, voluntary and community sectors, in addition to the wider ‘Health and Social

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110 A new Regional Community Development Strategy for health and social care in Northern Ireland, op.cit.
111 Pacesetters Programme, op. cit.
112 www.engage.hscni.net
113 www.engage.hscni.net
Care family’. The resources section of the e-network site will act as a repository for examples of best practice that have been demonstrated to work. While it is intended to support the e-network with a discussion forum, providing a platform for shared information and ongoing dialogue on key issues and ‘hot topics’, this has been temporarily suspended and remains suspended at time of writing (December 2009).

**PATIENT CLIENT COUNCIL (PCC)**

Perhaps the most significant element of the NI government’s commitment to PPI, has been the establishment of the Patient Client Council (PCC). The PCC is a Non-Departmental Public Body, accountable to the DHSSPS and through the Department to the Minister and the Northern Ireland Assembly. The key functions of PCC are:

- To represent the interest of the public
- To promote PPI
- To provide assistance to individuals making or intending making a complaint
- To promote the provision of advice and information to the public by HSC bodies about design, commissioning and delivering of HSC

All Health and Social Care bodies must co-operate and consult with the PCC and have due regard to the PCC’s advice. The PCC has power of entry to HSC facilities and Health and Social Care bodies must provide information to the PCC. 114 (See also Appendix VI.)

**REGIONAL HEALTH AND SOCIAL CARE BOARD & THE PUBLIC HEALTH AGENCY**

The single Health and Social Care Board for Northern Ireland has replaced the four Health and Social Services Boards. Its focus is on commissioning, resource management and performance management and improvement.

As part of the development of the Draft Schemes, the Public Health Agency (PHA) and the Health and Social Care Board (HSCB) agreed a collaborative approach. The two bodies have published a joint PPI Update on the Internet, detailing progress on the implementation of PPI. An initial discussion with a variety of stakeholders took place in November 2009, subsequent to which these bodies’ Draft Consultation Schemes were submitted to the DHSSPS. At the request of stakeholders the PHA and HSCB hosted a workshop in January 2010 for HSC organisations to discuss working together in a more coordinated way. At that workshop, stakeholders asked for clarification on the roles and responsibilities of each of the HSC organisations in relation to PPI. The DHSSPS will formally

114 Modernisation and Improvement Programme Board. *PCC – Strategic Relationship between PCC and HSC bodies, DHSSPS, 2009.*
clarify the position when it updates its guidance on *Strengthening Personal and Public Involvement in Health and Social Care*. HSC organisations were unanimous in their support for the establishment of a regional HSC group to progress PPI and the first meeting took place at the beginning of April 2010.\textsuperscript{115}

**LOCAL COMMISSIONING GROUPS**

The Local Commissioning Groups – only recently formally established (January 2010) – are at different stages in respect of progress on their Stakeholder Engagement Plans. Some LCGs have already completed a round of stakeholder meetings, regarding the health and social care services they should commission on behalf of the population of their areas. For example, the Southern Local Commissioning Group (LCG) has already undertaken three public engagement meetings to identify and prioritise the current health and social care needs of the people living in the Southern area. Invitations were sent out to almost 400 individuals/organizations and the events were widely publicized in GP Practices, Dental Practices and Pharmacies in the Southern area. Press releases were also sent to all the local papers and the event was publicised on the Health and Social Care Board website. In total, 70 people attended the three events. Each event was held café style which gave those who attended the opportunity to circulate around different themed tables. The tables were themed-based on the draft Priorities for Action themes as identified by the Department of Health Social Services and Public Safety.

“The engagement process highlighted many of the priorities and areas of concern that the local population have regarding health and social services as they are currently provided in the Southern area. People raised issues such as open and transparent communication, early intervention and prevention, strengthening the partnership working of the community and voluntary sector with the public/statutory sector. The challenges facing both acute hospital services and community services in maintaining a good quality service in the difficult economic climate and tight financial controls imposed by the government was a dominant feature in the discussion.”\textsuperscript{116}

Based on recommendations from the event the Southern LCG will develop a Southern LCG User, Communication and Engagement Policy and a Southern Local Commissioning plan to address the identified needs of the population of the Southern area in line with regional guidance and priorities and within its allocated budget.

\textsuperscript{115} *PPI Update*, Issue 1, Public Health Agency and Health and Social Care Board, March 2010.
Working Together – Top Ten Tips

1. Good user involvement is about asking the right people the right questions at the right time.

2. One size doesn’t fit all – there is no one way to do user involvement.

3. User involvement isn’t about ticking the box; it is about improving services by understanding the needs, experiences and expectations of those using them.

4. Sweeping consultation documents, no matter how glossy, are rarely effective. The more focused the consultation the more likely it is to be constructive. Asking people with a particular condition what they think about your services will yield real information, not consultation fatigue.

5. Patients have expertise in the areas of their own experience – use it. But there is no perfect patient.

6. Patients and users need to have an effective support and feedback mechanism – they won’t know all the answers themselves and need to be in touch with others if they are to make an effective contribution. Patients’ organisations have an important part to play and can bring expertise and experience to the process.

7. User representatives need to be properly recruited and trained, and their roles clearly defined.

8. Effective user involvement can improve health outcomes and efficiency but it does need investment, in time and in capacity building. Users – and professionals – need training and backup in working in new situations and relationships.

9. User involvement should be a genuine, two-way exchange of information and involves real sharing in decision making. It must be clear, transparent and continuous, driven forward at a senior level but impacting and involving all levels.

10. Achieving effective user involvement should be measured as part of an organisation’s targets and goals.

(Long Term Conditions Alliance, 2008)
CHAPTER 5:
PATIENT AND PUBLIC INVOLVEMENT IN THE REPUBLIC OF IRELAND

NATIONAL STRATEGY FOR SERVICE USER INVOLVEMENT IN THE IRISH HEALTH SERVICE

In the Republic of Ireland, the commitment to partnership and consultation has been frequently reaffirmed. Objective 4 of the Health Service Executive’s Corporate Plan for 2005-2008, states for example,

“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.”\(^{117}\)

In the Republic, the terminology is ‘Patient and Public Involvement’. The Irish Health Act 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.”\(^{118}\) [our emphasis].

PPI policy for the health services is set out in the *National Strategy for Service User Involvement in the Irish Health Service 2008 – 2013*.\(^{119}\) The Strategy has been developed to ensure a systematic and consistent approach to service user involvement across the health and social services. The document comprises a statement of principles and specific goals together with relevant actions. In her introduction to the Strategy, the Minister for Health and Children, Mary Harney, explained the approach being taken:

“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 being 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.”\(^{120}\)

The Strategy is intended to build on prior work of the HSE in engaging with people who use or who may have reason to use its services such as the *Your Service Your Say* Compliments and Complaints policy, and as such “represents a significant step forward” in actively involving the public in the Health Services’ programme of change. The Strategy is based on three levels of involvement:

1. Individual service users: involvement in their own care;
2. Community: involvement in local service delivery and development; and

\(^{118}\) *The Health Act*, 2004.
\(^{120}\) *Ibid.*
3. National: strategic policy informed through involvement of service user organisations in partnership with health care professionals.

“We describe three different levels of involving people who use services - consultation, collaboration and user control. Whilst there is a role for each of these levels of involvement within health and social care, it is important that service users are clear as to which level of involvement is being sought.

**Consultation:** When you consult people who use services, you ask them for their views and use these views to inform your decision-making. For example, you might hold one-off meetings with people who use services to ask them for their views on a research proposal. You will not necessarily adopt those people's views, but you may be influenced by them.

**Collaboration** involves active, on-going partnership with members of the public in the overall process. For example, people who use services might take part in a steering committee for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project.

**User control** might be broadly interpreted as where the focus of power, initiative and subsequent decision making is with service users rather than with the healthcare professional. It does not mean that service users undertake every stage of the process, or that ‘professional’ researchers are necessarily excluded from the process.”

Service users are defined as patients, carers, parents and guardians, organisations and communities that represent the interests of people who use health and social care services, and members of the public and communities who are potential users of health services and social care interventions.

‘Involvement’ is defined as,

“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.”

The Strategy sets out a number of Guiding Principles for Service User Involvement that include a recognition of the right to be involved, particularly for seldom heard groups. Its principles also recognise the importance of “open dialogue, trust and mutual respect,” “clear channels of communication with the health service,” and “accurate and timely feedback and information to service users.” The Strategy makes clear that the term service user takes account of the rich diversity of people in society, who may have very different health needs and concerns.

“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 of the delivery of patient-centred care. ... 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.”

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121 www.hse.ie


123 Ibid.
The HSE and You: Proposed National Charter/Guide

### Health Responsibilities –

The duty of healthy and sick people to maintain, improve or restore their health, to respect the health of others and to help the Irish health service to run efficiently.

**The HSE and You: What service users can expect from the HSE and what the HSE can expect from service users**, is a service users’ charter or guide, developed by the DoHC and the HSE and was still at the consultation stage at time of writing (April 2010). The document, which has been developed to implement Goal 4 of the National Strategy for Service User Involvement, “A Patients Charter,” sets out supporting arrangements for a partnership of care between everyone involved in healthcare – patients, families, carers and health care providers; and outlines what service users can expect from the health services and what their health responsibilities are when using health services.

A set of common values form the basis of this document.

1. **Access**: Our services are organised to ensure equity of access to public healthcare.

2. **Respect**: We treat service users with respect, dignity and consideration during provision of care that is respectful of culture, beliefs and values in line with clinical decisionmaking.

3. **Safety**: Our services are provided with professional care, skill and competence in a safe environment.

4. **Communication**: We communicate clearly with the service user throughout the period of care.

5. **Information**: We provide understandable information which is essential to empower patients to participate in their own care and to know what to expect in relation to service delivery, treatment and care.

6. **Participation**: We involve service users in decision making about care, including informed consent, prior to any procedure with discussion of the options available.

7. **Privacy**: We maintain strict confidentiality of personal health and other information gathered from service users.

8. **Being Heard**: We facilitate service users to comment on care, to make a complaint and to have their concerns addressed.

9. **Prevention**: We provide information to service users on how to take care of yourself and how to promote and protect your health and prevent the spread of infection.

The National Service User Guidelines will be incorporated as an indicator of the HSE Integrated Quality, Safety and Risk Framework, this will enable the Charter/Guide to be applied in practice and will provide a process to monitor how they are used and implemented locally. As part of the consultation process, HSE services have been asked to consult and develop implementation plans for how the Charter/Guide will be implemented locally in 2010.

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124 *The HSE and You: What service users can expect from the HSE and what the HSE can expect from service users*, Consultation document, Health Service Executive, Naas, 2010.
“Implementation plans will need to outline how the Guide/Charter will be promoted locally among service users and what obligations are on healthcare providers at following levels of the organisation, 1) individual 2) ward/programme/service 3) organisational 4) strategic.”

Audits of compliance carried out at local level by members of patient partnership forums will help to assess whether the Charter/Guide is being implemented effectively. In relation to each target such as outpatient waiting time, diagnostic wait time, discharged at etc. there will be a standard method outlined by which people can notify the HSE of its failure to provide services/appointments within the target wait time. Regional training workshops and an online training manual will be developed to support health care providers to implement and evaluate the implementation of Charter/Guide in a systematic and effective way. A programme of awareness raising and communications for service users will be developed nationally and for all HSE services at a local level.

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125 The HSE and You, op.cit.
126 Ibid.
The role of community involvement in planning hospital services

ENGAGEMENT AND PPI IN PRACTICE IN THE REPUBLIC OF IRELAND

The Department of Health and Children holds responsibility for strategic and policy issues, and is accountable through the Minister to Dáil Eireann. Responsibility for delivery of all health and social care services lies with the Health Service Executive (HSE).

The HSE’s Consumer Affairs division is responsible for developing best practice models of customer care. The Office of Consumer Affairs has responsibility for developing and implementing best practice models of customer care within the HSE and promotes service user involvement throughout the organisation through the concept of ‘Your Service Your Say’. It is committed to the delivery of a high quality service and has national responsibility for the following functions:

- Comments, Compliments and Complaints
- Freedom of Information
- Data Protection
- Records Management
- Service User Involvement

Why Involve Service Users?

**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.

National Strategy for Service User Involvement in the Irish Health Service 2008 – 2013
• Appeals
• Liaison with the office of the Ombudsman
• Liaison with the office of the Ombudsman for Children
• Liaison with the Information Commissioner’s Office

In 2009, the HSE developed advocacy in residential care, drafted guidelines for involving children and young people and carried out research into the patient’s experience of health services, among other projects. Service user involvement is well established in mental health care services, for example. Ireland recently hosted an ‘International Initiative for Mental Health Leadership’ (IIMHL) event on the theme ‘Citizens in Partnership – Inclusion or Illusion,’ reflecting the central importance of the service users perspective and the path to recovery from mental illness. This event involved leaders from Government departments, major service providers, service users and carer leaders from around the world and provided a platform to showcase Irish innovation in mental health and to gain an insight into emerging trends and promising practice from other member countries. In announcing the event, Minister of State John Moloney TD said

“one of Ireland’s significant achievements is the active involvement of service users which has been achieved over a relatively short period of time. We are now at the stage that we could not countenance change in mental health policy or legislation without reference to the user movement”.

‘YOUR SERVICE YOUR SAY’

On 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. Complaints and service user comments on health and social services will be integrated with the service user involvement process outlined in the Strategy for service user involvement. The ‘Your Service Your Say’ webpage provides practical information for anyone wishing to make a comment, compliment or complaint about health services

127 The HSE and You, op.cit.
The role of community involvement in planning hospital services

The role of community involvement in planning hospital services received in Ireland and for those working to involve people in the design, development and delivery of health and social services.

**The National Health Consultative Forum**

The National Health Consultative Forum is convened by the Minister under Part 8 of The Health Act, 2004, to advise the Minister on matters relating to the provision of health and personal social services. The National Health Consultative Forum is comprised of approximately 350 representatives from senior public and private hospital management, a wide range of health professionals, academic institutions, voluntary and community groups, advocacy groups, professional representative bodies, trade unions and relevant Government departments. The 2008 National Health Consultative Forum was on the theme “Best practice in change programmes having particular regard to the move from hospital to community based health services, incorporating current thinking on innovative practices and flexible working ways.” The day started with an address from the Minister for Health and Children, Mary Harney T.D. followed by presentations from guest speakers regarding their experience of change programmes in the Australian health care system, the transport industry, the Revenue Commissioners and a speaker who addressed tactics for changing the culture of an organisation. Speakers were followed by high level parallel sessions on the Prevention and Management of Chronic Illness; Access to Health and Personal Social Services by Vulnerable Groups; and Innovative Work Practices and Flexible Ways of Working and a Question and Answer Session. Approximately eighty percent of the participants were either health professionals or public officials. Neither the structure or the content of the National Health Consultative Forum would appear to encourage the voices of service users to be heard and it is unclear how the opinions of participants will influence policy or practice in the health service. In any case, the National Health Consultative Forum has not met since 2008.

**Regional Health Forums**

As provided for under Section 42 of the Health Act 2004, each of the HSE’s four administrative areas has a Regional Health Forum, which comprises representatives from the city and county councils within that area. The four Regional Health Forums made representations to the HSE on a range of health and personal social services during 2007. The four Regional Health Forums are:

- Regional Health Forum, Dublin Mid Leinster (40 members);
- Regional Health Forum, Dublin and North-East (29 members);
- Regional Health Forum, South (39 members); and
- Regional Health Forum, West (40 members).
CONSUMER PANELS/SERVICE USER PANELS

Whilst more commonly referred to in the literature as a ‘consumer panel’, a service user panel is a method of involvement that enables a range of stakeholders to come together to discuss an issue(s) and reach consensus on ways to improve delivery and quality of services. Consumer panels have been a method of service user involvement within the HSE for several years. The National Strategy for Service User Involvement in the Irish Health Service 2008-2013\textsuperscript{130} has given a renewed impetus to the establishment of consumer panels at various and diverse areas of the health service. The Strategy also identified the need to review consumer panels for their effectiveness in influencing service decisions and in involving socially excluded groups and to make recommendations to build on good practice. Best practice guidelines have been developed by the HSE and these are referenced below. However, there is not yet other available documentation drawing on the experience of consumer panels within the health service.

Within the HSE, the decision to implement service user panels is the responsibility of the relevant local health manager (LHM) and hospital network manager (HNM) who may designate responsibility to a general manager or head of department. If a panel is deemed by the relevant HSE service management team to be the most suitable process for involving service users within their respective setting it is essential that the following criteria are in place:

- Clear leadership
- Clear aims and goals that can be monitored and measured
- Organisational and management support and commitment to the process
- Resources to support the organisation and development of the panel
- Support and capacity development to ensure that the voices of those who are seldom heard are listened to and responded to throughout the process
- Diversity of participation and that the panel is a just, open, non-discriminatory equality proofed forum
- A structure for clear lines of communication between the service user panel and relevant service management to help ensure appropriate actions are put in place.\textsuperscript{131}

The main functions of a service user panel are to:

- Encourage service user involvement at frontline level and provide an opportunity to reflect, listen and learn from the experiences of service users
- Provide an opportunity to involve service users, particularly for those whose voices are seldom heard

\textsuperscript{130}National Strategy for Service User Involvement in the Irish Health Service 2008 – 2013, op.cit.
\textsuperscript{131}Best Practice Guidelines for Establishing and Developing a Service User Panel within a Health Setting, Health Service Executive, Naas, no date.
• Provide advice and guidance to HSE management on a particular issue(s) and subsequently help improve delivery and quality of services
• Ensure responsiveness to the needs and concerns of the public and contribute to developments such as integrated care
• Establish potential networking opportunities within the organisation.

Qualities of an effective panel member

- An ability to appreciate the common good
- Understands the need to work as a team
- Addresses issues from the perspective of the service user
- Has strong communication skills and will be assertive and persistent if necessary
- An ability to listen and respect the views of others as well as putting their own opinions forward
- Communicates effectively and finds solutions and common ground with others
- Exercises good judgement
- Respects cultural differences
- Has an openness to engage in constructive dialogue
- Demonstrates a comprehensive understanding of confidentiality

A service user panel should be composed of a Chairperson; Co-ordinator; and approximately 12 (minimum eight) Panel members. The chairperson should be “someone of good standing and is independent of the particular health service for which the panel has been established.” A chairperson should not be currently receiving a salary from the HSE, have any personal conflicting interest in the development of services in the HSE or “demonstrate any bias towards the health service.”

“An effective panel member is someone who brings the service user perspective to the consultation process and is open to constructive dialogue. Together service users bring the knowledge and experience that enables health service providers to develop a clear understanding of the elements of a successful solution and a clear understanding of the consequences of particular decisions for those groups represented.”

CHAPTER 6:
COMMUNITIES’ EXPERIENCES OF HEALTH SERVICES REORGANISATION

As explained in the Introduction, the Centre for Cross-border Studies organised a series of focus groups across the Border region during January and February 2010. In addition to several hundred postal and email invitations to community groups, elected representatives and other individuals, the focus groups were also publicly advertised and were open to anyone who wanted to attend. Other community views were obtained through interviews and questionnaires. Participants were asked to address some basic questions about health service reforms, covering their awareness of and attitudes to the reasons for the reorganisation of hospital services; whether or not they agreed with the changes to service delivery; and their own experience of consultation by the health services they had as patients or as members of the wider community. Those who participated in the research chose to participate because they had specific opinions and experiences they were motivated to share, and are thus not necessarily representative of all sections of their communities. Nevertheless, there are striking similarities in the opinions expressed by people about their experiences in different communities on both sides of the border.

Many of the changes taking place within the health services North and South such as the delivery of services previously available only in hospitals in local primary and community settings have been generally well accepted and indeed welcomed by people living in border communities. Other elements of the reconfiguration of hospital services have been highly controversial. Many people in local communities are, however, very skeptical that the primary motivation for change is a concern about the quality or effectiveness of health services. Indeed, across the border region there have been sustained campaigns against changes that have inevitably been perceived and experienced as cuts to services. Not surprisingly, the most hotly contested changes have been the transfers of A&E and maternity services from local hospitals to larger regional hospitals. The fears that lives may be lost because of additional travel times required to reach hospital in an emergency are both well-founded and widespread among people living in rural border communities. They also have less tangible, but significant concerns about loss of community identity, for example that babies are no longer born in County Tyrone. And finally, the transfer of core services such as A&E and maternity are frequently perceived as the beginning of a process that leads, ultimately, to the loss of other hospital services as it becomes difficult to retain staff, and resources are allocated elsewhere. People living in border communities fear – with some justification – not only that they will lose essential
health resources, but that the downgrading of local hospitals will lead to wider social and economic decline in a region that is already disadvantaged.

The reconfiguration of hospital services has therefore not been easily accepted by many communities in the border counties. In rural communities and towns on both sides of the border, reform of the health services have been experienced as cuts and reduced access, particularly to key services such as Accident and Emergency (A&E) and maternity services. The background to this study is the emergence, alongside the implementation of the reorganization of the health services, of a number of local campaigns to oppose the downgrading of local acute hospitals. The response has been similar in towns across the border region. There have been public campaigns involving almost all sections of the community – patients, carers, trade unions, elected representatives and community organisations – in every case where services have been transferred from local hospitals to regional hospitals. A reflection of the strength of community support for these campaigns has been the success of single issue – save our hospital – candidates in both Monaghan and Tyrone. Paudge Connolly, a psychiatric nurse and trade union activist, was elected to Dáil Éireann in 2002 for the constituency of Cavan Monaghan. (He lost his seat in the 2007 election.) Similarly, as part of the campaign against proposals to transfer services from Tyrone County Hospital (see Chapter 11), local GP Dr Kieran Deeny was elected as a single issue candidate to the Northern Ireland Assembly in 2003.

Over the past decade, community campaign groups have fought against downgrading and closures at the South Tyrone Hospital in Dungannon, the Louth County Hospital in Dundalk, and Monaghan General Hospital. While the transformation of the South Tyrone Hospital is now well established, and patients have generally accepted that they must travel to Craigavon for acute services, feelings still run high. Elsewhere, many community campaigners have not yet accepted that their battle for retention or reinstatement of acute services is over.

In Dundalk, the Save Our Hospital Services Committee has campaigned against the ‘domino effect’ – starting with the closure of the maternity ward, acute surgery and loss of children’s A&E services. In April 2010, it was announced that Louth County Hospital’s A&E, Intensive Care Unit and Acute Medical Services are also to close. The Save Our Hospital Services Committee has claimed unanimous community opposition to the plans to remove services from Dundalk to Our Lady of
Lourdes in Drogheda: “Nobody living in this area supports the plans to close A&E, Intensive Care and Acute Medical Services.”

In Monaghan, while changes have been taking place since the early 1990s, the closure of maternity and other facilities and services in 2002 was a catalyst for the Monaghan Community Hospital Alliance to step up protests against the downgrading of Monaghan General Hospital. Monaghan General has seen the gradual loss of services since 2002, when its maternity unit and other facilities and services closed. An attempt to take a judicial review against removal of maternity services in Monaghan was defeated in 2004. All acute surgical and medical services at Monaghan were finally closed in July 2009. The County Community Alliance to Restore Acute Services at Monaghan General Hospital continues to argue for the retention and redevelopment of services at Monaghan General Hospital.

Although neither the promised new acute hospital in Enniskillen nor the new ‘local enhanced hospital’ in Omagh have yet been built, services have likewise been removed from the Tyrone County Hospital in Omagh. The last acute medical services at the Tyrone County Hospital were finally closed in March 2009. While work at both the Enniskillen and Omagh sites is continuing, the latest cuts to the Northern Ireland health budget make it unlikely that the new Omagh hospital will be built for some years. The implications of the cuts for the planned new acute hospital in Enniskillen are less certain.

The Western Health and Social Care Trust announced on the 22 January 2009 that it would no longer be in a position to provide acute medical care at the Tyrone County Hospital in Omagh from the beginning of March 2009. Alongside the plan to build a new acute hospital in Enniskillen, there has been a plan to build a new ‘local enhanced hospital’ at Omagh, replacing Tyrone County Hospital. While recognising that only one acute hospital in that part of the country is viable, people in Omagh have consistently argued that the regional acute hospital should be located in Omagh. (This argument has not surprisingly been supported by many people in Enniskillen.) They have also consistently raised concerns about the gradual transfer of existing services from the Tyrone County Hospital and that the new local enhanced hospital will not be built. It now appears that the Omagh community’s fears have been realised. In Chapter 11, we present a detailed case study of the Hospital Campaign for the Rural West to save services at the Tyrone County Hospital and for a new acute hospital to be located in Omagh.

133 www.louthhospital.com
134 www.saveourhospital.com
As this report was being finalised, two of the significant remaining plans for the reconfiguration of Northern Ireland’s hospital services from the Developing Better Services report – the closure of A&E services at the Whiteabbey and Mid-Ulster Hospitals – was being implemented. Once again, there has been an angry response from the trade unions, service users and the wider community. Within days of the announcement, there were public protests and concerns raised about the inability of the Antrim Hospital to cope with the increased demands on its facilities. The recent protests are, of course, just the most recent manifestation of a pattern that has been well established on both sides of the border over the past number of years. What may be different at this time, however, is that the massive impending health service cuts have removed any element of hope that rationalisation of service will deliver improved services. Indeed, almost immediately there were reports that the A&E facility at Antrim is having difficulty coping with the additional patient load from the Mid-Ulster and Whiteabbey.

Those who chose to attend the focus groups in the Irish border region convened as part of this research project, or to respond in other ways to this research, could be expected to be more aware than others in the community about health services reorganisation and the reconfiguration of hospital and other health and social care services. It is perhaps not surprising, therefore, that most of those who responded to questionnaires or attended focus groups were relatively well-informed about the reorganisation of the health services and many had considerable experience of engaging with health care bodies. Nevertheless, there were complaints from people across the border region that the changes to the delivery of health services, including acute services, were not well communicated and about a lack of information until after important decisions had been made.

“The public doesn’t always understand the factors on which decisions are made.”

“There’s been no real consultation. We’ve been presented with ‘facts on the ground’. There’s a lot of political influence.”

“Most people don’t know what’s happening. Community groups don’t know what’s happening.”

“...the decisions are already made. They’re just going through the motions. The people have not been listened to.”

People opposing hospital closures and transfer of services have been offended by what they consider to be unfair characterisations by civil servants and health professionals. Many people who came to the focus groups were aware of the EU directive on doctors’ working time. They also understand the need for a ‘critical mass’ of patients for specialised services requiring capital intensive resources or highly trained medical personnel. The comment below is typical of several similar complaints from people in different areas of the border region.
Service users are prepared to travel if necessary. It is generally accepted, for example, that it might be necessary to travel for elective procedures. There was a strong consensus among participants in the focus groups that the overriding issue was the quality of service. Nevertheless, there are differences about how quality care should be defined and there were frequent references to the importance of patients having the benefit of treatment close to home in a familiar environment. The concept of care in the community is popular, but as noted below, the reality has often not lived up to the promise. There were suggestions that much more could be done in delivering services locally through use of telemedicine, and through health promotion and a greater focus on prevention of illnesses.

“Services do need to be rationalised, but there are other models. The professionals could travel to the patients. They could do remote diagnostics, even surgery can be done from remote locations. Patients shouldn’t always have to travel.”

“People from rural areas are well used to having to travel, but hospitals should serve patients, not doctors.”

“Specialists are not prepared to travel to Dundalk. There’s reluctance on the part of medics to engage with people.”

Many people raised concerns about inadequate ambulance services and threats to cutback the ambulance and A&E services that are currently available. Although accepting that it makes sense to concentrate elective surgery and certain very resource-intensive specialisms in a few centres, reduced access to maternity and life-saving services were among the most frequent complaints about the reconfiguration of services. There were frequent complaints also about slow responses from doctors on call that in turn led to misuse of A&E services. The inability of the Doctor on Call to return calls from landlines on the other side of the border had also created problems in the past.

Some people had other priorities, such as for coronary care and treatment for cancer patients to be delivered as close to home as possible so that people did not have to travel to Belfast, Galway or Dublin.

“We don’t live in an ideal world – but big is not always beautiful.”

“The clinical arguments about the benefits of bigger hospitals are counterbalanced by accessibility issues, higher infection rates, lack of communication between primary and acute care services lack of continuity of care. It’s much more impersonal. Craigavon is more difficult for people to travel to [than South Tyrone Hospital], especially for older people and single parents.”

Transportation difficulties in border communities came up in every focus group. In addition to concerns about access to emergency services, there were also numerous complaints about
outpatient clinics and other services being transferred to hospitals such as Cavan, Drogheda and Craigavon, without regard to the lack of public bus services connecting to the hospitals. Others raised the problem of lengthy travel times by car, particularly in winter, and the trauma experienced in travelling long distances when someone was dying. Again and again, in focus groups across the border region, people referred to the challenges arising from the rurality of the border region. Participants in a Dungannon focus group commented,

“Centralisation would be ok if there was a good road and transport infrastructure. But not the way things are. We no longer have any A&E or maternity service in all of County Tyrone. Getting to Craigavon can be a problem; Derry, Antrim or Belfast even more so. It’s difficult enough to get to appointments in Belfast if you have to go by public transport.”

Attending clinics in Craigavon works as long as you are healthy. The TB clinic is in Craigavon, but it can be difficult to get to appointments. You have to take the 7am bus from Dungannon to Craigavon, then you have a long wait. Meanwhile, you’re missing a day’s work.”

While not objecting in principle to the reorganisation of health services and the shift of services from the acute to the primary and community sectors of the health services, people have important criticisms of the implementation of the reforms. One focus group participant commented that it was,

“... not so much ‘Transformation’ as ‘Bedlam’.”

There were many references in the focus groups to conditions in acute hospitals such as Craigavon and Cavan that are being overwhelmed by additional patient loads. Services have been transferred to a few centres with little or no additional capacity created. Patients are suffering through long waits to be treated and having to spend lengthy periods on trolleys because of non-availability of beds. Service users from ethnic minority communities, particularly those who speak little or no English, have faced additional problems in using hospital services. Examples were given of negative experiences in Craigavon Hospital,

“Sometimes children are required to translate for adults: for example a fourteen year old boy was asked to translate in a labour ward. There’s a real need for training – from the receptionists up to the medical staff.”

“Belfast is more patient-centred, more aware of interpretation needs. In Craigavon, you have to ask for a translator on each occasion. There can be a reluctance to get interpreters; they use the excuse that it’s too short notice. Really, there is resistance to using translation services because of the cost, but it could be organised more efficiently, by grouping patients together. There is a 24-hour interpreter service available, but it’s not well used.”

There were, also, many criticisms of Our Lady of Lourdes Hospital in Drogheda, which, it was suggested, is unable to cope with increased demand after closure of acute services in Dundalk. There were anecdotes about women south of the border taking out credit union loans to pay for maternity services in Daisy Hill Hospital in Newry, rather than go to Drogheda. Indeed, frequent criticisms were
made about the standards of care available at the Drogheda hospital. Our Lady of Lourdes was widely criticised for its hygiene standards and there was a high level of awareness of the poor ratings from the Health Information and Quality Authority.135

“Places of excellence must be excellent in reality, not just name. Drogheda has been fined for its bad hygiene standards.”

“Newry is benefiting from an increase in private patients from the south. Even medical card users would rather get a credit union loan to go to Newry than have their babies in the Lourdes.”

There were numerous anecdotes also, about scarce resources not being used effectively. One example mentioned was the HSE paying for taxis from the border region to Dublin for people travelling for dialysis. Others in the South talked of the excessive costs involved in sending patients to Britain for treatment and to accompanying family members whose travel and accommodation costs were also paid from the health service budget. There were other suggestions of where savings could be made, such as:

“The HSE could save by using more generic drugs, but that wouldn’t go down well with Big Pharma.”

There were some complaints that even where the local community had fundraised to provide facilities, these were not being properly utilised. One example given was that of a scanner sitting unused in Louth because staff were not available to run it. It was also suggested that because staff in Monaghan were not redeployed when the services were cut, they had been left with little or no work to do – wasting vital resources for a considerable period of time.

In some cases, there were objections to what was considered to be a wasteful expenditure on management and administration at the expense of front line services. It is believed by many that the reorganisation of health service bodies has not resulted in appropriate rationalisation of management structures:

“The health service has been handed over to the HSE. There’s a proliferation of offices and administrative waste while frontline services suffer.”

“There are too many chiefs on both sides of the border.”

“RPA has left too many middle level managers. The blockages are at mid-management level. Those that left under RPA were the most receptive. There’s a ‘that’s not my job’ mentality.”

“There are bureaucratic barriers. Messages don’t go up the line. Under RPA, the health and social care bodies are the most hierarchical.”

135 National Hygiene Services Quality Review 2008, Health Information and Quality Authority, www.hiqa.ie. HIQA rated the hospital’s hygiene standards as “Poor” in both 2007 and 2008; indicating that it required significant improvement in both service delivery and in corporate management. In addition at least one area of specific risk was highlighted by the assessors
At a number of the focus groups, concerns were expressed about the “money follows the patient” policy, which it was suggested, could work against the delivery of services in the community and result in less, rather than more choice. Cynicism about this policy is reflected in the words of focus group participants, who commented:

“Money follows consultants, not patients.”

“Money follows insurance, not the patient.”

“The policy that ‘money follows patients’ just means that decisions are being made for financial reasons, then rationalised by clinical arguments.”

“The high payments to consultants is what’s driving centralisation. It’s all about vested interests.”

“The Royal Colleges are very powerful. Decisions are made in the interests of doctors and consultants. Medical staff do not want to work west of the Bann. Working hours and conditions for medical staff are the determining factors. Patients are not put first.”

“Patient safety was the argument used to withdraw services. The real reasons were fiscal. And the interests of the Royal Colleges.”

**NEED FOR ‘JOINED UP GOVERNMENT’**

Others were angry and concerned that decisions were taken by health service planners without any apparent consideration of the wider context and in apparent contradiction to other public policy objectives.

“In the south, policy is not joined up. The political system is based on clientelism. Politicians have vested interests and the politics take over.”

“There’s a huge economic value in having a regional hospital in the area. It’s a generator of development and leads to the town being a centre for other development. It’s not just a question of the health budget.”

“The downgrading of services in Donegal is a worry. We suffered from enormous economic decline during the Troubles. It’s important to hold on to what is here.”

Indeed, many of the issues raised are outside the remit of health planners, but are extremely important in shaping perceptions and real experience of accessing hospital and other health services. One focus group participant in Dundalk asked, for instance, “What happened to rural proofing of the Transformation Programme? What about the environmental impacts?”

While having accepted that a reconfiguration of acute services into a smaller number of regional centres is necessary and inevitable, some focus group participants questioned the definition of the ‘region’. Participants in the Dundalk focus group, for instance, indicated that people in the town felt a greater affinity to Newry than to Drogheda, and would prefer to access acute services in Newry rather than travel south. Some of those at the focus group suggested that locating acute services in
Drogheda should be seen as a temporary solution only and referred to the Newry-Dundalk Twin City Strategy, that aims to to shape the future development of Newry and Dundalk within the wider context of their pivotal role on the Belfast/Dublin corridor.

**LOSS – NOT ENHANCEMENT OF COMMUNITY SERVICES**

When talking about cuts that had been made to their local hospital services, many people believe that there has been a deliberate strategy of running down viable services until there was not a ‘critical mass’ or until staff became demoralised and went elsewhere; making closure of facilities inevitable.

“The Children’s Ward [Dundalk] was deliberately downgraded. It was an end result decided years ago. They took away the ‘critical mass’.”

“There’s a lack of community services in South Tyrone. We’ve had closures but no replacements. It’s difficult to recruit medical staff because there’s no job security.”

“Change hasn’t made it better.”

On both sides of the border, there were frequent complaints raised that while services have been removed from their local hospital or a hospital has been closed, the alternative provision has not been put in place. Rather than enhanced community services, many people complained about the loss of community services that had previously been available. Community care is not being resourced as promised:

“They’re putting the onus on voluntary carers. There’s been an erosion of services. Home help hours are being reduced. Elderly people are living in isolation but elderly people don’t have a voice. And the politicians are choosing not to do anything.”

“Community hospitals are really glorified nursing homes. They’re desperately underfunded.”

“Maternity services have deteriorated.”

“We were promised the labs would stay in Monaghan. Blood samples and files are carried back and forth in taxis. What about patient confidentiality? Blood tests taken in Monaghan have been contaminated in transit to Cavan.”

“The Centres of Excellence concept is a good one, but the social care is missing.”

“Community services are fragmented and failing the elderly and disabled.”

“Local community care hasn’t happened.”

There was also significant opposition to specific decisions and cynicism about the reasons for them.

“The Health Board is driven by economic savings. It’s robbing services from five hospitals to put them in Drogheda.”

“Newry is not one of the Golden Six – so there have been cuts in departments and resources transferred to Craigavon.”

“What we’re seeing is a process of cuts and relocation of services. It has nothing to do with a vision. It’s all about cuts and saving money.”
“It’s all about PR – giving the impression there will be centres of excellence.”

Promises had been made that services would be enhanced, but while acute services have been transferred or cut entirely, the shift to care in the community and to Primary Care Teams has not been implemented. Many people said, in different ways, that they had been misled:

“We were promised there would be no loss of existing services until the Centre of Excellence was in place.”

“We were promised a midwifery-led unit in Cavan. We’re still waiting.”

“Health managers think the public are the enemy. There is contempt for families.”

“They’ve attempted to spoof the people about the reorganisation.”

“We were sold down the river.”

The pressure faced by health service staff in managing the transition to care in the community was illustrated by a professional working in Northern Ireland:

“It became more a process of managing reaction to contentious financial decisions. It was dreadful for managers, who were squashed between strategic direction and financial realities. It became about ‘weathering the storm’ over unpopular decisions. The managers couldn’t see a way of doing things differently. There were real cuts in community-based services, but these weren’t explained to people.”

Perhaps not surprisingly, there is considerable bitterness, particularly among people who were involved in long campaigns to oppose cuts and closures.

“We were strung along and told nothing but lies.”

“The ‘Transformation’ Programme is nothing but lies and propaganda.”

“I’ve a total lack of faith. I’ve lost all faith in the HSE, the boards, the government.”

“We’ve had nothing but outrageous deceit from the Board. We were promised no service would be removed before the alternative was in place. Then they starved [the hospital] of funding.”

“They can consult all they want on the glossy documents. In the end it was just deceitful.”

“The consultation [about Monaghan] was only after the decision was taken. No one accepts responsibility. The campaign had no impact. It was a one-way discussion. There were no crumbs from the table.”

“They dress up the bad news as good news. They give clinical reasons for cuts and promise better services. Why do they lead people up the garden path and tell people they have a choice? When the government talks about choice, that’s when it is being taken away.”

“The idea that ‘People are at the centre of planning’ is a big lie.”

“They tell you there will be discussion then you read the decision has been made.”

This perception was supported by some of health services personnel working on both sides of the border. A health service manager working in the Republic commented,

“People are right to say that they were promised centres of excellence before local services were wound down. The reality is the opposite: it’s been closures first.”

The pressures on community and primary care services are, likewise immense.
The role of community involvement in planning hospital services

“The primary care strategy isn’t being implemented. There are big differences between [primary care] teams. There’s been a loss of services to people with disabilities and the elderly.”

“Plans for the Primary Care Teams haven’t materialised on the ground. Community care is worse than before.”

“There are no resources in the community. We’ve actually seen the rationing of incontinence pads. Home care packages are not a reality.”

“There are longer waits for GP appointments – up to three weeks in Dungannon – then you have to wait for a specialist appointment. Local surgeries can’t register any new patients.”

“One local surgery just refuses to register non-English speakers, because the GP doesn’t want to work with interpreters.”

“In Strabane there are just two GPs and three surgeries for a very large rural area.”

“Doctors on Call refuse to travel to North Monaghan.”

In turn, these can result in increased demand on the acute sector. Migrant workers have additional problems that are not being adequately addressed in the community sector.

“There can be a five-hour wait at Craigavon A&E. It’s much the same in Derry. Many of the people there should really be going to a GP.”

“Patients who need language support have to book ten days ahead. Patients arriving at the out of hours service find it easier to drop into Craigavon hospital. So there are lots of appointments made and then missed. If you are ringing the out of hours service, it can be four hours before there is a response. So people aren’t using the out of hours service correctly. It’s just too difficult to arrange by phone, especially if you don’t speak English. All the services are overstretched.”

“Mental health services are under-resourced. Migrant workers have particular problems around domestic violence and child protection issues. There’s an increased chance of children being taken into care and it can be more difficult for parents to work with health and social care bodies. They can’t access things like anger management courses and counselling. Often, women are forced to continue living with an abusive partner because of her dependence upon his work status.”

“Social workers may have a sense of superiority. They may lack respect for migrant clients and lack an understanding of other cultures. This leads to more children in care or on the at risk register. The thresholds are lower for migrant families.”

For non-English speaking service users the problems are compounded by language barriers:

“The Southern Trust has translated some of its health promotion information, but some of the translations are quite poor.”

“The information leaflets there are aren’t always readily available. Health professionals don’t know about them. There’s a lack of sharing across Trusts. Resources such as the NHS A&E phrasebook should be widely available.

“Generally, there’s a lack of information about services. GPs are unaware of people’ rights and don’t know their obligations in respect of providing translators. Things have improved recently in Dungannon, but not in the rural areas.”

“What’s also needed is to recruit more bilingual doctors and nurses. There needs to be progress on the transferability of qualifications. There are extraordinary barriers and there are qualified doctors and nurses working as clerks. We also need more locums and health visitors from other countries.”

“Leaflets in many languages should be in GP surgeries and other places. These should be produced at Departmental level; every Trust doesn’t need to re-invent the wheel.”
There are other cultural barriers. The health and social care sector is particularly difficult for migrants, asylum seekers and others from outside the island:

“There can be a lack of cultural sensitivity. Assumptions can be made about religious beliefs, such as thinking that all Poles are Catholics. Clergy have been called in without consultation.”

“There can be a lack of respect, such as objections to food being brought to patients in hospital. Nurses have made comments and made excuses about medical hygiene, when that’s not the issue at all.”

“The person who is the patient is not seen.”

“People at the first point of contact such as receptionists need cultural awareness training. There also needs to be a change to the organisational culture.”

“There should be compulsory diversity training – including refresher courses – for HSC staff such as nurses and social workers.”

“The Equality Unit at Knockbracken is a good resource that is not used enough.”

The picture is not entirely negative, however. The SureStart programme in Northern Ireland was recommended as a good practice example that can be adapted and adopted by other public health and social service providers. SureStart has produced guidance to clarify the responsibilities of providers for ensuring the implementation of race equality in early years settings, SureStart’s diversity and equality policy states that,

“Accessible and affordable childcare and early years services are vital for all children and families, and key to developing an equitable society. The Sure Start, Extended Schools and Childcare Group values diversity and is determined to ensure that all individuals are treated fairly, with dignity and respect. It recognises the importance of preparing all our children to live in a diverse, multiethnic society. It is committed to helping ensure that all Sure Start Early Years and childcare services: are open to all; adhere to and implement equality and inclusion policies, procedures and practices; provide appropriate, relevant and accessible activities; provide a safe, supportive and welcoming environment. The Sure Start, Extended Schools and Childcare Group also recognises the need to support practitioners in developing inclusive services.”

Likewise, a scheme under which people from within the Traveller community are trained as health visitors was recommended as exemplary.

CONCLUSIONS

Most of the people who participated in this research are relatively well-informed about the reorganisation of the health services. Many have considerable experience of engaging with health care bodies. Nevertheless, there were complaints from people across the border region that the changes are not well communicated. There is a lack of information until after important decisions had been made. People opposing hospital closures and transfer of services have been offended by what they consider to be unfair characterisations by civil servants and health professionals. People in

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136 Jane Lane, Promoting Race Equality in Early Years, SureStart, 2004.
137 http://www.dcsf.gov.uk/everychildmatters/earlyyears/equalityanddiversity/equalityanddiversity/
the focus groups were aware of the EU directive on doctors’ working time. They also understand the need for a ‘critical mass’ of patients for specialised services requiring capital intensive resources or highly trained medical personnel. While not objecting in principle to the reorganisation of health services and the shift of services from the acute to the primary and community sectors of the health services, people have important criticisms of the implementation of the reforms.

The overriding concern is about the quality of hospital services. The concept of care in the community was popular, but the reality has often not lived up to the promise. There were suggestions more could be done through use of telemedicine, and through health promotion and a greater focus on prevention of illnesses. Many people raised concerns about inadequate ambulance services and threats to cut back the ambulance and A&E services. Reduced access to maternity and life-saving services are among the most frequent complaints about the reconfiguration of services. Similarly, access issues included difficulties in getting to appointments by public transport and the need to take excessive time off work to attend outpatient appointments.

Service users identified a number of examples where they believed scarce resources were not being used effectively. It is believed by many that the reorganisation of health service bodies has not resulted in appropriate rationalisation of management structures and that there is wasteful expenditure on management and administration at the expense of front line services. Concerns were expressed about the “money follows the patient” policy, which it was suggested, could work against the delivery of services in the community and result in less, rather than more choice.

There are many complaints about the pressure on services outside the acute care sector. Rather than enhanced community services, many people complained about the loss of community services that had previously been available. On both sides of the border, there were frequent complaints raised that while services had been removed from their local hospital or a hospital had been closed, the alternative provision had not been put in place. Community care was not being resourced as promised and those hospitals that were offering acute services such as maternity and A&E were being overwhelmed. Hospitals such as Craigavon and Cavan were overcrowded without little or no additional capacity created to accommodate patients who would previously gone elsewhere.

When talking about cuts that had been made to their local hospital services, many people believe that there has been a deliberate strategy of running down viable services until there was not a ‘critical mass’ or until staff became demoralised and went elsewhere, making closure of facilities inevitable.
Others were angry and concerned that decisions were taken by health service planners without any apparent consideration of the wider context and in apparent contradiction to other public policy objectives. Many of the issues raised are outside the remit of health planners, but are extremely important in shaping perceptions and real experience of accessing hospital and other health services. It is the responsibility of both health service planners and government to ensure that health policies and other public policies are consistent in addressing the social determinants of health and health inequalities.
CHAPTER 7: COMMUNITIES’ EXPERIENCES OF PERSONAL AND PUBLIC INVOLVEMENT

ENGAGEMENT WITH THE NEW STRUCTURES

Several health advocacy and other voluntary organisations had extensive experience of lobbying and making submissions on at least some of the key health service policies linked to the ‘modernisation’ and ‘transformation’ processes—although their experience in respect of either feedback or having influenced policy is quite mixed. Organisations generally also had extensive experience of dealing with the Departments (DHSSPS and DoHC), the Health Service Executive (HSE) or the Health and Social Care Board (HSCB), HSC Trusts and Expert Advisory Groups.

For the majority of individual participants, on the other hand, awareness of health service policy is generally limited to what they have heard or seen in the media. There appears also to be limited familiarity with the new consultative structures that have been established on both sides of the border.

“Transformation is a slow process, but there’s no confidence that it will be delivered. No one has painted a vision. There’s no communication.”

Several respondents indicated that they did not consider the “Engage” and “Your Service Your Say” websites useful as consultation mechanism, but rather found it more effective to deal with health service personnel directly. One campaigning group said that they had made a number of comments on the “Your Service Your Say” website, but had never received a response:

“It is useless as it is not consultation or participation, but institutional and dictatorial.”

The majority of people participating in this research, however, had little or no awareness of the websites and had certainly not used them.

“There’s a lack of communication. If you’re not computer literate, too bad.”

Indeed, even some of the health service professionals interviewed are not familiar with their Department’s consultation website.

Some Southern elected representatives – at least those from non-Government parties – are critical of the changes to health service structures, which they consider to be less democratic than the former health boards. Politicians, both TDs and councillors, indicated that they believe they have little or no influence on decisions.
“Consultation has been minimal with public representatives. In fact, our perception was that the HSE did not want their reconfiguration plans to be available to the public or public representatives until such a time as they had advanced them to a stage where it was difficult to challenge the proposals. I realise the historical context in which it has always been difficult to reconfigure hospitals because of local opposition, but in my view, the behind closed doors approach fosters distrust in the public and in public representatives. I believe that a more open and trusting approach is likely to be more positive in the end.”

In the Republic, prior to the restructuring of the health service, politicians were well represented on the health boards and other management structures. Health services were determined locally; now decisions are made centrally and there is less political representation. While there are political representatives on the Regional Health Fora, these are not management structures.

“Before the HSE was set up, people’s voices could be heard. Now we’re told what is to happen. Since the Health Act [2004], there isn’t the same role for elected representatives – we’ve been railroaded.”

“Can a cross-border health service be worse or less democratic than the present set-up? The relationship between the HSE and the Minister is unclear. There’s a lack of accountability.”

“When the health boards were abolished, local politicians were sidelined. The Regional Health Forums are just talking shops. The HSE does what it wants. There’s no accountability.”

“Even the County Council can’t get a meeting with the HSE. There must be accountability from the top.”

“The community has had no involvement in planning hospital services – that is the problem! The community has in fact been excluded from such a role and this has been done to facilitate the disastrous Government and HSE policy of centralisation of hospital services. Elected representatives – except those in Government – have no role in decision-making processes regarding the configuration and deployment of hospital services. … The abolition of the Health Boards removed elected representatives from even a consultative role and put in place the unaccountable bureaucracy of the HSE. The establishment of the HSE also entailed a distancing of the Minister from accountability. For example, an increased proportion of Dáil questions to the Minister, instead of being answered within the parliamentary deadline, were referred for answer to the HSE.”

“It has been frustrating and debasing to engage with the Department of Health and Children and the HSE. We were hoodwinked by the politicians.”

This view is supported by people working within the system. In the words of one health professional,

“Under the new system, there is limited political representation. It’s very dependent upon who the local representative is and not necessarily reflective of the population’s views. Within the HSE there are systems for service user feedback, but uptake is poor. There is no promotion by the HSE to encourage feedback. The CEO has called for people to complain about poor services. … It’s a shame, the HSE is not communicating.”

The National Health Consultative Forum and the Regional Health Fora are not – for the few respondents who have experience of them – meaningful avenues for influencing decisions:

138 Communication to the author.
139 Communication to the author.
“Regional Health Forums are no more than talking shops and have no role whatsoever in the planning of hospital or health services. ...the Forum is essentially a place where the HSE is questioned by elected members and that is as far as accountability and responsibility goes.”\(^\text{140}\)

Similarly, in Northern Ireland, there are criticisms of the winding up of the Health and Social Services Councils, and in particular the changed role of elected representatives.

“The HSS Councils had clout. So they were abolished. The Patient Client Council is a paper tiger. The Southern area got only one place. There are no places for political representatives. Now there’s an application form, an interview. The civil service run the country. The minister appoints on the basis of political balance, not knowledge. The PCC has no presence in Newry and Mourne.”

“There’s a sense of sourness [West of the Bann] about appointments to the PCC. There’s a feeling that there’s a city focus filtering the representation. Councillors’ role on health has been reduced to work on behalf of individual constituents.”

“We were involved in the PCC consultation on their priorities for action. What are the criteria for its decisions?

“The replacement of the HSS Councils with the PCC affects the ‘local’ aspect of dealing with patient issues. When it is a regional organisation, it is less focused on the more ‘local’ or ‘geographical proximity’ issues and more on the bigger picture issues. Representation on the PCC is less ‘local’ too.”

On the other hand, others are more positive about the establishment of the PCC. In particular, they are enthusiastic about the obligation of other health and social care bodies to cooperate with the PCC and its power to enter any HSC facility. However, it is generally agreed – by those who were aware of its existence – that it is still too soon to make an assessment of the PCC’s impact.

Some community activists complained that the decision-making process is chaotic because whatever the plan, it can be changed quite arbitrarily for reasons of political expediency. Elected representatives could not be effectively held to account. Some people shared bitter anecdotes of being encouraged to believe that they had the support of high level politicians, who then acted in contradiction to what they had apparently promised.

Some organisations and individuals indicated that they had worked with their elected representatives and/or political parties and had found this a useful means of engaging on health and hospital issues. Several people were keen to stress, however, that this while this is “an important avenue”, it is “only one of many avenues.”\(^\text{141}\) A patient advocacy group commented that working with elected representatives is a “slow and tedious process.”\(^\text{142}\) Another commented,

“...engagement with elected decision makers on the issues affecting them ... should always be used as a route. However, there are downsides due to the centralised nature of our democracy

\(^{140}\) Communication to the author.
\(^{141}\) Questionnaire response.
\(^{142}\) Questionnaire response.
and political party structures. It is important for politicians to see beyond the political point scoring and to work to get the most acceptable/beneficial outcome for their constituents.\(^{143}\)

A third patient group that has lobbied elected representatives for years, and found it “very hard work”, devised an innovative way of getting the attention of the politicians,

“We offered all the elected members of the Dail and Seanad the opportunity to have their kidney function checked. Over 100 presented themselves. ... They were all afraid, like the general public, of bad news.”\(^{144}\)

While campaigners valued the support of politicians, they are equally anxious to protect their autonomy and not be seen to be too close to any particular party or to have their agendas ‘hijacked’ by party political interests. Some Northern participants questioned whether local politicians, including ministers; actually have any power to decide health care policy:

“The decisions are made by the civil servants. Direct Rule and local ministers don’t have the knowledge to make the complex decisions on things like health care. Local politicians have no influence. We had thousands of people on the streets and it changed nothing.”

Comparisons were also made between the governance of the health services north and south, with the south comparing badly in the views of some southern service users.

“In the North, there’s a level of trust in the service. There’s a pride in the NHS. In the South, there’s a fundamental distrust.”

“The Patient Client Council has some power – we need a Patients’ Charter in the south.”\(^{145}\)

“There are too many vested interests. The politics need to be taken out of it. This is a difference from Northern Ireland.”

**HOW COMMUNITIES HAVE INFLUENCED DECISIONS**

While there were widespread complaints about how the reconfiguration of hospital services was and is being carried out, the picture is somewhat different in respect of consultation with individual service users and patient groups that are in a position to develop relationships with specific health professionals. As will be seen in the cases of Co-operating for Cancer Care NW and the Cystic Fibrosis Trust/Cystic Fibrosis Association of Ireland (see Chapters 8 and 9), organised advocacy groups can influence both policy and the delivery of services. The Irish Kidney Association also expressed the view that they had been able to influence key policies and gave one example:

“Without pressure, the National Audit of Potential Donors, conducted by the HSE, would never have happened. We were shown a draft and had strong influence in correcting some final arguments and conclusions.”\(^{146}\)

\(^{143}\) Questionnaire response.

\(^{144}\) Questionnaire response.

\(^{145}\) A Patients’ Charter is one of the goals of the HSE’s *National Strategy for User Involvement 2008 – 2013* and a consultation on a Patient’s Charter is underway at time of writing.
There are, however, major concerns about whether community-based efforts to influence change are having much impact. Indeed, there some people questioned whether it is possible to influence change at all.

“Community representatives find it hard to be heard on primary health care consultative bodies. We make recommendations but are not listened to.”

“Communities must take what they’re given. The HSE and the Department never listen to the ordinary person.”

“Consultation is very often undertaken after the final decision has been taken. Therefore the ability to influence key decisions can be minimal.”

“Community involvement has influenced planning only to this extent – it has slowed down but not halted the process of centralisation of services, involving the removal of services from hospitals. This exclusion of the community and their elected representatives is deplorable, especially given the level of community concern and active engagement in support of hospital services.”

“I have yet to see good practice in carrying out community engagement on a public policy issue. The outcome has already been decided and the route to the end plan accepted before consultation – which makes it a paper exercise, causes opposition and breaks trust and interest.... It is a waste of time as implementation is as they decide and seldom do they listen to patient views.”

From inside the system, not surprisingly, things can look very different. A health service manager in the North gave an example of a good consultation process that had been negated by a Ministerial decision – and left the Trust to deal with the public’s distrust and anger.

“There was interference by the Minister in the decision. The Minister stopped all closure of care homes despite feedback from the consultation process that the decision should be slowed down. There’s a huge gulf between the Trust and the public. It’s no surprise that people believe the only way to influence decisions is through politicians.”

Some people felt that they had no choice but to campaign against cuts in services but that these efforts had ultimately been fruitless:

“We had a town hall meeting of 7,000, but it was just a political rally. There was no place for real discussion.”

“We had delegation after delegation. We had expert reports. It was all ignored.”

People who had been deeply involved in community campaigns to save their local hospital from closure or oppose the transfer of services are frequently bitter, but still inclined to believe that they have managed to delay the implementation of some decisions. Despite the many setbacks and considerable disillusionment, some hospital campaigners have chosen to regroup and continue to work for the retention of local hospital services. The South Tyrone Hospital Community Forum, for example, is lobbying for the extension of the minor injuries unit and for weekend opening.

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146 Questionnaire response.
147 Communication to author.
148 Questionnaire response.
“If we weren’t organized and still there, it would be easier to withdraw services. There’s a need for vigilance.”

Most seemed to feel in retrospect, however, that they had always been fighting a losing battle.

“The South Tyrone campaign was one of the largest hospital campaigns. It was well supported by both communities even though we were living through the Troubles. Despite a unified community, we still lost services. It was quite a memorable campaign, but it was impossible to fight against the powers that be.”

“[Monaghan hospital campaign] had many meetings with local Councillors, local and national TDs and Senators, Ministers, and the Taoiseach on four occasions, but Minister Harney has continually refused to meet us. All trust has been shattered at this stage.”

While there is widespread frustration and cynicism about the consultation process at community level, people with personal experience as patients with long term conditions did have some positive experiences. For example, a man who had involvement with a diabetic information group in Louth Hospital believed that patient representatives had been listened to and that their opinions had been reflected in changes to services. ‘Patient Involvement’ does seem to be easier for the health services north and south than ‘Public Involvement.’ Although there are serious resource issues, this is an area with considerable potential.

The concept of the ‘Expert Patient’ and self-management for patients with long term conditions have been enthusiastically embraced by professionals and service users in both jurisdictions. The knowledge and experience held by patients with particular chronic diseases such as diabetes, arthritis or epilepsy has been an untapped resource. In recent years, however, research and practical experience have shown patients with chronic diseases need not be mere recipients of care but can become key decision-makers in the treatment process. An English Department of Health report explains the concept of Expert Patient:

“By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. Self-

149 Questionnaire response.
management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy.\textsuperscript{150} 

The Long Term Conditions Alliance, has championed the self-management approach from patients’ perspective:

“... user and patient involvement is in its infancy in Northern Ireland, but has very real potential for improving the patient experience and improving service delivery. Effective user involvement engages patients in their own care, which is vitally important for people with long term conditions. ... Good patient involvement is not easy, and requires time and effort of both sides, but it is worth the effort.”\textsuperscript{151} 

The Northern Ireland Self Management Network – set up in 2008 as an outcome of a self-management workshop organised by HPSS, University of Ulster, the Long Term Conditions Alliance and the voluntary sector – stresses that a major principle of self-management is that it is user-led rather than facilitated by a health professional. The Network offers a range of definitions of self-management, noting:

“Self management may mean different things to providers and individuals. For most people it means developing an understanding of how their condition affects their lives and how to cope with the symptoms. Self management may therefore be defined as a range of resources such as information leaflets, training courses, structured education and one to one support to enable people to develop an understanding of their condition and to actively manage their illness, identifying what support they need and how to find it.”\textsuperscript{152} 

One of the seven goals of the HSE’s Strategy for Service User Involvement is “Patient involvement in their own care.” The Strategy specifies that 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.\textsuperscript{153} The HSE has restructured its Consumer Panels and is currently developing an ‘Expert Patients’ project for the management of long term conditions that will inform delivery of services.

A health professional working on PPI issues commented:

“The consumer panels have worked better in some areas such as renal services and chronic illnesses. They have huge potential to make use of information from service users.”

However, the consumer panels, and other PPI activities, are not always being adequately resourced. The staff responsible for ‘consumer’ involvement frequently have other priorities that take

precedence. They can find themselves and their colleagues with competing action plans on which to deliver and scarce resources with which to deliver them.

“It is getting harder being one of only a few pushing a community health approach. It’s difficult to get things on the agenda. A&E is always top of the concerns and takes up a lot of time. There’s not space to discuss PPI issues.”

“Cost is an issue. We still haven’t sorted out budgets to pay panel members’ travel expenses, or even for the venue or hospitality.”

“It can be difficult to get medical staff to attend Consumer Affairs workshops.”

“HSE staff are demotivated. People don’t feel valued. PPI is seen as an optional extra. The ‘core business’ is the integration of acute and community care. The public are seen as complainers.”

A Northern health service professional commented:

“Managers are so stressed. ... There’s no time to do PPI properly. It’s possible to influence decisions at the blue sky planning stage – key priorities for action plans, low level decisions. But not the big contentious decisions where Trusts have little room to manoeuvre. ... The transition phase should be taking place in a planned way over a decade. But we’re being forced to cut. So engagement with the community becomes about managing the flack. How should we engage at local level about big decisions? How do we bring together complex views? The challenge is about unpopular and complex decisions. How can the Trusts deliver coherently when decisions are being made in a fragmented, cost-cutting way?

There have been other problems identified. For instance in the one Community Health Forum, it has proved difficult to keep professional staff engaged:

“The Community Health Forums elect representatives to the Primary Care team. It worked well at first, but now there’s a split between business and clinical meetings. The community is excluded from clinical meetings. The professionals are reluctant to attend business meetings.”

WHAT WORKS BEST?

One example of good practice in carrying out consultation or community engagement on a public policy issue or programme that was suggested by some health advocacy organisations was the Health Service Executive’s Intercultural Health Strategy,\(^\text{154}\) which was developed on foot of the National Action Plan against Racism. The Strategy Steering Group comprised HSE and DoHC representatives, along with representatives of the Ethnic Minority Health Forum, the Immigrant

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Council of Ireland, Cáirde, NCCR Pavee Point and Spirasi, who made up one-third of the membership. The Strategy was developed through an extensive series of national consultations with service users, statutory and voluntary sector, NGOs and HSE staff. Interested stakeholders were invited to engage in a pre-consultation exercise to give their views on the current provision of health and support services to persons from diverse cultural and ethnic backgrounds together with suggestions around the enhancement of the development of these services. The pre-consultation exercise was used to shape a series of focused questions that were used in the subsequent major consultation events. These events were extensively advertised in several languages and through a wide range of health service, commercial and community outlets. Supports around interpretation and childcare were offered to facilitate optimal participation by service users in the consultations. A broad range of people attended the consultation events, with Travellers and asylum seekers being particularly strongly represented. HSE staff who participated in these consultations also represented a range of disciplines, with people involved in direct service delivery, including public health nurses, therapists, and medical doctors especially prominent. All themes emerging from the consultation process were reflected in the report of the consultations and are incorporated, as far as is possible, into the strategy. Perhaps most importantly, the outcome of the consultation exercise was a Strategy that linked specific actions to the issues identified.

Another example of good practice is Levelling Up - Ireland’s first Cross Border Plan for Social Inclusion, led by the Derry Well Woman Centre.

“It was done from the ground up, highly inclusive of diversity and validated the community development approach. It was based on women’s experiences and an assumption that institutions should serve the people.”

Almost 400 individuals and 60 organisations as well as political parties, were involved in the process of developing this plan. Those involved are members of the Cross Border Women’s Health Network, a cross border partnership of statutory, voluntary and community sector organisations based within the North West of Ireland working together to improve health status and reduce health inequalities. A chapter of their report is devoted to detailing the key stages in the process of developing the plan. The starting point was a commitment to the Health For All principles (see box). The additional elements of good practice identified by the Cross Border Women’s Health Network include:

- a commitment to addressing poverty and social exclusion in the border area and increasing cross sector and cross border work;
- a clear purpose to improve health status and reduce health inequalities;
- building on a strong and credible foundation of previous work;

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- a determinants focused approach was dependent on a public health rather than a medical model of health care – central to which was the creation of an efficient cross-sectoral and cross border partnership
- having the right people involved to ensure a sense of ownership by a broad section of society;
- a cross border agenda relevant to women from the North West of Ireland;
- a series of Cross Border Negotiating Change Workshops during which specific cross border actions to give life to the agenda were drafted
- a cross border Negotiating Change Forum at which the case for political change was presented to Politicians to secure political buy-in

Despite a somewhat fraught history with consultations on the reconfiguration of hospital services, Health Service bodies are also able to offer good practice models for community consultation processes. The Western HSC Trust consultation scheme for the 2006 Section 75 review,\(^{156}\) based on the Equality Commission’s guidelines, was adopted by all the Northern Ireland Health and Social Care Trusts. The WHSC Trust’s *Disability Action Plan*, produced in partnership with the other four HSC Trusts, has also been recommended as an example of good consultation process.

“When developing the Plan, the Trusts contacted a wide range of organisations and individuals. From their comments, common priorities relevant to all the Trusts were identified. The Trusts realised that their Plans would be more effective if they agreed key actions that they would all take forward, regionally and locally. This partnership approach aims to maximise the positive impact on disabled people who live and work in all five Trust areas. The actions set out in this Plan were developed from the many contributions received from the groups, organisations and individuals listed ....”\(^{157}\)

**HEALTH FOR ALL PRINCIPLES**

**Equity** Existing inequalities in health must be reduced so that the poorest and most vulnerable sections of the community enjoy similar levels of health as the better off

**Empowerment** Given the necessary improvements in social and environmental conditions, individuals should be enabled through health promotion to realise their full physical and mental potential

**Participation** Communities should be well informed and be supported to participate in decisions affecting their health and sense of wellbeing

**Inter-agency Cooperation** All sectors – statutory, business, voluntary and community should work together to develop strategies that will bring about health improvements

**Local Primary** Health Care Community needs will best be met through services provided as near as possible to where people live and work, readily accessible and acceptable to all, and based on community participation

**International Cooperation** Countries need to cooperate to address health problems that transcend national boundaries

**Healthy Public Policy** To ensure that environments are developed that bring long term health benefits

**Sustainability** Ensuring that the quality of the environment and the health of the population are protected.

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**WHAT NEEDS TO CHANGE? HOW CAN CONSULTATIONS BE IMPROVED?**

Participants in one focus group made the point

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that there is a very different culture of consultation in each of the two jurisdictions. While there has not been a ‘Social Partnership’ process in the North, there has been a long standing obligation on the part of public bodies to consult with their ‘stakeholders’. In the South, the understanding of consultation is very different.

“In the South, there is no culture of consultation. Social Partnership is not a reality; the understanding of consultation is very different. The community and voluntary sector in the North is highly professionalised. Consultation in the South is reactive to the ‘hot potatoes’. You have health activism in the voluntary sector, but not so much in the community sector.”

Some people suggested that a lack of community networks in the South is an impediment to consultation: “How do the health services consult? Who are they consulting with?” It was also suggested that tensions between elected representatives and the community and voluntary sector about who should speak for the community presented some problems, although this can be an issue on both sides of the border.

A complaint by several of those who had made written submissions to health service consultations was that while in some cases, meetings had been organised to provide general feedback, frequently they had received only an acknowledgement of their contribution. There were also complaints about consultation processes that appeared to be skewed to get a particular set of results,

“I can’t see any real benefit to their [DHSSPS] consultation processes – they’re really only to string out decisions. They use templates with questions that lead to the answers they want.”

“The agency responsible for the consultation exercise should publish the range of participants and their comments and indicate how or not the views have influenced their deliberations and decision making processes.”

The major factor that needs to be addressed may in fact be the lack of trust by the public in public consultation processes.

“Service user involvement does not exist. Service users who say the wrong thing are sidelined and excluded.”

“People give their opinions, but what happens then? Who listens? There’s never feedback. We’re constantly making the same points. Nothing ever changes.”

“There’s consultation fatigue. We’re inundated with things like consultations on cleaning fluids. But no one wants our opinion on patient transfers.”

“The legislation requires them to consult, but it’s just a box ticking exercise.”

Asked how this mistrust could be overcome, people in focus groups across the border region replied that change must be driven from and supported by, those at the top of the health services. There needed to be evidence that in asking for views of patients and the public, that these views would be genuinely listened to, and that consultation would bring change. There needs to be honesty in letting people know what is not negotiable.
“Communities will find it difficult to believe – there’s no trust at local level. It would need a visible and cohesive approach from the top – led by the HSE and the Minister.”

“Evidence and good practice models are not enough. There’s a need for a shared vision and a belief that change is possible.”

“There is a need for honest representation of the data and to listen to the public.”

“Decision-makers need to demonstrate that they have listened. They need to be held to account. They don’t understand life in rural areas. There are too many people from the east making decisions. We need more local input into decision-making bodies, but not if they are just talking shops. Community people don’t want to be held responsible for decisions that they can’t really influence.”

“Honesty is good practice. Be clear about the limitations.”

The importance of honesty was also stressed by a health service manager,

“We need to make information honest and accessible. What are the hard choices and why are they being made?”

As will be seen from the case study on cancer care in the North West (see Chapter 9) the picture is not an entirely negative one, but the voluntary efforts put into community campaigns are not sustainable in the long term and certainly would be a deterrent to many people. Those who have been through the bruising process of an extended campaign such as that around the Monaghan Hospital or the campaign in Omagh (see Chapter 10), will be hard to convince that a request for their participation in a future health service consultation is offered in good faith and the efforts expended are worth the results obtained.

Asked to identify what they considered the essential elements of good practice in community consultation, focus group participants on both sides of the border came up with similar priorities:

- Communities must be involved at all stages;
- There must be leadership and commitment to community development approaches from the highest levels;
- Need for skills development on part of consulters and consultees;
- Health professionals need to hear real life experiences;
- Consultation must be meaningful – decisions must be open to change.

Too often, however, people who have engaged with public bodies – including the health services – say they have encountered a culture that is hostile to community development approaches. Rather than offering a supportive environment, resources have been withdrawn from community reference groups.

“The community is treated as valuable only so long as we are deemed useful. Then the rug is pulled from under us.”

“There are forums in local areas, but community input is not valued or taken seriously.”

“Real consultation takes place on local radio.”
This picture is not by any means universal, however. Good practice examples from the Western HSC Trust have been referenced above. The Southern HSC Trust, under the umbrella of its Promoting Well Being Department, provides community development support through its User Involvement and Community Development teams, and actions and key targets within the Trust’s Promoting Well Being Action Plan. “These are reflective of the SHSSB Community Development Strategy 2008-2009 Working in Partnership, the ongoing needs of local communities and the work of the legacy Trusts.”

The Promoting Well Being Department works across all Directorates and Programmes of Care within the Trust. The staff complement includes a Head of Service for User Involvement who is also the Professional Lead for Community Development and two User Involvement Development Officers. Building on the work of the legacy trusts (pre health service reorganisation) the Southern HSCT developed a PPI Action Plan Framework. Following an extensive consultation process, the Trust conducted a mapping exercise to identify and evaluate existing user involvement and Directorate baseline reports provided the basis for PPI action plans that are reflected in the Trust’s overall PPI Action Plan. The Southern HSC Trust’s PPI team has developed a ‘toolkit’ for staff that includes a poster, leaflet and fact sheets, detailed PPI monitoring template for use by project teams within the Trust as well as guidelines and procedures for recruitment and selection to a PPI panel and reimbursement to service users.

The Southern HSC Trust’s consultation report does note that Personal and Public Involvement is not a new concept and that responses to their consultation reflected many negative and positive experiences over the years. While negative experiences were referenced, however, this was not the main focus of responses and respondents identified their willingness to work with the Trust to improve the involvement of users and carers. The Trust’s Draft Action Plan Framework identifies five levels of engagement. Feedback to the Trust’s consultation, did however, reflect the difficulties of engaging at different levels:

**Level One** – Service Users are directly involved in the planning, delivery and monitoring of their individual care or service either at home, in the hospital or in the wider community: ... it was highlighted that ... where the ultimate decision making lies very much with what can be done within the Trust’s budgetary constraints creates a reluctance to ask for additional assistance in case it compromises existing provision. ... that there is a need to begin to work more closely in partnership to come up with innovative solutions. This will require Trust staff to be open to sharing information differently and to shift the power balance from those who hold information/power to those who need information/power.

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158 Promoting Well Being Department Update, Southern Health and Social Care Trust, Armagh, January 2010.
159 The Draft Action Plan Framework to enhance Personal and Public Involvement within the Southern Health and Social Care Trust, Consultation Report, Southern HSC Trust, March 2009.
160 Promoting Well Being Department Update, op.cit.
161 “Record of PPI Activity”, Southern Health and Social Care Trust. No date.
Level Two – Individuals, families, carers and the community are supported to influence and shape the provision of care and the quality of services provided: Feedback from the voluntary/community sector suggests that this is not happening to any large extent although there appears to be some movement in this direction within the Disability Directorate and that this is to be welcomed.

Level Three – Individuals, families, carers and the community are supported to influence and shape the planning, development and delivery of services on specific issues or areas.

Level Four – Service Users, carers and communities are actively involved in strategy development, including needs analysis, planning, commissioning and changes to significant areas of service development and provision.

Level Five – Communities, stakeholders and partner organisations are actively involved in shaping the corporate and organisational priorities and the overall direction of the Trust: It was identified that while at an organisational level there is much more involvement than there would have been pre RPA; there is little evidence of individual’s families and carers being greatly involved. However, it is recognised that this is at an early stage.  

Letterkenny Hospital has undertaken surveys of both inpatients and outpatients and it has a Patients’ Forum that meets bi-monthly. The Forum is publicly advertised and membership is open. Senior staff, including the Director of Nursing and the hospital’s Clinical Director attend. A review of the hospital’s visiting policy was undertaken and the policy amended in response to feedback from the Patients’ Forum. The Patients’ Forum will also be involved in peer review of the patient information booklet.

Some focus group participants suggested that in addition to better information, there needed to be more support offered to allow people to engage effectively.

“Community groups are not skilled to express concerns about health.”

“Real consultation requires tenacity and persistence. There is a need to build capacity. Identify goals and how to achieve them. We need shared goals and an end to clientelism and independence of community voices.”

It was suggested that other weaknesses of the community and voluntary sector also need to be addressed; there is too much competition between voluntary organisations.

162 The Draft Action Plan Framework to enhance Personal and Public Involvement within the Southern Health and Social Care Trust, op.cit.
Some health service bodies have been more proactive than others in offering training for staff in delivery of PPI strategies. In the South, there has been some success with consumer panels in the primary care sector. Indeed, the HSE’s Community Participation Primary Care Funding Initiative may be a model that can be adapted. The 19 projects under this Initiative were each funded between €10-15K to support development of relationships and joint working between Primary Care Teams and community organisations. Of these ten have established or are in the process of establishing Community Health Forums; and six have carried out joint training (with PCT members and community representatives). This has helped to establish joint working practices and in some cases a basis for further consultations in the community. Two projects have dealt specifically with the needs of ethnic minority communities.

While there is interest by both community campaigners and health service personnel in the idea of a joint community/health service cross border programme aimed at developing better community involvement strategies, several health service professionals considered that particularly in the present economic climate, it would be difficult to get staff released and to pay for travel.

“Training for staff must not take up too much time. It must be mandatory, preferably located at the workplace, and timing is important. It’s hard to free up time and the manager must agree and ensure that key people are given cover.”

Innovative ways of delivering a programme specific to the acute sector would need to be explored in order to ensure the commitment and full participation of health service personnel.

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**Lessons from the HSE**

**Community Participation Primary Care Funding Initiative**

- The need for resources to sustain of community participation in the long term;
- The importance of community consultation in disadvantaged communities and a focus on the wider context of health;
- The importance of establishing representative structures in the form of Community Health Forums, which can nominate community representatives to sit on Primary Care Teams;
- The need to understand the different backgrounds and roles of community and HSE representatives, and methods to promote joint working and reconcile different perspectives and working methods;
- The role of external facilitation and support has been very important to project activities; in particular external facilitation can be very helpful as it brings objectivity and independence to meetings;
- The HSE in the future can utilise expertise from its own staff, supports and networks, which in turn will be vital to supporting community participation in the future.

CONCLUSIONS

Several health advocacy and other voluntary organisations had extensive experience of the key health service documents, although their experience in respect of either feedback or having influenced policy is mixed. The awareness among majority of individuals to health service policy is generally limited to what they have heard or seen in the media.

There appears also to be limited familiarity with the new consultative structures on both sides of the border. Most of the specific criticisms of the new consultative and governance structures came from elected representatives. Politicians from across the political spectrum and on both sides of the border consider the new structures to be undemocratic ‘talking shops’.

Some community activists complained, however, that the decision-making process is chaotic because whatever the plan, it can be changed quite arbitrarily for reasons of political expediency. While campaigners valued the support of elected representatives, there were mixed views about working with politicians. Community activists are anxious to protect their autonomy and not be seen to be too close to any particular party or to have their agendas “hijacked” by party political interests.

There is some question about the power of local politicians, including in the North, ministers in the NI Executive and their Direct Rule predecessors.

The major factor that needs to be addressed may in fact be the lack of trust by the public in public consultation processes. Participants in this research expressed an extremely high degree of cynicism, distrust, and ‘consultation fatigue’. They felt decisions were already made in advance of the consultation process – then imposed from the top irrespective of the depth of public opinion. They are angry about what they consider to be a series of “broken promises” about how services would be enhanced and improved, while the experience on the ground had in reality been a loss of local services with increased pressure on those facilities where services had been transferred. People who have engaged with health service bodies say they have encountered a culture that is hostile to community development approaches. There were frequent complaints about lack of information and poor communication.

The picture is not an entirely negative one, but the voluntary efforts put into community campaigns are not sustainable in the long term and certainly would be a deterrent to many people. Those who have been through some of the most bitter community campaigns around hospital closures will be hard to convince that a request for their participation in a future health service consultation is offered in good faith and the efforts expended are worth the results obtained.
‘Patient Involvement’ does seem to be easier for the health services north and south than ‘Public Involvement.’ Although there are serious resource issues, this is an area with considerable potential and both health services are making some progress. Both organised patient advocacy groups and individual patients with chronic illnesses reported that they had had some influence in respect to policy and delivery of services in areas such as cancer care, diabetes, renal and cystic fibrosis services. The HSE’s *Intercultural Health Strategy*, the Cross-Border Plan, *Levelling Up –Securing Health Improvement by Promoting Social Inclusion*, and the Western HSC Trust’s *Disability Action Plan* were all cited by research participants as examples of good practice in consulting with service users. The work of the Southern HSC Trust’s Promoting well Being Department and the HSE’s Community Participation Primary Care Funding Initiative also provide useful models for implementing a holistic approach to PPI.

While there is widespread frustration and cynicism about the consultation process at community level, people with personal experience as patients with long term conditions did have some positive experiences. The concept of the ‘Expert Patient’ and self-management for patients with long term conditions have been enthusiastically embraced by professionals and service users in both jurisdictions. The knowledge and experience held by patients with particular chronic diseases such as diabetes, arthritis or epilepsy has been an untapped resource. In recent years, however, research and practical experience have shown patients with chronic diseases need not be mere recipients of care but can become key decision-makers in the treatment process. The elements of good practice are well documented and enshrined in the PPI policies of both health services. Good practice models do exist, however PPI activities are not always adequately resourced. The staff responsible frequently have other priorities that take precedence find themselves in competition for scarce resources.

While there is interest by both community campaigners and health service personnel in the idea of a joint community/health service cross border programme aimed at developing better community involvement strategies in the present economic climate, it will certainly be difficult to get staff released and to pay expenses for such a programme. Innovative ways of delivering a programme specific to the acute sector would need to be explored in order to ensure the commitment and full participation of health service personnel.
CHAPTER 8:
CROSS BORDER ISSUES

Among both service users and health professionals, a strong consensus for more cross border cooperation is one of the clearest messages emerging from this research process. The sharing of hospital and other health services is recognised as logical and cost effective. However, health professionals said that they did not have enough information about what is being done on the other side of the border and that they would like more contact with their counterparts. Likewise, service users expressed a desire to know what services are available and what their entitlements are in using services in the other jurisdiction.

The difference in funding regimes north and south is probably the greatest single factor that deters people from accessing services across the border. It has been suggested that there is a significant use of hospital services in the North by former Northern Ireland residents who are now resident south of the border; however, it is not possible here to assess the numbers of people to which this would apply. There is also a relatively widespread perception that the quality of public services in the South is not as good as those in the North. Research participants gave anecdotal accounts that indicate there is a significant level of traffic by private patients in both directions. For example, some people attending focus groups in the North referred to people travelling to the Mater Private and Blackrock Clinics in the Republic. It is not possible to know, however, whether the treatment of Northern patients attending these facilities was paid for by their respective HSC Trust personally financed. Travel North for treatment by patients from the Republic is – at least in the case of Daisy Hill hospital in Newry – by the statistics. More than one in every eight babies born at Daisy Hill in 2009 – a total of 289 babies – was born to a mother from the Republic. While the explanation offered by research participants for choosing Daisy Hill over the Our Lady of Lourdes in Drogheda was concern about standards in Drogheda, the significant difference in consultants’ and hospital fees must also be a factor.\(^\)\(^\)\(^a\)

CAWT – A MODEL OF GOOD PRACTICE

The work of Cooperation and Working Together (CAWT) is well respected among those who are aware of it. There is much praise for CAWT’s strategic role and the fact that it had been able to overcome administrative and cultural barriers to deliver vital services such as diabetes and renal care on a cross border basis. CAWT, however, is not able to replace services already existing on one

or other side of the border, and there is much concern among those familiar with CAWT that its current level of programmes will not be sustained when the EU funding that supports them is withdrawn.165 People in the focus groups convened for this research recognized CAWT’s role:

“CAWT is a good example of cross border co-operation. But it’s all project funded and almost all their money is from the EU. There needs to be mainstream funding for cross border health and social care projects. There are no other cross border social care projects other than what CAWT is doing.”

“The CAWT concept of cross border care should be expanded. What will happen after 2013?”

Similar views were expressed by a health professional interviewed for this research:

“People don’t know about CAWT. Only those within the system know about it. In the South, the perception is that CAWT is more of a northern thing. Huge money has gone into CAWT, but is it being mainstreamed? You hear about CAWT training, what are the outcomes? What joint projects or shared services have developed as a result? How sustainable is it?”

**POSSIBILITIES FOR CROSS-BORDER SERVICES**

Among members of the public, health advocacy groups and health service professionals, there is enthusiasm for an extension of cross border arrangements for hospital and other health care services. The priority is that services be of high quality, physically accessible and affordable.

“The first decision needs to be on what is the region? There are natural catchment areas. A&E, acute medicine, and Intensive Care must be close to communities. People don’t care which side of the border it’s on. They want to know they’re in safe hands.”

“We support any initiative that would improve the access and health of those people living in border areas. Our members in the North West have been participating in a number of initiatives to improve access. Members are strong in their opinion that whilst it is reasonable to travel for specialist services, there needs to be strong community-based health services in place for public patients on both sides of the border.”

People participating in the research were able to make a number of specific recommendations about what some of the services that should be prioritized for cross border arrangements. Mental health services were raised by people in more than one focus group as being a priority for cross border reorganisation. Likewise mental health professionals indicated that the border currently impedes the delivery of care to residents of the other jurisdiction after they are discharged from acute care, 165 CAWT’s role is to facilitate cross border health and social services. Their primary programme of work is to deliver the European Union INTERREG IVA Priority 2, Theme 1, “Putting patients, clients and their families first” on behalf of the Department of Health, Social Services and Public Safety, Northern Ireland and the Department of Health and Children, Republic of Ireland. CAWT also delivers other cross border projects on behalf of its partner organisations and the Departments of Health in both jurisdictions. On behalf of the Departments of Health, CAWT is managing the implementation of 12 EU INTERREG IVA funded large scale cross border health and social care projects. The projects have been categorised into five strategic themes: Acute Hospital Services; Primary, Community and Continuing Care (PCCC); Mental Health; Population Health; and Disability. Under INTERREG IIIA, CAWT managed funding in the region of €10.45m / £6.74m for thirty-seven cross border health and social care projects and a further seven PEACE II funded projects to the value of €1.57m / £1.08m.
because it is not possible to provide after care and liaison with primary care providers on the other side of the border.

“If a Northern patient is detained in a [Southern] acute mental hospital, the patient must be kept in hospital or discharged. There are no transfers to community based or home based nursing care.”

There are also problems in arranging transport for a patient who lives in the North on being discharged: “An ambulance brings them in, but it’s harder to get them taken out.”

As will be seen in Chapter 8, a radiotherapy unit at Altnagelvin Hospital in Derry that will provide services for cancer patients from both sides of the border is planned, and expected to come on line in 2015. This unit will make a tremendous difference for cancer patients in the North West and hopefully, will lead to closer relationships between professionals in the region and the further development of shared services. Hydrotherapy is another service that people in Donegal might prefer to access in Derry.

Similarly, there is a proposal for a unit to be developed at Altnagelvin Hospital in Derry that will serve people with Cystic Fibrosis in the North West and border areas. It is the view of those who are involved in planning this service that this example of cross border cooperation will make a significant difference to people with CF who will no longer have to travel long distances for the care they need. (See Chapter 9.)

“Cross border co-operation offers much scope for delivering cost effective and efficient health care provision. Needs that could be addressed through cross border services include renal services, cancer treatments, mental health provision, diagnostic services, etc.”

There is a strong demand for greater sharing of ambulance services on a cross border basis. There are some operational problems to be addressed, however. There was anecdotal evidence, for example, about an unnecessary delay because of decisions to wait until an ambulance was available from the Dundalk depot, rather than call for an ambulance from the northern side.

“There’s only one Advanced Paramedic for all of County Monaghan and parts of Louth and Cavan. What happened to the promised advanced ambulances with Advanced Paramedics? What happened to the pilot Civil Defence defibrillator service?”

There are concerns that the Clones to Cavan road is frequently closed, causing ambulances to detour. Once again, rurality and distance are big issues:

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166 Advanced Paramedics are trained and accredited to administer drugs and advanced airway procedures. Civil Defence is an organization of approximately 6000 volunteers trained in skills such as First Aid, Search and Rescue, Fire Fighting, Boating Techniques, Radiation Monitoring, Radio Communications and Welfare Provision. Civil Defence Units are located in each county in the Republic of Ireland.
“People with heart attacks have to go to Craigavon. That means the ambulance travelling 50 or 60 miles.”

There are also opportunities to develop existing cross border arrangements, for example:

“The use of haemodialysis centres in the North is very helpful. The border counties haemodialysis units and Northern haemodialysis units share a common computer software to allow ease of transfer of patient information. Many more patients could avail of Northern services.”

“There could be more cross border cooperation in promoting or delivering health care services in pregnancy, diabetes awareness and diabetes education for children and adults. People in the border counties should have the option to attend the closest centre.”

Perhaps the most frequently expressed concern among research participants is that centralisation of hospital services has resulted in a loss of acute and other hospital-based services locally available to people in the border counties. They are aware that the pattern of reconfiguration has been similar on both sides of the border, and thus are supportive of any prospect of services being geographically accessible within the border region, irrespective of which jurisdiction it is located. A Monaghan resident attending the Castleblayney focus group commented, for example:

“Hospitals cannot offer all services to all patients as there will be duplication of services in an unsustainable manner, but we should be able to look North as well as South. One hour and ten minutes takes us to Belfast, but it takes more than two hours to reach a hospital in Dublin.”

The closure of Monaghan General Hospital, along with the loss of services in Tyrone and elsewhere, is of concern to people, but it was suggested that Monaghan and Armagh could between them create sufficient demand for shared services. There is considerable interest – particularly among people living in Cavan and Leitrim – in the planned new hospital in Enniskillen. Meanwhile, they missed having the option of using services in Monaghan.

“We’ve lost acute services in the whole central border region. Decisions should have taken into account what existed and what is planned for the other side of the border.”

“Prostate services in Monaghan served Northern patients as well. Monaghan ENT patients could go to Omagh. Now Monaghan patients have to travel all the way to Dublin.”

“Monaghan was a real loss to people in this area. Once you’re been admitted, the medical care in Cavan [General Hospital] is good, but there’s bad management and it’s overcrowded. There’s no fracture clinic. It would be better to go to Enniskillen than to Drogheda.”

Even people in Fermanagh seemed to be unsure of what services would be available in their new hospital and are anxious to have the hospital open.

**Concerns about using cross border services**

Irrespective of the fact that some people felt that they had no choice but to opt for private care because of long waiting lists, how services would be paid for and how much they might cost were

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167 Questionnaire response.
168 Questionnaire response.
probably the most frequently raised concerns about accessing acute and other health services in the other jurisdiction. Most Northern residents who are used to the NHS model are unwilling to pay – often substantial amounts – for services at the point of delivery. Southern residents are worried about whether medical card holders and those with insurance would have the same access to services in the North. Even for those with insurance, there are concerns about whether hospital costs incurred in the North would be covered. Some people reported problems they had had with VHI in getting reimbursed for scans in the North, despite having been referred there for treatment.

“You would need reciprocal agreements for cross border services. There are vast differences in service delivery and very different funding regimes.”

Privatisation – creeping privatisation in the North and privatisation as a central element of health service policy in the South – is a major issue. There is already significant travel by patients in both directions – several people referred to people being sent to the North under the National Treatment Purchase Fund and as noted above, Daisy Hill in Newry attracts large numbers of southern maternity patients. Despite doubts about the quality of public hospitals in the South – according to focus group participants – Blackrock, St James’s and the Mater Private Hospitals serve significant numbers of patients from the North. Nevertheless, the NTPF and the two-tier model of acute services are seen as major threats to the development of quality public services.

“The business for-profit model is not appropriate.”

“The National Treatment Purchase Fund is part of the drive to privatisation. Hernia operations could be done in Monaghan for €7,000. They were costing €60,000 in Liverpool.”

“The NTPF is a way of subsidizing the profits for some.”

“Private interests are undermining cross border solutions.”

“The conflicts of interest are staggering. The experts formulate government policy, but then undermine it through their private interests. One example is the private radiation service in Waterford.”

This concern about privatisation is also reflected in the views of the voluntary organizations who responded via questionnaire:

“We are extremely concerned about the increased level of privatisation within the public health system. We believe that recent policies concerning tax breaks for the building of private facilities, the co-location of private hospitals on public sites and the perverse incentives created by the National Treatment Purchase Fund will not bring the nation any closer to the vision expressed in the National Health Strategy, Quality and Fairness.”

“The instigation of commercial haemodialysis centres [in the Republic] has been conducted in a poor manner. ‘Tendering’ for delivery of treatment has not worked.”

It was suggested that there is a substantial demand on health care services from people now living in the South who retained Northern Ireland National Insurance numbers. This placed additional demands on services that are not in health budgets based on capitation formulae. In particular,
Craigavon and Daisy Hill were identified as having a significant number of service users from the South who are being treated on the NHS. It is hard to know, however, whether at least some of these patients are in fact private patients paying for the use of services in the North.

Concern about quality of services in Southern public hospitals was also frequently cited as the reason that people living in the North would be reluctant to seek treatment in hospitals the Republic:

“People in the North might be reluctant to cross the border. There are fears about quality and safety. You just have to listen to the Joe Duffy Show sometimes.”

“There’s a lack of confidence in Southern services, a perception that the quality is lower, although, when you get into the system there are high standards of care and compassion. It’s access that’s the real problem.”

“Newry people would not go to Dundalk or Drogheda. They have bad reputations; but they would go to Blackrock, the Mater and St James’s.”

A health service professional offered an additional reason for the tendency for cross-border flow of patients to be mainly South to North, noting also that there can be problems about after care when services are purchased on an individual private patient basis:

“There is a huge use of maternity services at Altnagelvin. Patients from the South paid to go privately, because until recently there was a lack of epidural services in the South. Therefore there were differences in follow-up for babies after discharge. Why are patients travelling north? Because the services are not in the South. There’s a perception that cross border relations can’t be developed because both North and South are at capacity. Why aren’t resources being invested?”

It was claimed by some participants that Southern GPs are reluctant to refer patients to the North and that there are issues about the non-compatibility of treatment and drug regimes.

Equality of access is a major concern in respect of whether patients would be prepared to use services in the other jurisdiction. There are concerns, for example, that patients from outside the jurisdiction would not be given the same priority; indeed, some people suggested that there is already a problem for residents of Northern Ireland in accessing hospital services if they are living beyond that hospital’s catchment area. Some people claimed that there is a bias against Southerners within the Northern health service and that patients from Donegal had experienced problems in getting beds in Belfast. On the other hand, they also suggested that there had been a small take-up by Donegal cancer patients under the agreement that allowed them access to treatments in Belfast.
People living on both sides of the border are enthusiastic about the prospect of increased cross border cooperation and sharing of services. Those from the southern side, however, suggested that there needed to be “co-operation in both directions”.

“Cross border collaboration always seems to be one way. There’s investment in the North – for example the radiotherapy unit in Altnagelvin – so the infrastructure is all being consolidated in the North.”

“Is there really any willingness by people in the North to travel south for health services?”

Some Southern focus group participants, however, suggested that cross border cooperation is still a very sensitive political issue and that, as a result of the Troubles, “some people still have fears about crossing the border.” Northern research participants insisted that “there are no chill factors,” and that “politics should be left out of it.” Political concerns about cross border co-operation were, it was claimed, not shared by most people living in the border region, who were more concerned about access to care in an emergency.

“Service users would be happy to use services wherever they are delivered, but people outside the border region can block change for political reasons.”

One man commented,

“I am a staunch unionist. But I’ve no problem whatsoever with any blue light service going anywhere it’s needed. If a life is in danger, they should be treated at the closest place. It doesn’t matter what side of the border it’s on.”

As noted above, physical access remains one of the most pressing concerns in respect of emergency, elective and outpatient hospital services. This could be alleviated by making it possible for people living in border communities to have equality of access to services irrespective of what side of the border they are located. It is also suggested that this greater choice would help to raise the standard of care.

Many people would prefer to travel North or east rather than south (Dundalk to Newry and Craigavon), Cavan/Leitrim to Enniskillen or Derry, Donegal to Derry and Belfast).

“People in Monaghan don’t have any choice. In an emergency, it’s either Cavan or Drogheda. If it’s for an elective procedure then it might be Dublin. For people in north County Monaghan, it would be easier to go to Belfast or Derry.”

For migrant workers and people from ethnic minority communities there are other issues about accessing cross border services. There are security barriers: even though there is a common travel area in operation, identity checks at the border can discourage or prevent people from crossing. If a person’s passport is held by the Home Office, not only can the person not cross the border, he or she is prevented from accessing GP or other health services. In theory, legal entrants should have
freedom to travel, but identity checks that are carried out on buses from Donegal to Dublin, for example, are a deterrent.

“There’s a fear of crossing the border because of immigration hassles. There’s a lack of understanding of people’s right to use services.”

**NEED TO PLAN FOR CROSS BORDER SOLUTIONS**

In the focus groups, particularly in Castleblayney, Letterkenny and Dundalk, there was reference to the *National Spatial Strategy* – a twenty-year planning framework designed to deliver more balanced social, economic and physical development between regions and, “provide a framework, in conjunction with the Regional Development Strategy for Northern Ireland, *Shaping our Future*, for the spatial dimension of the development of an all-island economy”. The *National Spatial Strategy* identifies Letterkenny/Derry, Sligo and Dundalk, as the large towns in the border region that have the potential capacity to become gateways and lead development in their regions and play a key role in achieving more balanced regional development. (Dublin, Cork, Limerick/Shannon, Galway and Waterford are the existing gateway cities). Gateways are defined as having a strategic location, nationally and relative to their surrounding areas, and providing national scale social, economic infrastructure and support services. A gateway town is characterized, among other things by a regional hospital/specialised care. Letterkenny/(Derry) is identified as a ‘linked’ gateway. A linked gateway is one in which two or more strong towns work in partnership to promote economic and social development in their region.

Both the Regional Development Strategy for Northern Ireland 2025, *Shaping Our Future*, and the *National Spatial Strategy* provide planning frameworks that enhance the potential for joint strategic co-operation and North/South economic activity. The National Spatial Strategy makes reference to the 2006 *Comprehensive Study on the All-Island Economy*, commissioned by the North South Ministerial Council, that highlighted the challenges, including long-standing regional imbalances and disadvantaged border regions, facing both economies. The *Comprehensive Study on the All-Island Economy* advocated strategic economic co-operation to take advantage of economies of scale and facilitate the adoption of co-ordinated approaches to capital and infrastructure investment.

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170 Ibid.
171 Ibid.
The National Spatial Strategy outlines the selection rationale for these designations:

“Derry is the fourth largest city on the island. Given its size, location and functions, Derry has been identified as a major regional city for the North-west including Donegal in *Shaping our Future* the Regional Development Strategy for Northern Ireland. Derry’s role has been reciprocated in the *NSS* in that Letterkenny has been identified as having a spatial and developmental function that could be co-ordinated with that of Derry to enhance critical mass and energise the wider Donegal and North-western areas. Letterkenny is a significant centre in its own right, as the focal point of transport networks in Donegal, having substantial capacity for development, good education (with Letterkenny Institute of Technology) and healthcare facilities as well as good connections to Derry, itself an important transport hub.

“Dundalk is one of the largest towns in Ireland and occupies a strategic position between Dublin and Belfast, proximate to the border with Northern Ireland. Dundalk is on nationally strategic road and rail links and is well positioned spatially to energise eastern parts of the Border area. Dundalk has substantial capacity for development in land and services terms and contains important facilities such as the Institute of Technology. Taking account of these strengths and the issue of ensuring development within the Dublin-Belfast corridor as well as at either end, Dundalk is a logical choice as a gateway.”

Making the case for Dundalk as the regional centre where there should be a regional hospital, one focus group participant spoke of the travel times needed to get to either Newry or Drogheda in an emergency. Daisy Hill was preferred over Our Lady of Lourdes, but in the views of this man,

“*Neither is suitable as a regional centre for the East Border Region. What happened to the National Spatial Strategy?*”

The National Spatial Strategy was also mentioned by participants in the Castleblayney focus group, who pointed out that Monaghan had been designated a ‘hub’ town. Hubs are towns that support the national and international role of the gateways and as such would be expected to have a hospital. They also made reference to the Chamber of Commerce’s report, *Monaghan - A Place to Live, Work and Invest*, which outlines the town’s expectation of future growth and development, in arguing that a regional hospital would be viable in Monaghan. The loss of the hospital has already had a big impact on the local economy and several Monaghan community representatives made it clear that they are still determined to see it reopened.

In several of the focus groups, reference was made to the two governments’ commitment to cross border cooperation that is enshrined in the Belfast/Good Friday Agreement. While praising CAWT, it is believed by some that the work being done by CAWT is not being sufficiently supported and complemented by the two departments of health.

“There are strong fears within the community in border areas about the centralisation of services to Dublin and Galway. We’re not hearing about cross border development. Even the cross border services that exist are not well publicised.”

There is an awareness that politicians – TDs and MLAs in particular – need to wholeheartedly support cross border solutions if they are to be made a reality.

“It’s no good just criticising officials. There must be pressure on the politicians. Communities will have to keep the pressure on.”

“The concept of shared cross border services is not accepted. The politicians are not on board.”

“There’s a lack of political commitment to shared services. The Dublin government is not committed to the border region’s needs.”

Participants in the research were critical that on both sides of the border there are similar plans for consolidation of health service resources and yet there is very little cross border planning. They also recognised and were concerned about the unnecessary costs as a result of duplication of services, when both health services are under severe financial pressures. While on the one hand, the financial crisis is making engagement more difficult, the fact that the financial pressures are so severe on both sides of the border could actually be an impetus for greater cooperation.

“There’s a duplication of administration costs North/South that could be saved by amalgamation.”

“The island should be one region for planning health resources.”

“If there were more cross border partnerships health delivery would be more effective.”

“Cross border services should have been developed since the ceasefire. There is greater expenditure because of lack of sharing of services.”

The views from service users have been supported by the comments of some of the health service professionals who were interviewed for this research. Again, the need for high-level cross border planning of health services was a consistent refrain:

“While health services across the border ‘help each other out’ when capacity on one side is stretched, this is done on an ad hoc basis. There is no shared planning of services for clients. It is certainly not patient-centred. It depends on who knows who.”

“Service planning in the South is based on the need for ‘critical mass’, but there is no looking across border. Why has more cross border strategic planning not happened at senior levels? It is not being led from the top, so it is very difficult at mid-management level. People are chipping away, but it has to be driven from the top and financially supported at policy level.”

“There is very strong desire among professionals for cross border relations with our counterparts. There is so much spending on planning use of resources, but those with responsibility never think in cross-jurisdictional terms about how resources can be used more effectively. On both sides of the border the services are rolling out similar practices. They could share and make better use of the resources we have. But we can’t because of the administrative barriers. A good example is the duplication in H1N1 (swine flu) prevention.”

The suggestion is made – by service users and professionals on both sides of the border – that a new cross border implementation body for health would help to ensure that there is a stronger imperative for practical cross border planning and delivery of health and social care services including acute hospital services. One health professional commented:
"There is a need for something like a North South Implementation Body. Ministers need to identify priorities such as chronic illness. There needs to be dedicated funding for border areas with teams in place to support cross border working. We need a 5-year plan for cross border funding and resources to implement priorities. At present, everything is piecemeal. It needs strategy and vision for management of priorities – commitment, publicity and funding. Cross border programmes shouldn’t be dependent upon EU funding."

CONCLUSIONS

The lack of consistency between government health policies and other policies such as the National Spatial Strategy in the Republic in decision-making about the location of hospitals was an issue raised by focus group participants in different parts of the Border region. Physical access to acute services in an emergency is probably the most pressing concern raised by the people who attended focus groups as part of this research. There is a very strong consensus among all those consulted for this research that there should be greater cross border cooperation in the delivery of acute hospital and other health and social care services. People living on both sides of the border are enthusiastic about the prospect of increased cross border cooperation and sharing of services. Those from the southern side, however, suggested that there needed to be “co-operation in both directions”.

There are a number of suggestions about priorities for service development – issues around ambulances and emergency care are the most frequently mentioned. As will be seen in Chapters 8 and 9, there are already plans for cancer care and Cystic Fibrosis treatment being developed that are well supported by professionals and service users and that need to be operationalised; mental health services and additional supports for people with chronic diseases were also mentioned. In particular, there is a strong perception that there are gaps in provision, particularly in the central border region, as a result of centralisation, and that some of these might be addressed through supporting greater access to services on the other side of the border. This would necessitate ensuring first of all that service users are aware of what services are available and their entitlements to use services in the other jurisdiction. Health service professionals also expressed a desire to have more information about what their cross border counterparts are doing. A key message, then, is that the work already being done by CAWT should be better publicised, built upon and mainstreamed. There are serious concerns about the sustainability of the existing cross border services now supported by CAWT with EU funding.

The difference in funding regimes is the main barrier that is of concern to service users. How services would be paid for and how much they might cost are probably the most frequently raised
concerns about accessing acute and other health services in the other jurisdiction. There are concerns about privatisation, particularly within the southern system. While some people had concerns about equality of access and the possibility of discrimination against people from across the border, most people insisted that in the context of health services there is no ‘chill factor’. There are, however, concerns about differences in standards of care, drug and treatment regimes and follow-on care. A number of specific problems are presented for migrant workers and their families and asylum seekers who have difficulties, or are prevented from crossing the border.

There were strong opinions expressed that the work being done by CAWT is not being sufficiently supported and complemented by the two Departments of Health. There needs to be greater political commitment to shared cross border services and cross border planning. Although the financial crisis is making engagement more difficult, the fact that the financial pressures are so severe on both sides of the border could actually be an impetus for greater cooperation.

A new North South Implementation Body for health would help to ensure that there is a stronger imperative for practical cross border planning and delivery of health and social care services, including acute hospital services.
CHAPTER 9:

CASE STUDY: CANCER SERVICES FOR THE NORTH WEST

While this chapter focuses on the involvement of community campaigners in lobbying for retention and improvement of cancer services for people in the North West of the island, it is important to acknowledge that this campaigning has not always been in an adversarial context. From the Health Services side, there have been different initiatives to address the tension between providing local access and providing a quality service, if volumes are low. There is a growing body of evidence that links volume of service to improved outcomes, and this has been a very large factor in determining the configuration and re-configuration of cancer services. The National Cancer Care Programme has, therefore, prioritised providing a high quality service even if this means that people have to travel for it. The NCCP has, however, provided significant funding to the Irish Cancer Society to develop the Travel to Care Programme which gives financial support to patients who have difficulties with travel arrangement in addition to existing supports for travel arrangements. Specifically with regard to the North West area, the arrangements for the facilitation of Donegal patients attending Belfast City Hospital for radiation oncology were led and funded by the HSE with all of the negotiations in relation to deciding on care-pathways brought forward by the Health Service personnel in both jurisdictions including the involvement of the CAWT organisation. HSE including National Cancer Care Programme personnel, have been directly involved for a considerable period in the ongoing initiative to provide radiation oncology access to Donegal patients at the planned new Cancer Centre at Altnagelvin Hospital, Derry that is discussed below.

Cancer services have been a major issue of concern for people living in the North West of Ireland for a number of years. Since 2005 the people in Donegal have been campaigning for the retention of existing services and improved and additional services. This campaign – involving many people who have personal experience as service users – is organised on a voluntary basis. It is a campaign that has combined lobbying politicians and health service organisations, with public information events combined with large and small public mobilisations at critical times. Since 2005 there has been a generally positive response from both Ministers of Health and health service professionals on both sides of the border. Services have indeed been saved, extended and there is a firm commitment to providing radiation services for Donegal patients in a new facility based in Derry.
Over time, however, there have been differences in strategy and tactics, and since 2007 there have been two groups working on the issues. The two organisations – Donegal Action for Cancer Care (DACC) and Co-operation for Cancer Care (NorthWest) (CCC(NW)) – have in common their commitment to campaigning for quality cancer services for Donegal. CCC(NW) explicitly advocates cross border solutions to the needs of patients in the North West while DACC has expressed concerns about proposed expenditure by the Irish Government in services delivered in the North.\textsuperscript{176} We have, therefore, concentrated mainly on CCC(NW) in this case study.

An important achievement was the campaign’s ability to influence the policy framework for provision of cancer services in the North West – contained in \textit{A Strategy for Cancer Control in Ireland}\textsuperscript{177} and \textit{The Northern Ireland Regional Cancer Framework}.\textsuperscript{178} Both documents recognise the need to address health inequalities and the need for improved services in disadvantaged areas. Both strategies commit to improved breast and cervical screening and treatment services for women. These documents have provided a framework that the campaign has been able to reference at different times, particularly when there have been concerns about services being retained or that additional promised resources might not be forthcoming.

Co-operating for Cancer Care NorthWest was also actively involved in the Cross Border Women’s Health Network’s \textit{Cross Border Action Plan for the North West of Ireland}.\textsuperscript{179} The Action Plan describes how 43 partners will work across sectors and across the border for the benefit of those most marginalised by health inequalities. The Cross Border Women’s Health Network is a cross border partnership of statutory, voluntary and community sector organisations based within the North West of Ireland that are committed to collaborative action to improve the health status and reduce health inequalities both within the North West of Ireland and other parts of Ireland.\textsuperscript{180} The process

\textsuperscript{176} See for instance, DACC’s concerns about funding to the Altnagelvin radiotherapy unit, \textit{Derry Journal}, 30 June, 2009.
\textsuperscript{180} The project steering group was split evenly between the voluntary and statutory sector - and also between organisations from Northern Ireland and the Republic of Ireland, including Altnagelvin Hospital Trust and HSE - North West Division. The project’s research steering group involved staff from the Centre for Cross Border Studies, the Women’s Health Council, University of Ulster and Derry Well Woman. The Cross Border Women’s Health Network member groups at the time of the publication of the \textit{Levelling Up} report were: Cross Border Partnership Organisations: Cooperation and Working Together (CAWT), Centre for Cross Border Studies, Northern Ireland Statutory Organisations: Western Health and Social Care Trust; Western Health and Social
for developing the action plan involved a number of sector specific, cross border ‘Negotiating Change’ workshops. In order to ensure that each of the 62 organisations that sent staff teams to the workshops would commit to the actions drafted by their representatives, drafted templates of the suggested actions were sent to all Chief Executives to be signed off, and the signed off actions are those included in the published action plan.

The Cancer Services workshop group that met in January 2008 agreed that

“border counties needed to share a common purpose and vision, working closely together to develop a coordinated cross border cancer service in the North West region. This was seen as preferable to parallel services, which would continue to leave women in the North West peripheral to centralised services in Belfast, Dublin and Galway.”

Equity of access to preventive and treatment services as well as end of life care as particular concerns. Breast cancer screening services were a particular priority for women living south of the border. “The absence of population-based breast cancer screening in counties Donegal, Sligo and Leitrim was raised as an urgent concern.”

Breast cancer is the leading cause of cancer and cancer-related deaths for women in the island of Ireland. This report notes that while in Northern Ireland breast cancer mortality rates fell by more than 20% between 1994 and 2000, they had remained the same in the Republic during this period. Nine percent of all new cases of breast cancer on the island of Ireland between 1998 and 2000 were diagnosed to women resident in the North West – in District Council areas Derry, Omagh, Strabane, and Limavady, and Counties Sligo, Donegal and Leitrim – and similarly nine percent of those on the island of Ireland who died of breast cancer were living in the North West region. “It was acknowledged that cancer strategies and regional planning of services...
within both jurisdictions had generally been developed in parallel, with little or no reference to what was happening across the border.”

The Action Plan commits the Network to cross border and partnership working to improve the lives of people with cancer in the North West region through:

- Developing a partnership approach to the creation of a Cross Border North West Radiotherapy Unit providing fair and easy access for the population of the North West of Ireland to radiotherapy services;
- Integrating cross border planning of cancer services;
- Improving cancer outcomes for socially excluded people;
- Providing better end-of-life care in border counties;
- Empowering women to have a say in cancer services; and
- The formation of an overarching group to be convened to work on the Cross Border Cancer Services agenda with coordinated sub-groups.

A number of actions were agreed to support this commitment. Among these actions were: the establishment of a Cross Border Cancer Services Group involving representatives from the health services North and South, users of cancer services and a ‘consolidated lobby’ for the roll out of the Breast Check programme in Donegal, Sligo and Leitrim. Local politicians would advocate for a Cross Border Radiotherapy Unit and the role of this unit would be considered within research on the feasibility of all-island cancer services. Significantly, agreed actions included,

“A Steering Group will be established by the HSE (West), WHSSB and the WHSCT together with users of cancer services to oversee research on approaches for meaningful engagement with users of cancer services in the North West.”

Without the momentum of a determined and very public campaign, however, it is likely that many of these objectives would have remained aspirational and indeed, dropped off the agenda. Over time, however, there have been differences in strategy and tactics, and since 2007 there have been two groups working on the issues. The two organisations – Donegal Action for Cancer Care (DACC) and Co-operation for Cancer Care (NorthWest) (CCC(NW)) – have in common their commitment to campaigning for quality cancer services for Donegal. CCC(NW), explicitly advocates cross border solutions to the needs of patients in the North West while DACC has expressed concerns about

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183 McAvoy, H. and Meehan, K., op. cit., p. 31.
184 Ibid., p.32.
185 BreastCheck is a statutory organisation separate from the Irish Cervical Screening Programme, which is provided by the HSE.
186 McAvoy, H. and Meehan, K., op. cit., p.33.
proposed expenditure by the Irish Government in services delivered in the North.\footnote{See for instance, DACC’s concerns about funding to the Altnagelvin radiotherapy unit, \textit{Derry Journal}, 30 June, 2009.} We have, therefore, concentrated mainly on CCC(NW) in this case study.

In 2005 doctors from Letterkenny General Hospital (LGH) addressed a public meeting in Moville. They reported that Letterkenny was in danger of losing its temporary breast surgeon and that there were no definite plans to provide the North West region with a radiation unit. It was in response to this information that Donegal Action for Cancer Care (DACC) was set up.\footnote{Interview with Noelle Duddy, \textit{Irish Times}, September 2009.} In 2005 DACC set its objectives as:

- The permanent appointment to Letterkenny General Hospital of a Consultant Breast Surgeon; a Consultant Colorectal Surgeon and a Consultant Radiation Oncologist;
- The retention of breast cancer services in Letterkenny General Hospital;
- The immediate introduction of Breast Check;
- The provision of 70 new beds at Letterkenny General Hospital;
- The establishment of a satellite radiotherapy unit in Letterkenny General Hospital; and
- Urgent designated funding to assist patients and their families who have to travel for treatments.\footnote{www.DACC.ie.}

DACC currently states that its primary aim is “to ensure the people of Donegal have access to world class cancer services whilst ensuring the retention and development of all cancer services at Letterkenny General Hospital.”\footnote{Ibid.}

In March 2007, a number of people resigned from DACC and set up a new organisation, Co-operating for Cancer Care NorthWest (CCC(NW)). The two organisations – DACC and CCC(NW) – have both remained active and members of both contributed to this research. While we have concentrated on CCC(NW) in this case study, it is important to acknowledge that the activities of DACC after March 2007 have been valuable in ensuring that cancer services for Donegal have remained a priority for the HSE. Examples of achievements prior to March 2007 include:

- Appointment of a permanent breast surgeon to Letterkenny General Hospital (agreed June 2006 – commenced in post August 2008)
- An ‘Awareness Rally’ in May 2006 that brought between 10,000 and 15,000 people into the streets of Letterkenny, demanding improved cancer care for the people of Donegal.
- The appointment of a Consultant Radiation Oncologist to Letterkenny General Hospital;
- Initiation of communication between HSE NW and Action Cancer, Belfast regarding provision of mammography services in the North West; and
Letterkenny General Hospital (LGH) produced an excellent information booklet for cancer patients at the request of DACC.

As mentioned above, in March 2007, a number of people resigned from DACC and set up a new organisation, Co-operating for Cancer Care NorthWest (CCC(NW)). CCC(NW) defines itself as

“a lobby group. It is a voluntary, non-party political group. We do not and will not provide services. We are not a registered charity. CCC(NW) do not fundraise. We do not have an office. ... CCC(NW) has also lobbied the Northern Assembly and health authorities.”

The aims of the new organisation, which represents cancer patients from Donegal and the wider North West region, are to achieve “public, equitable and accessible cancer services as near to home as is safely possible that will be of a standard not less than best practice with best outcome for the patient.”

A CCC(NW) spokesperson explained,

“The North West region of Ireland has no designated cancer centre. We have to travel distressing hundreds of miles throughout Ireland to access a fragmented cancer service. Between Donegal and Derry, we have a cross border population of over half a million people, more than enough to secure a cross border cancer service in partnership between Letterkenny General Hospital and Altnagelvin.”

One of the group’s first actions was to work for an end to the waiting list for breast screening at Letterkenny Hospital. When the campaign started, approximately 400 women were on the list; some of them having waited more than two years for an appointment. By August 2007, the waiting list had been eliminated. Between April and July 2007, the group convened a series of meetings with the HSE, Breast Check and three cancer charities – Action Cancer in Belfast, the Marie Keating Foundation and the Irish Cancer Society – to explore the feasibility of developing cross border inter-agency cancer prevention education and early detection services. The HSE awarded a grant of €30,000 to Action Cancer to deliver mammogram services in the period prior to BreastCheck being

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192 Interview with Noelle Duddy, Inish Times, September 2009.
193 Ibid.
The role of community involvement in planning hospital services

rolled out in Donegal. Over 600 women used the service in the first six months. CCC(NW) claimed their work had resulted in success:

“We demanded that in the absence of the ‘roll-out’ of BreastCheck, remedial action be taken to provide healthy women with the opportunity to access mammography. The HSE listened to us ... We demanded that action be taken to eliminate the waiting list in LGH for women referred by their GPs for a breast appointment ... LGH listened to us ...”

The cervical cancer screening service CervicalCheck service offers free cervical cancer screening for women between the ages of 25 and 60. Approximately 34,700 Donegal women are eligible for cervical smear tests. When questions were raised about the possibility of Letterkenny Hospital losing its colposcopy services (for patients who required further investigations after their smear tests), CCC(NW) talked with Mr Tony O’Brien, CEO of the National Cancer Screening Services (NCSS) and Mr Seán Murphy of the hospital. The positive outcome of these talks was that Letterkenny’s services were brought up to the quality standards required by the National Cancer Strategy and the LGH unit was secured as a national centre to receive CervicalCheck referrals. CCC(NW) welcomed the retention of the service at Letterkenny: “This is a good day for Donegal women and LGH. ... Credit must be given to the LGH team and in particular, Seán Murphy, General Manager, for the speed in which they responded to the NCSS ...”

A meeting was held between CCC(NW) and Taoiseach Bertie Ahern in March 2007 (at which the proposal for a cross border radiation unit was also discussed).

The HSE announced in September 2007 that that the National Cancer Control Strategy recognised the unique geographical position of Donegal and that Letterkenny Hospital would continue to provide breast cancer services. Letterkenny is the only hospital outside the eight designated cancer centres in the Republic that continues to provide breast services. It is linked to Galway University Hospital. This was a decision for which members of CCC(NW) had lobbied:

“We presented the Government and the HSE with comprehensive, well researched arguments/papers detailing our difficulties regarding the future provision of cancer services in Donegal and the North West and we have, and continue to, provide them with potential solutions to these difficulties.”

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195 CCC(NW) Address to Donegal County Council, 8 October 2007.
197 CCC(NW) Report of Public Meeting, 16 July 2009..
CCC(NW) claimed a victory for the community campaign: “We demanded the retention of our cancer and breast services. The Government and the HSE listened to us.”\(^{201}\)

Patients are now offered a choice of Dublin, Galway or Belfast for radiation treatment. CCC NW) told Donegal County Council that, “We demanded a Consultant Radiation Oncologist attend Outpatient Clinics in Letterkenny General Hospital. St Luke’s [cancer centre in Dublin] listened to us ...”\(^{202}\)

The two Ministers for Health met in October 2007, after which it was announced by Junior Minister Pat ‘The Cope’ Gallagher that one of the meeting’s main outcomes was the decision to look at the feasibility of creating a new cancer centre in the North West, although no decision had been made at that time whether the new facility would be in Derry or Letterkenny.” Minister Gallagher stated "I am anxious to ensure equal access to cancer services based on clinical need and not which side of the border you are on."\(^{203}\) In a press release, CCC(NW) commented,

> “CCC(NW) is lobbying on both sides of the border for a cancer unit for the people of the North West. As a region, we have ... a population large enough to provide the NW with cancer services similar to that which Waterford Regional Hospital is to receive ... The NW doesn’t want a slice of cancer services, it wants the whole pie: multi-disciplinary cancer teams from Letterkenny General Hospital and Altnagelvin Hospital providing cancer treatments for the people of the North West. On provision of a ‘split-site’ cancer unit, cancer patients and their families will have travelling, financial burdens, emotional and physical distress minimised.”\(^{204}\)

Minister Harney received a CCC(NW) delegation in October 2007 and they also attended a Donegal County Council meeting that month. Meetings with local authorities would become a regular feature of the group’s activities. These meetings provide CCC(NW) with an opportunity to ensure that councillors are up to date on developments and to marshal the support of politicians across the parties when required.

Members of the group met the Northern Ireland Health Minister, Michael McGimpsey, early in 2008, who advised them that an initial assessment suggested that Derry was the best option for a radiation unit serving both sides of the border. CCC(NW) stated that they supported the unit in either Letterkenny or Derry, but that it was essential a decision was reached as a matter of urgency. The group, did however have strong views about other criteria for the unit:

> “There should be true partnership between Letterkenny General Hospital and Altnagelvin, including the appointment of consultant radiation oncologists in both hospitals. We also believe that there should be continued choice for Donegal patients to access Belfast treatment until

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201 CCC(NW) Address to Donegal County Council, 8 October 2007.
202 Ibid.
such time as the northwest has its own centre. When established, the radiation unit would need to be linked to a mother cancer centre in Galway or Belfast.\textsuperscript{205}

In April 2008 Minister McGimpsey, formally announced plans for the new radiotherapy unit at Altnagelvin to serve the North West. The announcement was warmly welcomed by CCC(NW), who commented that they were pleased a decision had now been reached as to which hospital would host radiation services for the North West. “Now we can all get on with the business of building this unit as a matter of urgency.” The group called for a re-evaluation of the proposed start date of 2015, clarification of the Southern Department of Health and Children’s position in respect of the business plan, and details of the partnership agreement between Letterkenny Hospital and Altnagelvin:

“The central ethos for this unit must be one of social inclusion, equal access according to need and cross border partnership between both health boards. Both health boards must have ownership of these services so that a comprehensive, fluent, seamless cancer/radiation service is provided for all cancer patients in the North West region. ...\textsuperscript{206}

CCC(NW) acknowledged that provision of radiation services was a complex issue and that a cross border catchment population of approximately 500,000 would be necessary for its viability.

“Co-operating for Cancer Care NorthWest recognised that either Altnagelvin Hospital or Letterkenny General Hospital was a suitable site for a satellite radiation unit in the North West. We acknowledge that the service could not be offered on both sites. CCC(NW) recognised that when this decision was reached, it must have the support of all involved as this vital service is needed immediately. Cancer patients do not have the time to have such a decision high-jacked or delayed by political, professional, business or personal agendas. CCC(NW) has always maintained that central to all decisions pertaining to cancer patients’ treatment is that of best interest/outcome for the patient.”\textsuperscript{207}

Donegal Action for Cancer Care, on the other hand, do not support the use of Irish Government funds for the establishment of the radiation unit at Altnagelvin. While Minister of Health, Mary Harney, said in her statement that there are “clear advantages to further co-operation to enhance services for patients, especially those living in the border counties,” DACC expressed concerns in that the proposed unit would be to the detriment of Letterkenny Hospital. DACC called upon people in Donegal to contact their elected representatives and “urge them to push harder for enhanced cancer-care services in Donegal.”\textsuperscript{208}

DACC proposed that rather than a cross border unit at Altnagelvin, there should be a ‘Centre of Excellence’ at Letterkenny, serving Sligo, Leitrim, Fermanagh and Derry. They repeated their concerns again in June 2009:

\textsuperscript{205}‘Inishowen cancer patients encouraged by Altnagelvin plan,’ \textit{Derry Journal}, 17 January, 2008.
\textsuperscript{206}CCC(NW) Press Release, 16 April 2008.
\textsuperscript{208}‘Growing Disquiet at Altnagelvin Decision,’ \textit{Derry Journal}, 22 April, 2008.
“We are not anti-Altnagelvin but we think the government should be making the investment here. It is now a more important time than ever – with the economic situation in the Republic – to invest in Donegal. We just feel if the investment is made in Altnagelvin then the other money will follow. In 10 to 15 years’ time Letterkenny will in effect become a community hospital. ... Why not invest in our own hospital? It’s absolutely crazy. People are just not tuned in.”

In contrast, Donegal Sinn Fein Councillor Padraigh Mac Lochlainn demanded that the unit be fast-tracked,

“...it is now almost two years since 15,000 people marched through the streets of Letterkenny in the pouring rain with a simple demand of equality in cancer care for patients and their families in Donegal and the North West. Minister McGimpsey’s announcement in recent days is a tribute to their tenacity and fierce determination...”

Donegal Fine Gael TD Mr Dinny McGinley asked a question in the Dáil in December about the plan to establish a North West cancer unit and likewise, Donegal Senators and TDs from all parties have consistently supported the campaign and raised questions in the Oireachtas about securing a radiation unit for the North West.

The Sub-Regional Radiotherapy Centre is to be linked to the Belfast Cancer Centre at Belfast City Hospital and is supported by the health services both sides of the border. The unit will provide both chemotherapy and radiotherapy. It will be sited at Altnagelvin and should be operational by 2015. The investment required for the Centre may be in excess of £50m. Enabling works are scheduled to take place in the 2010/11 financial year, although there are uncertainties around capital funding.

A delegation from CCC(NW) met Deputy First Minister Designate, Martin McGuinness, MLA, at the beginning of May 2007 to discuss the proposal for a public satellite radiation unit. Mr McGuinness promised to pursue the issue urgently upon the restoration of the NI Assembly and Executive, and to arrange a meeting with the Northern Ireland Health Minister.

CCC(NW) held a public meeting under the slogan, “No to Death by Geography” on 21 May 2007. The meeting was supported by the European Anti-Poverty Network, who urged people to attend the meeting, linking Donegal’s high poverty levels and the deficit in cancer care services. EAPN urged Government to “rethink their policies and work with the communities in partnership to bring about the delivery of cancer services at a local level.”

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209 ‘Cancer group have fears on Altnagelvin funding,’ Derry Journal, 30 June, 2009.
211 Dáil Questions, 16 December, 2008.
212 Omagh Hospital Joint Liaison Group, Notes of Meeting 30 September, 2009.
CCC(NW), while focused on provision of quality cancer services for the NW region, set their campaign in the framework of opposition to a two-tier health care service.

“The mushrooming of ‘for-profit’/private hospitals in the country, since the introduction of tax incentives in 2001/2 causes us great concern as they have the potential to undermine public health service development. We firmly believe that a universal public health care system is not only attainable but justifiable and necessary for the health of the Irish population.”

This position in principle turned into a more practical and immediate issue when CCC(NW) joined forces with The Health Services Action Group and Patients Together – a campaign organised by patients and relatives in response to the crisis situation in Southern A&E departments – to claim that they had documents about fraud settlements involving a US-based medical company involved in delivering cancer services in Ireland. The groups said that they were concerned about the involvement of outside companies in private hospitals providing services for public patients. Referring to the information about legal settlements in the US, a CCC(NW) spokesperson appealed to the Government not to sign contracts “until we all know what they are talking about.”

A proposal for a private ‘cancer’ hospital near Letterkenny Hospital was reintroduced in June 2007. Plans for a private breast screening facility were announced in August 2007.

CCC(NW) issued a statement to the press making its opposition to privatised services and restated that it was campaigning for a public cross border satellite radiation unit, integrated with the National Radiation Network and lobbied vigorously against plans for private cancer services. In December 2006, the HSE announced that it would not proceed with building a private hospital on the grounds of Letterkenny General Hospital as no “suitable partner” had been found for the site. The group is aligned to a national campaign to protect and improve public health services and a CCC(NW) speaker addressed a Trade Unions and Patients Together rally in Dublin in October 2008, opposing cutbacks in the health service and opposing the privatisation of public health services.

While not afraid to assert its opposition to public policies when it feels that is required, CCC(NW) is more than happy to seize any opportunity to co-operate with public health service professionals and bodies when it can. CCC(NW) took an opportunity to thank Action Cancer and the HSE for providing a “good example of services on both sides of the border co-operating together” and to commend

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220 ‘HSE won’t build private unit at Letterkenny Hospital,’ *Donegal Democrat*, 7 December, 2006.
the HSE for “actively listening to and engaging with the concerns of women in Donegal.” 221 The group used this statement to publicise the commencement of BreastCheck in Donegal and remind the public that the CCC(NW) had “long campaigned” for its roll-out. BreastCheck commenced screening services in Donegal in October 2009.

December 2008 saw the opening of the Breast Unit in LGH, run by Letterkenny’s first permanent breast surgeon. CCC(NW) welcomed this development and suggested that other cancer services might also be delivered through the Galway link.

The British Irish Intergovernmental Council announced an agreement for the referral of some Donegal cancer patients to Belfast City Hospital in October 2006. A year later, the two Ministers for health announced the future expansion of radiotherapy for patients living on either side of the border. CCC(NW) welcomed this announcement, “based on the principle of equal access according to need and not according to where one lives or how one can pay.”222

The Department of Health and Social Services and Public Safety and the Department of Health and Children commissioned CAWT to support the development of a project that examined the feasibility of Donegal patients accessing radiotherapy services in Belfast City Hospital.

“The project examined the viability of changing the patients’ existing pathway to St Luke’s Hospital in Dublin and the operational arrangements to support such a change. The benefit to patients is significantly shorter journey times, in some cases a reduction of up to 3 hours.

“The first year review has reflected positively across all aspects and patients find the service convenient for both themselves and their families. The implementation phase was initially slow with only one or two patients at any one time choosing the Belfast location. However, as service users became more aware of the options there has been a greater uptake with three or four patients receiving their treatment at any one time. The HSE has committed resources to extend this valuable service. Furthermore, based on predicted service capacity in Belfast City Hospital, it is now recognised that more locally based radiotherapy services in the North West may need to be developed.”223

CCC(NW) however, pointed out that although the agreement allowing Donegal cancer patients to Belfast for radiotherapy has been in place since 2006, this does not include patients requiring palliative radiation treatment. In August 2009, CCC(NW) was able to report that Professor Tom Keane, Interim Director for the National Cancer Control Programme, had promised to explore with the Department the possibility of expanding this service to patients requiring palliative radiotherapy.\textsuperscript{224}

CCC(NW) met with Mr Michael McGimpsey, Minister for Health in Northern Ireland to argue for provision of a cross border satellite radiation unit for the North West. Following this meeting, Mr McGimpsey and the RoI Minister for Health, Ms Mary Harney, agreed to support a radiation unit in Altnagelvin hospital in Derry in April 2008. A deputation from CCC(NW) met with Mary Harney, TD, Minister for Health in August of that year to discuss North-South developments in realising/providing a cross border satellite radiation unit for the people of the North West Region and the Government’s ongoing commitment to cancer services at Letterkenny Hospital.\textsuperscript{225} The \textit{Inishowen Independent} reported in April 2009 that the Western Health and Social Care Trust had secured a promise of £60m for the unit. Mr Joe Lusby, Deputy Chief of the WHSCT, commented that the unit was “very important to us in terms of our commitment to the future.”\textsuperscript{226}

In August 2009, CCC(NW) met with CAWT to discuss planned developments for vascular and urology services at Letterkenny and were advised that a second urology consultant and nursing and support staff were to be appointed at the hospital and that vascular patients would

\textsuperscript{224} \textit{Inishowen Independent}, 25 August 2009.

\textsuperscript{225} CCC(NW) Press Release, 13 August 2008.

\textsuperscript{226} ‘Donegal Cancer patients will be treated at new satellite unit,’ \textit{Inishowen Independent}, 16 April, 2009.
benefit from a cross border vascular surgery service that would reduce the number of patients having to travel to Galway or Dublin.²²⁷ Speaking on behalf of CCC(NW), spokesperson Noelle Duddy commented,

“These projects have the potential to reach deep into the needs of the cross border populations and effect meaningful change in how we communicate and deliver the health and social care required for this region which has for too long been neglected. By working together, it is very obvious that neighbours on either side of the border can benefit in kind and by working together we can meet critical mass criteria and present joint arguments to both governments to realise affordable, sustainable, workable health and social care for people living in this region.”²²⁸

Two months before, CCC(NW) had a meeting with Tánaiste, Mary Coughlan and received assurances that “Minister Harney is committed to providing capital funding for this project and funding for the costs of Donegal patients receiving treatments at the unit.” CCC(NW) lost little time in making these commitments public. Noelle Duddy told the *Derry Journal,*

...The meeting was very productive. An Tánaiste has given an undertaking to meet with Minister Mary Harney and brief her on the details of this meeting so that when a delegation from Co-operating for Cancer Care NorthWest meet Minister Harney ... she will be in a position to address the outstanding issues.”²²⁹

The CCC(NW) also reported through this newspaper article on progress with bringing the BreastCheck programme to Donegal and on plans for the cross border radiation unit at Altnagelvin. The group also raised concerns about the impact of budget cuts on the National Cancer Control Programme (NCCP) and the development of Galway as a Specialist Cancer Centre and asked for clarification from the Minister on how the cuts would impact on delivery of cancer services to people in Donegal and the HSE West Region.²³⁰

The group met with Health Minister Mary Harney on 29 June, 2009 and received again assurances on the progress on the cross border radiation unit. On the agenda were issues in respect of the budgets for the unit, services and travel costs for Donegal patients and the confirmation of a “true cross border partnership between LGH and Altnagelvin.”²³¹ The group also took this opportunity to raise their concerns with the Minister about private sector provision of cancer services undermining the National Cancer Strategy and a number of other issues.

Minister Harney subsequently facilitated a meeting for CCC(NW) with Professor Tom Keane, the Interim Director for the National Cancer Control Programme. At this meeting Prof Keane advised

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²²⁸ Ibid.
²³¹ CCC(NW) Agenda for Meeting with Minister for Health and Children, 29 June 2009.
them that he would be visiting Letterkenny Hospital in the near future to discuss future cancer services and needs, including colorectal services. The group were informed that the proposed cross border radiation unit was still under consideration by the Department of Health and Children. CCC(NW) also took this opportunity to lobby for a second breast surgeon at Letterkenny.

At this meeting also, CCC(NW) received assurances that the pilot Rapid Access Prostate Clinics in Galway and Dublin planned for 2010 would not replace existing urology services at Letterkenny Hospital, but would provide an additional service for patients identified as having a higher risk of prostrate cancer. CCC(NW) is advocating that diagnostic services be developed at Letterkenny under an arrangement with Galway similar to that in place for breast cancer.

Also at the end of June 2009, CCC(NW) participated in an Advocacy Meeting at the Irish Cancer Society, where it raised concerns about the potential for professional conflicts of interest in relation to the private sector’s role in provision of cancer services; travel for patients from the North West to cancer care services; the omission of Letterkenny Hospital from Irish Cancer Society literature; costs of cervical vaccine; bowel cancer screening and the role of and pressures upon cancer support groups and expectations on these groups to do the work of statutory bodies.

At a meeting with CAWT in August CCC(NW) were assured that the proposed radiation unit at Altnagelvin was “on track” and the business plan near completion. The unit is expected to be operational by 2015, and cross border health professionals are meeting regularly to discuss how best to develop clinical pathways. The unit at Altnagelvin will be a satellite centre, linked to Belfast City Hospital. Cross border health professional teams are meeting on a regular basis to discuss how best to develop clinical pathways.

CCC(NW) has lobbied for other changes that will make access to cancer care more affordable and accessible.

“Not only is money required to develop the infrastructure of LGH’s breast/cancer services, but money is also necessary to supply adequate transportation services; accommodation for family members travelling to support patients; financial arrangements to alleviate the extra financial burden imposed on cancer patients and families required to travel for treatment.”

In November 2009, Tony O’Brien, Acting CEO, National Cancer Control Programme, met with CCC(NW) and informed them that the Breast Check mobile screening unit would remain in Donegal.

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until all 10,500 eligible women in the county had been offered an appointment. It was anticipated that this would take approximately one year. Women will receive their mammogram results within 21 days and if follow-up is needed, be referred to Galway for further tests and treatment if necessary. However, women with breast symptoms continue to attend their GP in the first instance, and then are referred to Letterkeny General Hospital. Ms Noelle Duddy of CCCNW stressed the different pathways to treatment,

“It is important that women understand that whilst both services may diagnose breast cancer how they access the service is different. One service – Breast Check – screens a healthy ‘symptom free’ population of women between the ages of 50-64 every two years and the other service – Symptomatic Breast Services – assesses/treats women referred by their GP to LGH. This group of women have presented themselves to their GP with symptoms/concerns about breast health.”

Based on their experience, CCC(NW) have identified a number of factors necessary for successful lobbying with politicians and public health bodies:

“First rule, understand that things are not always what they appear to be. Just because you are told something doesn’t mean that it is true! Listen carefully and question.

“Do your homework. Know what you are talking about. Research, research, research. Pay attention to the smallest detail. Meet and talk to everyone who may be able to advance your case.

“Never lose the run of yourself. When you see an opportunity, seize it.

“Believe everyone but trust nothing until you have checked it out with your sources, several times over.

“Know when to hold your peace and most importantly, maintain a sense of humour.

“We have found that if you do most of the above, you will earn the respect of those you are lobbying and you can effect change.”

“Of great importance to us is that we stay focused on our task and remain open and transparent in all that we do. We do not allow any political party, politician, health professional or business person to represent us or ‘high-jack’ our work. We keep our objectives clear and simple.

“We keep the public informed of our progress through the media and we hold public meetings. ... We have an open-door policy with all our public representatives who regularly contact us for information, advice and updates.”

Community campaigners have been very successful, first of all, in influencing public policy and priorities for cancer services in the North West through working with statutory and community health bodies and other organisations. A strong community-based campaign has been mobilised at critical times, supported by effective information and lobbying work. Co-operating for Cancer Care NorthWest has established itself as a respected and independent voice for cancer patients and the wider community while building effective relationships with other stakeholders. This hard work by a

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238 “Breast Check now operating in Donegal”, Irish Times, 4 November 2009.
239 Ibid.
240 Irish Times, September 2009. CCC(NW).
core group of voluntary activists has been rewarded by a generally positive response from both Ministers of Health and health service professionals on both sides of the border. Services have indeed been saved, extended and there is a firm commitment to providing radiation services for Donegal patients in a new facility based in Derry.
CHAPTER 10:
CASE STUDY: CF TRUST AND CF ASSOCIATION OF IRELAND

Cystic Fibrosis (CF) is Ireland’s most common life threatening inherited disease. Ireland has the highest prevalence of CF in the world, with 1 in 19 carrying the CF gene. Ireland also has the most severe strain of the CF gene in the developed world. Cystic Fibrosis (CF) is an inherited chronic disorder of the exocrine glands that affects the lungs and the digestion of food leading to frequent chest infections and under-nutrition. The disease causes progressive disability and early death and is characterised by a production of viscid mucous that obstructs the pancreatic ducts and bronchi, leading to infection and fibrosis. Difficulty breathing is the most common symptom and results from frequent lung infections. In the Republic of Ireland, approximately one in 1,460 are born each year with Cystic Fibrosis, while the estimate for Northern Ireland is 1 in 1,850 births. This frequency is higher than in other European populations (1 in 3,500 births) and England (1 in 2,500 births). A recent World Health Organisation (WHO) publication lists Ireland as the country with the highest known incidence of Cystic Fibrosis. There are currently 250 adults and 190 children in Northern Ireland who have CF; in the Republic the total number of people with CF is approximately 1,100.

Until recent decades CF was considered a disorder of childhood; improved survival rates now mean that the number of adult with CF now exceeds the number of children. Not only is there an increasing proportion of adult patients, but the progression of the condition means that adults with CF are likely to develop more severe disease complications than children and to need a greater amount of in-patient intervention.

The Cystic Fibrosis Trust in Northern Ireland and the Cystic Fibrosis Association of Ireland (CFAI) in the South are the two organisations that have been responsible for ensuring that the voices of people with CF and their families, along with health service professionals are influential in shaping the delivery of CF services on the island.

Although working in different health service contexts, both the Cystic Fibrosis Trust and the Cystic Fibrosis Association of Ireland have much in common. Both are well established voluntary organisations with considerable resources. They bring together consultants, researchers and other professionals in modern multi-disciplinary CF teams as well as the experience, expertise and

241 Health Service Executive (2009) Services for People with Cystic Fibrosis in Ireland: Conclusions of a Working Group established by the Health Service Executive.
242 Interviews with author.
243 Services for People with Cystic Fibrosis in Ireland: Conclusions of a Working Group, op.cit.
commitment of people with CF and their families and friends. The considerable financial contribution that the Trust and the Association bring to the table ensures that they are able to have a significant influence on the research agenda. They are also able to fund facilities, thus having a direct impact on what services are delivered in what hospitals. For example, following a high profile campaign by the CFAI in 2008/2009, a new ward block is to replace the inadequate existing Cystic Fibrosis (CF) accommodation at St Vincent’s, Dublin, the national adult referral centre for CF patients in Ireland. The CFAI hopes to raise over €2.5 million to ensure that young people living with CF have dedicated CF units in their regions, taking pressure off the major CF centres in Dublin.

Similarly, the CF Trust is the largest funder of CF research in the UK. Half of the CF Trust’s budget is spent on research. In the year ended 31 March 2009, the Trust spent a total of £10,301,000 in the UK: 50% of it on research; £859,000 on clinical care; and £923,000 on information, advice and support. Since 2002 it has supported the UK CF Gene Therapy Consortium involving 80 scientists and clinicians and has funded £775,000 of non-gene therapy projects in the last financial year. The UK CF Gene Therapy Consortium Scientific Advisory Committee is chaired by Professor Stuart Elborn of Queen’s University of Belfast and Belfast City Hospital and Professor Gerry McElvaney, of the Department of Medicine, Royal College of Surgeons in Ireland is also a member. The UK CF Microbiology Consortium (completed in 2009) recruited four PhD candidates to work with experienced CF researchers at the Universities of Cardiff, Edinburgh, Liverpool and Queen’s University, Belfast. The CF Trust is currently funding twelve research projects with a combined budget of £1,394,931. Three of the twelve projects are being carried out in Belfast at the Belfast City Hospital and Queen’s University Belfast. These three projects have a combined budget of £303,353.

Since 1997 the Cystic Fibrosis Trust has invested well over £10 million in the National Health Service to improve the care of the 8,500 people in the UK with CF; helping fund doctors, nurses and multidisciplinary teams. The CF Trust also provides training grants to doctors who want to become specialist CF consultants. In the last financial year the CF Trust spent over £1.1 million on care and campaigning.

Both organizations have developed infrastructures that ensure that they are able to support the involvement of people with Cystic Fibrosis in decisions affecting their care and to draw on their experience and knowledge to influence the decision-making process at more strategic levels.

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244 www.cftrust.org.uk
THE CYSTIC FIBROSIS TRUST

As the UK’s only national charity dedicated to improving the length and quality of life for those with Cystic Fibrosis, in addition to funding medical research the CF Trust provides information, advice and support to those with CF and their families. In 2006, the CF Trust published its CF Patients Charter, setting out what services people with CF should be able to expect access. (See box.)

The CF Trust has a number of Expert Patient Advisers (EPAs), all people with CF, who represent the views of the ‘expert’ patient to anyone who is responsible for commissioning or influencing the provision of clinical and social care for patients with CF. The main role of the Expert Patient Adviser is to influence policy and improve the provision of clinical and other care for people with CF. The Expert Patient Advisers also engage with the ‘CF community’ as appropriate in order to be able to represent their views and to inform and update them as appropriate. The secondary objective is to put specialist CF care on the agenda of Primary Care Trusts (PCTs), and to monitor how PCTs deal with commissioning CF care. The role of the EPA is directed towards achieving the following outcomes:

- Improved clinical care for people with CF;
- More equitable access to a high level of CF care throughout the UK;
- Improved physical health for children and young adults with CF;
- Improved ability of people with CF to live an independent life;
- Allowing people with CF to live longer and more fulfilled lives;

CF Patients’ Charter

“Patients should have access to comprehensive care from a specialist front line team which consists of:

- a consultant with a special interest in Cystic Fibrosis (paediatrician or adult physician)
- a junior doctor (usually a registrar)
- dietitian
- CF nurse specialist
- physiotherapist
- social worker

This team should be supported by a number of other specialists.

Children who live some way away from a recognised Specialist CF Centre can sometimes receive some CF care from their local district hospital, but this is only advisable if the local hospital has a proper shared care clinic with well recognised links with the CF Specialist Centre. When this arrangement is agreed, sometimes children with CF will visit the CF Centre but on other occasions they will see their local CF team. In some places the Specialist CF Centre team will attend appointments at your hospital on a regular basis, so children with CF get the benefit of both teams. Adults with CF should attend a major Adult Specialist CF Centre for all their hospital care.

When the diagnosis of CF has been confirmed ... and a full assessment of the patient’s condition has been completed, the family should receive a full explanation of Cystic Fibrosis, together with information about treatment from the multidisciplinary CF team. At this stage the family should be offered genetic counselling. Suitable written information should be provided for the family to take away and absorb.
The role of community involvement in planning hospital services

- Giving people with CF the ability to participate more fully in economic and social life in the community.  

At present, there is one EPA who covers Scotland, Northern Ireland and North East England.

As well as providing a channel for people with CF to influence policy and practice in CF care, the CF Trust’s fundraising activities make a crucial contribution to the ability of the NHS to deliver services. The CF Trust helped to set up and staff 45 specialist CF treatment centres throughout the UK, and since 1997 has invested well over £10 million fund doctors, nurses and multidisciplinary teams. In the last financial year, the CF Trust spent over £1.1 million on care and campaigning. Each year the CF Trust offers training grants to doctors who wish to become specialist CF Consultants.

The CF Trust’s Peer Review process is also an important element of its work. During a peer review, an independent panel of experts in CF care visits a CF Centre or Clinic. Over the course of their one-day visit, they discuss with the local CF team how they manage their service and identify any problem areas. A detailed report is then sent to hospital managers and commissioners, highlighting what is being done well and any areas that need attention. The aim is to help improve the level of care that specialist CF Centres and networked clinics in the UK can offer to their patients. As a result of the peer review programme, some Centres have received significant funding increases.

“A peer review is a process whereby a CF service is reviewed by a panel of experts from a similar CF unit. The peer review panel consists of two CF consultants and two of the following: a specialist CF nurse, physiotherapist or dietitian. There is also an adult patient or parent representative, and a senior member of the Cystic Fibrosis Trust on the panel, as well as a note-taker. The objective of a peer review is to make a fair, constructive appraisal of the service, acknowledging aspects that are of a high standard and making recommendations as to where improvements need to be made."

Staff from Belfast City Hospital have been involved in peer reviews of CF services in Britain, and have been peer reviewed in return.

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The role of community involvement in planning hospital services

In 2001, the CF Trust published its *Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK*\(^{249}\) (See box at left) that, alongside the more recent EU Consensus Document,\(^{250}\) has provided a benchmark for the development of appropriate care. These documents provided the basis for the analysis of CF services in the Republic of Ireland, undertaken by Professor Ronnie Pollock discussed below.

The CF Trust has also been involved in lobbying for better dietetic support for people with CF and better access to specialist CF dietitians. Similarly, a survey on physiotherapy services has identified gaps in service provision and the CF Trust plans a similar fact finding and lobbying effort in respect of psycho-social services, which have also been identified as lacking or inadequate in some Centres and Clinics.

The UK CF Registry is another project of the CF Trust. A database of all those with CF in the UK, it “continues to provide invaluable data about CF, enabling us to

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\(^{249}\) CF Trust, *Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK*, The CF Trust’s Clinical Standards and Accreditation Group, May 2001.

identify patterns and anomalies in CF care and outcomes across the UK, and tailor our campaigning and clinical care programmes more effectively. We set national standards on clinical care, provide and fund a UK CF Clinical Database and measure levels of service provision.”

The CF Trust’s helplines offer a confidential advice, support and information service on any aspect of Cystic Fibrosis. There are specialist helplines on benefits and how to apply for them and how to access small grants from the Cystic Fibrosis Trust and other organisations, including criteria guidelines and application forms. The CF Trust also has a number of online fora targeted at teenage and adult people with CF, parents and carers, partners of people with CF, and fundraisers.

**The Cystic Fibrosis Association of Ireland (CFAI)**

The Cystic Fibrosis Association of Ireland (CFAI) is a voluntary, non-profitable, charitable organisation. It was set up in 1963 to increase knowledge and awareness of CF and to give advice and support to people with Cystic Fibrosis and their families. There are currently 22 branches of the Association throughout the Republic, with approximately 1,500 members. CFAI is, therefore, “a force to be reckoned with in local community fundraising and political awareness.” In the Association Newsletter in Spring 2009, Godfrey Fletcher, then CFAI Chief Executive, wrote,

“I firmly believe that CFAI is no longer the “shrinking violet” of the voluntary sector but is now seen and regarded as a professional patient organisation whose views have to be taken seriously. In 2005 I could count on one hand the number of families who were prepared to go public with their stories to the media. Today, Cystic Fibrosis is mentioned daily in all forms of media with a huge public awareness and support for Cystic Fibrosis from the general public.”

The Association has also been highly successful in attracting support from elected representatives and CF services have been the subject of discussion by politicians from different parties.

A key challenge for anyone trying to engage with people with CF is that the dangers of cross-infection preclude groups of people with CF from gathering in the same room. As the representative body for people with CF, the CFAI has developed a number of ways to ensure that the views of people with CF and their families determine the Association’s agenda. Much of the Association’s work is therefore carried out using internet and telephone connections. There is a People With CF Group within the CFAI that organises monthly teleconferences and the Association also has a forum for its members, *CF Ireland Online* – “A voice for the Irish CF Community.” The People with CF Media

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251 [http://www.cftrust.org.uk](http://www.cftrust.org.uk)


253 *Ibid*.

254 See, for example: Dáil Debates, 21.06.2005 and 15.10.2008.
Team responds to requests for people with CF to talk about their condition. CFAI has also produced booklets for employers and schools that have included the personal experiences of people living with CF. The Association also supports involvement of people with CF in a Patient Liaison Group at St Vincent’s Hospital.

CFAI collects and collates information from members, CF care staff and others to monitor trends and identify key issues. Some of the issues raised can be addressed directly. Others contribute to the Association’s advocacy campaigns and strategic development. Issues are categorised as relating to: hospital facilities / staffing; organ donation / transplantation; social welfare / HSE entitlements; insurance; home distress; and other. There are two CFAI advocacy officers who deal with day to day issues that people with CF and their families encounter. The ethos of this advocacy function is to empower people with CF to take control of their own circumstances psychologically, physically, medically and socially.

The members of all CFAI branches actively fundraise, and CFAI funds several major research projects seeking to improve methods of treatment for people with CF. In addition to research, the Association is currently funding three major practical initiatives: provision of a dedicated CF Paediatric Unit containing four isolated ensuite beds at Our Lady’s Childrens’ Hospital, Crumlin; provision of a new National CF Microbiology Reference Laboratory in the grounds of Tallaght Hospital and provision of three en-suite rooms in St Anthony’s Ward in University Hospital Galway.

In recent years, CFAI has advocated actively and with considerable success for improved services for people with CF. After a very strong public campaign in 2008, eight ensuite CF rooms opened in St. Vincent’s and plans for the further development of 30 rooms were at an advanced stage by early 2009. Additionally a further six en-suite rooms at Beaumont Hospital were promised and plans had been announced for improvements in Cork University Hospital and Galway University Hospital. In its Spring 2009 Newsletter, the CEO commended the local branches in these areas for “their hard work and long hours spent on these campaigns,” much of it attributed to the work of the People with CF Group.

Another key achievement of the Association was its establishment of the Cystic Fibrosis Registry of Ireland in 2001 with a grant from the Department of Health and Children. It began data collection in 2002. The Registry is now independent from CFAI and has received increased funding from the HSE. While this funding is still on a year by year basis, the HSE has recognised the importance and the current and future capabilities of the CF Registry. A high proportion of people with CF are now on...

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255 CFAI Newsletter, Spring, 2009.
the CFRI and the data it holds is very robust. The CEO of CFAI is Chairman of a working group that is reviewing Patient Registries in Ireland in association with other patient groups, the HSE, the Health Research Board and the Health Information and Quality Authority.256

Newborn screening has been an issue upon which the Association has been campaigning for some years. The Department of Health and Children published *The Interim Report of the Working Group on Newborn Cystic Fibrosis Screening*257 in April 2000. This report recommended the establishment of newborn screening for CF, and a group to plan implementation. A *Programme of Action for Children* established a Working Group on Newborn Cystic Fibrosis Screening that reported in March 2004 with recommendations for a two-tier programme integrated with the existing Newborn Screening Programme and produced a detailed costed proposal. The report also recommended the development of a small number of specialist centres, adequately resourced to ensure optimal outcome. These recommendations were similar to those of the Pollock Report discussed below. CFAI continues to be actively involved in the preparations for the introduction of newborn screening for CF. Screening for Cystic Fibrosis will be integrated into the existing newborn screening programme with the target date the end of 2010.258 (Similarly, the CF Trust in the UK has also been lobbying for neonatal screening. At present, only 20% of newborns in the UK are currently screened for CF. The Cystic Fibrosis Trust has welcomed the British Government’s recent support for a national neonatal CF screening programme.259)

The Cystic Fibrosis Association of Ireland in conjunction with the Irish Donor Network has lobbied extensively for a review of organ donation, procurement and transplantation in Ireland since 2003. Both life expectancy and the quality of life for people with CF can be significantly improved through a lung transplant:

“The level of transplants in Ireland over the last couple of years has been very disappointing to say the least. In recent discussions we have seen some signs of progress on this front and the Association is continuing to work closely with the relevant HSE and Hospital authorities to improve this area of treatment.”260

The Irish Lung Transplant Programme commenced at the Mater Misericordiae Hospital, Dublin in 2005, when the first lung transplant (single lung) was performed at the hospital. The first and only domestic double lung transplant on a CF patient was carried out at the Mater Hospital in August

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256 CFAI Newsletter, Spring, 2009.
259 http://www.cftrust.org.uk
260 CFAI Newsletter, Spring, 2009.
2007. Currently Irish CF patients awaiting a lung transplant have the choice to be registered on
either the Mater or Newcastle (England) list. CFAI are currently in active engagement with the HSE to
see what can be done to immediately address the issue in both the short and long term. According
to the Association, an Irish lung transplant programme should be doing at least 20 double lung
transplants a year by now. CFAI is calling for:

- a properly resourced independent transplant body that can co-ordinate all aspects of donor
  identification and transplant co-ordination;
- specially trained transplant co-ordinators in the major ICU’s;
- monetary incentives to hospitals that provide organ donors;
- properly resourced transplant teams made up of retrieval teams and transplant teams available 24/7
  365 days a year; and
- transplant friendly legislation.\textsuperscript{261}

The need for coordination and monitoring of transplant services in Ireland was highlighted by the
CFAI at its national seminar on transplantation in November 2009. The HSE has agreed to establish a
transplant unit in 2010 as part of the recently published HSE \textit{Corporate Business Plan}.\textsuperscript{262}

\section*{The Pollock Report}

As has been seen, the Cystic Fibrosis Association of Ireland (CFAI) has had considerable success in
shaping strategies for care of people with Cystic Fibrosis within the Republic of Ireland. The
outstanding achievement for the Association has been the acceptance by the Health Service
Executive of most of the findings and recommendations of the Pollock Report. In 2004 the CFAI
commissioned Dr R. M Pollock, a partner of MPA Health Strategy and Planning Ltd in the UK, to
undertake a study of hospital services in Ireland for people with Cystic Fibrosis. His report, entitled
\textit{Towards a Better Service}\textsuperscript{263} (also known as the Pollock Report) was published in February 2005. This
report summarised the findings of and produced recommendations for service development
involving the establishment of nine specialist Cystic Fibrosis centres across the country. The report
drew attention to the following issues:

- the large number of units in the context of the overall population;
- the number of centres with very small patient numbers;
- the imbalance between child and adult service provision;
- staffing deficits; and

\textsuperscript{261} CFAI Newsletter, Spring 2009.
\textsuperscript{262} E-Bulletin from Cystic Fibrosis Association of Ireland Issue 9, March 2010
\textsuperscript{263} Dr Ronnie Pollock, \textit{Towards a Better Service, The Treatment of Cystic Fibrosis in Ireland: Problems and
variation in the suitability of physical accommodation with particular reference to infection control.

Professor Pollock’s recommendations included:

- Centralised care at a smaller number of specialist units, five of which would be in Dublin (2 adult and 3 children’s) and four outside Dublin providing adult and children’s services;
- Increased provision of care (including transition) for the growing numbers of adults;
- Designation of tertiary service centres for adults and children;
- Facilitation of cross-border access to services in Belfast / Derry for patients;
- Establishment of a microbiology reference laboratory in Dublin; and
- Introduction of neonatal screening for Cystic Fibrosis.

The Pollock Report, significantly, recommended that there should be facilitation of patients resident in the south to use CF services in Northern hospitals:

"Cross-border arrangements should be facilitated if this provides closer access to specialist care and is the preference of the person with CF. These would be to the Belfast City Hospital at present and possibly to Altnagelvin Hospital in Derry where a service is currently being developed."\textsuperscript{264}

There would appear to be a significant potential take-up of services in Belfast and Derry by people in the southern Border Counties if appropriate cross border arrangements can be put in place.

### Prevalence of People with CF in the Border Counties by county of residence

**- December 2005**\textsuperscript{265}

<table>
<thead>
<tr>
<th>County</th>
<th>Total Population</th>
<th>People with CF</th>
<th>Rate / 1000 Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cavan</td>
<td>63,961</td>
<td>23</td>
<td>0.36</td>
</tr>
<tr>
<td>Donegal</td>
<td>146,956</td>
<td>15</td>
<td>0.10</td>
</tr>
<tr>
<td>Leitrim</td>
<td>28,837</td>
<td>10</td>
<td>0.35</td>
</tr>
<tr>
<td>Louth</td>
<td>110,894</td>
<td>28</td>
<td>0.25</td>
</tr>
<tr>
<td>Monaghan</td>
<td>55,816</td>
<td>17</td>
<td>0.30</td>
</tr>
<tr>
<td>Sligo</td>
<td>60,863</td>
<td>19</td>
<td>0.31</td>
</tr>
<tr>
<td><strong>RoI</strong></td>
<td><strong>1,093</strong></td>
<td></td>
<td><strong>0.26</strong></td>
</tr>
</tbody>
</table>

Source: HSE Census of CF Users (Dec 2005) and 2006 Census Figures (preliminary)

The CFAI presented the Pollock Report to the Health Service Executive for consideration. The HSE responded quickly and a Working Group was established in April of the same year. The terms of reference for this Working Group were:

"To review the current configuration and delivery of services to CF patients in Ireland, across hospital and community, and to make recommendations for reconfiguration, improvement and

\textsuperscript{264} Dr Ronnie Pollock, \textit{op.cit.}

\textsuperscript{265} Services for People with Cystic Fibrosis in Ireland: Conclusions of a Working Group established by the Health Service Executive, Health Service Executive, Dublin, 2009.
development. The working group will consider the report prepared by Dr. Ronnie Pollock on behalf of the Cystic Fibrosis Association of Ireland and will encompass aspects of service alluded to but not covered in depth in that report including: CF services delivered in the community, the CF register, training and development of clinical staff, cost structures and cross border arrangements. [Our emphasis.]

The Working Group had a multi-disciplinary membership to undertake a wide-ranging review of the current infrastructure for CF in Ireland, including the Chief Executive and the Vice Chairperson of the CFAI. Views of voluntary organisations involved in advocacy for people with Cystic Fibrosis were obtained through representation on the Working Group, attending the annual conference of CFAI and meeting other groups not represented on the Working Group.

Both the Pollock Report and the HSE Working Group agreed that that the European Consensus on standards of care for patients with Cystic Fibrosis best addresses the needs for a model of care in Ireland and would provide a basis for international comparison of the range of services to which a person with Cystic Fibrosis should have access. Optimum care for people with CF as defined by the European Consensus document is based upon multi-disciplinary care supervised by a specialist centre that has close links with consultants within the hospital or in nearby hospitals specialising in gastroenterology, hepatology, endocrinology, ear, nose, and throat (ENT) surgery, general, hepatobiliary and paediatric surgery, radiology, obstetrics and gynaecology (including assisted conception), infectious diseases and infection control, rheumatology, ophthalmology and nephrology.

However, as the HSE commented:

“It is clear that these requirements cannot be met in all of the hospitals currently providing CF care and that a new structure is required which coordinates:

- an appropriate level of care for patients at the most convenient location;
- access to all of the specialist elements required for optimum outcomes;
- appropriate transition between child and adult services;
- information required to plan for a rapidly changing population which has ongoing service requirements;
- access to care in an appropriate environment, e.g. facilities which enable infection control measures.”

The Pollock Report identified an urgent need to develop adult service provision, as it is primarily only available in Dublin at the present time. The HSE Report noted that ten centres in Ireland currently meet the patient number requirements for CF specialist or satellite shared care centre as defined by the European Consensus report. Of these only one – Drogheda – catering for 36 patients – is in the

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266 Services for People with Cystic Fibrosis in Ireland. Conclusions of a Working Group, op.cit.
268 Services for People with Cystic Fibrosis in Ireland. Conclusions of a Working Group, op.cit.
The role of community involvement in planning hospital services

border region. Sligo, Letterkenny and Cavan General Hospitals also have units caring for CF patients. There are potential difficulties in the provision of shared care, particularly for adults where expertise in adult requirements does not exist in many general hospitals to the same extent as it does for children. This model, does, however, offer a means of providing specialist care for large numbers of patients whilst minimizing travel for patients and improving local expertise and community support.269

The Working Group agreed that key stakeholders and the constituent groups represented by the membership of the Working Group should be invited to comment on the content and recommendations of the Pollock Report. Responses were received between April and late July 2005. There was broad agreement with the conclusions and recommendations of the Pollock Report, but some concerns were raised that the consultation process supporting the Pollock Report was inadequate and failed to reflect the viewpoints of a number of smaller, more geographically isolated centres and also that the membership of the HSE CF Working Group may not have addressed this issue either. There was significant concern regarding the potential increase in patient travel time and rapid access to services associated with establishment of specialised centres and the associated transfer of services from smaller centres. A Consultant Paediatrician from Sligo General Hospital suggested that CF services in Sligo should be improved and supported with regular input from a specialist CF centre, commenting:

“A key factor in travel to Dublin, Galway or Derry is distance – most patients would not seek to travel to this extent on a regular basis; the distance involved could be problematic in emergency cases. · In the UK, CF services are provided locally even where numbers are small. A team from the specialist CF centre visits the local centre on a regular basis in place of patients travelling to the specialist centre.”270

A second Consultant Paediatrician from Sligo General Hospital disagreed with the Report’s conclusions regarding the North West and suggested that most patients from the North West would have closer links to Dublin than Galway and would prefer to go to Dublin for CF services. This respondent also emphasized the need to examine the benefits of shared care between satellite centres and a national centre and the need to avoid the disruption associated with a regular travel to a geographically distant national centre. There were also objections from clinicians in Drogheda. It was suggested that there should be development of outreach CF services in Drogheda and that it would be “more logical to develop a regional centre in Drogheda than in Waterford and that such a

269 Services for People with Cystic Fibrosis in Ireland. Conclusions of a Working Group, op.cit.
270 Ibid.
centre would better serve the needs of patients from the North West than a centre in Derry would."271

Another Drogheda-based Consultant commented,

“While benefits of greater centralisation of services are clear, that there are two problems. First, there is no dedicated CF centre north of a line between Dublin and Galway; and Secondly, patients living some distance from CF centres may have difficulties accessing services due to problems with bed availability."272

The recommendations of the HSE review endorsed many aspects of the Pollock Report in identifying deficits in staffing levels and appropriate accommodation across the country which has not kept pace with the increase in the CF population. The HSE Working Group concluded that the needs of the CF population would be best met by specialist Cystic Fibrosis centres offering either full care or supervision of structured shared care with satellite CF centres in Dublin (Beaumont and St Vincent’s); Cork University Hospital, Regional Hospital, Limerick and Galway Regional Hospitals. The Working Group also recommended that Waterford Regional Hospital and Our Lady of Lourdes Hospital, Drogheda should provide shared paediatric care with a designated specialist centre. “In the case of patients opting for shared care, a structured package should be agreed between the participating specialist centre, the local unit and the person with CF.”273 By spring of 2009, the Godfrey Fletcher of CFAI was able to report that,

“Progress has been made, the wheel of change has taken time to gain momentum. However, I believe that it will be very difficult to stop the implementation of CF service improvement even in this time of cutbacks in the health service.”

After the Pollock Report was published in 2005, funds were made available by the HSE and the Department of Health and Children, with contributions from the CFAI, for specialist CF personnel and some of these posts have now been filled.274

In its December 2009 E Bulletin, the CFAI was able to report that there would be increased capacities and new facilities at both Crumlin Children’s Hospital and Temple Street Children’s Hospital. A new CF unit at Our Lady’s Hospital, Crumlin is to be completed by June 2010 and a new state of the art dedicated Cystic Fibrosis and Respiratory Unit at Temple Street Children’s University Hospital should be completed in Spring 2010. However, in the same issue, Philip Watt, the new CFAI Chief Executive, commented that, “despite some important improvements, the level CF services in Ireland remains

271 Ibid.
272 Ibid.
273 Ibid.
274 www.cfireland.ie
unsatisfactory and much remains to be done to bring Ireland in line with international best practice.”

By January 2010, CFAI was able to look back at the past year and identify a number of key achievements, including:

- The successful campaign to ensure the new CF Unit in St Vincent’s University Hospital was secured and built on time;
- Important steps towards better inpatient and outpatient facilities in CF Centres across the country;
- The unprecedented media coverage and public pressure related to Cystic Fibrosis, which has meant that CF is now more of policy priority than before;
- The announcement at the CFAI annual conference in May 2009 by Health Minister Micheál Martin that the screening of new born children for CF would commence in 2010;
- The publication of the HSE CF Services Report in October 2009 which provides the blueprint for CF Services in Ireland and which was substantially shaped by the CFAI’s Pollock Report;
- The renewed focus on double lung transplantation and organ donation and coordination arising from our seminar in November 2009;
- Support for important internationally validated research projects and research facilities;
- A pro-active response to the Swine Flu crisis to help ensure that people with CF were prioritised in the information and vaccination process.

While many of the recommendations of the Pollock Report are now integrated into health service planning by the HSE and hospitals throughout the Republic that are delivering CF services, progress has been slower on the implementation of the report’s recommendation for access by Southern patients to CF services in Northern Ireland – a recommendation that is supported by the CF Team at Belfast City Hospital.

**PROPOSAL FOR A NEW CF UNIT IN THE NORTH WEST**

The CF team at Belfast City Hospital has a proposal for a new CF unit at Altnagelvin Hospital in Derry that would cater for patients from both sides of the border. There has been no increase in inpatient beds at the City for the past 15 years and the unit is working at capacity. A peer review carried out at the City also supported the recommendation for a centre in the North West serving people from both sides of the border. It has been suggested that initially at least, local clinics could be organised in either Altnagelvin or Enniskillen.

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Irrespective of the cross border demand, the need for a CF unit in the North West was explained by a person with CF who lives in Derry, but who travels to Belfast for treatment. This person explained that because people with CF can’t use public transport, it can be difficult.

“When I’m feeling sickest, I can’t always travel to Belfast for appointments and it’s difficult to get physio in Derry. If I was living in Belfast I could go to outpatients whenever I wanted to. It’s possible to make informal arrangements at Belfast City. There is a plan to train carers to carry out some physio, but it’s not the same as a proper physiotherapy service and there’s no money for that. I have to go to Belfast for blood tests, because although a district nurse can take the blood sample, it’s important to have things under the care of a CF team. So that means a 150 mile trip for a blood sample. Physio and bloods should be done in Derry.”

This person with CF stressed, however, that the full service offered at Belfast City – where there was a CF specialist, a nurse consultant, dietician and social workers on the team – was essential.

Belfast City, it was argued is a good practice model:

“I’m very happy with the support I get there; I have a good relationship with the CF team. The CF Trust does not need to campaign in Northern Ireland. The local service is very good. They’re under pressure sometimes, but you can get a bed almost immediately.”

The proposal for a CF unit in the North West is enthusiastically supported by the CF Trust in Northern Ireland. It is referenced in the HSE’s response to the Pollock Report, yet plans for the new unit are not well developed. While there is a general consensus of the need for such a unit among health service professionals and people with Cystic Fibrosis on both sides of the border, lack of funding has delayed its development. Nor is it yet clear how much involvement and sharing of planning and delivery there will be between the HSE and the DHSSPS or the relevant HSC Trusts in the North and likewise, how the views of people with Cystic Fibrosis and their families will be taken into account. The HSE Working Group convened to consider the findings of the Pollock Report proposed a cross border working group be set up but to date, there has been little progress. Most recently CAWT have indicated an interest in taking this proposal forward.

The CFAI and the CF Trust are both well-established voluntary organisations with substantial resources – financial and human – to support their engagement with the health services. They have effectively overcome the difficulties in engaging with service users to ensure that the concerns and experiences of people with CF are understood and taken into account by service providers and policy makers. They have forged strong alliances between CF experts and people with CF and their families and as a result have considerable influence in shaping the research agenda, service standards, policy and service delivery in Ireland and the UK.

277 CF patient, Interview with author.
278 CF patient, Interview with author.
279 CF patient, Interview with author.
280 HSE manager, Interview with author.
CHAPTER 11:

CASE STUDY: HOSPITAL CAMPAIGN FOR THE RURAL WEST

The Hayes Report, published in June 2001, recommended that a new ‘Level 3’ hospital be located at Enniskillen and that a new ‘local hospital’ be located in Omagh. Implementation of this recommendation would result in the loss of all acute services in Omagh – including A&E. Coming just three years after the town of Omagh had been devastated by the ‘Omagh Bombing,’ this recommendation galvanised people in Omagh town and county. The local Tyrone County Hospital and its staff had played a pivotal role in the saving of lives on that day and many survivors were still dependent on its services for their ongoing recovery. However, even before the Hayes Report, many acute services had already been removed from Tyrone County Hospital. Inpatient and maternity services were transferred to Craigavon Area Hospital in 1998, A&E and then general surgery followed in 1999. This left Tyrone County Hospital with minimal anaesthetics and radiology services and concerns were raised about the hospital’s capacity to deliver emergency medical services in the absence of a surgical service. Subsequently, with the withdrawal of training recognition, effective from August 2000, the hospital ceased to provide emergency medical services. As noted in the Hayes Report, the experiences at Tyrone County Hospital highlighted the difficulties that arise when services are withdrawn from one hospital before there is evident capacity in another nearby to absorb the resultant demand.

The Hospital Campaign for the Rural West has, over the course of the past decade, dealt with seven Ministers of Health. It has drawn upon expert opinion to develop responses to a number of reports addressing clinical and political issues raised. Large rallies have mobilised tens of thousands of people and smaller protests took place weekly over a period of some years. The campaign’s communication strategy kept its arguments in the public eye and ensured that local communities were constantly informed of all developments. In many ways, it was a textbook example of a community campaign. The campaign brought together all sections of the community. It had the support of politicians from all political parties and was supported officially — and financially — by

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281 On 15 August 1998, a ‘Real IRA’ car bomb in Omagh town centre killed 29 people and injured 220 others. It was Northern Ireland’s largest Troubles-related incident.

282 There have been two Ministers for Health Social Services and Public Safety who have been part of the Northern Ireland Executive: Bairbre de Brun (2001/03) and the current Minister, Michael McGimpsey. During two suspensions of the NI Assembly, the post of was held by George Howarth, Des Browne, Angela Smith, Shaun Woodward and Paul Goggins.
Omagh, Strabane and Dungannon District Councils. The churches and clergy came together to express their solidarity. Teachers and students, health professionals, artists and musicians, community leaders, patient groups and survivors of the bombing all participated actively and volunteered their time and skills. A research working group ensured that the campaign was equipped with analysis of statistics and policy proposals and responses to these. There were also PR/lobbying and fundraising task groups set up to share the workload.

Others ensured that at each step, the campaign’s voice was heard by government and by the people of Omagh. From the beginning, the Campaign Steering Group ensured that local people were kept informed and alongside regular press releases from the Steering Group, supporters of the campaign were encouraged to make their individual voices heard by writing letters and volunteering.

When the Minister ultimately ruled that the new acute hospital would be sited in Enniskillen, the HCRW went to law, seeking a judicial review, and when that was denied, appealed the court’s decision. However, eventually it became clear that the battle had been lost. Many of those centrally involved in the campaign now believe that it was always unwinnable; that the decision had been made with the publication of the Hayes Report; that much of the subsequent consultation process was simply “judicial review-proofing” of the decision to choose Enniskillen over Omagh. Indeed, some campaigners were convinced from the start that the important decisions had already been taken. In October, 2001, SDLP Councillor Pat McDonnell, writing in the Belfast Newsletter expressed his concerns about,

“entrenched medico-civil servants driving forward a vision of the Golden Six Hospitals, with Altnagelvin the western outpost and the Hayes Review a cloak of respectability designed to create an expectation of a new acute hospital at Enniskillen which will simply never happen.”

Similar views were expressed by Ulster Unionist Councillor, Ross Hussey in 2005. He stated, “I have no trust in the Sperrin Lakeland Trust, the Western Health and Social Services Board or the Department of Health.”

This perspective would, of course, be challenged by the various Ministers and civil servants involved in the decision-making process. The suspension of the NI Assembly must also be a factor in that the various Direct Rule Ministers were unwilling to take a decision that was in contravention to the opinions of the Department’s expert advisors.

283 Conversations with author, January and February 2010.
284 “Points of View: Omagh is the rightful home for new hospital,” The Newsletter, 1 November, 2001.
In more recent years, the focus of most local politicians and activists has been on protecting the remaining services at Tyrone County Hospital – so that the maximum may be transferred to the promised new enhanced local hospital in the town – and arguing for optimum development of the new Omagh hospital. At the time of writing (April 2010), however, many of those most involved in the campaign believe that their worst fears are being realised. Health Minister Michael McGimpsey has recently publicly acknowledged that the new hospital in Omagh may not, after all, be built – despite almost £14m having already been spent or committed for preparatory work. “...Minister Michael McGimsey admitted there were financial difficulties relating to the construction and operation of the planned £190m local hospital.”

It is outside the scope of this report to assess the arguments for an acute hospital in Omagh versus Enniskillen. Certainly, a strong case was made by the people of Enniskillen in favour of situating the acute hospital there; with Enniskillen demanding the rapid implementation of the Hayes Report. Rather, this case study sets out to describe the multi-faceted engagement process between people in Omagh, the Department and the Trust. In the present climate of uncertainty about the Omagh Hospital’s future, however, it may be hard to build the necessary relationships of trust and clarity on options needed for productive engagement.

**THE HAYES REPORT**

The Hayes Report (see Chapter Two) was commissioned by the then Minister of Health, Bairbre de Brun in August 2000, “to review the current provision and, taking account of the issues of local accessibility, safety, clinical standards and quality of services, to make recommendations to the Minister on the future profile of hospital services.” It was tasked “to take into account the views of individuals, organisations, and groups with an interest or involvement in the production of hospital services and to assess the scope for co-operation in the provision of local services with hospitals in other parts of the island.” The Report was published in June 2001, with a public consultation period that closed in October 2001.

The Hayes Report concluded that the entire population of Northern Ireland should normally expect to be within one hour’s travel time of high quality emergency care and inpatient maternity services. The location of a new acute hospital for the South West of Northern Ireland should maximise access to acute services for the South West’s dispersed population of some 115,000 persons and ensure

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286 “£14m being spent on hospital amid fears it may not be built,” *Irish News*, 15 April, 2010.

that it attracted sufficient patients to sustain the safe delivery of a necessary range of high quality services.

There were strong arguments in favour of both the Omagh and Enniskillen locations for the new acute hospital. Omagh would provide a slightly larger caseload but would leave a larger number of people outside acceptable access times. Enniskillen offered the better location for a hospital providing emergency care, inpatient, and maternity services. Having weighed up the various considerations, the Hayes Report recommended that a modern local hospital facility should be developed in Omagh, linked to a new ‘level 3’ acute hospital for the South West at Enniskillen.

While welcoming the proposal for a new acute hospital for the South West, Omagh District Council had a number of concerns about the proposed location of the hospital, the proposed facilities and the services to be provided. The concerns also included issues around accessibility and sustainability of the proposed services, the greater potential for cross boundary flows, the lack of integration of the developments with the local economic development plans and a loss of the region’s long established unique western identity.288

Mr Danny McSorley, chairman of the Hospitals Review Steering Group, told the press that,

"We need to ensure that the minister is fully aware of the strength of feeling of the people over the Hayes recommendations. ... We must ensure that the minister rejects these proposals and decides to proceed with the development of a new area hospital in Omagh delivering quality services to Tyrone and Fermanagh."289

In response to the Hayes Report, Michael Gallagher, whose son Aidan was among those killed in the 1998 Omagh bombing, said:

"It’s unbelievable. After what happened, it’s unthinkable something like this could happen. Omagh doesn’t need heart or brain surgeons, but an accident and emergency department is the most important of any hospital followed by maternity."290

Indeed, survivors and relatives had campaigned against the rundown or closure of Tyrone County Hospital even before the publication of the Hayes Report. Within months of the bombing, elected representatives south of the border, including An Taoiseach, Bertie Ahern, were called upon to support the fight to save the hospital.291

The implications of the Hayes Review were debated in the NI Assembly on 13 February 2001. Mr Joe Byrne, SDLP MLA for West Tyrone said the gradual but consistent reduction in the level of acute services over a number of years had heightened the “real sense of social exclusion and marginalisation” felt by the population in this region. There had been a gradual deterioration in acute services since 1979. Mr Byrne called for a speedy decision on the Hayes Report,

“Since the publication of the Western Health and Social Services Board’s report, there has been a crisis of confidence among the population in the south-west because the Minister of Health and her Department appear to be avoiding the need to make a decision. The Minister and her Department have increased the level of anxiety and uncertainty around this issue. Many people in west Tyrone believe that the Department was dithering and delaying taking any decisions by commissioning, in July last year, a further review of acute services.”

Stressing the need for joined-up Government, he insisted that the Minister’s decision must also be made with reference to other Government policies and the requirements of the equality legislation, New TSN (targeting areas of special need), spatial equity and sustainable development.

In supporting Mr Byrne, DUP MLA Mr Oliver Gibson stated that “staff feel demoralised, people have held street rallies, but they feel as though no one is listening.” Sinn Fein MLA Mr Pat Doherty argued that many of the inequalities in the provision of acute care were a direct result of the fragmentation of planning and the parochial nature of the health boards. He called on the Department to establish a body comprising service users or their representatives, trade unions and the full range of health care professionals and develop regional patterns in the siting of acute care:

“Such an approach could be expected to provide major benefits that would obviate duplication of services and produce savings through the sharing of resources. That would also enable cross-border co-operation on high technology, leading to the distribution of complex and expensive procedures to designated centres of excellence throughout the island, as well as a greater responsiveness to the more isolated communities, such as West Tyrone.”

The Minister of Health, Social Services and Public Safety, Bairbre de Brun, responded that she shared many of the concerns expressed and agreed that local communities must play a part in the development of services in their area. She would consult fully on the Hayes Report when it was received, before coming to any conclusions and in the meantime, expected trusts “to maintain their current acute services in our smaller hospitals, unless that would seriously compromise patient care and treatment.”

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293 Ibid.
294 Ibid.
295 Ibid.
In June West Tyrone MLAs Mr Oliver Gibson and Mr Derek Hussey (UU) and Mr Joe Byrne protested about the Hayes report proposal that A&E services at Tyrone County Hospital should be axed. Mr Byrne sought assurances from the minister that "nothing underhand had taken place to the detriment of Omagh."296 Minister Bairbre de Brun assured the Assembly that no decision had been made about accident and emergency services in Omagh. Mr Hussey sought a guarantee that she would meet people from the area about their concerns at the Hayes Report proposal.

THE HOSPITALS REVIEW STEERING GROUP

Omagh District Council established the Hospitals Review Steering Group. (This later became the Hospital Campaign for the Rural West.) Its objective was to, “Secure a new sustainable ['level 3'] Area Hospital in Omagh to serve the needs of the population of the Rural West.”297 It was thought that ‘Rural West’ was a more appropriate term than ‘South West’.

The Hospitals Review Steering Group campaign was based on a multi-faceted argument that took into consideration demographic factors such as the rurality of the area; deprivation and lack of transport, public services and other infrastructure and an increasing population. Travel times were key to the campaign’s case: Omagh provided a greater catchment area and a higher proportion of that catchment population could travel to Omagh within 30 minutes than could reach Enniskillen.

In opposition to the Hayes Report, the Group argued for:

- A sustainable Level 3 hospital supported by ...
  - A locally-appropriate ambulance service
  - A local healthcare management and planning
  - A seamless system of cross-border health care.298

The Acute Hospital Review Group’s brief included a requirement to consider the potential for cooperation with health care systems in the South. The Hayes team considered the potential for Sligo General Hospital to complement a hospital located in Omagh but concluded that the condition of the road between Blacklion and Sligo involved travelling time in excess of an hour. While there were plans to improve some small stretches of this road it was unlikely that they would make a significant difference to travelling times. They did not express any view about Cavan/Monaghan Hospitals.299

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296 “No final decision yet on Omagh A&E; No decision without consultation: de Brun,” Belfast Telegraph, 26 June, 2001.
299 Her Majesty’s Court of Appeal in Northern Ireland, Neutral Citation No [2004] NICA 10, 9 March 2004.
The potential for cross-border co-operation in delivering acute hospital services in the South West of Northern Ireland was always at the centre of the debate. At their meeting with the Hayes review group in October, 2001, a delegation from Omagh were forceful in challenging the Review Group on “their failure to take on board the cross-border dimension of their brief – in particular their failure to recognise the role which Sligo and Cavan Hospitals could play in delivering A & E services to the people in Fermanagh south and west of Lough Erne.”

**York Health Economics and Stutt Reports**

The Omagh Steering Group moved quickly (October 2001) to commission York Health Economics Consortium (YHEC) to review the Hayes Report. The YHEC study recommended that “a new acute hospital to serve the South West of Northern Ireland should be sited at or near Omagh with a community hospital at Enniskillen rather than site the main acute services at or near Enniskillen ...” The York group also found that an acute hospital in Omagh would benefit the population of the wider South West area, not just the population of Omagh, and that “siting a new hospital in a more central location will ensure a larger and more viable hospital,” because there would be more A&E attendees; maternity and general acute services would serve a larger population; and sub-regional ENT and renal services could be retained in the locality. The York study was also critical of the Hayes Report methodology and in particular, the criteria adopted by Hayes. The York study produced a series of arguments in support of its recommendations using a framework based on: accessibility; sustainability; socio-economic factors; and clinical criteria.

The York Health Economics Report highlighted the relevance of Cavan General Hospital as a potential source for patients from the south and west of Lough Erne and argued that the Hayes Report did not fully consider the implications of Cavan as a potential source of acute hospital services for that area of County Fermanagh. In their view, cross-border health services and delivery of cost effective services across the whole of Ireland was “a very sensible way forward.”

Meanwhile, Fermanagh District Council commissioned Colin Stutt Consulting to prepare another report, published in October 2001: *A New Acute Hospital for the South West of Northern Ireland.*

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302 John Posnett, Karin Lowson, Stephen Chaplin and Sophie Beale, *op.cit*, p 2.
The Stutt Report also reviewed the Hayes Report and added to the discussion a geographically based analysis of access to an acute hospital at Omagh and Enniskillen and analyses of sustainability and equity of the acute service options for the South West.

**THE HOSPITAL CAMPAIGN FOR THE RURAL WEST**

The public campaign – the Hospital Campaign for the Rural West (HCRW) – led by the steering group set up by Omagh District Council, was launched “in a blaze of publicity” at the Long Gallery in Stormont in September 2001, while a protest was staged outside Stormont. A local launch in Omagh took place later in the day. Councillor Barry McElduff, chairman of Omagh council, said:

"Launching our campaign at Stormont will send out a very clear message to the decision-makers that the siting of the proposed new hospital for the rural west in Enniskillen is not acceptable. It will send out a clear message to the Health Minister, Bairbre De Brun, that we, the people of Tyrone, demand first-class services for first-class citizens, and it will send out a very clear and important message to the people of Tyrone, who, under Hayes, would be left without acute hospital services, that this battle can be won."

The Hospital Campaign for the Rural West revealed plans for a series of community information evenings, a leaflet drop, a website and a public rally aimed at persuading the minister to ignore the recommendation of the Hayes Report. Thousands of people took to the streets of Omagh a few days later to join a rally and march organised by hospital staff – the ‘Campaign of Hope’ – to save hospital services and local sustainable services.

Omagh ground to a standstill the following month as thousands of people swamped the town centre in protest against plans to remove the area’s acute hospital services.

“A sea of faces stood in the street below Omagh Court House, demonstrating their anger at the threat in a show of strength aimed at getting Health Minister Bairbre de Brun’s attention. The 20,000-strong crowd included people from all sections of the community. Some waved banners and placards declaring: ‘The people have spoken, listen,’ and ‘Ear nose and throat, come to your senses Mr Hayes.’

Throughout the campaign, there were ongoing meetings with the Department, the Western Health and Social Services Board and Sperrin Lakeland Trust. From the start, the campaign pursued a rigorous series of meetings with senior politicians. A petition with 30,000 names was delivered to Stormont. Omagh council leader Cllr Barry McIlduff and chief executive Mr Danny McSorley met

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Health Minister Bairbre de Brun and senior officials. This was followed by meetings with the political parties represented in the NI Assembly.

**THE HINDLE REPORT**

The next instalment in the battle of the reports was, *A Critical Review of Two Reports on Options for Acute Hospital Services in the South West of Northern Ireland,* by Dr Tony Hindle in March, 2002. Hindle’s review of the York and Stutt reports is critical of the methodology and findings of both. He deemed the quantitative analysis in both reports to be “seriously flawed”. Both had failed to reach the standards required. Hindle commented that the two reports,

> “provide readable and generally well-prepared arguments in favour of two diametrically opposed ‘solutions’ to the location and management of acute hospital services in the southwest of Northern Ireland. The York report argues in favour of a single-site major acute hospital located in Omagh (with a community hospital in Enniskillen) and the Stutt report argues in favour of the opposite solution.”

At the NI Assembly in June 2002, the Minister of Health, Bairbre de Brun indicated that the view that the balance lay in locating the new hospital in Enniskillen was based on all the information available, including the reports by York Economics, Colin Stutt and Dr Hindle. However, the consultation would continue and she was prepared to consider new proposals and additional information that arose from that.

**DEVELOPING BETTER SERVICES REPORT**

In June 2002 the Department of Health, Social Services and Public Safety published *Developing Better Services: Modernising Hospitals and Reforming Structures.* (See Chapter Two.) Tyrone County Hospital would become an ‘enhanced local hospital’ and there would be a new acute hospital in or to the north of Enniskillen. The consultation period for this document, published in June 2002, was extended to the end of October 2002.

The *Developing Better Services* Report undertook additional analysis in assessing journey times within Fermanagh/Tyrone and between the counties and adjacent hospitals in the south. Activity and staffing data covering Sligo, Cavan, Monaghan and Letterkenny Hospitals were analysed in order

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311 Minutes of Meeting of Strabane District Council, 13 November 2001.
312 Hindle, Dr. Tony, *A Critical Review of Two Reports on Options for Acute Hospital Services in the South West of Northern Ireland.* March 2002.
313 Ibid.
314 Ibid.
315 Assembly Hansard Reports 17 June 2002, from Judicial Review.
to help to establish the current potential of these hospitals to contribute to the provision of acute services in Northern Ireland:

If the use of hospitals in the south was not taken into account and a new Fermanagh/Tyrone hospital was situated in or to the north of Enniskillen around 8,744 people in Fermanagh/Tyrone area would have travel times of over 45 minutes of whom 2,131 would be between 50 and 55 minutes travelling time from the hospital. None would be more than 55 minutes away from the hospital. This compared with an Omagh location where 24,250 people in the Fermanagh/Tyrone area would be more than 45 minutes away, of whom 21,234 would be more than 50 minutes away, with 9,749 more than 60 minutes travelling time from the hospital.

If hospitals in the south were able to provide A&E and a full range of acute services to the population and this was factored into travelling times no one in Fermanagh or Tyrone would have to travel more than 55 minutes to an acute hospital regardless of the chosen location. In this scenario the differences between access times were much closer. If the hospital was located in or to the north of Enniskillen, around 6,525 people in the Fermanagh/Tyrone area would have travel times of over 45 minutes, none of whom would be more than 50 minutes away from the hospital. This compared with an Omagh location where 4,626 would be more than 45 minutes away, of whom 2,365 would be between 50 and 55 minutes away from the hospital.\(^{317}\)

*Developing Better Services* noted that a group established by the North/South Ministerial Council (NSMC) had been tasked with identifying service areas/specialities for cross-border or all-island co-operation which could be of mutual benefit. The health departments in Northern Ireland and in the south were working collaboratively on A&E planning for major emergencies, co-operation on high technology equipment, cancer research and health promotion. It stated that such collaboration was in the best interests of patients, North and South and it was important that the full potential of such co-operation was realised.

Towards the end of April, 2002, a meeting in Dublin took place between the HCRW, officials from the Department for Health and Children and the Republic’s North Eastern and the North Western Health boards. Opportunities for cross-border co-operation in the delivery of acute hospital services topped the agenda and the Department for Health and Children agreed to refer the issue to the North South Ministerial Council for consideration.\(^{318}\)

In June 2002, the Hospital Campaign Steering Group expressed its “dismay and disappointment” at the proposal to site a new acute hospital for Fermanagh and Tyrone in Enniskillen. The campaign chairman argued that this proposal failed to take into account evidence presented by York

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Economics 319 “that an Area Hospital in Omagh, complemented by hospitals in Sligo and Cavan, provides the best solution for the people of Tyrone and Fermanagh.” 320

In June 2002 Minister de Brun answered an Assembly question about meetings that had taken place with Micheál Martin, TD, Minister of Health and Children, in respect of the future of acute care; any actions considered in terms of north/south co-operation; and what impact any such discussions had had on the detail of their proposals. She stated that she had spoken with the Minister for Health and Children and had sent him a copy of Developing Better Services: Modernising Hospitals and Reforming Structures. From communication at a senior level between the Department of Health and Social Services and Public Safety and the Department of Health and Children it was apparent that there was uncertainty as to whether the relevant hospitals in the South would, over the longer term, deliver the capacity and services equivalent to those provided by the nine acute hospitals in the North. This degree of uncertainty had to be taken into account in deciding the best location of the new hospital with a potential life span of 60 or more years. Any information that emerged during the consultation process would be considered before final decisions were reached. On almost every occasion that she had spoken with Micheál Martin, the issues raised had touched on acute hospital provision.” 321

The Hospital Campaign for the Rural West Steering Group organised a conference – “Health care provision to rural & border communities” – in June 2002. 322

The Omagh & District General Practitioners’ Association made a public declaration of its support in July 2002. The Sperrin Lakeland Trust had totally failed the Association’s 60,000 patients and misinformed and misled the public about the “unjust and seriously flawed ministerial recommendation.” They pledged not to “refer or admit our patients to the proposed new hospital in Enniskillen just to help sustain or make viable this proposed new hospital,”

“The inaccurate, irresponsible & totally misleading public statements by our trust have our patients believing that we will have an Enhanced Local Hospital in Omagh (24 hour A&E, Coronary Care, Medical Inpatient beds) and a good chance of the one protected elective centre earmarked for West of the Bann. On reading Minister Bairbre de Brun’s document "Developing Better Services.", nothing could be further from the truth. ...

Finally, to all of our patients, we believe that your health care needs and rights will be denied you if this recommendation is implemented and we urge you not to accept it. ... We promise now that we, your General Practitioners in Omagh & District, will make every effort and explore

319 J. Posnett, Karin Lowson, Stephen Chaplin and Sophie Beale, op.cit.
321 Assembly Hansard Reports 17 June 2002, Judicial Review.
every avenue to secure the same standard and quality of health care services for you as provided for the rest of the Northern Ireland population.\textsuperscript{323}

At a meeting on 25 July 2002, the two Ministers for Health again discussed the capacity of hospitals in the south to deal with additional numbers of service users from the north who chose to access services in the south; the long term plans for development of hospital services in the south; the potential for the development of complementary services north and south of the border corridor approx to Fermanagh, Cavan and Sligo; and the future plans of road upgrades in the south in areas adjacent to the border. They agreed that a small DHSSPS team would visit Cavan, Monaghan, Sligo and Letterkenny Hospitals to access their potential to deal with estimated increased capacity from the north and also to consider the opportunity for complementary services north and south. The DoHC would establish what plans there might be to upgrade roads in areas adjacent to the border, particularly in relation to routes to Cavan, Monaghan and Sligo Hospitals.

In August, the Committee for Health, Social Services and Public Safety heard evidence in response to \textit{Developing Better Services}. This included a written submission by Dr Kieran Deeny on behalf of the Omagh & District General Practitioners’ Association. Omagh District Council and the HCRW made a joint written submission in September. They welcomed the decision by the Health Committee to scrutinise the Department’s proposals, because these were based on the Hayes’ Report’s “flawed thinking and lack of an evidence-based approach”\textsuperscript{324} Their submission offered a detailed response on the issues raised in the various reports detailed above, but explained that their ability to respond was hampered because the Department had not made promised information on access times available.\textsuperscript{325}

The DHSSPS team visited the southern hospitals in September 2002 and the officials discussed the number of people that might realistically expect to travel south for acute admissions in an emergency. They estimated that of the population south and west of Fermanagh Lakes around 826 people might be expected to be admitted to Cavan /Monaghan Hospital Group and approximately 118 to Sligo General Hospital. Subsequently, Minister de Brun wrote to her Southern counterpart, Minister Martin

\begin{footnotesize}
\begin{enumerate}
\item Dr Kieran Deeny, Chairman, “Trust has Failed our Patients”, Statement from Omagh & District GP Association, 4 July, 2002.
\item Written submission by Omagh District Council, Minutes of the Health, Social Services and Public Safety Committee, Northern Ireland Assembly, 9 September 2002.
\item Ibid.
\end{enumerate}
\end{footnotesize}
“...I should therefore be interested to know whether within your plans for development of acute services in the North Eastern Board area is it likely that within our estimated planning timeframe of seven years additional capacity would be available in both Cavan/Monaghan Hospital Group and Sligo General Hospital to absorb our estimate of additional service users from the north.”

Following the visits to the hospitals in the south where the issue of complementary services was discussed, the broad consensus was that complementary services were to be welcomed and encouraged particularly for a triangle of hospitals including Cavan/Monaghan Hospital Group, Sligo and the new hospital in Fermanagh/Tyrone. However, it was considered that the opportunity lay around specialities and sub-specialities delivered by a network of hospitals. Minister de Brun’s letter continued:

“Consequentially until I make my decision on the location of the new hospital in Fermanagh/Tyrone it would be difficult to make any real progress on the issue. Once my decision is taken then work should begin in earnest to develop complementary services which might impact upon the final profile of services for the new hospital in Fermanagh/Tyrone. There is also a view that complementarities should be developed under the auspices of the North South Regional Hospital Services Group drawing on the work already done by CAWT. I would endorse this approach.”

“... one of the issues which I must address in coming to a decision on the siting of a new acute hospital for Fermanagh/Tyrone is long term plans in relation to hospital capacity of hospitals in the south, particularly at Cavan, which appears to be operating at full capacity. It would therefore be of particular benefit to me if you could indicate as soon as possible whether, in light of the estimated figures provided in this letter, and over an estimated planning timeframe of seven years to construct a new hospital in Fermanagh/Tyrone there would be sufficient capacity planned for Cavan/Monaghan Hospital Group and Sligo General Hospital to absorb the additional numbers of people travelling from the north that I had indicated.”

Minister de Brun requested an early response on the issue of whether there would be sufficient capacity planned for Cavan/Monaghan Hospital Group and Sligo General Hospital to absorb the additional numbers of people travelling from the north to allow Minister de Brun to put the response into the public domain in sufficient time to allow the information to be considered during the remainder of the consultation period. No response was sent until 23 January 2003, by which time the Assembly had been suspended and Direct Rule Minister Des Browne had taken over the health portfolio at Stormont.

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326 Letter from DHSSPS Minister Bairbre de Brun to the Minister for Health and Children Micheál Martin, 9 October 2002, quoted in Her Majesty's Court of Appeal in Northern Ireland, Neutral Citation No [2004] NICA 10, 9 March 2004.

327 Ibid.
The next report off the blocks was a briefing paper produced by the University of Ulster, *The Report of the Panel Conducting the Public Examination for the Hospital Campaign for the Rural West*. This panel was established as a facility to allow local organisations and individuals to express their views on the proposals in *Developing Better Services* and to have these views interrogated by an independent panel of experts. The panel considered 49 written submissions and heard 24 oral views. Around the same time, the Western Health and Social Services Board held its own meetings in Strabane, Omagh and Enniskillen.

The report summarised the main themes contained in the submissions, many of which were about sustainability and accessibility; concerns about loss of services and social and economic factors. They noted also that respondents, “were keen that the full potential of North-South cooperation in A&E and acute services should be developed.” The Panel made a number of conclusions based on analysis of the evidence presented, recommended that the Department should engage in comprehensive discussion about a number of matters perceived to be of major importance and identified a number of issues that required further research and analysis.

A substantive response to *Developing Better Services* from the Hospital Campaign for the Rural West was submitted in October 2002. This document incorporated the evidence presented to the University of Ulster panel. It argued that the Department had based its proposals exclusively on the criteria of accessibility, but that there were six criteria that should underpin any decisions taken by the Department:

1. Strategic Fit
2. Accessibility
3. Sustainability
4. Quality and Clinical Standards
5. Social Economic Impact
6. Integration

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330 *Developing Better Services: Modernising Hospitals and Reforming Structures; A Response*, Hospital Campaign for the Rural West, October 2002.
It concluded that, both in terms of the convenience of the greater number of patients and in terms of proximity to an acute hospital, the Omagh location is “by far the preferable option.”

With the Assembly now suspended, a delegation from HCRW met Health Minister, Des Browne on 15 January, 2003. The Minister promised his decision by the end of the month, based on a reasoned and balanced approach and having carefully considered all the evidence available to him. Early in 2003 also, the campaign group met with the four main political party leaders.

The Minister for Health and Children, Micheál Martin responded to the questions in Bairbre de Brun’s letter of the previous October on 23 January 2003. Writing now to Des Browne, he referred to previous correspondence and discussions concerning the scope that existed for improved cross-border co-operation on acute hospital services,

“I am aware that you are anxious to reach an early decision on the location of a new acute hospital to service the Fermanagh/Tyrone area and that in that context questions have been raised about whether the hospitals at Sligo and Cavan/Monaghan would be in a position to provide services to people in south and west Fermanagh who are willing to avail of services there. ... Following consultation with the Chief Executive Officers of the North Western and North Eastern Health Boards our assessment is that in aggregate terms patient flows of this order could be accommodated. However, it would be necessary to look at the case load likely to be involved in terms of specialty and complexity in more detail in order to make a definitive commitment in this regard. In regard to future developments here, the Government is committed in the Health Strategy to a further expansion of capacity in the acute hospitals. The further analysis required to determine the specialty and geographic distribution of the additional beds is currently under-way in the Department. ...”

Minister Browne, in turn, issued a press release a few days later confirming that he would announce his decision on 24 February. One of the factors leading to his announcement was the need to consider the letter from Minister Martin in relation to the use of hospitals in the Republic. He therefore would not make a decision at the end of January after all:

“This letter and further work by the Department recently undertaken in relation to journey times and hospital catchment should I believe be put into the public domain to allow time for people to consider this information and to respond if necessary in good time before I make decisions. This means I will not be able to make my decision at the end of January as planned.”

Finally, however, in February 2003, the Minister for Health, Des Browne, announced that the decisions on Developing Better Services had been “broadly endorsed” in the consultation process.

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331 Developing Better Services: Modernising Hospitals and Reforming Structures; A Response, Hospital Campaign for the Rural West, October 2002.
333 Hospital Campaign for the Rural West, Campaign Update.
There would be a £500 million start of a capital investment programme in acute hospitals amounting to £1.2 billion over the next 10 years.

The most difficult decision, wrote the Minister, was the site for the new acute hospital for the South West. He said the arguments were finely balanced and an acute hospital developed on any of the proposed sites, [a site near Ederney had also been suggested] could be sustained and would attract the numbers of patients required to enable clinicians to develop and maintain the specialist skills required to deliver a range of acute services. After careful consideration of all the arguments, however, the Minister had concluded that “the interests of both Fermanagh and Tyrone are best served by siting the new acute hospital at Enniskillen.”336 In relation to the new hospital in the South West, Mr Browne said:

“This was by far the most difficult decision facing me. I considered all the evidence before me, it was a finely balanced decision but I have concluded that the interests both of Fermanagh and Tyrone are best serviced by siting the new hospital to the north of Enniskillen. Throughout this process I have been very aware of the destabilising effect on hospital services in both Omagh and Enniskillen. This lack of a decision has caused [damage] and without a decision this damage to both hospitals could very quickly become irreversible...”337

As part of the campaign against the proposals to close the hospital, the Chairman of the Omagh & District General Practitioners’ Association, Dr Kieran Deeny and nurse Olive Wylie stood as independent hospital candidates in the 2003 Northern Ireland Assembly elections on the single issue of retaining the hospital. Dr Deeny topped the poll.

Omagh District Council responded to Des Browne’s decision by seeking a Judicial Review, supported by Strabane District Council and Dungannon District Council. On 9 May 2003, Mr Justice Kerr refused Omagh District Council’s application for leave to apply for judicial review of Mr Browne’s decision on the location of the new acute hospital for the South West. A special meeting of Omagh District Council was called on 15 May, 2003 members of the Council unanimously supported lodging an Appeal.338 The appeal by Omagh District Council from the order made by Justice Kerr was heard on 9 March, 2004. The Court dismissed the appeal and refused leave to renew the application for leave.339

339 Her Majesty’s Court of Appeal in Northern Ireland, Neutral Citation No [2004] NICA 10, 9 March 2004.
Omagh District Council’s application for a Judicial Review was based on the contention that the Minister failed to investigate adequately the contribution hospitals in the Republic of Ireland might make in deciding whether the hospital should be sited north of Enniskillen or at or near Omagh.

The Council challenged the decision by Health Minister Des Browne on the basis of the manner in which the Minister dealt with the possibility of hospital cover for Northern Ireland patients in hospitals in the Republic of Ireland. It was also argued that the Minister failed to carry out his duty of enquiry adequately, not least in view of Strand 2 and the Annexe thereto of the Belfast Agreement. 340

The judge, however, took the view that the Minister had adequately investigated the situation in the Republic of Ireland and held that it was entirely reasonable that he should decide the matter when he did and considered that the applicant had not raised an arguable case. 341 The Court’s opinion was that the Minister was not obliged to take up the offer by the Minister for Health and Children in the Republic, to contact him if he required any further information or clarification. The Department of Health in the Republic had not been able to give a definitive commitment that the Cavan and Sligo Hospitals would provide the services available in an acute hospital in Northern Ireland. It was only if a definitive commitment had been given by the Department for Health and Children that Cavan Hospital and Sligo Hospital would provide acute emergency services in the same way as an acute hospital in Northern Ireland for patients from South and West of Lough Erne that the decision made to site the hospital north of Enniskillen could have been changed. “Mr Martin was careful to avoid giving such a commitment ...” 342

Meanwhile, the public campaign continued. Survivors of the Omagh bombing were also involved in making the case for retention of A&E and acute services at Omagh. The hospital had already lost its maternity services. One survivor addressed Prime Minister Tony Blair through the press in March 2003:

> “Mr Blair, you have gone back on your words. Days after the Omagh bombing, you stood by my bedside and promised my family, when questioned about the closure of the Omagh hospital, that it would never happen. ... Once again we feel like second-class citizen here. Northern Ireland has six golden hospitals, five of which are within a 20-mile radius of Belfast and we do not have acute services here in Tyrone. ... After the Omagh bombing, Belfast’s Royal Victoria Hospital reported that we would have had a death toll of over 70 if it had not been for the location and expertise of the Tyrone County Hospital.” 343

340 Her Majesty’s Court of Appeal in Northern Ireland, Neutral Citation No [2004] NICA 10, 9 March 2004.
341 Ibid.
342 Ibid.
A report on services that would be delivered at the new acute hospital in Enniskillen and the local enhanced hospital in Omagh was made public by the Sperrin Lakeland Trust in March, 2003. The Trust claimed that the new hospital in Omagh would continue to provide 80 percent of the services currently being offered at the Tyrone County. There would be no job losses, and in fact new jobs would be necessary in both Omagh and Enniskillen.\(^\text{344}\)

By the beginning of 2004, however, local elected representatives were warning that services were being run down. In January, all the local MLAs and local MP Mr Pat Doherty met to discuss the situation. Dr Kieran Deeny, MLA said that the Tyrone County was "not far away from closure: "staff were demoralised and moving elsewhere and this was threatening the viability of services. His claims were denied by the Trust, although it was admitted that there were “significant pressures” and some difficulties in recruiting staff.\(^\text{345}\)

A few weeks later the Health Minister – now Angela Smith – pledged a commitment to saving major services at Tyrone County Hospital in Omagh until a new acute hospital was built – probably in seven years time. Mrs Smith emphasised the importance of maintaining acute services – including at Tyrone County – until alternative capacity is available. The Minister stated, that the Department, the HSC Board and the Western HSC Trust were all “fully committed” to putting in place a substantial programme of investment aimed at sustaining and developing services at the Tyrone County Hospital.\(^\text{346}\)

Minister Angela Smith, announced in January 2004 that she had agreed to meet West Tyrone MLAs to discuss their concerns about the provision of acute services in Co Tyrone arising from the decisions made by Minister Des Browne on Developing Better Services. However, she would not meet them until after the outcome of the appeal against the decision not to allow the judicial review was known and while she would “listen and consider carefully what the MLAs have to say,” she agreed with the decision made by Des Browne and her Department would “continue vigorously to defend the legal challenge by Omagh District Council.”\(^\text{347}\)

In February 2004 the Hospital Campaign for the Rural West undertook a ‘symbolic protest’ to mark the first anniversary of Des Browne’s decision to locate the new acute hospital for the South West of the province in Enniskillen, and “effectively strip acute services out of Co. Tyrone”. Chairman of the campaign Steering Group, Mr Danny McSorley said that the campaign to have the decision reviewed would continue: the Minister’s proposals had been comprehensively rejected by the people and the

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\(^{344}\) “Omagh hospital will continue to have large range of services,” The Newsletter, 24 March 2003.

\(^{345}\) “Omagh hospital is close to closing, says MLA GP,” Belfast Telegraph, 9 January, 2004.


\(^{347}\) “Minister to Meet with West Tyrone MLAs,” 23 January, 2004.
success of the Hospital Candidate Dr Kieran Deeny in the recent Assembly election was a clear statement by the people of West Tyrone. Furthermore, the four main political parties the Assembly elections have given their commitment to reviewing the proposals when they hold the Health Ministry in a new Executive.  

The following March, after another meeting with the MLAs, Minister Smith pledged to do everything she could “to ensure that no acute services are withdrawn from the Tyrone County Hospital - or any other hospital - until appropriate alternative provision is available elsewhere.”

A public meeting at the town’s leisure centre in April 2004 was called to share information on the campaign and the judicial review application outcome with the Tyrone public. Meetings of the Sperrin Lakeland Trust Board and the Western Health and Social Services Board were occasions for regular protests by hospital campaigners. In the run up to the EU elections of 2004, a road signs were erected on all approach roads into Omagh and a number of other towns. In July, large trailer advertisements were placed at Ballygawley, on the A5 and the Derry Road Roundabout.

The HCRW unveiled a new series of posters and launched a new phase of the campaign on the steps of Stormont in September 2004. The launch was planned to coincide with the political negotiations at Leeds Castle to emphasise to all those involved the urgency of getting a devolved local administration. The campaign group had been assured by the four main parties that the removal of acute hospital provision from Tyrone would be examined by the Health Minister in a new devolved administration.

Although not accepting that the decision to locate the new acute hospital in Enniskillen was the right one, the focus of many local politicians and activists gradually shifted to protecting the remaining services at Tyrone County Hospital and arguing for optimum development of the new Omagh hospital. In October 2004, the press reported that Sperrin Lakeland Trust has been holding discussions on the removal of ENT and the acute surgical services from Tyrone County Hospital within six months, even though Trust chief executive Hugh Mills had promised that all dealings would be carried out with transparency.

“The News Letter can reveal that meetings took place on September 24 ... Four days later, a Sperrin Lakeland Trust annual meeting took place but the talks were not mentioned. During this

351 Hospital Campaign for the Rural West, Campaign Update.
meeting, there was heated debate around speculation that the accident and emergency service at the Omagh hospital was to be stepped down in favour of a nurse-led minor injuries unit. This was emphatically denied.” 354

The trust issued a statement admitting that discussions had taken place but insisted that no decision was made. HCRW Chairman, Mr Danny McSorley, said: “It would be a cause for major concern to learn that the removal of any acute services from Omagh in the near future is being discussed. There was a commitment given that acute services would continue in the Tyrone County Hospital until such time as the new acute hospital was operational. 355

The Hospital Campaign for the Rural West organised a protest at Omagh Library Headquarters on 15 March, 2005. HCRW Chairman, Mr Danny McSorley told a meeting of Strabane District Council’s Economic Development Committee that although after four years it was a challenge to maintain high levels of public interest, it was still possible to influence the decision as the project was unlikely to reach approval stage before June 2005. Mr McSorley advised the committee that a protest presence at the monthly Sperrin Lakeland Trust and Western Health and Social Service Board meetings was still continuing. 356

At the Trust meeting on the 15th, there were “angry scenes.” The board was expected to decide on a site north of Enniskillen for the acute hospital but protestors thwarted all efforts to open proceedings. Eventually the trust was forced to suspend the meeting and members were “jeered out of the building by the hostile crowd.” When the meeting was reconvened at the Tyrone and Fermanagh Hospital, protestors stormed that gathering and “a scuffle ensued with members of the board claiming that the second meeting was a private affair.”357 The Sperrin Lakeland Trust announced the sites for the two new hospitals in Omagh and Enniskillen on 30 April, 2005.

The Direct Rule Minister for Health in 2005 was Mr Shaun Woodward. A delegation including Omagh District Council officials, MLAs, councillors and community representatives delivered a letter to Minister Shaun Woodward in June, calling for urgent action in response to the report into the Risk and Governance Review of Acute Services in Sperrin Lakeland Trust. They called for the Intensive Care Unit at Tyrone County Hospital to be reinstated and the establishment of an Independent Public Enquiry into the “mismanagement of hospital services in the Sperrin Lakeland Trust Board

355 Ibid.
area.\textsuperscript{358} The Steering Group met with him in July and then followed up in writing, stressing yet again their argument about sustainability.\textsuperscript{359}

Busloads of hospital campaigners were taken to Belfast followed by a parade in Omagh town on 4\textsuperscript{th} July 2005. In the crucial days leading up to a decision by the Health Minister on the future of the hospital, Hospital Campaign Steering Group Chairman, Mr Danny McSorley said: "The fight to save the Tyrone County Hospital must be kept going. We want to make a strong statement and bring it right to the heart of the British Government."\textsuperscript{360}

Omagh bomb survivor, Donna Marie McGillion, and a group of 24 others, took the campaign to Health Minister Shaun Woodward’s constituency office in England in September 2005. On their first visit, a secretary informed her that the Minister was unavailable. When they returned the next day, the office was closed. Staff had been given a day off. Ms McGillion said:

"What’s he afraid to face? Why won’t he talk with us? ... We’ve had acute services removed from all three hospitals in our area. We have no A&E, no maternity unit, no breast unit and no in-patient paediatric unit. We’ve been assured by many ministers we’ll be looked after. Tony Blair even told me face-to-face that Tyrone County would never be closed. So how do we explain what’s happening there now? ... "I want to ask him to explain why my life was valuable enough to save six years ago when I was blown up in the Omagh bomb, and it’s not that valuable today. What’s changed?"\textsuperscript{361}

The Royal College of Surgeons issued a report in September 2005 that highlighted significant risks in the accident and emergency departments, and with emergency and major elective surgery at Tyrone County Hospital. A press report commented that, “It now seems inevitable that Health Minister Shaun Woodward, who yesterday launched a two-week crisis consultation process, will axe acute services at the Tyrone County.”\textsuperscript{362}

A meeting in September between senior Department of Health officials and Omagh District Council to discuss the hospital crisis was acrimonious. During the meeting the Department’s representatives informed councillors they were not there for consultation but as part of an engagement process.\textsuperscript{363} Danny McSorley, chief executive of Omagh District Council and chairman of the Hospital Steering Group, informed the department that the council believed the trust would be acting illegally if it implemented its proposal to remove A&E and Acute Surgical services from Tyrone without

\textsuperscript{358} Hospital Campaign for the Rural West, Press Release, 7 June, 2005.  
\textsuperscript{359} Letter from D McSorley to Mr Shaun Woodward, MP, 21 July, 2005.  
\textsuperscript{360} “Fight on to save hospital,” The Newsletter, 28 June 2005.  
\textsuperscript{361} “Shut Out: Omagh victim Donna Marie McGillion brings her hospital protest to Minister Woodward’s home town ... but he Closes his office and sends his staff home,” The Mirror, 10 September, 2005.  
\textsuperscript{362} “Hospitals are risking lives,” Newsletter, 20 September, 2005.  
\textsuperscript{363} “Hospital crisis meeting turns into war of words,” The Newsletter, 29 September, 2005.
complying with its statutory equality obligations to consult properly with the community and not just communicate intention.\textsuperscript{364}

In October 2005 Mr Woodward announced the plan to remove A&E services and acute surgery from the Tyrone County. Emergency and major elective surgery would be transferred to the Erne in the first few months of the New Year. Once again, the campaign mobilised the public to protest.\textsuperscript{365} Omagh hospital supporters blocked the road at Stormont in the wake of the announcement.\textsuperscript{366} Minister Woodward denied claims that the government would not fund the construction of a new hospital in Omagh. He said that the work would definitely start in 2007:

"I am spelling this out, clearly and plainly, because the public of Fermanagh and Tyrone should be left in no doubt that they will have two new hospitals. We will spend £270 million building these new state of the art facilities. The public of Fermanagh and Tyrone should be left in no doubt that they will have two new hospitals. Anyone who says otherwise, anyone who gives you the impression that one or other hospital will not be built is misleading you. Anyone who tells the people in Omagh that the current hospital in Tyrone is closing and will not be replaced is not telling the truth."

Health Minister Shaun Woodward, 12 October, 2005

Another rally of several thousand people took place in mid-October against removal of A&E services acute surgery from the Tyrone County. Chairman of Omagh District Council Michael McAnespie, said: "The time has come for the people of this district to mobilise en masse and send a clear and defiant message to Shaun Woodward. We will not go away."\textsuperscript{367}

\begin{quote}
\textbf{"Mr Woodward’s actions have united the people of Tyrone unlike any other issue. There is unprecedented cross-community opposition to his proposals. Every single elected representative, every church and every community group, regardless of politics, religion, race, creed or colour stand united against the proposals to remove accident and emergency and other life saving services from Tyrone County Hospital. On this historic day the people of Tyrone send their clear and powerful message. For the first time in history we are here together—you must listen to us, otherwise there is no justice and no value in the word democracy."

Statement by HCRW, 22 November 2005\textsuperscript{1}
\end{quote}

\textsuperscript{364} “Hospital crisis meeting turns into war of words,” The Newsletter, 29 September, 2005.
\textsuperscript{365} “Omagh hospital campaigners defiant,” Belfast Telegraph, 17 October, 2005.
\textsuperscript{366} “Hospital will Close…but we’ll build 2 more,” The Mirror, 12 October, 2005. See also: “£270m hospital plans get public showing,” Belfast Telegraph, 11 October 2005.
\textsuperscript{367} “Work on new hospital to begin in 2007,” The Newsletter, 12 October, 2005.
Early in November 2005, the campaign held a rally at Belfast City Hall. The rally was one part of a five-week action strategy by campaign co-ordinators, leading up to a mass rally in Omagh on November 28. Buses were organised to bring protesters from Omagh to the city and Belfast residents were encouraged to join in.\footnote{Hospital protest in City,” The Newsletter, 8 November, 2005.} Ms McGillion returned to England later in November with all six West Tyrone’s MLAS to deliver a petition against the closure of Tyrone County Hospital’s A&E facilities to Prime Minister Tony Blair at Downing Street. Donna Marie McGillion was on this occasion joined by a cross-party group of Assembly members.\footnote{Hospital SOS by bomb girl,” The Mirror, 24 November, 2005.}

At the end of November 2005, an estimated 24,000 – 30,000 people once again took to the streets, to protest against the decision to scrap accident and emergency services in Tyrone. (The population of Omagh town was then 23,000 with a wider Tyrone population of 160,000.) The biggest public rally ever staged in Tyrone, all of the town’s schools and many shops closed for the event. Campaign Chairman Danny McSorley told the people gathered that “the manner in which Health Minister Shaun Woodward and his officials have been pursuing this has been deceitful, reckless and totally oblivious to the needs of the people.”\footnote{Omagh protesters voice feelings of betrayal. 24,000 take to the streets in a bid to keep their hospital,” Belfast Telegraph, 29 November, 2005.}

A total of 180 separate responses were received to the the Sperrin Lakeland Trust consultation document, \textit{Making Services Safer in the Sperrin Lakeland Trust} consultation paper. In addition the Trust received six petitions containing a total of 1002 signatures, and individual responses from 277 pupils from three schools. 94\% were opposed to the proposal to.\footnote{Sperrin Lakeland Trust, \textit{Making Services Safer in Sperrin Lakeland Trust: Analysis of Responses to the Consultation Document}, December 2005.} Nevertheless, by the end of 2005, also, Trust had lodged plans for the new hospital with the Department of Environment planners. Feedback from the public was invited on the proposed building and facilities.\footnote{“£100m plan for new Omagh hospital,” The Newsletter, 22 December, 2005.}

HCRW undertook a strategy review early in 2006 and reworded the campaign’s objective to incorporate more clearly the concept of sustainability in relation to the location and services offered: “To secure a sustainable acute hospital at Omagh that will meet the needs of the people of the Rural West.” A number of action points were agreed for the coming year. It was agreed to have a high profile relaunch of the campaign and the new action plan so that the wider community was aware of

\begin{quote}
\textbf{“The manner in which Health Minister Shaun Woodward and his officials have been pursuing this has been deceitful, reckless and totally oblivious to the needs of the people.”}
Mr Danny McSorley, Chair HCRW
\end{quote}
what was proposed and to “help the wider community to determine how they can play their part in assisting the campaign to meet its objective.” The campaign working groups would also be restructured.\textsuperscript{374} On 29 March, 2006 the campaign group mounted a protest at the Tyrone County Hospital on the eve of the transfer of acute services from the hospital.\textsuperscript{375}

In May 2006, the new Health Minister, Paul Goggins, welcomed the proposals for the new hospital planned for completion by 2010/11. The local hospital in Omagh would, he said, provide 70 to 80% of the hospital services required by the local population, “in a modern and welcoming setting.”\textsuperscript{376}

Two meetings were held with Minister Goggins in June 2006. The Minister was requested to “honour the ministerial assurances given which were not honoured, referring particularly to A Smith’s regarding maintaining services until alternative arrangements were in place ...” Mr McSorley explained that as a result,

> “the community felt continually belittled and the response was therefore anger and no confidence in the health institutions whether it was the Department or the Trust. He went on to point out that due to so many broken promises, people do not believe anything that is said anymore.”\textsuperscript{377}

At the second meeting, the Minister asked for suggestions as to how to deal with the mistrust issue. The new HCRW Chairman, David McKee responded that “no rationale had ever been given for the decision and that all logical, sensible comments and consultation responses given by the Campaign Group and Omagh Council had never been listened to.”\textsuperscript{378}

The DHSSPS Permanent Secretary, Mr Andrew McCormick, met a campaign delegation at the end of February 2007. The Review of Public Administration was a major discussion. Questions were asked whether staff including consultants would work in more than one hospital. The delegation suggested that patients were bypassing the Erne Hospital and travelling to Altnagelvin and Craigavon, even though there was evidence that Altnagelvin gave priority to patients from within its own catchment area. Patients from Tyrone were being disadvantaged and a delegate asked, “How do you propose to address this serious lack of confidence among the people of this area?”\textsuperscript{379}

\begin{footnotes}
\item[375] Letters from Danny McSorley, 29 March, 2006.
\item[377] Minutes of Meeting of Delegation from Omagh District Council and Hospital Campaign Steering Executive with Mr Paul Goggins, MP, Minister for Health, Social Services and Public Safety at Stormont Castle, Belfast on Tuesday 6 June 2006.
\item[378] Minutes of Meeting with Mr Paul Goggins, MP, Minister for Health, Social Services and Public Safety on Tuesday 27th June 2006.
\item[379] Hospital Campaign for the Rural West, Briefing Paper for the meeting with Mr Andrew McCormick, Permanent Secretary, Department of Health, Social Security and Public Safety, 27 February, 2007.
\end{footnotes}
The HCRW met with Minister Michael McGimpsey in May 2007, shortly after his appointment as Minister in the reconstituted NI Executive. The group offered an overview of the issues and linked their opposition to the Hayes Report and Developing Better Services to current pressures of overcrowding in Altnagelvin and Craigavon. The HCRW also asked for a moratorium on the use of the Private Finance Initiative to deliver the new Omagh hospital. Minister McGimpsey responded that while the new hospital at Enniskillen was already underway, it was important to find common ground and focus on what services would be delivered in the new Omagh hospital.

"Whether Enniskillen was the correct decision or not was taken before me. I want to ensure there is money to deliver a hospital in Omagh. What do you want delivered? We need to find a common view. As far as I am aware, it is a lot more than a local hospital. ...."

The campaign delegation made clear that they were not asking for sub-regional services such as cancer care to be available at Omagh, but that emergency services did need to be available. One delegate explained the morale of the community at this time,

"The people here feel that the ‘rug has been pulled from under their feet’. They don’t know what is on the drawing board. If you take treatment and diagnostics out of the TCH, then there is not much left. Confidence needs to be built up in this community and we need to work together and in co-operation to encourage people to use services. The profile promised is not the profile we have today."

At its Annual General Meeting in June 2007, the Hospital Campaign for the Rural West reaffirmed that the campaign continued its fight to secure high quality, sustainable acute services in Omagh for all the people of the Rural West. In July, the Assembly Health Committee met an HCRW delegation. Health Minister Michael McGimpsey visited Omagh Hospital in August 2007, when he met staff from Tyrone County Hospital and the Western HSC Trust as well as members of the Hospital Campaign Group and local representatives. He was, he said, aware of the concerns of people in Omagh and the surrounding areas over the future of hospital services. The new £150m local hospital complex in Omagh would provide important local services including outpatient clinics, diagnostics, renal dialysis, day surgery, inpatient beds, services for children and urgent care. It would include a mental health facility and a health and care centre, creating, an exciting and very innovative model for the future delivery of a wide range of integrated hospital and primary care services on a single site.

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Health Minister Michael McGimpsey, August 2007

\[380\] Notes taken during meeting between HCRW Research sub-group, Health Minister and Department of Health Officials, Monday 21 May, 2007, Health Campaign for the Rural West.

\[381\] Ibid.
day surgery, inpatient beds, services for children and urgent care. It would include a mental health facility and a health and care centre, creating, “an exciting and very innovative model for the future delivery of a wide range of integrated hospital and primary care services on a single site.”

In September, the Health Committee noted that a response was still awaited on the issues raised. In October, the campaign organised a lunchtime protest at a public meeting of the Western Health & Social Care Trust. At the Assembly, the Minister responded to a question about mental health provision west of the Bann by repeating a pledge that there would be 97 mental health beds, some of which would be acute, in the new hospital in Omagh.

The HCRW made a written submission to a WHSSB consultation on a free-standing midwifery-led maternity unit (MLMU) for Omagh in December 2007. The HCRW was supportive of the proposal and noted that a recent public meeting had also expressed strong support for a MLMU to be provided at the earliest opportunity.

In January 2008, the Minister promised that services in Omagh would include a doctor-led, 24/7 Urgent Care and Treatment Centre, day case surgery, inpatient beds, renal dialysis, a new health and care centre and a major acute inpatient mental health facility. In addition, the Western Board had been asked to draw up proposals to improve the ambulance response in Fermanagh and West Tyrone. Acute inpatient services would be provided from the new hospital in Enniskillen. Both new hospitals in the South West would work with Altnagelvin and Craigavon to share best practice and deliver high quality health services to people living in the west.

The Department had established a liaison committee with an intended membership of elected representatives from Omagh and the health and social care trust. Until this point, however, none of the Omagh Councillors had agreed to participate. A cross-part delegation from Omagh District Council had met with Minister McGimpsey on 20 February 2008. The Councillors accepted that while they still considered the decision to locate acute services in Enniskillen rather than Omagh was fundamentally flawed, the objective of the meeting was to “open up the way for all of us to enter into discussions to agree a profile of services in Omagh that will meet the needs of our community.” The Council was anxious to work with the Minister to find a resolution. If agreement could be reached on the profile of services to be provided, that might open the way for participation by the

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383 Northern Ireland Assembly debates, 1 October 2007.
386 Omagh District Council, Structure of meeting with Mr Michael McGimpsey MLA, 20 February, 2008.
An Enhanced Local Hospital: The Omagh Model

1. **Urgent Care and Treatment Centre** – incorporating a Clinical Decision Unit. This must be Consultant-led and available 24/7. All patients presenting at the Centre would be clinically-assessed and a decision taken regarding the most appropriate location for treatment.

2. **Acute Medicine, Coronary Care and HDU** – this would necessitate anaesthetic services also being retained and would provide support/backup for the Clinical Decision Unit.

3. **Ambulance Protocols** – needs to reflect the new role of the Urgent Care and Treatment Centre, no bypassing the door by Blue Light Ambulances.

4. **ENT Inpatient Unit** – to include children.

5. **Day Surgery Unit** – expanded and work to complement the other two hospitals in the Western Trust.

6. **Renal Services** – with dialysis and laboratory support to be retained.

7. **Imaging Services** – to be retained and enhanced utilisation.

8. **Community Midwifery Unit** – to be established.

9. **Outpatient Services** – to be enhanced.

10. **Rehabilitation** – to include beds for long stay care of the elderly.

11. **Rotation of professional clinical staff** – between the three hospitals to ensure retention of skills.

12. **Site Manager** – should be appointed to co-ordinate and develop all services on the site.

Hospital Campaign for the Rural West, February 2008

Council in the proposed liaison arrangements. The Councillors accepted that acute services would not be provided in Omagh and presented a 12 point proposal to the Minister that HCRW representatives had already discussed with him and that were broadly endorsed by the Council.

In June the District Council met with the NI Assembly Health Committee. Summarising “Where Are We Now?” the Council presentation listed: Bypass protocol for all blue light ambulances; Inadequate roads infrastructure; underutilised facilities at TCH; Demoralised staff; Population confused as to location and level of services; People at risk. They presented also the Omagh community campaign’s 12 point plan (see box).

A few months later, however, the Minister issued an ultimatum to campaigners. It was to be an enhanced local hospital or nothing. He told the Belfast Telegraph:

“What I am saying is basically if they (Omagh council) don’t get on board then I can’t see how I can go forward on Omagh at this moment in time. And I am asking the people of Omagh: do these councillors, do these folk who are campaigning against this hospital really represent what the people of Omagh believe? ...
"I have very precious resources and am trying to spend £190m in Omagh and am being told by the local council that they don't want it as things stand. They want, effectively, a full acute service in Omagh which is not, under the plans, going to happen. It can't happen. These decisions were made before I got near it."  

The Minister warned that the allocated money could be spent elsewhere:

"I have asked the council to support it. I have had meetings with MPs, MLAs, councillors, Omagh hospital campaign groups and various other folks at various other times.

"What I have been saying is they have to get behind this hospital and support it. And indicate on behalf of the local council that they want this hospital because it's very hard for me to build a local hospital if it's in the teeth of local opposition, because effectively if people don't want it they will by-pass it and go to Altnagelvin or Enniskillen or Craigavon.

"My capital fund is about 50% of what I need and the hospital infrastructure in Northern Ireland is about 50-years-old and needs replaced and hasn't had the investment. So there is enormous competition for re-development."

These comments by the Minister were, not surprisingly, deeply concerning for Omagh District Council and other campaigners. The ODC Chairman and Chief Executive met with Council Party Leaders, the Chamber of Commerce, the HCRW and West Tyrone MLAs to clarify and consolidate their response. A special Council meeting was held at the end of October to discuss and amalgamate the views and comments from these meetings. The Council had written to the Minister on two occasions suggesting a meeting. The Minister had now agreed to meet a small delegation, "not to debate the issues, but to provide clarity on the way forward," and to discuss the liaison committee; however it also reiterated that there would be no acute services in Omagh.  

In his letter, the Minister said that he refuted the Council's suggestion that the views and input of the Council had been totally disregarded. He was fully committed to providing as wide a range of services in the enhanced local hospital as possible,

"and the views of the local community, as expressed by the Omagh District Council, have been important in influencing that approach. ... The Council's engagement in the liaison committee would be instrumental and would help ensure the people of Omagh receive the maximum benefit from the planned investment. ...

"In conclusion, I ask that you accept the proposed model of service for the enhanced local hospital and urge you to join the liaison committee. My decision on whether to commit funding for the enhanced local hospital must be confirmed in the very near future and I will not commit such funding without the unequivocal support of the Omagh community."

The Council CEO told the MLAs that the Minister's comments about Council opposition to a hospital in Omagh were inaccurate. Omagh District Council had never opposed the build of a new hospital.

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389 Lesley-Anne Henry. "The deal’s off if Omagh hospital plan is resisted, warns minister." Belfast Telegraph, 9 October, 2008.

390 Ibid.

391 Meeting of Chief Executive and Chairman, Omagh District Council with West Tyrone MLAs, 28 October, 2008.

392 Ibid.
After much discussion, it was agreed that the hospital being offered could not be rejected and that local elected representatives had a duty to try to secure the investment, while continuing to lobby and build on the services secured. There was considerable concern that the Council would be blamed if ultimately, the finance was withdrawn. It was agreed to become involved with the liaison group after the terms of reference had been received. It was important to consider who would represent the Council and how people could be best kept informed. This was a difficult decision, and once made, caused dissension within the ranks of the campaign. Councillors who had enjoyed community consensus for their stand on the hospital issue were now being accused by some of their own voters of betraying the trust of the community, of being ‘Lundys’ and traitors.

The Joint Liaison Group comprises six representatives of Omagh District Council (specified as the leader of each political group and the Council Chairman) and the Western HSC Trust. The Chairman is the Deputy CEO of the WHSCT and the Vice-Chairman is the Chairman of the Council. The Council elected representatives have equal status with the Trust and have Officer and specialist support if required. The Terms of Reference, when agreed, stated that the purpose of the Group was to:

“provide a channel of open and transparent communication between the Council and the Trust. The Joint Liaison Group will consider any issues relevant to the community currently as the new hospital project proceeds will help to determine and shape services to maximise opportunities for the local community.

“It will be the responsibility of the Chair to ensure that the collective view of the Group informs the model of service for the new hospital and the buildings in which those services will be provided.”

It was expected that the Joint Liaison Group would also be able to facilitate and progress discussion with other agencies and stakeholders such as Road Service and public transport services.

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393 Ibid.
394 Conversation with author, January 2010.
395 Joint Liaison Group Terms of Reference (no date).
In 2009 the Council accepted the terms of reference of a Joint Liaison Group between the Council and the Western Health and Social Care Trust that were framed in the context of Developing Better Services and the withdrawal of acute services from Omagh. The terms of reference specify that the “collective view of the Group informs the model of service for the new hospital and the buildings in which those services will be provided.” Some Omagh Councillors however, indicated that they did not have confidence that the deliberations of the Joint Liaison Group would be influential in shaping the decision-making process.

Preparations for the hospital were “well underway” by March 2009. The Minister welcomed the programme of site works then valued at £5.5 million, including some building demolition, decanting existing accommodation and putting in place the infrastructure for essential services for the new hospital such as water, electricity, sewage and drainage. The estimated cost of the hospital had by now risen to £190m and once again the Minister stated that it would meet 70%-80% of the local community’s health and social care needs. The new hospital complex would open in 2012 and work completed by 2013.

The Joint Liaison Group, meets every two months and the minutes indicate that the meetings do provide a good channel of information with the Trust reporting on developments and Councillors able to ask questions and make suggestions. It has, however, been described as little more than a “talking shop” by at least one Councillor. Most of the decisions recorded in the minutes are for more information to be provided or promises for updates on specific issues.

Concerns were raised at the Joint Liaison Group in July 2009, that the Council had received a report that funding for the new Local Hospital was not going to be available. On behalf of the Trust, it was confirmed that the Minister was undertaking a review of the available procurement routes and a decision would be made by the end of the summer. He assured those present that “there is no reason to believe there has been any change in direction,” and that the Trust was working towards completion by 2013. “The Minister has been clear that he will not accept anything less than the delivery by the Trust of the two new hospitals by the deadline, and at present, work is still moving forward on the site whilst a formal decision is awaited.” Cllr McGowan commented that it was difficult to convince people that the Hospital would be built.

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396 Joint Liaison Group Terms of Reference (no date).
397 Conversations with author, January 2010.
400 Joint Liaison Group, Notes of Meeting, 22 July, 2009.
At the next meeting in September 2009, the Group was informed that a decision had not yet been made, and was now expected at the end of October. The Business Case was being revised to consider the Private Finance Initiative and the revised Business Case would be submitted to the Department. The Trust was continuing to progress enabling works that to date had totalled a spend of approximately £7m.\(^{401}\) The Minister responded to a question in the NI Assembly about progress on the Omagh Hospital in January 2010, by commenting that he had set up a liaison committee, which included Omagh Council, to ensure that those concerned are kept informed of progress.\(^{402}\)

The Council’s and the HCRW’s worst fears were, however, realised on 9 April 2010, when the Minister acknowledged that there were financial difficulties relating to the construction and operation of the planned Omagh hospital. Phase 1 of the enabling works have already seen £6.6m spent on demolition, electricity upgrading and sewage works and an additional £7m allocated for roadworks and waste water treatment. The Department confirmed that Phase 2 of the preparatory works would commence at an unspecified date in 2010. It will include provision of new and upgraded roads, further demolition and site modelling. Building work will not, however, commence until the Department has approved the business case and funding.\(^{403}\) The Minister responded to an Assembly question from Mr Pat Doherty, MLA saying that budget constraints prevented him from giving a firm commitment to any project in the planning stage until funding was in place and that in the case of Omagh, “cuts to my department’s budget make this difficult.” The Irish News reported that a meeting of the Joint Liaison Group had taken place on 14 April, at which the funding of the hospital was given priority.\(^{404}\) On 22 April, however, it was reported that members of the Joint Liaison Committee had met with the Minister and received no assurances that money would be available to build the hospital. One Councillor told the Irish News that the Councillors had left the meeting “more disillusioned than before.” The Department of Health told the newspaper that it could not comment until a Trust business case had been approved and the necessary capital funding had been made available. While the £7m has been allocated for

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\(^{401}\) Joint Liaison Group, Notes of Meeting, 30 September, 2009.  
\(^{402}\) Northern Ireland Assembly Debates, 11 January 2010.  
\(^{403}\) “Fears new hospital may never be built,” Irish News, 9 April, 2010, and “£14m being spent on hospital amid fears it may not be built,” Irish News, 15 April, 2010.  
\(^{404}\) Ibid.
phase two of the preparatory works, a Trust spokesperson was unable to comment on when it would begin, saying that it was a matter for the Department of Health.

CONCLUSION

The Hospital Campaign for the Rural West (HCRW) brought together all sections of the community – Protestants and Catholics; Nationalist and Unionist politicians – local Councillors and MLAs; health professionals; teachers; artists; community leaders; clergy; and patient groups including survivors of the Omagh bombing. It was supported by the expertise and financial resources of Omagh, Strabane and Dungannon District Councils. Indeed, the campaign not only achieved a strong consensus among all sectors of the local community, it was able to count on the active commitment of people from all walks of life and social backgrounds. Thousands of people were mobilised at different points throughout the years of campaigning. However, after almost ten years of intensive engagement with health and social care bodies, and seven Health Ministers it was not possible to reverse the original proposal contained in Developing Better Services. Nor does there seem much prospect of restoring community confidence in the engagement process, as the worst predictions that health services once lost to the town of Omagh will not be replaced appear to have been realised, with the likelihood that the promised local enhanced hospital will be deferred indefinitely.

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CHAPTER 12:
CONCLUSIONS AND RECOMMENDATIONS

COMMUNITIES’ EXPERIENCE OF HEALTH SERVICE REFORMS

Most of the people who participated in this research are relatively well-informed about the reorganisation of the health services. Many have considerable experience of engaging with healthcare bodies. Nevertheless, there were complaints from people across the border region that the changes are not well communicated. There is a lack of information until after important decisions had been made. People opposing hospital closures and transfer of services have been offended by what they consider to be unfair characterisations by civil servants and health professionals. People in the focus groups were aware of the EU directive on doctors’ working time. They also understand the need for a ‘critical mass’ of patients for specialised services requiring capital intensive resources or highly trained medical personnel. While not objecting in principle to the reorganisation of health services and the shift of services from the acute to the primary and community sectors of the health services, people have important criticisms of the implementation of the reforms.

The overriding concern is about the quality of hospital services. The concept of care in the community was popular, but the reality has often not lived up to the promise. There were suggestions that more could be done through use of telemedicine, and through health promotion and a greater focus on prevention of illnesses. Many people raised concerns about inadequate ambulance services and threats to cutback the ambulance and A&E services. Reduced access to maternity and life-saving services are among the most frequent complaints about the reconfiguration of services.

Service users are able to identify examples where they consider scarce resources are not being used effectively, such as misuse of A&E departments because of problems in accessing GP services. It is believed by many that the reorganisation of health service bodies has not resulted in appropriate rationalisation of management structures and that there is wasteful expenditure on management and administration at the expense of front line services. Concerns were expressed about the “money follows the patient” policy – the new NHS financial regime of payment by results, where money follows patient according to a tariff set for each procedure – which it was suggested, could work against the delivery of services in the community and result in less, rather than more choice.
There are many complaints about the pressure on services outside the acute care sector. Rather than enhanced community services, many people complained about the loss of community services that had previously been available. On both sides of the border, there were frequent complaints raised that while services had been removed from their local hospital or a hospital had been closed, the alternative provision had not been put in place. Community care was not being resourced as promised and those hospitals that were offering acute services such as maternity and A&E were being overwhelmed. Hospitals such as Craigavon and Cavan were overcrowded with little or no additional capacity created to accommodate patients who would previously have gone elsewhere.

When talking about cuts that had been made to their local hospital services, many people believe that there has been a deliberate strategy of running down viable services until there was not a ‘critical mass’ or until staff became demoralised and went elsewhere. This then makes closure of facilities inevitable.

Others were angry and concerned that decisions were taken by health service planners without any apparent consideration of the wider context and in apparent contradiction to other public policy objectives. For example, the apparent contradiction of decisions to downgrade hospitals in towns such as Dundalk and Monaghan that are identified as gateway or hub towns in the National Spatial Strategy, and transfer of services to regional hospitals without adequate public transportation to allow service users to attend appointments. Many of the issues raised are outside the remit of health planners, but are extremely important in shaping perceptions and real experience of accessing hospital and other health services.

**COMMUNITIES’ EXPERIENCE OF PATIENT AND PUBLIC INVOLVEMENT**

Several organisations had extensive experience of the key health service documents, although their experience in respect of either feedback or having influenced policy is mixed. The awareness among many individuals who participated in this research about health service policy is often limited to what they have heard or seen in the media.

There appears also to be limited familiarity with the new consultative structures on both sides of the border. Most of the specific criticisms of the new consultative and governance structures came from elected representatives. Politicians from across the political spectrum and on both sides of the border consider the new structures to be undemocratic ‘talking shops’.
Some community activists complained, however, that the decision-making process is chaotic because whatever the plan, it can be changed quite arbitrarily for reasons of political expediency. While campaigners valued the support of politicians, there were mixed views about the difficulties of working with politicians. Community activists on both sides of the border, but particularly in the South, are anxious to protect their autonomy and not be seen to be too close to any particular party or to have their agendas “hijacked” by party political interests. There is some question about the power of local politicians, including ministers; and indeed the Direct Rule ministers that had preceded them.

The major factor that needs to be addressed may in fact be the lack of trust by the public in public consultation processes. Participants in this research expressed an extremely high degree of cynicism, distrust, and ‘consultation fatigue’. They felt decisions were already made in advance of the consultation process – then imposed from the top irrespective of the depth of public opinion. They are angry about what they consider to be a series of “broken promises” about how services would be enhanced and improved, while the experience on the ground had in reality been a loss of local services with increased pressure on those facilities where services had been transferred. People who have engaged with health services bodies say they have encountered a culture that is hostile to community development approaches. There were frequent complaints about lack of information and poor communication.

The picture is not an entirely negative one, but the voluntary efforts put into community campaigns are not sustainable in the long term and certainly would be a deterrent to many people. Those who have been through some of the most bitter community campaigns around hospital closures such as in Omagh, will be hard to convince that a request for their participation in a future health service consultation is offered in good faith and the efforts expended are worth the results obtained.

‘Patient Involvement’ does seem to be easier for the health services north and south than ‘Public Involvement.’ Although there are serious resource issues, this is an area with considerable potential and both health services are making some progress. While there is widespread frustration and cynicism about the consultation process at community level, people with personal experience as patients with long term conditions did have some positive experiences. The ‘Expert Patients’ approach is in line with recognized international standards of good practice such as the Stanford Self Management Programme.

The elements of good practice are well documented and enshrined in the PPI policies of both health services. Good practice models do exist; however PPI activities are not always adequately resourced.
The staff responsible frequently have other priorities that take precedence or find themselves in competition for scarce resources.

**CROSS BORDER ISSUES**

There is a very strong consensus among all those consulted for this research that there should be greater cross border cooperation in the delivery of acute hospital and other health and social care services. People living on both sides of the border are enthusiastic about the prospect of increased cross border cooperation and sharing of services. Those from the Southern side, however, suggested that there needed to be “co-operation in both directions”.

There are a number of suggestions about priorities for service development – issues around ambulances and emergency care are the most frequently mentioned. As will be seen in Chapters 8 and 9, there are already plans for cancer care and Cystic Fibrosis treatment being developed that are well supported by professionals and service users and that need to be operationalised; mental health services and additional supports for people with chronic diseases such as diabetes, although some cross border work in this area is already underway through CAWT. In particular, there is a strong perception that there are gaps in provision, particularly in the central border region as a result of centralisation, and that some of these might be addressed through supporting greater access to services on the other side of the border. This would necessitate ensuring first of all, that service users are aware of what services are available and their entitlements to use services in the other jurisdiction. Health service professionals also expressed a desire to have more information about what their cross border counterparts are doing. A key message, then is that the work already being done by CAWT should be better publicised, built upon and mainstreamed. There are serious concerns about the sustainability of the existing cross border services now supported by CAWT with the expected reduction in EU funding.

The difference in funding regimes is the main barrier that is of concern to service users. How services would be paid for and how much they might cost are probably the most frequently raised concerns about accessing acute and other health services in the other jurisdiction. There are concerns about privatisation, particularly within the Southern system. While some people had concerns about equality of access and the possibility of discrimination against people from across the border, most people insisted that in the context of health services there is no ‘chill factor’ in the sense of hostility to cross border co-operation. There are, however, concerns about differences in
The role of community involvement in planning hospital services

standards of care, drug and treatment regimes and follow-on care. A number of specific problems are presented for migrant workers and their families and asylum seekers who have difficulties, or are prevented from crossing the border.

There were strong opinions expressed that the work being done by CAWT is not being sufficiently supported and complemented by the two departments of health. There needs to be greater political commitment to shared cross border services and cross border planning. Although the financial crisis is making engagement more difficult, the fact that the financial pressures are so severe on both sides of the border could actually be an impetus for greater cooperation. Cross border solutions offer added value for scarce resources – they are not an ‘optional extra’.

While there is interest by both community campaigners and health service personnel in the idea of a joint community/health service cross border programme aimed at developing better community involvement strategies, particularly in the present economic climate, it may be difficult to get staff released and to pay expenses. Innovative ways of delivering a programme specific to the acute sector would need to be explored in order to ensure the commitment and full participation of health service personnel.

A new cross border implementation body for health would help to ensure that there is a stronger imperative for practical cross border planning and delivery of health and social care services, including acute hospital services.
RECOMMENDATIONS

Based on the research and main findings of this research study, we have formulated a series of proposals set out in the following paragraphs.

- If the concepts of Patient and Public Involvement (PPI) are going to contribute effectively to the achievement of health service objectives, it is essential to address the legacy of mistrust that has been an outcome of the implementation of the reconfiguration of hospital and other health and social care services in the border counties. The principles of PPI are enshrined in health service policies in both jurisdictions. The implementation of PPI must be given priority and leadership from the highest levels of the health service, including the allocation of appropriate and adequate resources.

- Reflecting the principle of PPI, service users – from both jurisdictions – should be involved in the planning, commissioning, delivery and evaluation of the Cross Border CF and Radiation Units at Altnagelvin, should these initiatives proceed.

- Planning for the new acute hospital at Enniskillen should involve health professionals, adjoining local authorities and other community interests in the Republic.

- Health service bodies should ensure that service users have information about their entitlements to use services in the other jurisdiction and how these can be accessed.

- The health services in both jurisdictions should build on the work of CAWT and explore development and implementation of cross border capacity building/skills development programmes involving both service users and health service professionals and administrative and ancillary staff to promote and encourage more meaningful and effective patient/public involvement.

- Structures and procedures for enhanced and increased cross border exchange of information between health professionals with responsibility for development, promotion and implementation of PPI strategies should be developed and supported.
The role of community involvement in planning hospital services

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<th>Event</th>
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<td><strong>July 2000</strong></td>
<td>NHS Reform Plan</td>
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<td><strong>June 2001</strong></td>
<td>Acute Hospitals Review Group – “Hayes Report”</td>
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<td>Acute Hospitals Review Group – “Hayes Report”</td>
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<td>“Quality and Fairness: A Health System for You”, National Health Strategy</td>
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<td>Review of Public Administration (RPA) launched by NI Executive (final outcome announced by the Secretary of State in November 2005)</td>
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APPENDIX II:

INDIVIDUALS AND ORGANISATIONS CONSULTED

Mrs Wilma Bennett  
Cllr Winston Bennett, Cavan County Council  
Mr Rod Bond, Netwell Centre, Dundalk Institute of Technology  
Ms June Boulger, Consumer Affairs, HSE  
Ms Sarah Boyle, Donegal Action for Cancer Care  
Ms Rosaleen Bradley, Donegal Centre for Independent Living  
Ms Bernie Brady, Director, AONTAS  
Mr Tom Brady  
Ms Finola Brennan, Donegal Women’s Network  
Mr David Buchanan, Willowbank Community Resource Centre  
Ms Mariane Butler, Dundalk Town Council  
Ms Linda Byrne, Lifefirst Lifford  
Ms Dymnna Cahill  
Ms Jennifer Campbell  
Ms Susan Carey, MS Society  
Ms Anne Carlin, SDLP  
Ms Lucia Carragher, Regional Development Centre, Netwell Centre, Dundalk Institute of Technology  
Mr Matt Cathy, County Mayor, Monaghan County Council  
Ms Kathleen Cassidy  
Ms Louise Cassidy, St Johnson Resource Centre  
Ms Margaret Caulfield, HSE Monaghan  
Ms Anna Clarke, Health Promotion & Research Manager, Diabetes Federation of Ireland  
Mr Seán Conlon, Monaghan County Council  
Mr Paudge Connolly, TD  
Mr John Conway, Oriel Property Management Ltd  
Mr Ivan Cooper, Director of Advocacy, The Wheel  
Mr Jim Cousins, Irish Senior Citizens’ Parliament (Louth Division)  
Mr Noel A Coyle, Donegal Action for Cancer Care  
Mr Gerard Creamer, Bee Park Community Centre Ltd.  
Ms Sheila Cronin, Justice Ireland/CORI  
Ms Mary Crossan, Coordinator, St Johnson Family Resource Centre  
Cllr JackieCrowe, Chairman, Sinn Fein, Castleblayney Urban District Council  
Dr Rachel Cullivan, HSE, Monaghan  
Ms Suzana Da Cunha, Interpreter, South Tyrone Empowerment Programme  
Ms Patricia Cushley, Willowbank Community Resource Centre  
Dr Krate Duke, Sligo Rape Crisis Centre  
Cllr Frank Feely, Newry & Mourne District Council  
Mr Enda Fields, Co Monaghan Hospital Alliance  
Mr Maurice Fielding  
Ms Gabrielle Fleming, People with Disabilities Ireland  
Mr Gordon Fleming, President, Monaghan Chamber of Commerce  
Ms Brid Foley, Lifford/Clonleigh Resource Centre  
Ms Edel Fox, Floating Support Service, South Tyrone Empowerment Programme  
Cllr David Funchion, Castleblayney Town Council  
Ms Rosaleen Gallagher, Belfast Unemployed Resource Centre  
Mr Phil Gallagher, Donegal Action for Cancer Care  
Ms Anne Gallen, Director, Nursing, Midwifery Planning & Development, HSE Letterkenny  
Mr Simon Gibson, Southern Health and Social Care Trust  
Ms Gráinne Gilfen, Donegal Action for Cancer Care  
Ms Nikki Girvan, User Involvement Development Officer, Southern HSC Trust  
Ms Phyllis Graham, Blind Northern Ireland  
Cllr Walter Greer, Cookstown District Council  
Cllr Alan Grehan, Louth County Council  
Ms Valerie Hall, Nurse Consultant, Adult Regional CF Service, Belfast HSC Trust  
Ms Lisa Halliday, Willowbank Community Resource Centre  
Ms Annie M Harte  
Ms Rose Harte  
Mr Brian Harvey  
Ms Vera Henderson  
Ms Betty Holmes, Donegal Action for Cancer Care  
Ms Yvonne Hughes, Expert Patient Adviser, CF Trust  
Cllr Derek Hussey, Strabane District Council  
Archbishop Michael Hynes, Chair, Louth County Community & Voluntary Forum  
Mr Peter Kearns  
Ms Brieg Kelly, Donegal Action for Cancer Care  
Mr John Kelly, Donegal Action for Cancer Care  
Ms Ann Kieran  
Ms Deirdre Kirk  
Ms Kasia Kmietowicz, Advice Worker & Interpreter, South Tyrone Empowerment Programme  
Ms Marcela Kyptova, Interpreter, South Tyrone Empowerment Programme  
Ms Margaret Lawton  
Mr Peter Lenagh  
Ms Geraldine Lennon, Irish Wheelchair Association  
Ms Claire Linney  
Mr Pat Love, North Leitrim Men’s Group  
Ms Ann Marron, Netwell Centre, Dundalk Institute of Technology  
Mrs Sonya McAnulla, Policy Officer, Omagh District Council  
Cllr John McCrindle, Staff Nurse, Newry & Mourne Trust  
Mr Steve McBride, Long Term Conditions Alliance
Mr Patsy McCabe, Co Monaghan Hospital Alliance
Ms Mary McCauley, Donegal Action for Cancer Care
Mr Brendan McCleary, Co Monaghan Hospital Alliance
Ms Kathleen McConville
Mrs Eithne McCord, South Tyrone Action Group
Mrs Catherine McCrory, Coordinator, Equality 2000
Mr M. McDaid, Donegal Action for Cancer Care
Dr Catherine McDonagh, HSE Monaghan
Mr Jim McFarland
Ms Grainne McGarrigle
Mr Brian McGonagle, Access Officer, Letterkenny Institute of Technology
Ms Ann McGlone, Willowbank Community Resource Centre
Mr Thomas McGrath, Willowbank Community Resource Centre
Mr Charles McGuinness, Monaghan Chamber of Commerce
Clr Brian McKenna, Monaghan County Council
Ms Kathleen McKenna
Ms Marian McKenna
Clr Sheila McKenna, Monaghan County Council
Ms Mary McKinney, Cooperating for Cancer Care North West
Mr John McLaughlin, Donegal Action for Cancer Care
Mr Padraig McLoone, HSE, Letterkenny General Hospital
Ms Louise McMahon, HSE
Mr Peadar McMahon, Emvoye Development Association
Ms Sean McMahon, Chairman, Irish Patients’ Association
Ms Sally McMenamin, Donegal Action for Cancer Care
Mr Dermot McNally, McNally & Finlay Furniture Association
Ms Rita McNulty, Donegal Action for Cancer Care
Mr Danny McSorley, CEO, Omagh District Council
Ms Bridget Meehan, Waterside Neighbourhood Partnership
Ms Moira Mills, NW Alcohol Forum Ltd
Ms Agnes Mooney, Community Resource Officer, Brainwave, the Irish Epilepsy Association
Mr Dermot Mooney, Cooley Environmental Group
Ms Sally Mooney, Lifestart, Lifford
Ms Joanne Morgan, Director, Community Development & Health Network
Ms Caitriona Mullan, CAWT
Mr Mark Murphy, Irish Kidney Association
Mr Peter Murray, Health Service Committee Member, Newry & Mourne District Council
Clr Mick Murphy, Newry & Mourne District Council
Ms Michelle Ni Chnaimhsí, Ionad Teampall Chróin Teo
Ms Christina O’Boyle
Mr Donal K O’Boyle, Post Polio Support Group
Mr Caomhghín Ó Caoláin, TD
Ms Catherine O’Connell
Mrs Maureen O’Donovan, Assistant Director of Nursing, Cork University Hospital
Ms Alma O’Donnell, Donegal Action for Cancer Care
Mrs Emily O’Donnell, Donegal Action for Cancer Care
Mr G. O’Donnell, Donegal Action for Cancer Care
Mrs Liz O’Donnell, Donegal Action for Cancer Care
Ms Mary O’Donnell, Women Making Waves
Mr Sean O’Donnell, Donegal Action for Cancer Care
Dr Petros B Ognyazghi
Mr Eamon O’Kane, NW Alcohol Forum Ltd
Ms Maire O’Leary, Social Inclusion Manager, Community Services, HSE Letterkenny
Ms Susie O’Leary, Lifford Resource Centre
Ms Nora O’Reilly
Ms Jo Osmond, Clinical Care & Commissioning Manager, Cystic Fibrosis Trust
Ms Jan O’Sullivan, TD
Ms Maura Pidgeon, Letterkenny Institute of Technology
Ms Teresa Porter, Lifford Resource Centre
Mr Michael Potter, Policy & Research Worker, South Tyrone Empowerment Programme
Ms Carrie Pringle, MEAS
Ms Eileen Quinn, Consumer Services Officer, HSE
Clr Alan Rainey MBE, Omagh District Council
Ms Aisling Rennick, Investing for Health Officer, Newry & Mourne District Council
Mrs Marie Reilly, Cavan County Council Peace Project
Ms Molly Reynolds, Donegal South Forum / Donegal Local Development
Ms Jacqui Rooney, Inishowen Women’s Information
Ms Maureen Sewell, Co Monaghan Hospital Alliance
Ms Miriam Sherry, Irish Farmers’ Association
Mr Patrick Shields, St Johnston & Corrigans FRC
Ms Hilary Sidwell, Western HSC Trust
Mr Alvaro Silva, Advice Worker & Interpreter, South Tyrone Empowerment Programme
Mr Cormac Skinnader, Inishowen Rural Transport
Ms Bridget Sparks
Dr Chris Sparks, Sligo Institute of Technology
Mrs Anne Stafford
Ms Sandra Stinson, Willowbank Community Resource Centre
Ms Louise Taylor, IFA Farm Family Focus Group
Clr Robert Turner, UUP, Armagh City and District Council
Ms Elizabeth Tilson, IFA Farm Family Focus Group
Clr Pat Treanor, ICABAN
Ms Padraigin Uí Mhurchaille, Monaghan County Council
Ms Joanne Vance, Health Officer, National Women’s Council of Ireland
Mr Philip Watt, CEO, The Cystic Fibrosis Association of Ireland
Ms Pauline Walsh, Coordinator, ROSA/Co Monaghan Community Network
Mr Robert Wilson, Monaghan Community Network
APPENDIX III:
MEMBERS OF THE RESEARCH ADVISORY GROUP

Mr Sean Brown, Head of Development & Corporate Services, Patient Client Council

Dr Patricia Clarke, Senior Policy Analyst, Health Research Board

Mr Tom Daly, Regional Development/ European Officer, HSE

Mr Colm Donaghy, CEO, Northern Health and Social Care Trust

Ms Alice McAndrew Department of Foreign Affairs (observer)

Dr Ambrose McLoughlin, Registrar / CEO, Pharmaceutical Society of Ireland

Mr Stephen McMahon, Chairperson, Irish Patients Association

Stephen Mulvany, Regional Director of Operations HSE - Dublin North East

Mr Andy Pollak, Director, Centre for Cross Border Studies

Prof Jonathan Tritter, Business School, University of Warwick

Ms Joanne Vance, Health Worker, National Women's Council of Ireland

Dr Jane Wilde, Director, Institute of Public Health in Ireland
APPENDIX IV: CROSS BORDER COOPERATION IN THE AREA OF HEALTH

Since February 2000, the North South Ministerial Council has had nine meetings to consider issues in the area of Health. At its first meeting the Council identified a programme of work on its priorities, identified as Cancer Research, Health Promotion, Accident and Emergency Services, Planning for Major Emergencies and Co-operation on High Technology Equipment. Since 2008, Child Protection issues have also been included under cross border cooperation in the area of health.

An outline of activities that have been undertaken and reported to the Council at its Health Sector meetings between 2001 and 2009 follows below.

JOINT FEASIBILITY STUDY FOR A MORE STRATEGIC APPROACH TO CO-OPERATION

At its November 2007 Health Sector meeting, the Council noted that in view of the reorganisation and reform programmes for health and social services in both jurisdictions, a joint feasibility study to identify the potential for a more strategic approach to co-operation in health and social well-being was underway. The Council received an update on this at its meeting in May 2008; however at time of writing (April 2010), this report is not yet in the public domain.

ACCIDENT AND EMERGENCY SERVICES

Co-operation in the area of Accident and Emergency Services was defined as covering,

“across hospital services generally as well as Accident and Emergency Departments. Cross border co-operation, covering hospital services in the border areas, and wider co-operation on a regional basis, covering specialist services which are, or could be only viable where delivered on an all-island basis have been identified as two broad areas for co-operation.”

In November 2001, A North/South Regional Hospital Services Group (NSRHSG) was established to consider the opportunities for developing partnerships covering the wider regional services. The Council noted the proposal to expand the membership of the NSRHSG to include a senior official from each of the border Health Boards. The Council requested the NSRHSG to consider suggestions in the report of the Acute Hospitals Review Group in the North, in respect of the potential to develop existing cross-border initiatives for the benefit of patients.

Since the Council was established cross border cooperation within the acute hospital sector has developed considerably. Work that has been reported to meetings of the NSMC has included:

- exchanges of information on reviews of renal services, including the potential benefits of North/South linkages
• progress on joint training, staff development and exchange opportunities in radiotherapy services.

• Progress on local cross-border initiatives being developed by CAWT (Co-operation and Working Together),
  - provision of neo-natal intensive care
  - the provision of tertiary cancer care, and
  - a cross border Consultant-led Breast Surgery Team in the North West.
  - shared services in dermatology and renal dialysis

• co-operation on assessing the potential for the development of organ transplantation services on an all-island basis

• research on the potential for all-island co-operation on procurement and operational training in essential support services in the acute sector

• paediatric and congenital cardiac services

• two pilot projects in the Derry/Letterkenny and Keady/Castleblaney catchment areas the implementation of a cross-border out-of-hours GP service intended to inform decision making on the provision of the GP services in border areas.

• co-operation on paediatric and congenital cardiac services between the Royal Victoria Hospital Belfast and Our Lady’s Hospital for Sick Children Dublin.

• an agreement between Belfast City Hospital, Altnagelvin Hospital and the HSE to provide cancer patients from County Donegal with radiotherapy treatment at Belfast City Hospital.

• a satellite radiotherapy centre at Altnagelvin Hospital and a cross border collaboration subgroup to advise on care pathways for the new radiotherapy facility, taking account of capacity for patients from County Donegal(see Chapter 9)

• a Service Level Agreement between the Health and Social Care Board (HSCB) for Northern Ireland and Our Lady’s Children’s Hospital in Crumlin (OLCHC) to support provision of paediatric congenital cardiac services (PCCS).

PLANNING FOR MAJOR EMERGENCIES

• a programme for cross border emergency planning training courses covering the medical response to a major incident

• proposals for the development of integrated communication protocols to activate hospital and community response in a major emergency.

• proposals for the introduction of "First Responder" schemes in border areas, and

• development of a Road Traffic Accident Response Strategy for Fire Brigades in Border areas.

• a programme of cross-border emergency planning training courses, covering the medical response to a major incident,

• a feasibility study and report on the costs and benefits associated with the introduction of an all-island Helicopter Emergency Medical Service

• Detailed recommendations in relation to the practical issues surrounding joint responses to Road Traffic Accidents (RTAs) in Border areas; e.g.
• compatibility of equipment and coordinated responses
• a phased programme of familiarisation and joint training among Fire Brigades located along the Border
• fire prevention awareness campaigns
• joint training for RTA responses and the further development of an RTA response strategy.
• joint North/South Fire Service training in the area of Road Traffic Accidents (RTAs)
• shared media campaigns on fire prevention and fire safety for schools in border areas.
• pandemic flu planning,
• co-operation on training and planning for major emergencies.
• infectious disease emergency planning
• co-operation between the fire and rescue services in dealing with emergencies and road accident responses in the border areas.
• a formal cross-border arrangement whereby Fire and Rescue appliances now respond jointly to incidents on the new road link between Newry and Dundalk

Cancer Research
• the launch of the All Ireland Cancer Incidence Report.
• establishing a Cancer Consortium between the National Cancer Institute in the USA, and the Departments of Health, North and South, has created a framework within which an all-Ireland infrastructure for joint programmes in clinical cancer research will be developed, including:
  o the infrastructure of hospitals to conduct high quality cancer clinical trials and co-ordination and joint funding of all-island clinical trial activity
  o telesynergy communications
  o a scholar exchange programme
• all-Ireland Cancer Incidence and Mortality Report and a common dataset to facilitate other research projects.
• the development of common protocols, definitions and datasets by cancer registries;
• the running of a Cancer Prevention Fellowship Programme;
• the use of telesynergy to aid the diagnosis of rare conditions and for research collaborations; and
• the operation of a Cancer Clinical Trials Co-operation Group
• the setting up of an all-island gene library
• extension of a Trinity College Dublin project on the human papilloma virus (HPV) into Northern Ireland
• progress in planning for a biobank for medical research in both jurisdictions
• report “Cancer Incidence Mortality, Treatment and Survival in the North and South of Ireland: 1994-2004”
• conferences on health economics and on cancer registries epidemiology.
HEALTH PROMOTION
• a collaborative health promotion work programme including:
  o folic acid campaign
  o public information campaign for physical activity
  o collaboration on smoking, targeting young smokers in particular.
  o all-island initiatives for improvement in nutrition.
  o tackling obesity
  o a joint strategically planned health promotion programme and training resource.
  o a major cross-border conference on physical activity
  o an all-island workplace health initiative
  o health promoting hospitals
  o research and training
  o men’s health,
  o mental health
  o breastfeeding
• an all-island suicide prevention action plan including Applied Suicide Intervention Skills Training
• All-Island Promoting Mental Health Public Awareness Campaign
• the work of the Institute of Public Health particularly in relation to addressing health inequalities.
• a planned programme of mutually beneficial joint activities to promote public health and to tackle health inequalities
• revised media guidelines on suicide prevention

CO-OPERATION ON HIGH TECHNOLOGY EQUIPMENT.
• a Joint Health Technology Group, charged with drawing up protocols for the assessment and evaluation of emerging and new technology, specifically:
  o the feasibility of the introduction and utilisation of Positron Emission Tomography (PET) technology within a joint framework.
  o the potential for the future development and distribution of specialised radiotherapy treatments for cancer
  o the potential for development of acute facilities support services, to see if there could be greater centralisation of essential support services, such as laboratory facilities, etc.
  o joint access to European Union Health Technology Assessment Networks and Expertise, to ensure the effective dissemination of the work of these groups to the maximum benefit of each administration.
  o the undertaking of a North/South Radiotherapy Physics Audit Scheme, of particular importance for the treatment of people with cancer, half of whom are treated by radiotherapy.
• a North/South radiotherapy physics audit scheme
• development of a framework for assessing the operation of Positron Emission Tomography (PET) technology on an all-island basis
• a joint workshop on emerging high technology developments
• a jointly hosted major health technology seminar in September 2002
• research and analysis to gauge the potential health gain from Positron Emission Tomography (PET) technology on an all-island basis

**CHILD PROTECTION**

• a work programme to intensify co-operation on Child Protection
• a cross-border awareness raising campaign in conjunction with non-governmental organisations to consider the increasing problems associated with the internet and social networking
• production of generic cross-border information using a variety of media dealing with such issues as the reporting of abuse; safe parenting; and good employment practice recognising the two separate legislative and structural arrangements
• cross border monitoring and management of sex offenders.
• Exchange of information on legislative measures to improve safeguarding of children and vulnerable adults and exploration of opportunities for achieving a consistency in approach.
• exchange of information and ideas on issues such as internet safety;
• the development of a protocol for the movement of vulnerable children and families across borders,
• advice and guidance material for parents, carers and employers aimed at strengthening safeguarding arrangements on both sides of the border.
• collaborative work within both jurisdictions on the management of sex offenders.
• the cross border Child Protection Group and its various sub-groups
• the exchange of information on internet safety and social networking sites
• co-operation on child protection research and knowledge transfer.
• a joint protocol on children in care, or on the child protection register, that go missing and children moving across the border where there are concerns.
• a joint draft communication strategy and leaflets with advice and guidance on what to do if worried about a child, and on safer recruitment procedures for employers
• a conference on vetting and barring
APPENDIX V:

CO-OPERATION AND WORKING TOGETHER (CAWT)

Cooperation And Working Together (CAWT) is a partnership between the Health and Social Care Services in Northern Ireland and Republic of Ireland, which facilitates cross border collaborative working in health and social care.

CAWT’s mission is to improve the health and well being of the border populations, by working across boundaries and jurisdictions.

CAWT’s role is to facilitate cross border health and social services. CAWT’s primary programme of work is to deliver the European Union INTERREG IVA Priority 2, Theme 1, “Putting patients, clients and their families first” on behalf of the Department of Health, Social Services and Public Safety, Northern Ireland and the Department of Health and Children, Republic of Ireland. CAWT also deliver other cross border projects on behalf of its partner organisations and the Departments of Health in both jurisdictions.

OBJECTIVES

The following strategic objectives have been identified for CAWT for the period 2007-2013: -

- To improve the health and wellbeing of the population of Ireland with a particular emphasis on the border
- To continue to have a focus in assisting border areas in addressing their peripherally from the centre of Government including addressing obstacles to cross border mobility
- To acknowledge the next stage in the development of CAWT requires a change in the strategic emphasis in both geographic and service remit which includes a more integrated approach to health provision on the island of Ireland
- To play a facilitating role in the provision of population based island health care and in particular contribute to the debate to achieve enhanced service provision and patient satisfaction
- To exploit the opportunities of joint working or sharing of resources particularly through the following: -
  - Engagement with the wider European community
  - Engagement with other public sector, community or voluntary initiatives
  - Better engagement with the providers of care
- To identify opportunities for co-operation in the planning and provision of services, particularly the sharing of best practice
- To promote and facilitate better engagement with users and patients
The role of community involvement in planning hospital services

- To seek to influence Government policy in respect of planning and provision of health and social care on a cross border basis and in particular promote cross border mobility issues

**EUROPEAN UNION**

On behalf of the Departments of Health, CAWT is managing the implementation of 12 EU INTERREG IVA funded large scale cross border health and social care projects. The projects have been categorised into five strategic themes; Acute Hospital Services, Primary, Community and Continuing Care (PCCC), Mental Health, Population Health and Disability.

Under INTERREG IIIA, CAWT managed funding in the region of €10.45m / £6.74m for thirty-seven cross border health and social care projects and a further seven PEACE II funded projects to the value of €1.57m / £1.08m. These projects involved the cooperation of hundreds of statutory/voluntary/community stakeholders from along the border corridor and have brought significant benefits to the resident population (see CAWT Legacy report ‘The CAWT Story: 2003 to 2008’).

**OTHER/COMMISSIONED PROJECTS**

CAWT has also undertaken cross border work commissioned by the two Departments of Health and its partner organisations.

**CAWT DEVELOPMENT CENTRE**

On behalf of the CAWT partners (Health Service Executive, Western Health and Social Care Trust, Southern Health and Social Care Trust, Western Health and Social Services Board and Southern Health and Social Services Board), the Development Centre facilitates cross border cooperation between the health and social care systems in both jurisdictions and is responsible for ensuring that European Union (EU) funded and other cross border projects are administered in accordance with the standards set out by the Special EU Programmes Body (SEUPB), CAWT partner organisations and other funders such as the Department of Health and Children in the Republic of Ireland and the Department of Health, Social Services and Public Safety in Northern Ireland.

**CAWT MANAGEMENT BOARD AND SECRETARIAT**

The CAWT Management Board comprises the Chief Executive Officers and Chairpersons of the Southern and Western Health and Social Services Boards and Chief Executive Officers of the Southern and Western Health and Social Care Trusts in Northern Ireland and senior personnel from the Health Service Executive Dublin North East and West regions in the Republic of Ireland. The
Board is the policy and decision-making forum responsible for providing strategic direction for the CAWT Partnership.

The CAWT Secretariat comprises senior management representatives of the partner organisations. The Secretariat aims to maximise the potential for cross border co-operation across all programmes of care. The Secretariat acts as a conduit between Strategy Groups, Project Boards and the Management Board. Members provide support to their respective Management Board representatives and implement the decisions of the Management Board.

**CAWT Strategy Groups**

Senior representatives from each of the CAWT partner organisations have been nominated by the CAWT Management Board to form cross border Strategy Groups to guide cross border strategy and integrate cross border work into mainstream activity. Each group covers one of the six service areas: Acute, Mental Health, Disability, Population Health, Primary Care and Older People and Children’s Services.

**CAWT Project Boards**

Under the EU INTERREG IVA programme twelve cross border project boards have been established to manage and implement their respective project. Each Project Board has a Project Executive who is the key decision maker. The Project Manager is responsible for the day to day management of the project and performs duties required by the Project Board.
APPENDIX VI:

HEALTH AND SOCIAL CARE STRUCTURES – NORTHERN IRELAND

REGIONAL HEALTH AND SOCIAL CARE BOARD

The single Health and Social Care Board for Northern Ireland has replaced the four Health and Social Services Boards. Its focus is on commissioning, resource management and performance management and improvement. The new Board together with its Local Commissioning Groups (LCGs) is accountable to the Minister for translating his vision for health and social care into a range of services that deliver high quality and safe outcomes for users, good value for the taxpayer and compliance with statutory obligations.

A key role of the new Board with the Public Health Agency (PHA) will be effective engagement with providers, Patient Client Council (PCC), local government, service users, local communities, other public sector bodies, the voluntary and community sectors.406

LOCAL COMMISSIONING GROUPS

Local Commissioning Groups (LCGs) are committees of the Health and Social Care Board. There are currently five (LCGs): the Belfast; Northern; South Eastern; Southern and Western Local Commissioning Groups. Each LCG is co-terminus with their respective Health and Social Care Trust area. Within the devolved authority of the HSCB, Local Commissioning Groups will be aligned to the boundaries of the existing HSC Trusts though this will remain subject to review pending the outcome of local government reform. LCGs are responsible for the commissioning of health and social care by addressing the care needs of their local population. They also have responsibility for assessing health and social care needs; planning health and social care to meet current and emerging needs; and securing the delivery of health and social care to meet assessed needs. Each LCG is chaired by a General Practitioner and members include three or four other General Practitioners, a dentist, a pharmacist, four local government representatives, two representatives from the community/voluntary sector, three representatives from the Public Health Agency, and two representatives of the HSC Board.

406 www.hscboard.hscni.net
PATIENT CLIENT COUNCIL

The Patient Client Council (PCC) is a regional body that replaced the Health and Social Services Councils with five local offices operating in the same geographical areas as the existing Trusts. The overarching objective of the PCC is to provide a powerful, independent voice for patients, clients, carers, and communities on health and social care issues:

“One of the aims of the RPA program of reform is to put in place modern, accountable and effective arrangements for the delivery of high quality health and social care services driven by and responsive to the needs of patients and clients. The creation of a health and social care consumer organisation to ensure a strong patient and client voice at both regional and local level will improve the way that people are involved in decisions about health and social care services. A key feature of this body is that, in line with Ministerial objectives, it will support democratisation and facilitate local government involvement.” ⁴⁰⁷

The PCC has the following functions:

- to represent the interests of the public by engaging with the public to obtain their views on services and engaging with Health and Social Care (HSC) organisations to ensure that the needs and expectations of the public are addressed in the planning, commissioning and delivery of health and social care services;

- to promote the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care;

- to provide assistance to individuals making or intending to make a complaint relating to health and social care; and

- to promote the provision of advice and information to the public by the HSC about the design, commissioning and delivery of health and social care services.

Under the legislation establishing the PCC, there are sixteen members, including five members of district councils, five representatives of voluntary organisations with an interest in health and social care; and one representative of a trade union.

HEALTH AND SOCIAL CARE TRUSTS

The five Health and Social Care Trusts – Belfast HSC Trust; Southern HSC Trust; South Eastern HSC Trust; Western HSC Trust; and Northern HSC Trust –were created from the merger of nineteen former trusts. HSC Trusts are the main providers of health and social care in Northern Ireland. They manage and administer hospitals, health centres, residential homes, day centres and other health

⁴⁰⁷ www.patientclientcouncil.hscni.net
and social care facilities and they provide a wide range of health and social care services to the community. They are funded mainly by the DHSSPS via the health and social care board and are accountable to the Minister. Composition of the Membership of the Trusts’ Boards comprises not less than 8 members, including: The Chairman of the Trust (Appointed by the DHSS&PS Public Appointments Unit); Up to 7 non-executive members (appointed by the DHSS&PS Public Appointments Unit); Up to 5 executive members (but not exceeding the number of non-executive members) including the Chief Executive and the Director of Finance.

**PUBLIC HEALTH AGENCY**

The Public Health Agency (PHA) has responsibility to drive the public health and social well-being agenda. It brings together the wide range of existing public health functions and “gives a renewed, enhanced and sustained focus to achieving key public health goals.” The broad functions of the agency will be health improvement; health protection; and provision of appropriate professional input to the commissioning role of the Health and Social Care Board. The board of the PHA is made up of four executive directors, including the chief executive, a non-executive chair and seven non-executive directors. The non-executive directors include a member from a Social Care background, a Trade Union Representative Member, two Local Government Representative Members and three Lay Members.

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APPENDIX VII:

HEALTH SERVICE STRUCTURES – REPUBLIC OF IRELAND

DEPARTMENT OF HEALTH AND CHILDREN (DoHC)

The Department of Health and Children's statutory role is to support the Minister in the formulation and evaluation of policies for the health services. It also has a role in the strategic planning of health services. This is carried out in conjunction with the Health Service Executive, voluntary service providers, Government Departments and other interested parties.

The DoHC comprises several divisions, all of which in turn comprise a number of specialised units.

The Acute Hospitals, Cancer and Associated Services Division has four sections:

1. **Acute Hospitals Division 1** is responsible for the policy on acute hospital services, with particular reference to the HSE South and West areas. The Division monitors and evaluates the delivery of acute hospital services in line with the HSE’s National Service Plan. The Division also has policy responsibility for ambulance and certain patient transport services, the National Treatment Purchase Fund and the Pre Hospital Emergency Care Council. Acute Hospitals Division 1 is also responsible for policy on Co-Location which entails the development of private hospitals on the campuses of certain public hospitals.

2. **Acute Hospitals Division 2** has responsibility for Accident and emergency services; Paediatric/Maternity Services (National Issues) - National Paediatric Hospital; Lourdes Hospital Redress Board; Renal and Organ Transplant Service reviews; Neurology/Cystic Fibrosis; and Dublin/North East/Midlands Hospitals Group.

3. **The Blood and Tissue Policy Unit** has responsibility for policy formulation, evaluation and monitoring of appropriate health and personal social services (including compensation schemes) for persons infected with Hepatitis C and HIV through the administration within the State of blood or blood products. It has responsibility for legal and other issues related to Hepatitis C and HIV, Haemophilia, blood transfusions and use of human tissues.

4. **The Cancer Policy Unit** is responsible for developing legislation and policy to support a national cancer control system. It supports the National Cancer Control Programme, the National Cancer Screening Service (including BreastCheck and Cervical Check), and the National Cancer Registry. It monitors the implementation by the HSE, the NCSS and the NCR of national quality assurance standards in the provision of services for site specific cancers and liaises with the HSE, the Health Research Board and National Cancer Registry Ireland in relation to funding and review of Ireland Northern Ireland Cancer Consortium initiatives.

HEALTH SERVICE EXECUTIVE

The HSE has operational responsibility for all public health services in the Republic of Ireland. Four Regional Director of Operations are responsible for managing all health and social services in the
four regions: Dublin North East; Dublin Mid Leinster; South; and West. The HSE is sub-divided into a number of Directorates. The Integrated Services Directorate combines responsibility for Primary, Community and Continuing Care and Hospitals.

**LOCAL HEALTH OFFICES**

The 32 Local Health Offices are service users’ entry points to community health and personal social services. Services provided through Local Health Offices and from Health Centres include general practitioner services, public health nursing, child health services, community welfare, chiropody, ophthalmic, speech therapy, social work, addiction counselling and treatment, physiotherapy, occupational therapy, psychiatric services and home help.