

Patient and Client Council

The People's Priorities for Transforming Your Care

A review of people's views on Health and Social Care
as expressed to the Patient and Client Council since
April 2009

November 2012

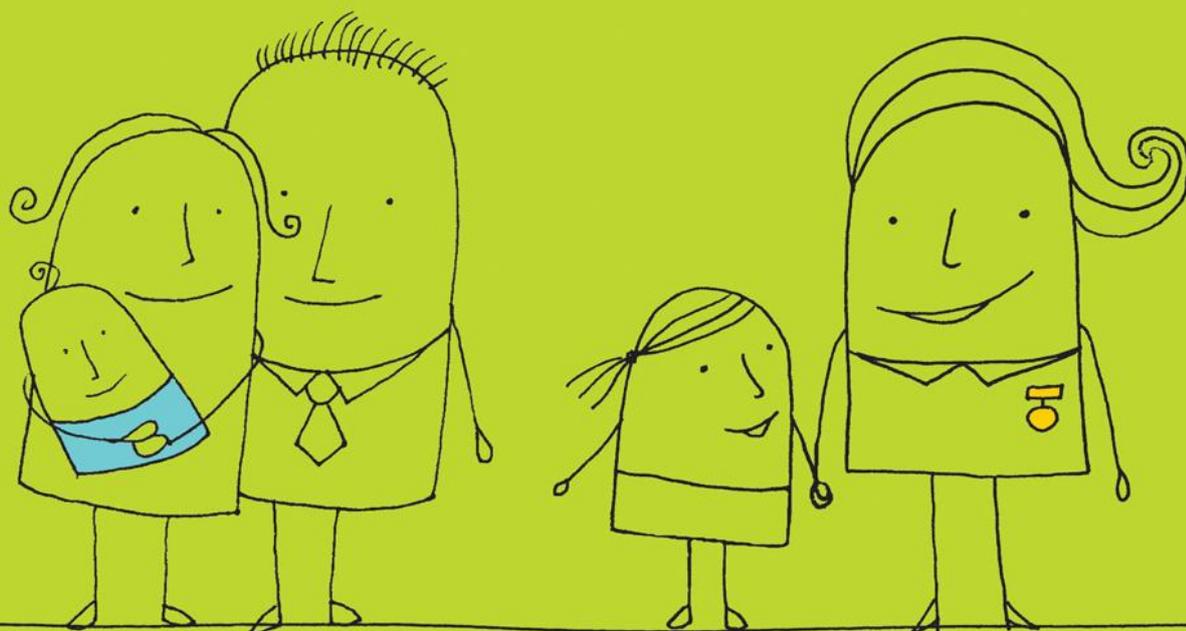


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Foreword

I am pleased to present this report, which captures the concerns and opinions of more than 13,000 people on a wide variety of health and social care issues, documented in the 34 reports published since the inception of the Patient and Client Council in April 2009.

The opinions and concerns of patients, service users, communities and the general public gathered through interviews, street consultations, surveys and small group discussions were wide and varied. Some key messages have emerged over this period, such as the importance of service user involvement, good communication between and within services and with the patient, timely and accessible information, continuity of care, support for vulnerable groups, support for carers and equal access to services, but what is evident from these reports is that people recognise that the way in which health and social care services are delivered in Northern Ireland has to change.

Some of the main issues addressed in these reports were: access to urgent care, either through accident and emergency or out-of-hours GP services; rare diseases; mental health; care of the elderly; nutrition; rurality; dental services; young carers; and dementia. Links to a full list of these reports which highlight the issues raised can be found on the Patient and Client Council web site at www.patientclientcouncil.hscni.net.

At the end of 2011, the Department of Health and Social Services and Public Safety (the Department) released their report “Transforming Your Care” (full report can be found at <http://www.dhsspsni.gov.uk>) which outlined 99 recommendations for the future provision of health and social care services in Northern Ireland.

There is a lot of common ground between the priorities for Health and Social Care identified by people in the Patient and Client Council reports and those outlined in “Transforming Your Care”. The emphasis in Transforming Your Care is on personalisation of care, placing the individual at the centre, integrated care, improved communication between services and a joined up approach to urgent care.

However, it is important to note that there are a number of major recommendations made in the review which are likely to challenge popular views on and priorities for health and social care as expressed to the Patient and Client Council over the past three years. The proposed shift of resources from hospital to community at the centre of “Transforming Your Care” will concern those who have expressed doubts about the delivery and quality of community based care. The recommendation to reduce the number of major acute hospitals in Northern Ireland, with the emphasis on care being delivered in the community and less reliance on hospitals, may also challenge the prioritised issue of equal access to quality hospital care, regardless of location.

Once again, I would like to express my sincere thanks to everyone who took part in the many consultations. Thank you for your generosity with which you gave of your time and sharing your experiences. Without your input, we would not have been able to document the issues raised and make subsequent recommendations.

I would also like to thank the staff and the volunteer Local Advisory Committee members who worked so hard to help us engage with people in many locations all over Northern Ireland.

During the next 12 months and beyond, we know that there will be significant changes in the way our health and social care services are delivered. The Patient and Client Council will ensure the voice of people in Northern Ireland continues to contribute to the debate on how services are delivered. This report will serve as a substantial basis for Patient and Client Council’s response to the Department’s consultation document (October 2012) “Transforming Your Care: From Vision to Action”.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Maeve Hully', written in a cursive style.

Maeve Hully

Chief Executive of the Patient and Client Council

Summary

The purpose of this report is to review people's views on health and social care as expressed to the Patient and Client Council since its inception in April 2009. During this period more than **13,000 people** have taken the time to offer their thoughts, concerns, observations and opinions, which have been captured in the **34 reports** produced by the Patient and Client Council to date.

The timing of this report is significant. In November 2011, "Transforming Your Care – A Review of Health and Social Care in Northern Ireland" (DHSSPS) outlined 99 recommendations for the future provision of health and social care services in Northern Ireland. The fundamental argument of "Transforming Your Care" is that change is not optional, it is essential. With health and social care services set to change significantly over the coming years, it is an opportune moment to review the key messages people have communicated to the Patient and Client Council since the beginning. This report considers those messages within the context of the recommendations for future services made in "Transforming Your Care" under the 'Ten Areas of Care' it identifies.

The main findings of the report include the following:

- The central message of "Transforming Your Care" is that change is essential, not optional. It is very evident across the reports of the Patient and Client Council that people recognise that the way in which health and social care services are delivered in Northern Ireland has to change;
- There is much common ground between the priorities for health and social care identified by people in the reports of the Patient and Client Council and those outlined in "Transforming Your Care", largely due to three shared underlying principles - placing the individual at the centre of any model of care, using outcomes and quality evidence to shape services and providing the right care, in the right place, at the right time;
- Key messages emerging from Patient and Client Council research to date are; the importance of service user involvement, good communication,

timely and accessible information, continuity of care, support for vulnerable groups, support for carers and equal access to services. Many of these issues are reflected positively within the 'Ten Areas of Care' addressed in "Transforming Your Care";

- The three most frequently raised concerns across the Patient and Client Council reports are communication, information and continuity of care. The emphasis in "Transforming Your Care" on integrated care, a joined-up approach to urgent care, improved communication between and within services and the proposal for a single robust community information system respond well to these concerns;
- There are a small number of major recommendations made in "Transforming Your Care" which are likely to challenge popular views on the priorities for health and social care expressed to the Patient and Client Council over the past three years, including the proposed reduction in number of acute hospitals and the shift in resources away from hospitals towards care at home and in the community;
- A central proposal of "Transforming Your Care" is that care should be provided as close to home as possible. This review of Patient and Client Council research finds a certain amount of support for the concept of 'home as the hub of care'; however the proposed shift in resources from hospital to community will concern those who have expressed doubts about the quality, planning and delivery of community care, particularly for the most vulnerable;
- Transforming Your Care recommends substantial change in the area of acute care, an area of care high on the list of priorities for people who have spoken to the Patient and Client Council. The more joined-up approach to unscheduled care laid out in Transforming Your Care should be welcomed by those who have frequently expressed concern with Accident and Emergency and Out of Hours services; however the proposed reduction from ten to 'five to seven' major acute hospitals is likely to challenge the

highly prioritised issue of equal access to quality hospital care, regardless of location.

1.0 Background and Purpose

As part of its work plan for 2012-2013, the Patient and Client Council decided to undertake a review of the 34 reports that it had produced since its establishment in 2009. This piece of work is timely as “Transforming Your Care”, a review of the provision of health and social care services in Northern Ireland, was published in November 2011. “Transforming Your Care” identified 99 recommendations for the future shape of services and provided a plan for their implementation.

The fundamental message of “Transforming Your Care” is that change is not optional, it is essential. This report considers some of the 99 recommendations made in “Transforming Your Care” alongside views and opinions that people have expressed in the reports of the Patient and Client Council since April 2009.

1.1 Background

The Patient and Client Council provides a powerful, independent voice for people.

The Patient and Client Council has four main duties. They are to:

- listen and act on people’s views;
- encourage people to get involved;
- help people make a complaint; and
- promote advice and information.

Since its establishment the Patient and Client Council has worked constantly with patients, services users, carers and communities across Northern Ireland, gathering their views on and aspirations for health and social care services in Northern Ireland.

To date 34 reports have been produced (a total of 55 reports have been published but 20 of these additional publications are variations or summaries of previous reports.

The Survey of Dental Practices was not used in this report). These reports have been

used as the basis for dialogue with decision-makers to help ensure that changes in health and social care are shaped by the people who use them.

This report summarises these views and, in particular, considers them in the context of “Transforming Your Care”.

1.2 Purpose

It is evident from the reports produced by the Patient and Client Council that people acknowledge the need for change in the way that health and social care services are delivered in Northern Ireland. The underlying principles for change outlined in Transforming Your Care are largely in tune with those voiced by patients, clients, service users and carers and many of the recommendations made in the review respond to issues that people have raised over the past three years. The first three principles for change stated in Transforming Your Care are particularly relevant:

- 1. Placing the individual at the centre of any model by promoting a better outcome for the user, carer and their family**
- 2. Using outcomes and quality evidence to shape services**
- 3. Providing the right care in the right place at the right time**

However, there are some recommendations included in “Transforming Your Care” that diverge somewhat from common concerns which appear time and again across the Patient and Client Council reports. These points of commonality and divergence are discussed in detail in the following three sections, under the umbrella title of “Transforming Your Care” in three main areas:

- Transforming Your Care
- Ten Areas of Care
- Implications for the Service

2.0 Transforming Your Care

In this section the most notable key themes of Transforming Your Care are discussed alongside views of the public gathered by the Patient and Client Council since April 2009 (quotations taken from these reports are presented in boxes). A full list of the Patient and Client Council papers that were consulted for this report is given in **Appendix 1**.

2.1 A Quality Service

From the outset, Transforming Your Care makes it clear that quality and outcomes are to be the determining factors in shaping future health and social care services.

Quality of services is prioritised throughout the Patient and Client Council reports, across all areas of care. 'Access to and quality of hospital care' and 'quality assurance of health and social care' bookend the top ten priorities identified by members of the public in 'The People's Priorities 2011'. Quality of care can mean many different things to people, ranging from basic nursing and medical care and the cleanliness of a facility, to good communication and experiencing dignity and respect when receiving care. Consequently, 'The People's Priorities 2011' recommends:

'That there is a renewed commitment by the commissioners to the full achievement of the Department's Quality Strategy, including the five experience standards as outlined in the Departments document entitled "Improving the Patient and Client Experience". The five experience standards cover the following areas: respect; attitude; behaviour; communication; privacy and dignity' The People's Priorities 2011 (PCC: 31)

2.2 Community Services

The central proposal of Transforming Your Care is that care should be provided as close to home as possible. As a result the model of care delivered by hospitals will change, requiring a shift of resources from hospitals to enable investment into community health and social care services.

While views expressed to the Patient and Client Council over the past three years suggest that many people would agree with the general concept of 'home as the hub of care', people have frequently voiced concern about the quality, planning and delivery of community based services. This is particularly true for the most vulnerable groups in society such as children, the elderly, learning disabled and those with mental health issues.

“There is widespread concern about community care – how it is planned and how it is delivered” Report on the Public Engagement on “Priorities for Action” 2009 (PCC: 18)

The additional recommendation in Transforming Your Care that a shift in resources should allow for further investment in and development of community services may respond to these concerns somewhat.

People have also suggested that community care can at times feel fragmented. The following recommendation recognises that better co-ordination between health and social care services and government departments is essential if the focus of care is to move towards the home and community:

“A greater focus on care in the community for the most vulnerable groups in society such as the elderly, children, learning disabled, and those with mental health problems. This will also require improved inter-departmental working by the Northern Ireland Executive, as well as better internal co-ordination and communication across health and social care organisations” The People’s Priorities 2011(PCC: 31)

2.3 Integrated Care

The establishment of 17 Integrated Care Partnerships to enable closer working relationships between hospital and community services is one of the key recommendations of Transforming Your Care. Furthermore, integrated planning, joined up services, named key workers and improved communication within and between services are specifically addressed in almost all ten areas of care in the review.

Closer working relationships between primary, community and hospital services will be seen as a welcome development, as two of the most frequently voiced concerns in Patient and Client Council consultations with the public are poor communication between services and a lack of continuity in care. An observation made in the Patient and Client Council's earliest reports sums up this issue, one which is often repeated across subsequent reports:

“People wanted to see services organised so there was a sense of continuity of relationship with health and social care services; whether in primary, community or hospital care, people reported rarely seeing the same person twice and having to explain their needs on each occasion - something they saw as, at best, time-wasting and, at worst, distressing” Report on the Public Engagement on Priorities for Action (PCC 2009: 11)

2.4 Personalisation of Care

Promoting independence and personalisation of care is a central theme of Transforming Your Care. The review recommends that patients and carers should have more direct control over their own care, including financial control, and should be helped to take the important decisions about their own health and care.

Across the reports of the Patient and Client Council people have expressed the desire to be more involved in the management and monitoring of their own care, especially in regards to community based health and social care. Personalisation of care is a particularly common theme in the areas of mental health and learning disability. Individual care plans for care received at home and patient/service user held records for people with long term conditions, rare diseases and complex physical and learning disabilities are considered important tools in the self-management of care.

“Everyone receiving care at home should have an individual care plan they hold personally” Report on the Public Engagement on “Priorities for Action” 2009 (PCC: 18)

However, some people, particularly older people, have expressed reluctance to take personal charge of their care. This is especially true of financial control. A further impediment identified by carers and service users is the lack of information and support in accessing Direct Payments in order to undertake financial management of

their care. It is evident from the Patient and Client Council reports that advocacy, support and clear information are crucial in helping people feel more confident about taking greater direct control over their care.

2.5 Prevention and Health Promotion

Enabling individual responsibility for health is an underlying principle of Transforming Your Care. A new focus on prevention and the promotion of good health and well-being is evident across all areas of care addressed in the review. The aim is to ensure that every individual will have the opportunity to make good decisions that will help maintain wellbeing and prevent poor health.

Public views on prevention and health promotion noted by the Patient and Client Council over the past three years are generally positive. The young people were particularly supportive of health promotion and education initiatives. Education, awareness raising and open discussion about health and social care issues are considered as important steps in creating more informed communities in which people can make better health decisions and understand the challenges faced by others.

2.6 Acute Care

Transforming Your Care recommends substantial changes in the delivery of acute care in Northern Ireland. The more integrated, joined-up approach to urgent care envisaged in the review is likely to be welcomed by members of the public who have frequently reported to the Patient and Client Council their frustrations when accessing unscheduled care, particularly Accident and Emergency and GP Out of Hours services. People consider clear communication a priority, in order to improve outcomes for those who need urgent care and to reduce inappropriate use of emergency services by people who could be treated in a more suitable care setting. This is recognised in the recommendations of “Transforming Your Care”. However, the proposed move from ten to ‘five to seven’ major acute hospital networks is likely to conflict with the views of people consulted by the Patient and Client Council who highly prioritise access to and quality of hospital care. For example, in The People’s Priorities 2010 access to local hospital services was identified as a top ten

priority. While there was some support for the centralisation of very specialist services, people wanted reasonable access to local hospital care, including Accident and Emergency and Outpatient services. Rural people are particularly vocal about the perceived reduction in local hospital services. Another common theme of the Patient and Client Council reports across every area of care is relevant here; people want to be assured that they have equal access to quality health and social care services, regardless of where they live.

3.0 Ten Areas of Care

The key recommendations of Transforming Your Care are presented across ten specific areas of care:

1. Population Health and Wellbeing
2. Older People
3. People with Long Term Conditions
4. People with a Physical Disability
5. Maternity and Child Health
6. Family and Child Care
7. People using Mental Health Services
8. People with a Learning Disability
9. Acute Care
10. Palliative and End of Life Care

In this section, the views that people have expressed to the Patient and Client Council over the past three years are discussed alongside some of the main recommendations made in each specific area of Transforming Your Care. The recommendations from Transforming Your Care are presented in bold, bullet point form. Direct quotations taken from Transforming Your Care and the Patient and Client Council reports are presented in boxes.

3.1 Population Health and Wellbeing (TYC Section 7)

There is a focus on prevention of ill health throughout Transforming Your Care. The recommendations of the review are aimed at ensuring every individual will have the

opportunity to make good decisions that will help maintain wellbeing and prevent poor health. In reflection of this, 'the individual', 'self-care' and 'good health decisions' are at the centre of the Future Model of Integrated Health and Social Care contained in Transforming Your Care:

“Prevention is integral to the delivery of sustaining health and social care. It enables individuals to make better health and wellbeing decisions ... Health and wellbeing is not just a matter for the health and social care system. It begins with the individual and the choices they make”. Transforming Your Care (DHSSPS: 12)

The Patient and Client Council has noted some public views on health promotion and prevention across its reports. These are discussed alongside some of the key recommendations in this area made in Transforming Your Care.

- **Renewed focus on health promotion and prevention to materially reduce demand for acute health services**
- **Incentivisation of Integrated Care Partnerships to support evidence-based health promotion, for example, clinician-led education programmes in the community**

Out of everyone who has contributed to Patient and Client Council's reports to date, the young people consulted for 'Young People's Priorities' (2012) were most vocal on the subject of health promotion and prevention. Health Promotion was rated fifth in the young people's top 10 priorities. The provision of accessible and coherent information and health screening programmes were believed to play an important role in tackling issues such as obesity, alcohol abuse, smoking and sexual health. Health education was identified as a particular priority and examples given were sexual health and healthy eating programmes in schools. The following recommendation from Young People's Priorities reflects the importance of this issue to young people:

“The Public Health Agency needs to build on key messages that have come from young people. This includes focus on health education in schools and further and higher education establishments in conjunction with the relevant Departments and education providers. Health promotion should also include a range of agencies and not just those directly involved in health and social care provision” Young People's Priorities in Health and Social Care (PCC, 2012: 34)

Health promotion and prevention or early intervention are also considered of utmost importance in Mental Health care. The promotion of good mental health is a recurrent theme across the Patient and Client Council's reports in this area. Again, education emerges as a closely related issue. Education and open discussion about mental health are seen as crucial in decreasing the stigma around mental illness and creating better environments in which to promote good mental health.

In recent reports, such as 'The People's Priorities 2011' and 'Young People's Priorities', there has been some suggestion that a greater emphasis on health promotion could help Health and Social Care services save money. A few people have gone as far to say that individuals whose condition is the result of smoking, alcohol or drug abuse, perceived as 'self-inflicted' illnesses, should contribute financially to their own healthcare.

People are clear however that health education is fundamental to creating more informed communities in which people can make better personal health choices, but also understand the health issues faced by others.

- **Consideration by the NI Executive of the wider role of the state in taking decisions impacting on health outcomes, for example: in relation to pricing of alcohol and 'junk' food; and further controls on tobacco use**

In 2010, the Patient and Client Council's paper 'Public Engagement on Alcohol Labelling' reported that the majority of people felt current alcohol labelling would have to be strengthened if it were to prove an effective measure against alcohol abuse. It was suggested that the more graphic images and warnings on cigarette packages were a more successful deterrent. More generally, there was support for further education on issues around alcohol consumption, especially in relation to longer term health risks.

- **Joint working pilot projects with other Government departments that enable resource sharing and control, for example in rural isolation and transport**

It is not surprising that transport and location of services emerges as a recurrent theme in the 2011 report 'Rural Voices Matter'. Transport, including rural community transport, was identified as an area of concern in 'The People's Priorities 2010'. It was suggested that access to and the cost of transport services was becoming more of an issue for people on low incomes, those residing in rural areas and elderly people. The underlying concern is that lack of transport consequently impacts on uptake of health, social and mental health services.

- **Maintenance of existing and implementation of new screening and immunisation programmes where supported by clinical evidence**

People recognise the importance of screening programmes, both as a preventive measure and in the early detection of disease. This is especially true in the area of Cancer Services, where improved screening has been identified as a priority.

- **An expanded role for community pharmacy in the arena of health promotion both in pharmacies in the community (sic)**

Pharmacy services had the highest overall "excellent" rating from rural dwellers in 'Rural Voices Matter'. The majority of people consulted said their local pharmacy provided a good service; further comments added that the pharmacy was accessible, staffed by knowledgeable professionals and a valuable source of information. It is evident from the report that pharmacies are a vital part of health service provision in rural areas. In light of this, one of the key recommendations of 'Rural Voices Matter' was to expand the range of services provided through community pharmacies:

"The Health and Social Care Board should commission a more extensive range of services through the community pharmacy services as a means of supporting the health care needs of rural dwellers" Rural Voices Matter (PCC, June 2011: 50)

- **Support for the health promotion and prevention role played by Allied Health Professionals, particularly with older people**

'Care at Home', a Patient and Client Council report into older peoples' experiences of domiciliary care, acknowledges the importance of Allied Health Professionals to

reablement schemes for older people, short-term interventions aimed at supporting older people to develop or regain skills and confidence necessary to live independently. The three essential elements of reablement, (physical rehabilitation, motivation and social inclusion), emphasise the important supportive role played by AHPs. See below for further discussion of reablement and the promotion of healthy ageing.

3.2 Older People (TYC Section 8)

Transforming Your Care states that Northern Ireland has the fastest growing population in the UK, and this is an ageing population. Older people are, understandably, significant users of health and social care services. However, it has been suggested in Transforming Your Care that, despite the many excellent services provided for older people, there is an over-reliance on institutional and hospital care and inconsistencies in the quality and range of services provided across Northern Ireland:

“Services are not currently meeting expectations in terms of quality and consistency. Too often they tend to focus on acute events and crises rather than providing the range of proactive and preventative support that can maintain the health and wellbeing of older people” Transforming Your Care (DHSSPS: 59)

The future of care for older people envisaged in Transforming Your Care is built around the key principle of ‘home as the hub of care’, with the necessary resources in place to see a shift in care away from institutional settings and a reduction in unnecessary and lengthy hospital admissions. Promotion of healthy ageing and a more joined-up approach to the provision of services for older people are also central:

“Care for older people should be underpinned by a consistent assessment process, and a more holistic approach to planning and delivering support taking account of physical, social and emotional needs” Transforming Your Care (DHSSPS: 67)

It is very evident from the Patient and Client Council’s reports to date that people are genuinely concerned about future of care provision for older people in Northern

Ireland. 'Care of the Elderly' was identified as one of the top three priorities in 'The People's Priorities' 2010 and 2011. In both reports, particular concern was expressed about the provision of care in the community for elderly people, principally the quality of domiciliary care. Respite support, appropriate care of the elderly in hospital and discharge arrangements on leaving hospital were also identified as issues warranting attention. Elderly care also featured as one of the top ten priorities in 'Young People Priorities'. As well as the issues mentioned in the People's Priorities reports, young people also considered the provision of day centres and activities to prevent social isolation amongst older people to be important.

- **Home as the hub of care for older people, with more services provided at home and in the community**
- **A major reduction in residential accommodation for older people, over the next five years**

'Care at Home', an in-depth report into older people's experiences of domiciliary care in Northern Ireland, concluded that one of the most valued aspects of domiciliary care was that it enabled people to remain in their own home. Most people said that they would prefer to receive care at home wherever possible, rather than face the alternative of residential or nursing care. The majority of carers who contributed to the report also expressed a preference for home care for their relative.

Domiciliary care is undoubtedly an invaluable service to many older people. Most people who contributed to 'Care at Home' said they were satisfied with the service they receive and rated the quality of care highly. However, older people did voice issues with the service, such as the short duration of calls by care workers, inconvenient or inflexible call times, inconsistent quality of care staff and lack of continuity in care. As a result, just over a quarter of the older people who contributed to the report said that the home care they received only improved their quality of life "a little" or "not at all". The report concluded that these inconsistencies must be addressed before a service based around home and community care could gain the full confidence of the older people who use the service, their carers and families.

- **A focus on promoting healthy ageing, individual resilience and independence**
- **A holistic and consistent approach to assessment of older people's needs across Northern Ireland and an equitable range of services**
- **More integrated planning and delivery of support for older people, with joined up services and budgets in health and social care, and pilots to explore budgetary integration beyond health and social care**

The information collected for 'Care at Home' reveals that receiving home care means more to older people than just physical help with everyday tasks. Many older people valued the home care service because it relieved a sense of social isolation; they depended both physically and emotionally on domiciliary care. It is clear that physical, emotional and social needs of people must be met in order to encourage healthy ageing and individual resilience amongst older people. A more integrated delivery of support for older people from a wide-range of services should help facilitate this all-encompassing approach:

“Domiciliary care provision should link clearly into wider policy initiatives such as Ageing Well, Investing for Health and the Older People’s Strategy in order to ensure that older people receive a joined up service” Care at Home (PCC 2012: 62)

- **A diverse choice of provision to meet the needs of older people, with appropriate regulation and safeguards to ensure quality and protect the vulnerable**
- **Personalised care designed to deliver the outcomes care users and their families want, with increasing control over budgets, and access to advocacy and support if needed**

As noted, there was a general consensus expressed in 'Care at Home' that home care services for older people should be more wide-ranging and should encompass physical, social and psychological needs. Many people were of the opinion that help with less personal tasks such as cleaning, laundry and shopping was just as essential in enabling older people to remain at home as personal care. When asked to identify other kinds of assistance that would help them to live more independently, the three most common responses given by older people were assistance with housework,

more company within the home or help getting out to socialise and equipment, aids or adaptations to their home. The most important message to take from this is that older people should be given more choice over the types of care they are offered at home or in the community, something that is reflected in the recommendations of the report:

“Older people should be provided with a range of choices which both address their needs and are seen by them as desirable options for their future care” Care at Home (PCC 2012: 62)

Older people sometimes need help to speak out, to express their own views and, where possible, make their own decisions about the care they receive. The importance of advocacy for vulnerable adults is recognised in the Patient and Client Council’s publication ‘Someone to Stand up for Me’, a toolkit to promote advocacy for older people in the independent care home sector.

- **Introduction of reablement to encourage independence and help avoid unnecessary admissions of older people into hospital**
- **More community-based step-up/step-down and respite care, provided largely by the independent sector**

Appropriate discharge arrangements for elderly people leaving hospital was identified as a priority in this area of care in both ‘Peoples’ Priorities’ reports. People wanted discharge planning to be more holistic. It was felt that planning for leaving hospital should begin on admission, with timely involvement of the individual, carers, family, community and primary services.

Reablement is often associated with post-hospital care. When questioned about reablement as part of the ‘Care at Home’ project, members of the public said that the scheme sounded good in concept as it would hopefully help older people to live more independently. However, people were concerned that it would be expensive to implement properly and could be abused as a money saving scheme to avoid long term domiciliary care packages. The policy of reablement has been welcomed by many as a meaningful way of supporting older people to regain the confidence needed to live independently, on the provision that the focus remains on improving the older person’s quality of life rather than reducing the financial cost of social care. A

recommendation from 'Care at Home' acknowledges the place for reablement within the wider context of healthy ageing and independence as discussed above:

“There should be an ongoing evaluation of the implementation of Reablement schemes. Reablement should be incorporated into the wider strategic framework for supporting the care needs of older people” Care at Home (PCC 2012: 62)

- **A policy review of carers' assessments and more practical support for carers including improved access to respite provision**

It is very evident from the 'Care at Home' report that older people rely heavily on informal support provided by family members, friends and neighbours. Domiciliary care was also important to families who wanted to keep their elderly relative at home. However, home care can have a huge impact on the full-time carer and be a limit on both their privacy and independence. Improved access to support services and respite would benefit both the individual and their carer.

Sometimes appropriate respite is just not available. Carers for people with dementia told the 'Respite (short breaks)' report that there were only a limited number of respite facilities that could meet the specific needs of someone with dementia. More practical and emotional support for carers, including improved access to realistic and appropriate respite provision, is a common theme throughout the reports of the Patient and Client Council.

3.3 Long Term Conditions (TYC Section 9)

Transforming Your Care describes Long Term Conditions (LTC) as people who have a condition which currently cannot be cured but can be controlled by medication and/or therapy. People with LTCs require a high level of care and consequently place a high demand on resources. It is the view of Transforming Your Care that this care is best provided at home, with primary care and the community playing a supportive role. The future emphasis for LTCs will be on prevention, early identification and self-management, with as little as possible care provided in an inpatient setting:

“The objective is to ensure better outcomes for patients. It is also important to understand that better organisation of care pathways will improve quality and value for money” Transforming Your Care (DHSSPS: 71)

The Patient and Client Council has heard evidence that people recognise the need for better co-ordinated care plans for managing long-term conditions. Receiving care at home or close to home and avoiding or reducing preventable hospital admissions are also seen as priorities. However, it should be noted that people have expressed anxiety about the quality of care provided in the community. Lack of continuity, poor communication and poor co-ordination of care are repeatedly voiced as issues that need to be addressed before people can have full confidence in community care.

- **Partnership working with patients to enable greater self-care and prevention**
- **Personalised care pathways enabling home based management of the LTC with expanded support from the independent sector**

From the beginning, the Patient and Client Council has heard that people want to be involved in the planning and delivery of community based health and social care. They want community care plans that are more sensitive to the needs of the individual. In the 2009 ‘Report on the Public Engagement on “Priorities for Action”’, the lack of patient, service user and carer involvement in decision-making about community care was the most commonly voiced concern. People reported feeling excluded from the process, resulting in personal care plans that were not as good as they should be or even unworkable. Furthermore, patients, clients and carers said that an individual care plan which they could hold in their own home was essential:

“People felt that this [individual care plan] was a fundamental communication tool to enable them to understand the level of health and social care that was agreed. They also stressed the importance of this to help them contribute to the management of their individual service provision” Report on the Public Engagement on “Priorities for Action” (PCC 2009:11)

Involving service users and carers in planning individual care pathways and providing personalised care plans that people can refer to in their own homes are considered

essential in enabling home based care and self-management for people with Long Term Conditions (LTCs).

- **Patients to have named contacts for the multi-disciplinary team in each GP surgery to enable more straightforward communication**

Good communication and continuity in care are key issues for people living with a LTC. People with LTCs come into contact with health practitioners on a frequent basis, so having a named contact and seeing familiar staff who are well informed of their medical history are of utmost importance. People have described frustration at having to relate their long history to health professionals unfamiliar with their case on each occasion they seek care. A continuous record of previous treatment would be welcome, especially as it is felt that health professionals do not always communicate well with one another. People living with a rare condition have said in the 2012 report 'Experience of Diagnosis', that they can feel very isolated, especially after they have left hospital care. They would value a named contact in the community who they could turn to for advice, information and support.

People have expressed concern about the existing level service provision and support for people living with LTCs. In the 'Peoples' Priorities' reports for both 2010 and 2011 people identified a possible skills shortage in community nursing, particularly a lack of specialist nurses to deal with conditions such as brain injury, Parkinson's disease, Motor Neurone Disease and Multiple Sclerosis. In the 2011 report, inadequate provision for patients with LTCs was given as an example of variation in quality across health settings. Young people acknowledged the emotional and psychological side of living with a LTC in 'Young People's Priorities', citing counselling and support services for people with terminal or long term illness and their families as an area of care which merited more funding.

- **Development of admission protocols between secondary care specialist staff and those in the community**

It has been suggested in the reports of the Patient and Client Council that the development of protocols should be extended to hospital discharge. People reported that the move from hospital care back into community care can be poorly co-ordinated

and that a lack of communication between hospital and community staff can lead to duplication of treatment, mixed advice and a general sense of confusion for patients.

3.4 People with a Physical Disability (TYC Section 10)

Personalisation, independence and control are central to Transforming Your Care's recommendations for people with a physical disability:

“The current service-led approach should be replaced by a more person-centred model in which statutory health and social care works as an enabler, working in partnership with the disabled person and their family/carers to help people access the support that meets their individual needs” Transforming Your Care (DHSSPS:78)

Transforming Your Care states that promoting increased independence for people with a physical disability will require a multi-agency approach. The community and voluntary sector have a vital role to play in providing support and advocacy. The input of other government departments will also be necessary, most notably in the areas of housing, education, employment and culture, arts and leisure.

- **Promoting independence and control for people with a disability, enabling balanced risk-taking**
- **More control for service users over budgets, with continued promotion of Direct Payments, and a common approach to personalised budget with advocacy and brokerage support where required**

General public feedback gathered by the Patient and Client Council suggests that people would support this direction. People have repeatedly spoken of the need for a more person-centred approach to meeting needs, more individual and carer input into care plans and the promotion of independence for people with a disability. This would depend, however, on giving people with a physical disability the necessary support to enable them to do this with confidence.

- **A shift in the role of the health and social care organisations towards being an enabler and information provider**
- **Joint planning of services for disabled people by the statutory, voluntary and community health and social care providers, and other relevant**

public services (e.g. housing) to ensure a wide range of services across NI

Services for people with a physical disability were mentioned in both the 2010 and 2011 People's Priorities report, particularly in the context of support not always being delivered in a timely fashion. For example, in the top three priorities in both reports was 'Concern about Increasing Waiting Times', which referred not only to waiting times for treatment but also for equipment. Long waiting times for equipment such as wheelchairs, shower supports and safety ramps were also reported in 'Care at Home'. These delays were said to be preventing people with a physical disability from living more independently. Transforming Your Care emphasises how vital the provision of equipment is to enable people with a disability to live well at home, but identified that recent research suggests "a lot of improvement" is needed to reduce long waiting times for equipment. Evidence from Patient and Client Council's reports support these findings.

'My Day, My Way', a report into day services for people with a learning disability, found further indication that people with a physical disability were not always offered the adequate support or facilities. For example, wheelchair users at two different day centres felt they could not attend clubs or groups outside the centre with their friends because the clubs did not cater for their needs. They felt this limited their choice. Wheelchair users in another day centre felt the doorways were narrow and difficult to get through and a student at one of the regional colleges made a similar comment.

It is evident from comments made in Patient and Client Council's reports that if the role of health and social care services is to move towards that of an enabler and information provider, more will have to be done to ensure that people with a physical disability are offered the necessary support in a timely fashion. It is also recognised that joint planning for people with physical disability across government departments and community and voluntary organisations will be necessary in order to achieve the key elements of personalisation, independence and control identified in Transforming Your Care.

- **Better recognition of carers' roles as partners in planning and delivering support, and more practical support for carers**
- **More respite and short breaks provision**

Greater recognition of the value and needs of carers has long been a central theme in the reports of the Patient and Client Council. Care plans that have been developed without input from the carer or without taking account of the carer's contribution are felt to be impractical and unnecessarily difficult. Time and again, people have stressed that it is only good common sense to involve carers in planning and delivering support at home.

However, carers have often spoken about demands of caring and their desire for improved respite services. The 'Respite (short breaks)' report may have focussed on carers of people with a learning disability and dementia, but it illustrates how vital and valued a service respite is for carers. Recognition of the role of carers and the importance of providing for the needs of carers themselves is reflected in the following recommendation from the first report produced by the Patient and Client Council:

“Every carer should have an assessment of their needs carried out. This assessment and the views of carers should be used to agree individual care plans as well as to provide for the needs of carers themselves” Report into the Public Engagement on “Priorities for Action” (PCC 2009:19)

3.5 Maternity and Child Health (TYC Section 11)

Transforming Your Care states that the birth rate in Northern Ireland increased by almost 18% in the first decade of the 21st century. This growth rate has undoubtedly placed extra demands on Maternity and Child Health services, and yet Transforming Your Care found that satisfaction levels with maternity services were generally high. However, room for improvement was identified, particularly in relation to significant health inequalities in maternal and infant outcomes that exist amongst women from socio-economically deprived backgrounds.

The Patient and Client Council has also found public feedback on maternity services in Northern Ireland to be generally positive. Maternity services are important to people – they were mentioned in both People’s Priorities reports and in Young People’s Priorities. The focus of comments in these reports were on the provision of maternity services and pre-natal care locally, ensuring adequate pain relief in maternity care and better support for pregnant mothers and new babies, including young mums.

However, while feedback has been largely positive, some issues with the service were raised in the 2010 report, ‘Maternity Services - Parents’ Views on the Review of Maternity Services for Northern Ireland’. These issues are indicated below alongside recommendations from Transforming Your Care.

- **Written and oral information for women to enable an informed choice about place of birth**

It has been suggested that mothers are not given a lot of choice as to place of birth and that home births are not promoted by GPs and nursing staff.

- **Services in consultant-led obstetric and midwife-led units available dependent on need**
- **Promotion of normalisation of birth, with midwives leading care for straightforward pregnancies and labour, and reduction of unnecessary interventions**

People have reported particularly positive experiences of community based and midwifery care. While the labour ward and community midwifery were identified as aspects of maternity care that are working well, some people felt that hospital care was too pressurised. Staff shortages, inadequate training for staff to recognise and respond to specific needs and a lack of access to medical consultant input were given as explanations for why this might be the case. It was suggested by some parents that medical interventions were too frequent, with little choice given to the mother.

- **Continuity of care for women throughout the maternity pathway**

The need for better continuity of care and improved communication with mothers, before and after birth, were commonly recurring themes. It was suggested that, in some cases, staff shortages led to poor continuity in care and mixed messages from staff during the birth. Parents noted inconsistencies in the approach and attitudes of the various staff members who attended to them, which could result in confusion and anxiety. More practical support after the birth, for example support with bathing the baby and breastfeeding, was also identified as a priority.

3.6 Family and Childcare – including Child Health (TYC Section 12)

Transforming Your Care cites evidence from a number of independent reviews to suggest that there is a significant under investment in children services within Northern Ireland compared to other parts of the UK. Feedback from the Patient and Client Council's engagement with the public is beginning to reflect this concern, with Children's Services ranking in the top ten People's Priorities for the first time in 2011. Prior to this, Children's Services was identified by the public as an area of care that should be secured extra funding.

<p>“More needs to be spent on the young as they are our future” The People's Priorities 2011 (PCC, Nov 11)</p>

- **Further development of childhood screening programmes as referenced in Health and Wellbeing section**
- **Completion of a review of inpatient paediatric care to include palliative and end of life care**
- **Close working between hospital and community paediatricians through Integrated Care Partnerships**

People consider good child health as one of the most significant aspects of Children's Services. Priorities identified in this area include prevention programmes aimed at children and young people, paediatric medicine and surgery and diabetic clinics for children.

- **Re-structuring of existing services to develop a new 'Headstart' programme focusing on 0-5 year olds**

Improved childcare for the very young has also been identified as a priority.

- **Completion of a review of residential care to minimise its necessity**
- **Promotion of foster care both within and out with families**
- **Development of a professional foster scheme for those hardest to place**

People have expressed concern that not enough support is given to children in foster care or children's homes. In previous reports, continuity in care during significant transitions, including young people leaving children's homes, was identified as an issue meriting specific attention.

In Young People's Priorities, 'Childcare' rates highly amongst the priorities identified that did not make it into the top ten. Comments expressed a general need for improved services for children as a whole; child protection services were, however, identified by many respondents as having particular significance. An improvement in child protection services was also given precedence in 'The People's Priorities 2011'.

- **Implementation of the RQIA recommendations in relation to CAMHS**

People's views on mental health services for young people are recorded under 'People Using Mental Health Services' below.

- **Exploration through pilot arrangements of budgetary integration for services to this group across Departments, under the auspices of the Child and Young People's Strategic Partnership**
- **Promotion of partnership working on children's health and wellbeing matters with other government sectors**

It is evident from a number of Patient and Client Council's reports that collaborative working between government departments within the Northern Ireland Executive is considered crucial in providing effective services for children and other vulnerable groups in our society.

3.7 People using Mental Health Services (TYC Section 13)

Transforming Your Care refers to the Bamford Review of Mental Health and Learning Disability, which has set the agenda for the reform and modernisation of law, policy and provision affecting people with mental health needs in Northern Ireland. The Transforming Your Care review found nothing which challenged Bamford, but did detect some level of “frustration” at the slow rate of implementation.

Reports in the area of Mental Health carried out by the Bamford Monitoring Group have arrived at a similar conclusion:

“People acknowledged that the Bamford review planted seeds of change and has begun to make a positive difference for people with mental health problems ... however, many people expressed their frustration at the slow pace of change and the long way to go” Is Bamford Making a Difference? Report from the Open Dialogue Mental Health Conference (PCC, Aug 2011: 47)

Mental Health has emerged as a priority in all three Patient and Client Council’s public engagements on ‘Priorities for Action’ since 2009, as well as the recently published ‘Young People’s Priorities’. People want to see the development of appropriate mental health services and the increased promotion of good mental health. They wish to see a move forward with the full implementation of the recommendations of the Bamford Review.

- **Continued focus on promoting mental health and wellbeing with emphasis on reducing suicide rates among young men**
- **Establish programme of early intervention to promote mental health wellbeing**

Mental Health emerges as a big issue in ‘Young People’s Priorities’, particularly mental health services for young people. Concerns were expressed about the perceived inadequacy of services specifically geared towards young people with mental health problems, reducing the stigma around mental health illness, the need for better counselling services and education on suicide awareness. The priority given

to mental health services by the young people consulted for this report is reflected in the following recommendation:

“Commissioners and providers should address young people’s concerns regarding the lack of appropriate mental health services relating specifically to their needs, including a focus on community based initiatives” Young People’s Priorities in Health and Social Care (PCC, May 12: 34)

This is further evidenced in other Patient and Client Council reports. When asked about mental and emotional wellbeing, young people felt that there should be more services, including counselling services, specifically geared towards young people. Confidentiality is also crucial for young people. Education on mental health issues from an early age at school and in the community was suggested as a means to reduce the stigma around mental health illness and encourage young people to talk about their problems. Furthermore, education to all sections of the community, at all ages, was felt to be an important step in reducing discrimination around mental illness.

The 2010 report, ‘The Mental and Emotional Health of 16 year olds in Northern Ireland’, made the link between poor mental health among young people and social deprivation. The findings of the report, based on the Young Life and Times Survey, point to the need for substantial investment in areas of social deprivation in Northern Ireland in order to reduce the prevalence of poor mental health.

- **Clearer information on mental health services should be available, making full use of modern technology resources**
- **Consistent, evidence-based pathway through the four-step model provided across the region**
- **Consistent pathway for urgent mental health care, including how people in crisis contact services, triage, facilities in A&E departments**

Consistent and accessible information about Mental Health services was considered a priority throughout the Patient and Client Council’s reports in this area of care. The report on the workshop ‘Shaping Information, Knowledge and Access to Mental Health Service’, emphasised the need for a single point of access for information and advice on services in order to ensure people have access to the right information, at the right time. People expressed concern about current access to mental health services and

some felt that the 'criteria' set around accessing services can sometimes act as a barrier. Contact with services during a crisis is still thought to be difficult. People evidently see the need for clear, consistent pathways for accessing mental health care.

Young people also felt that information on mental health services for their peer group should be more easily accessible. What is more, it was suggested that jargon and acronyms can be off-putting and that information must be presented in a style easy to understand and relevant to young people.

- **Review approach to home treatment services for children and young people, learning disability and psychiatry of old age**
- **Further shift of the balance of spend between hospital and community, with reinvestment of hospital savings into community services**
- **Greater involvement of voluntary and community sector mental health organisations in planning provision as part of Integrated Care Partnerships**

It is evident from the Patient and Client Council reports and public consultations that mental health illness is often very complex and it has been suggested on several occasions that a multi-agency approach to tackling poor mental health would prove most beneficial to individual. The vital role of voluntary organisations and community in terms of supporting individuals and families is a recurrent theme in discussions about Mental Health services:

“It was highlighted that greater collaboration and partnership working is necessary to improve the interface with the statutory sector” Is Bamford Making a Difference? (PCC Aug 11: 47)

This is linked to the point made above on accessible information. It has been suggested that a single point of information that covers statutory, voluntary and community bodies would be of great advantage to people seeking help:

“It was thought that statutory and voluntary organisations need to come together, and a map or directory of services of what help is available in each area was suggested” Shaping Information, Knowledge and Access to Mental Health Services (PCC, Oct 2010: 10)

Developing support in the community, particularly in light of the reduction of hospital-based services, is clearly considered of utmost importance to service users, carers and members of the public. Many people have stated a preference for treatment as close to home as possible, near to family, friends and a familiar environment. However, it should be noted that people have also expressed concern about the level of care received in the community.

A final recurrent issue in the reports of the Patient and Client Council is the importance of keeping service user and carer voice central to the Bamford change process. Service user involvement is seen to be crucial in every aspect of this process. Examples given are: involving people and carers in the development of information and advice about accessing mental health services; adopting a participatory approach to mental health services for young people in order to help improve attitudes towards mental ill-health amongst that peer group; and consulting with and keeping service users and carers fully informed about proposed changes to services in order to reduce anxiety about change.

3.8 People with a Learning Disability (TYC Section 14)

Transforming Your Care describes learning disability as a lifelong condition that requires long-term support. It is an area of care which demands close collaborative working within the Northern Ireland Executive:

“Provision of services for people with a learning disability requires a multi-agency and integrated approach – it is not solely a health issue” Transforming Your Care (DHSSPS: 94)

It is noted in Transforming Your Care that, as was the case with Mental Health services, the review team did not hear anything to challenge Bamford in the area of Learning Disability services, only frustration at the slow pace of implementation.

Learning Disability Services has emerged as a priority in all three Patient and Client Council public engagements on 'Priorities for Action' since 2009, as well as the recently published 'Young People's Priorities'. People want to see the development of appropriate services and equality of treatment for people with a learning disability. The protection of vulnerable adults living in the community and greater inter-departmental working in areas such as supported living, transport and day opportunities were suggested as areas for improvement.

- **Development of a more diverse range of age-appropriate day support and respite and short-break services**

The extensive Bamford Monitoring Group report on day opportunities for people with a learning disability, 'My Day, My Way', found that choice, flexibility and independence were key aspects in the development of appropriate day support services. It is clear from the report that people with a learning disability really value having a variety of activities to do during the week, be that college, work, volunteering, social enterprise schemes, day centres or clubs. However, the general consensus that "no size fits all" should be noted, and a key conclusion taken from the reports of the Bamford Monitoring Group to date is that learning disability services must be based around the individual and their specific needs:

"There is a clear call for a person-centred approach to day care services and day opportunities, planning around the needs of the individual" My Day, My Way (PCC Aug 2011: 100)

'My Day, My Way' did find evidence of efforts in recent years to expand on the day services available and offer people with a learning disability a more diverse range of opportunities. However, concerns were expressed over poor staffing levels and a reduction in activities provided at day centres, the lack of new educational courses for people with a learning disability at college and the limited availability of employment opportunities open to people with a learning disability. The findings of 'My Day, My Way' support the observation made in Transforming Your Care, that provision of services for people with a learning disability requires a multi-agency and integrated approach in order to fully meet the needs of those who use them. This is reflected in a key recommendation of the report:

“The Department of Health, Social Services and Public Safety should work in collaboration with government departments delivering the Bamford Vision action plan to identify a clear post-school pathway for people with a learning disability including all the options for education, training, work and leisure that are available” My Day, My Way (PCC, Aug 2011: 102)

The clear message from people with a learning disability, family members and carers is that respite and short breaks are essential. However, it was suggested that respite could be improved with greater availability and more local respite facilities. As with day services, respite/short breaks should be age-appropriate and flexible, with individuals able to choose from a range of respite services.

- **Development of information resources for people with a learning disability to support access to services**

An information resource for people with a learning disability was identified as a priority across the Patient and Client Council's reports in this area of care. There appears to be an 'information gap' as regards both day services and respite services - on many occasions, people with a learning disability, their carers and family members reported that they were simply unaware of the opportunities available in their local area. A lack of information about Carers Assessments and Direct Payments, what they are and how to access them, was also highlighted.

- **Greater financial control in the organisation of services for individuals and carers, including promoting uptake of Direct Payments with involvement of current recipients to share their experiences, and advocacy where needed**
- **Advocacy and support for people with an LD, including peer and independent advocacy**

As part of the 'Respite (short breaks)' report, people were asked about their usage of Direct Payments. The response points to a clear lack of information about Direct Payments amongst carers. Some people said they either had difficulty in accessing them or had never even heard the term before. Subsequently, the report recommends that the HSC Trusts should ensure all families in their area are informed about and offered the opportunity to access Direct Payments and the HSC Board should

continue to influence the uptake of Direct Payments. Advocacy and support for people with a learning disability is an important part of this process.

It is evident across the reports of the BMG that advocacy groups and opportunities for people with a learning disability, their carers and parents to share their views, get involved and contribute to decision-making about their services are of utmost importance. For example, it was apparent in 'My Day, My Way' that people with a learning disability had little real choice of how they spent their day; they did not know about the range of day opportunities available locally and thus were not able to choose what they wanted to do. As the report concludes, advocacy has an essential part to play in helping people with a learning disability make their own decisions:

“People with a learning disability can identify what they want to do, but they do need good information, support and advice to get there” My Day, My Way (PCC Aug 2011: 99-100)

At the BMG workshop, 'Are You Being Heard', people with a learning disability voiced frustration at not being fully involved in decisions being made about their own lives and what they felt to be their lack of independence:

“People with a learning disability should be able to live a normal life, just like other people, and have equal rights” Are You Being Heard Workshop (PCC June 2010: 5)

- **Further development of the current enhanced health services on NI basis**
- **Support from Integrated Care Partnerships to improve clinicians awareness of the needs of individuals with Learning Disability**

Carers and parents of people with a learning disability have said that access to key services such as Speech and Language Therapy and Occupational Therapy can prove problematic and needs to improve. Some people with a learning disability suggested that communication can be an issue when accessing GP or emergency care services. They felt that some GPs were not trained appropriately to listen to them specifically.

- **Commitment to closing long stay institutions and to completing the resettlement process by 2015**

Closing long stay institutions for people with a learning disability was identified as an important issue by people with a learning disability attending the 'Are You Being Heard Workshop' (2010):

"People with learning disabilities are left in learning disabilities hospitals for years and can't get out" Are You Being Heard (PCC 2010: 4)

3.9 Acute Care (TYC Section 15)

Public concern about the delivery, accessibility and quality of acute care in Northern Ireland is apparent across the reports of the Patient and Client Council to date. Nowhere is this more evident than in 'The People's Priorities' for 2010 and 2011 and the 2012 report 'Young People's Priorities in Health and Social Care'. The top ten priorities identified by members of the public in these three reports reflect the very real concerns people have about acute care, especially in regards to hospital care, accident and emergency services, out of hours care and waiting times for appointments, diagnostics and treatment.

The need to secure funding for these services is also a recurrent theme across the reports. Members of the public who responded to the Department's Draft Budget proposals for the period 2011-15 identified hospitals, the ambulance service and GP services as the three most important services delivered through funding provided by the Department.

In Transforming Your Care the delivery of acute care is considered in two main areas; unscheduled care and planned (elective) care.

3.9.1 Unscheduled Care

Transforming Your Care envisages substantial changes in the area of unscheduled care. Failure to meet acceptable Accident and Emergency waiting times, staffing

issues and a recurrent problem with organisational resilience are all given as indication that the current system of unscheduled care is no longer delivering:

“Evidence suggests the [current] system for delivering unscheduled care is increasingly not fit for purpose in the 21st Century” Transforming Your Care (DHSSPS: 98)

Three broad levels of unscheduled care are considered in Transforming Your Care; major trauma, emergency intervention (999), and urgent care/Out of Hours care. The priority when treating major trauma in the future will be delivering timely initial interventions in an acute setting where staff have the appropriate specialist skills – even if this is not the closest hospital. For emergency interventions, the Northern Ireland Ambulance service will be key to ensuring people are treated in the right setting and should be able to transfer people to a range of locations such as Accident and Emergency, Urgent Care Centres, Minor Injuries Units or GP Out of Hours. An integrated urgent care model should support A&E Departments on a 24 hour basis, providing services such as minor injuries, specialist nurses, urgent care GPs, urgent care social workers and specialist teams such as mental health crisis response team.

- **Ensure urgent care provision is locally available to each population**

Views and comments collected by the Patient and Client Council suggest a level of public support for this joined-up model for the provision of 24 hour urgent care, reflected in the following recommendation from ‘The People’s Priorities 2011’:

“A joined up systems approach to the future development of hospital care, Out of Hours services to include GP Out of Hours services, minor injuries units and accident and emergency services” The People’s Priorities 2011 (PCC: 31)

Unscheduled care is high on the list of priorities for people who have spoken to the Patient and Client Council over the past three years. Accident and Emergency services are of particular concern, especially in relation to waiting times for treatment, staffing levels, access to local emergency services and communication between staff, patients and carers.

Communication is a big issue in the delivery of urgent care. The results of the 'Survey of Patient Experience in the Emergency Department of Antrim Area Hospital' indicate that patients were generally positive about the actual treatment they were receiving in the emergency department. However, the survey also highlights a number of issues, such as waiting times, seating and facilities in the waiting area and, above all, communication. One of the main findings of the report was that most people were unsure or unaware of the self-select system in operation, where patients could select to go directly to Minor Injuries or opt to stay in the main Emergency Department. Consequently, many of the recommendations made in the report are based around communication:

**“The Trust should review communications at every stage of the patient journey”
“There is a need to address waiting times, at the very least to keep people better informed” “The self-select procedure is not understood by a majority of patients: the Trust needs to find a way to communicate this procedure better so that patients will know what it means”** Survey of Patient Experience in the Emergency Department of Antrim Area Hospital (PCC: 28)

People have also expressed dissatisfaction over the provision of GP Out of Hours services. Access to and quality of GP services, including Out of Hours services, was prioritised in both People's Priorities reports and people felt strongly that GPs should be available after working hours, including weekends, and that local GPs should be involved in Out of Hours services:

“There was a strong desire to improve access to primary care services over a 24 hour period and for more services to be available at primary care level” The People's Priorities 2011 (PCC: 20)

Accident and Emergency and GP Out of Hours services, along with hospital outpatient services, received the three lowest ratings from rural people in 'Rural Voices Matter'. These services were rated poorly across the countryside, in all four Trust areas – 41% of those consulted for the report considered Accident and Emergency services to be “poor”. Rural people also identified a range of issues with GP Out of Hours services, including initial difficulties getting through on the phone, travelling long distances to the

nearest clinic and difficulty getting the doctor to make a home visit. A recommendation of 'Rural Voices Matter' reflects this key concern:

“The HSC Board should address the specific concerns of rural dwellers in the commissioning of GP Out of Hours services.” Rural Voices Matter (PCC: 50)

3.9.2 Planned Care

Transforming Your Care states that better organisation of planned or elective care is essential. Lower waiting times, improved diagnostics and a reduction in unnecessary inpatient admissions are the key objectives of improved organisation. Networked working supported by technology, such as shared live information on patients, is thought to be fundamental to the future delivery of both planned and unscheduled care:

“To ensure good patient outcomes no hospital in the future can work other than as part of a network” Transforming Your Care (DHSSPS: 107)

- **Over time, move to a likely position of five to seven major acute hospital networks in Northern Ireland**
- **Set targets for the reduction of hospital admissions and end of life care**
- **Set targets for the reorganisation of outpatient and diagnostic services between hospitals and Integrated Care Partnerships**

It is evident from the Patient and Client Council's reports to date that hospital services are of utmost importance to people in Northern Ireland. Access to and quality of hospital care was identified as the number one priority in 'The People's Priorities 2011'. People have raised a range of issues with hospital care across the reports, such as quality of care, staffing levels, access to local hospital services and long waiting times for appointments, diagnosis or surgery.

“People are concerned about the future of hospital care and treatment. They want to be assured that their families have access to hospital services within a reasonable timescale and be assured of the quality of care they can expect.”
The People's Priorities 2011 (PCC: 30)

- Quality of Hospital Care

Across all ten priorities in both the 2010 and 2011 reports, people voiced strong concerns about the quality of care delivered in hospitals. There are clear messages from the public in these reports about the provision of basic nursing care, staffing levels, care of the elderly in hospitals, hospital cleanliness, nutritional care and communication.

- Access to Hospital Services

Access to services has been a central theme of Patient and Client Council's reports from the outset. In the 2009 'Report on the public engagement on "Priorities for Action"', people stressed the importance of equal access to services for everyone, regardless of where they lived. There was a perception that the same standard of service was not available across localities.

Access to local hospital services, including A&E and outpatient's services, was prioritised in both People's Priorities reports. In the 2010 report in particular, people identified the need for access to local hospital care in their area. While there was support for the centralisation of very specialist services, people wished to have local access to accident and emergency care, minor injuries, maternity services, diagnostic and outpatient clinics.

It is evident that people who live in rural areas feel particularly vulnerable as a result of the perceived erosion of local services. 'Rural Voices Matter' identified waiting times for treatment and care and access to local services as the two main areas of concern for rural dwellers. Another recurrent theme was the distance people have to travel to access services, especially in regards to GP Out of Hours services. Transport to services is important to people and they have repeatedly expressed the view that the financial implications and physical practicalities of travelling longer distances to access services should be taken into account.

“People want to be reassured that they can have reasonable access to advice, a professional opinion, and care and treatment when they need it” The People's Priorities 2011 (PCC: 30)

- Waiting Times

Concern about waiting times for acute care is widespread amongst members of the public. Waiting times for treatment and care has appeared in the top three priorities in both the 2010 and 2011 People's Priorities reports, as well as Young People's Priorities. Most comments relate to the unacceptable time people have to wait for elective in-patient and out-patient treatment, diagnostics, accident and emergency, equipment and primary care. The following recommendation from 'Young People's Priorities in Health and Social Care' indicates the high levels of public concern surrounding waiting times for health and social care:

“The Health and Social Care Board should ensure that existing management arrangements are effective in reducing the length of time that people have to wait to be seen by a health or social care professional. This relates to waiting for appointments with GPs, hospital consultants and others and also subsequent delays in being seen when people turn up to those appointments”
Young People's Priorities in Health and Social Care 2012 Recommendation (PCC: 34)

Waiting times for diagnosis and treatment emerged as a key concern in two areas of care in particular. Cancer services are identified as a priority in several Patient and Client Council's reports, and a central aspect of this is a desire to see shorter waiting times for diagnostics and treatment. 'Experience of Diagnosis', which details the views of patients and carers living with a rare disease, identified some clear issues around diagnosis of rare disease in Northern Ireland and the need to support initiatives that raise awareness and improve access to timely diagnoses.

Long waiting times can have psychological as well as physical implications. People have spoken to the Patient and Client Council in the past about the detrimental impact waiting for diagnosis, treatment or surgery had on their quality of life, affecting both their physical and mental well-being.

- Staffing Levels

The protection of front line staff, especially nurses, was the number one priority in The People's Priorities 2010. Staffing levels were also prioritised in the 2011 report and in Young People's Priorities. It was felt that numbers of medical staff need to be strengthened in order to ensure safe services. People have also expressed the desire to see nurses return to more practical hands on nursing and more power transferred to

the ward manager/sister in a supervisory role. In 'The Ward Manager', a report into patient views on the role of lead nurses on hospital wards, people said that the nurse in charge of the ward should be easily identifiable and visible to patients, speaking to them regularly. Yet again, communication is seen as key to patients and carers.

People have also raised some practical issues in relation to hospital services. For example, two reports into car parking facilities at hospitals and Health and Social Care facilities relate a lack of availability of car parking spaces leading to long delays and resulting in late or missed appointments. Disabled people have voiced particular difficulties with car parking. Another issue for people in general had been the quality and provision of food in hospital. A report into hospital meals, 'Food for Thought', found that while the quality of food was generally thought to be acceptable, there needs to be greater choice, better staff awareness of the dietary requirements of individuals and assistance with eating for vulnerable patients when needed.

3.10 Palliative and End of Life Care (TYC Section 16)

The recommendations made in Transforming Your Care in the area of Palliative and End of Life Care strongly reflect public perspective on this subject as expressed to the Patient and Client Council. Evidence for this was taken largely from the PCC report 'Patient, Service User and Public Perspective on End of Life Care Strategy in NI' published in February 2010.

Palliative care is defined in Transforming Your Care as, "the active, holistic care of patients with advanced progressive illness". The word "holistic" is important here, as people have made clear that palliative and end of life care should involve both practical and emotional support for patients, carers and families.

- **Individual assessment, planning, delivery and co-ordination of end of life care needs by a key worker**

Good co-ordination between services and continuity in care are identified in Transforming Your Care as vital elements of palliative and end of life care. This is

supported by the findings of the Patient and Client Council report on End of Life Care Strategy in Northern Ireland:

“There was strong support for a ‘key worker’ for patients, clients and families ... 91% of respondents thought that there should be one person to co-ordinate patient care and advocate on their behalf. The majority didn’t specify who the person should be, but all agreed that they should be accessible, flexible and knowledgeable and able to build a relationship with the patient and their family and carers” Patient, Service User and Public Perspective on End of Life Care Strategy in NI (PCC, Feb 2010: 6-7)

Transforming Your Care makes further recommendations which encourage better organisation and co-ordination of information in the area of palliative care, such as the development of a palliative and end of life care register to enable speedy transfer of information required by those providing care and electronic patient records that the patient, their family and staff can access. The majority of people consulted by the Patient and Client Council viewed better availability of information as a key priority. More accurate, timely and easily understood information plays a fundamental role to support people in making quality decisions under such difficult circumstances.

- **Targets to reduce the level of inappropriate hospital admissions for people in the dying phase of an illness**

Enabling people to spend the final stages of their life in their own home is largely supported in research carried out by the Patient and Client Council:

“83% of people asked would choose to stay at home, provided they had good support from health and social care, primarily for reasons of comfort and familiarity, and the ease of which friends and family could visit” Patient, Service User and Public Perspective on End of Life Care Strategy in NI (PCC, Feb 2010: 13)

“People’s Priority 8 – Access to and Quality of Cancer Services – better support to enable the terminally ill to remain in their own homes” The People’s Priorities (PCC, Nov 2010: 19)

However, it should be noted that this preference for home over a hospital setting in these circumstances was very much dependent on receiving the proper support from community services. This applies equally to support for carers of those who are terminally ill. A common theme of the End of Life Strategy report is the vital role of

carers in end of life care and the lack of respite and adequate care packages necessary to care for someone in the end stages of an illness.

“If more people are to remain in the community/their own home the need for properly resourced support packages is critical. The primary concern for the majority of people questioned was the issue of burdening family members with their care. Better provision of care packages, home help and respite care will alleviate this concern” Patient, Service User and Public Perspective on End of Life Care Strategy in NI (PCC: 13)

4.0 Implications for the Service

The final fourteen recommendations made in Transforming Your Care refer to the overarching implications the new model of care will have on the way in which health and social care services will be delivered in the future. Many of these have already been discussed in detail within the ten areas of care above. This section will therefore recap on some of the key implications for the future delivery of services.

4.1 Integrated Care and Hospital Services

At the centre of the new model of care is the major shift to care delivered within people’s home, which will subsequently impact on the type of facilities and workforce required to deliver services. The implementation of this shift in resources will be based on population plans developed by each of the five Local Commissioning Groups.

- **Creation of 17 Integrated Care Partnerships across NI enabling closer working between and within hospital and community services**
- **Development of new workforce skills and roles to support the shift towards prevention, self-care, and integrated care that is well co-ordinated, integrated and at home or close to home**
- **Development of clear patient pathways for networked and regional services**

Services in the home and local community will be delivered through Integrated Care Partnerships. These multi-professional community integrated teams will provide the core support for people in their own homes. Where people cannot be cared for at home or in the community they will be referred to hospitals.

Hospitals will work as a system, with each facility contributing to the provision of a total service to its population (DHSSPS: 116). The services each hospital is likely to provide are urgent care, GP led out of hours, elective surgery, inpatient medical care, diagnostics, rehabilitation and midwife led obstetrics. The five to seven major acute hospitals will provide care that requires centralisation so that patients are treated by senior medical staff. Services provided by acute hospitals should include emergency department, emergency surgery, critical care, paediatrics and specialist diagnostics all on a 24 hour basis, as well as complex elective surgery, undifferentiated inpatient medicine, consultant led obstetrics and outpatients (DHSSPS: 117-8). Clear patient pathways will be in place for inpatient care provided on a regional or sub regional basis, such as cardiac surgery, to assure equal access to all populations and very specialist services will continue to be networked with ROI and GB.

Transforming Your Care acknowledges that this represents a major restructure of how hospital services are currently delivered, and reflecting on this makes the following observation:

“The Review wishes to make clear that maintaining an ‘as is’ model cannot be successful in delivering against the key principles or the guidelines already described” Transforming Your Care (DHSSPS: 119)

It is clear from Patient and Client Council engagements with the public to date that people recognise that the current model of health and social care cannot be maintained. People want to see changes in the way that health and social care services are delivered in Northern Ireland; the long list of frustrations and concerns people have reported to the Patient and Client Council over the past three years is evidence that this is the case.

However, as the section on acute care reveals, people are very concerned about the future provision of hospital services. People want to be assured that they will have timely access to hospital care when they need it. Equal access to quality services regardless of location and not having to travel long distances for urgent care are also important to people.

What is more, people have repeatedly expressed their concerns about the quality, delivery and planning of community care services. One of the most common themes recorded by the Patient and Client Council is that people feel that services are fragmented and that their care subsequently suffers from a lack in continuity.

Integrated care and networked working are key elements of the vision for the future delivery of services laid out in the recommendations of Transforming Your Care. However, the Patient and Client Council reports reveal a widely held public perception that Health and Social Care services do not communicate well with one another and that health professionals working in different parts of the service also communicate poorly. People have reported lost notes and diagnostic reports, but more often frustration at never seeing the same person twice. For some people, having to repeat their full medical history every time they were treated by someone new creates a sense that the service is too fragmented to plan and deliver a coherent programme of care. The following recommendation from People's Priorities 2010 highlights the importance of proper co-ordination and good communication between services in ensuring the best outcomes for patients:

“The Department should set further standards for communication and pay particular attention to patient concerns around fragmented services and the reported lack of continuity of care” The People's Priorities 2010

4.2 Right Care, Right Place, Right Time

One of the most central objectives of Transforming Your Care is that the change it recommends will result in more people receiving 'the right care, in the right place, at the right time'. This is inarguably an objective that members of the public would support. Indeed, much of what people have said to the Patient and Client Council

about health and social care services over the past three years reflects this basic principle.

People have identified several aspects which they see as key to receiving the right care, in the right place, at the right time - clear information, good communication and accessible patient records. People want to be well informed about the range of services available, when they should use them, how to access them and that the necessary information will be available to care professionals when they get there.

- **Introduction of a single robust community information system**

Better availability of information on health and social care is undoubtedly one of the major themes of the Patient and Client Council reports. The call for clear and accessible information has been made by members of the public across all areas of care. Particular 'information gaps' have been identified in a number of areas of community care, including: information on services for people with a learning disability, mental health services, GP Out of Hours, registration requirements for dental practices, generic drugs and common health related illnesses. Carers would like to be better informed about respite services, Carers Assessment and Direct Payments. The following recommendation from the most recent People's Priorities report is illustrative of the importance the public places on clear, accurate and timely information:

“The Department and the Health and Social Care Board should address the need for an information and advice service for people in Northern Ireland that will provide accredited information on health and social care, the services available and the standards they should expect” The People's Priorities 2011 (PCC: 31)

- **Introduction of a single telephone number for urgent care**

It has been suggested in the Patient and Client Council reports that part of the problem when accessing unscheduled care is a lack of clarity amongst people about where they should go in a crisis. The need for clear protocols for the point of contact for urgent care is recognised in the recommendations of Transforming Your Care, which states that clear communication with the public as to the types of facilities

available, where they are located and under what circumstances they should be used will be central to the successful delivery of unscheduled care in the future (DHSSPS: 103). A single telephone number for urgent care is integral to the new model. Furthermore, as already mentioned above, Transforming Your Care recommends that the NIAS should have the ability to transfer patients to a range of urgent care settings rather than defaulting to a major acute hospital.

Views on this area of care expressed to the Patient and Client Council would suggest support for any moves that make accessing urgent care more straightforward at what is often an anxious time for people. People want to be well-informed about where they should go in a crisis, but they also want to have help in making those decisions at the time of crisis.

- **Full rollout of the Electronic Care Record Programme**

Transforming Your Care endorses the full rollout of an individual electronic care record for every patient in Northern Ireland that will share acute, community and primary care information. A continuous record of each individual's care and treatment to date available at the point of care delivery would be a welcome development for those who have recounted, to the Patient and Client Council, incidents of lost notes, misplaced diagnostic reports and frustration at dealing with health and care professionals who have no knowledge of their medical history. This might also give people more confidence that services are working together and their care is better co-ordinated.

4.3 Funding Health and Social Care in the Future

- **Initiation of a sensible debate about growing income within the spirit of the NHS principles**

In 'The People's Priorities 2010' the need to secure funding for health and social care was identified as a top priority. People said they wanted to see greater accountability for existing funding and to be assured that money was not wasted on inefficiencies such as inappropriate use of services, prescription drugs and high management costs.

In its 2011 equivalent, people were asked more directly to identify priorities for saving money in health and social care. Some people found this question difficult to answer, however the majority of responses focused on three suggestions – less bureaucracy, improved efficiency in service delivery and the reintroduction of prescription charges. People were even more reluctant to offer their views on whether individuals should contribute to the cost of their own health care. About a quarter of respondents agreed that people should make some contribution, with paying for prescriptions being the most common way in which they would envisage doing so.

It should be noted that many people do feel very strongly that services should continue to be free at the point of delivery. When, as part of the 'Care at Home' report, members of the public were asked who should pay for domiciliary (home) care services, almost two thirds identified the health service or government. The main reason given for this response was that people contributed into the system throughout their working lives through taxes and National Insurance. Just less than a third of people suggested that the person receiving care should also make a contribution and only two per cent felt that individuals should cover the entire cost of their own care.

While some people may find it difficult to approach the subject of paying for care and others have very strong views on the matter, a common theme of the Patient and Client Council reports to date is that patients, service users and carers want to be fully involved in any discussion or decision-making about future funding for health and social care services.

5.0 Conclusions

It is clear from this review of Patient and Client Council research to date that people recognise the central theme of Transforming Your Care, that the current model of health and social care cannot be maintained. People inarguably want to see changes in the way that health and social care services are delivered in Northern Ireland.

Indeed, there is much common ground between Transforming Your Care and the reports of the Patient and Client Council, largely because the underlying principles for future health and social care services are so similar – placing the individual at the centre of any model of care, using outcomes and quality evidence to shape services and providing the right care, in the right place, at the right time.

Many themes that run throughout Transforming Your Care echo those voiced by patients, clients, service users and carers to the Patient and Client Council over the past three years. The personalisation of care is one example. From the beginning the Patient and Client Council has heard that people want to more involved in the planning and delivery of their care, from involving patient, client and carer in developing personalised care plans that people can hold in their own home to service user involvement in decision making about services. Recommendations made in Transforming Your Care positively reflect other recurring themes in Patient and Client Council reports, such as more focussed support for carers and education, awareness raising and open discussion about health and social care issues.

The central proposal of Transforming Your Care is that care should be provided as close to home as possible, with a shift in resources from hospital to community enabling this transition. This review suggests there is a certain amount of support for the concept of 'home as the hub of care'. However, it is evident that many people do not have full confidence in community based services. Across the reports people have voiced concern about the quality, planning and delivery of community care, particularly for the most vulnerable in society. The 'Care at Home' report into domiciliary care for older people provides a good example of this dilemma; while most people said they would prefer to receive care at home where possible, many raised concern about the inconsistent delivery and quality of home care.

Central to these concerns surrounding community services are three of the most frequently raised issues across the Patient and Client Council reports – communication, information and continuity of care. There are recommendations made in Transforming Your Care that address these issues. People have said that community care can feel fragmented. The establishment of Integrated Care Pathways to enable closer working relationships between primary, secondary and community services, another central aspect of Transforming Your Care, reflects this concern. More integrated planning, joined up services and improved communication between and within services will be seen as a welcome development for the many people who have spoken about their experiences of poor communication and lack of continuity in their care. The recommendation for a single robust community information system is also notable.

This shift towards primary and community care will inevitably impact on how acute care is delivered in the future, and Transforming Your Care recommends substantial change in this area. Unscheduled care is high on the list of priorities for people who have spoken to the Patient and Client Council over the past three years. The more joined-up approach to unscheduled care envisaged in Transforming Your Care responds well to people's oft-repeated concerns about Accident and Emergency and Out of Hours services. However, people also prioritise access to quality hospital services and the proposed reduction from ten to 'five to seven' major acute hospitals is likely to concern people who want to be assured they have equal access to local hospital care, regardless of where they live.

This is an opportune time to reflect on the research carried out by the Patient and Client Council since the organisation's beginnings in 2009. Some key messages have emerged over this period, such as the importance of service user involvement, good communication between and within services and with the patient, timely and accessible information, continuity of care, support for vulnerable groups, support for carers and equal access to services. It is a positive sign that the recommendations made in Transforming Your Care respond well to many of these issues. However, it is important to note that there are a number of major recommendations made in the review which are likely to challenge popular views on and priorities for health and social care expressed to the Patient and Client Council over the past three years.

Appendix 1

List of Patient and Client Reports Consulted

- Report on the Public Engagement on Priorities for Action (December, 2009)
- Patient, Service User and Public Perspective on End of Life Care Strategy in Northern Ireland (February, 2010)
- 'Are You Being Heard' Workshop (June, 2010)
- Public Engagement on Alcohol Labelling (June, 2010)
- The Ward Manager (September, 2010)
- The Mental and Emotional Health of 16 Year Olds in Northern Ireland (June, 2010)
- Young People's Thoughts on Young Life and Times Survey Findings (June, 2010)
- Public Engagement on the Development of a Ten Year Strategy for Quality in Health and Social Care in Northern Ireland (June, 2010)
- Patient and Client Views on the Reform and Modernisation proposals in the South Eastern Health and Social Care Trust (September, 2010)
- Parental Views on Maternity Services (October, 2010)
- Shaping Information, Knowledge and Access to Mental Health Services (October, 2010)
- The People's Priorities 2010 (November, 2010)
- Car Parking Charges at Altnagelvin Area Hospital (December, 2010)
- The People's Response to Draft Budget Proposals for the Department of Health Social Services and Public Safety over the period 2011-15 (February, 2011)
- Swine Flu (February, 2011)
- Talking Teeth: Patient Views of General Dental Services in Northern Ireland (February, 2011)
- Survey of the Patient Experience in the Emergency Department of Antrim Area Hospital (February, 2011)
- Food for Thought: Views of Patients and the Public on Hospital Meals (March, 2011)
- How Involvement Can Liberate Health and Social Care (April, 2011)

Rural Voices Matter (June, 2011)

People's Views on Prescription Charging and Products Available on Prescription (June, 2011)

Young Carers in Northern Ireland (July, 2011)

Respite (short breaks) (August, 2011)

Is Bamford Making a Difference? (August, 2011)

My Way, My Day (August, 2011)

Further Education (August, 2011)

Online Mental Health Information for Young People (August, 2011)

The People's Priorities 2011 (November, 2011)

District Nurse Consultation Response (December, 2011)

Car Parking at Hospitals and other Health and Social Care Facilities (January, 2012)

Experience of Diagnosis (February, 2012)

Someone to Stand Up for Me Advocacy Toolkit (March, 2012)

Young People's Priorities in Health and Social Care (May, 2012)

Care At Home (June, 2012)

List of Other References

Transforming Your Care: A Review of Health and Social Care in Northern Ireland (December 2011)

Appendix 2

List of Acronyms and Abbreviations Used

The Department – The Department of Health, Social Services and Public Safety

PCC – The Patient and Client Council

RQIA – Regulation and Quality Improvement Authority

TYC – Transforming Your Care

www.patientclientcouncil.hscni.net

Remember you can contact us by

Telephone 0800 917 0222

E-mail info.pcc@hscni.net

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