

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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INTRODUCTION

This study examines, on the basis of extensive consultations, the role of community involvement in decisions regarding the re-configuration of local hospital services in the Irish border region. Based on the consultations carried out, the study provides proposals relevant to the future planning of hospital services in the border region that reflect *patient needs*, as espoused by the community groups considered in the study and supported by the health services authorities on both parts of the island of Ireland.

The research reported here is part of two elements 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'. The key focus of the overall project is to support strategic cross border co-operation for a more 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 that is being undertaken by the Centre for Cross Border Studies (CCBS) under the title - **Ireland Northern Ireland Cross border Cooperation Observatory (INICCO)** - funded by the European Union Interreg IVA Programme.

This particular research study 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)*¹ and *Surveying the Sickbeds: initial steps towards modelling all-island hospital accessibility (2008)*.²

OVERVIEW OF METHODOLOGY

The fieldwork for this study was conducted during the latter half of 2009 and during January through March 2010. During the latter sub-period, the CCBS organised a series of focus groups in Castleblayney, Cavan, Derry, Dundalk, Dungannon, Enniskillen, Letterkenny, Manorhamilton, Newry and Omagh. Invitations were issued to the community groups, elected representatives and other individuals living in the border region who are on the CCBS's mailing list. In addition, the focus groups were 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. Approximately 150 people participated in these events. In addition, a number of face-to-face and telephone interviews were conducted with key community representatives 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. The views of a number of voluntary and community sector health advocacy

groups were sought through a postal questionnaire sent out in the autumn of 2009. A diverse group of councillors and council officials, community activists, people with disabilities and carers, professional and lay health workers, and other interested people from nationalist, unionist and ethnic minority communities on both sides of the border have contributed towards the research.

The findings and recommendations set out in this research study are based on the strands of fieldwork undertaken and these were presented to health service professionals from both sides of the border at a Study Day convened by the CCBS on 20 April 2010 - the discussion and feedback from this event has informed the final recommendations contained here.

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

Over the past decade there have been a number of 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. 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)³ and the *Audit of Structures and Functions in the Health System* (the Prospectus Report)⁴ and the announcement of the Health Service Reform Programme to implement recommendations of Prospectus

and Brennan. Under the Reform 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.

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. While these developments have still not been completed, the streamlining and rationalisation of public bodies has 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 2009.⁵

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*⁶. 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*⁷ 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.

LEARNING FROM PPI THEORY AND PRACTICE IN THE UK, EUROPE AND BEYOND

The health services in both jurisdictions have drawn upon much of the same literature and definitions of Patient/Personal and Public Involvement (PPI) concepts, which emphasise patient needs and public involvement in planning.

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.

SUMMARY OF MAIN FINDINGS – COMMUNITIES’ EXPERIENCES OF HEALTH SERVICE REORGANISATION

Most of the people who participated in the research study are relatively well-informed about the reorganisation of health services. Many have considerable experience of engaging with health care bodies. However, many felt that the changes to local hospital services in both parts of the island are not well-communicated. Participants identified a lack of information until after important decisions had been made. While aware of the EU directive on doctors’ working time and understanding of the need for a ‘critical mass’ of patients for specialised services requiring capital intensive resources or highly trained medical personnel, people who partook in our focus groups were nevertheless critical of the implementation of the reforms.

The overriding concern expressed concerned 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 cutbacks

of ambulance and A&E services. Reduced access to maternity and life-saving services were among the most frequent complaints about the reconfiguration of services.

Many of those consulted believe 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 also 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 for services users.

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.

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.

SUMMARY OF MAIN FINDINGS – COMMUNITIES' EXPERIENCES OF PERSONAL AND PUBLIC INVOLVEMENT

Based on the fieldwork, there is limited familiarity among users with the new consultative structures on both sides of the border.

'Patient Involvement' appears to be easier to implement 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 (CF) services. In southern Ireland, the HSE's *Intercultural Health Strategy*;⁸ from Northern Ireland, the Western HSC Trust's *Disability Action Plan*;⁹ and the Cross border Plan, *Levelling Up - Securing Health Improvement by Promoting Social Inclusion*¹⁰, and were all cited by research participants as examples of good practice in consulting with service users. The work of the Promoting well Being Department in the Southern HSC Trust (Northern Ireland) and the HSE's Community Participation Primary Care Funding Initiative was also cited as providing potentially useful models for implementing a holistic approach to PPI.

There is evidence from the research that 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 have been an untapped resource.

SUMMARY OF MAIN FINDINGS - CROSS BORDER ISSUES

There is a strong consensus among all those consulted for this research study 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.

According to the consultations, 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. These developments would help

to facilitate a better-working cross border health services delivery.

The difference in funding regimes was cited as the main barrier of concern to service users, according to the research study. 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 were also concerns about differences in standards of care, drug and treatment regimes and follow-on care after the patient gets home on the other side of the border.

CASE STUDY: CO-OPERATING FOR CANCER CARE NORTHWEST

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 - has been 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. Community campaigners have been 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. The work of this group, on a voluntary basis, 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 CCCNW made a significant contribution to securing a commitment to providing radiation services for Donegal patients in a new facility based in Derry.

CASE STUDY: THE CYSTIC FIBROSIS TRUST AND THE CYSTIC FIBROSIS ASSOCIATION OF IRELAND

The Cystic Fibrosis Trust in Northern Ireland and the Cystic Fibrosis Association of Ireland in the Republic of Ireland 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 organisations have much in common. Both are well-established voluntary organisations with considerable resources. They bring together consultants, researchers and other professionals in the modern multi-disciplinary CF teams as well as the experience, expertise and commitment of people with CF and their families and friends. Both organisations have developed infrastructures that ensure that they are able to support the involvement of people with CF in decisions affecting their care and to draw on their experience and knowledge to influence the decision-making process at more strategic levels.



The Cystic Fibrosis Association of Ireland (CFAI) has had considerable success in shaping strategies for care of people with Cystic Fibrosis (PWCF) within the Republic of Ireland. The outstanding achievement for the Association has been the acceptance by the Health Service Executive (HSE) of most of the findings and recommendations of the Pollock Report. While many of the recommendations of the 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 that there should be facilitation of patients resident in the south to use CF services at Belfast City and Altnagelvin hospitals.

There would appear to be a significant potential for take-up of services in Belfast and Derry by people in the southern Border Counties if appropriate cross border arrangements were in place. The case for a new CF unit in the North West is also backed by the CF Team at Belfast City Hospital. 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.

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.

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, a many acute services had already been removed from Tyrone County Hospital. 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 (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 bombing. It was supported by the expertise and financial resources of Omagh, Strabane and Dungannon District Councils.

The campaign 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. The campaign's communication strategy kept its arguments in the public eye and ensured that local communities were constantly informed of all developments. When the Minister ultimately ruled that the new acute hospital would be sited in Enniskillen, HCRW went to law, seeking a judicial review and when that was denied, appealed the court's decision, but eventually it became clear that the battle had been lost.

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.

<p>1 Jamison, J. And Butler M. <i>Removing the Barriers: An Initial Report on the Potential for Greater Cross border Co-operation in Hospital Services in Ireland</i>. Centre for Cross Border Studies, Armagh, 2007.</p> <p>2 Foley, Ronan, Martin Charlton and Patricia Clarke, "Surveying the Sickbeds: initial steps towards modelling all-island hospital accessibility, <i>Journal of Cross Border Studies</i>, No. 3, Spring 2008.</p> <p>3 <i>Commission on Financial Management and Control Systems in the Health Service (the Brennan Report)</i>, The Stationery Office, Dublin, 2003.</p> <p>4 <i>Audit of Structures and Functions in the Health System on behalf of the Department of Health and Children</i>, (The Prospectus Report), Department of Health and Children, Dublin, 2003.</p> <p>5 NIA Bill 21/07 Health and Social Care (Reform) Bill.</p>	<p>6 <i>Developing Better Services, Modernising Hospitals and Reforming Structures</i>, Department of Health, Social Services and Public Safety, Belfast, 2002.</p> <p>7 <i>A Healthier Future: A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005-2025</i>, Department of Health, Social Services and Public Safety, Belfast, 2004.</p> <p>8 <i>National Intercultural Health Strategy 2007 - 2012</i>, Health Service Executive, Dublin, 2008.</p> <p>9 <i>Disability Action Plan January 2008-December 2010</i>, Western Health and Social Care Trust, Londonderry, 2007.</p> <p>10 McAvoy, H. and Meehan. K. <i>Levelling up - Securing Health Improvement by Promoting Social Inclusion: A Cross Border Action Plan for the North West of Ireland</i>. Institute of Public Health in Ireland, Dublin, 2008.</p>
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