

Patient and Client Council

The People's Priorities

**A View from Patients, Service Users, Carers,
and Communities on Future Priorities for
Health and Social Care in Northern Ireland.**

November 2011

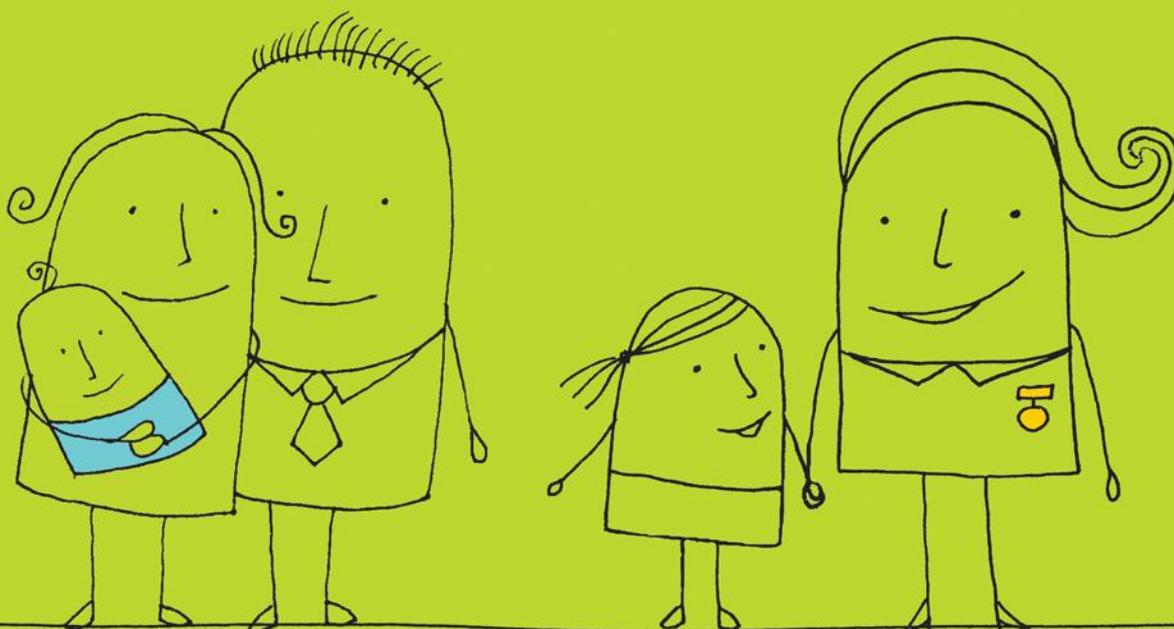


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Foreword

Dear Reader,

I am pleased to present this report of our engagement with almost 3,500 people across Northern Ireland regarding their views on future priorities for health and social care. This is the third year that we have produced such a report and this year the project was expanded. It also includes some groups of people who had been more difficult to target, including men of working age and migrant workers.

The reports produced in 2009 and 2010 have been used by decision makers to underpin commissioning plans and implement new systems and standards of care.

The timing of this project coincides with a major review of health and social care in Northern Ireland requested by the Minister for Health. Therefore the Patient and Client Council believes that there has never been a more important time for people to have a say in the future of these important public services. The fact that so many people took time to give us their views is a clear sign that they really wish to have their voice heard in the debate on the future of health and social care services. From our many conversations it is clear to me and the staff of the Patient and Client Council that people really value these services and the efforts of staff who deliver care and treatment.

There are important messages for the Minister for Health, the Department of Health, Social Services and Public Safety (the Department), the Health and Social Care Review Team and key decision makers in this report. The report makes it clear that people support the setting of targets and welcome the improvements in service delivery which have come about as a result of these targets. However, they are concerned about issues such as the accessibility and quality of hospital care, the care of the elderly, waiting times for hospital treatment and care, access to their GP, cancer services, mental health and learning disability services.

I would like to express my sincere thanks to everyone who took part in the various consultations. Thank you for the generosity with which you gave of your time, and

shared your experiences. Without your input this report would not have been possible. The Patient and Client Council will strive to ensure that the voices captured in this report and resulting recommendations influence decision making in 2012 and beyond.

I would also like to thank the staff and Local Advisory Committee members of the Patient and Client Council who worked so hard to help us engage with people in many locations, in all weathers, and at all times of the day.

During the next 12 months and beyond, we will see a significant change in the way our health and social care services are delivered. This report will help to ensure that the voice of people in Northern Ireland contributes to how services are delivered into the future.

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 help ensure that the process of setting future targets for health and social care reflects the opinions of people who use the services. A total of **3,461** people took part in this process; 3,238 individuals completed a short questionnaire in “one to one” interviews during street consultations and 223 took part in small group discussions.

The opinions and needs of patients, service users, carers, communities, and the general public are wide and varied. The direct quotations used in this report are from people who participated in the engagement process. Despite the broad range of opinion which exists there are many common themes in relation to issues affecting health and social care in Northern Ireland.

The scope of this study illustrates one aspect of the successful development of the Patient and Client Council in its efforts to build capacity and confidence in service users and communities to enable them to have a say in the future of these important services.

Participants expressed a desire for the public to be better informed about the Department’s “Priorities for Action” targets, and, the performance of the Health and Social Care Trusts in achieving those targets. Seventy percent of people felt that targets were important to the delivery of health and social care. In particular, they felt that targets provide a goal, a focus or a standard against which services must be delivered. They expressed the view that targets have improved the efficiency, responsiveness, and accountability within health and social care services. They particularly value the reduction in waiting times in recent years. They fear that a reduction in targets could lead to a lesser service and a return to the very long waiting times experienced some years back.

Each individual was asked to suggest up to three priorities. This question generated 8,534 responses. Of these responses 5,965 (70%) of the issues identified were represented in the top ten priorities. The top ten priorities identified were as follows:

- Priority 1 Access to and Quality of Hospital Care**
- Priority 2 Care of the Elderly (Including Care in the Community)**
- Priority 3 Waiting Times for Hospital Care and Treatment**
- Priority 4 Cancer Services**
- Priority 5 Mental Health and Learning Disability Services**
- Priority 6 Health and Social Care Staffing Levels**
- Priority 7 Access to GPs and Primary Care**
- Priority 8 Children’s Services**
- Priority 9 Reducing the costs of administration and management**
- Priority 10 Quality Assurance of Health and Social Care Services**

The themes identified this year had definite similarities with those identified in 2010. Table 1 below provides an overview of the top ten priorities from 2010 and 2011.

Table 1 – The People’s Top Ten Priorities 2010 - 2011

	Top Priorities 2010	Top Priorities 2011
1.	The Protection of Front Line Staff, Particularly Nurses	Access to and Quality of Hospital Care
2.	Concern About Increasing Waiting Times	Care of the Elderly (including Care in the Community)
3.	Care of the Elderly, including Domiciliary Care	Waiting Times (Hospital Care and Treatment)
4.	Developing Appropriate Services for Mental Health and Learning Disability	Cancer Services
5.	The Need to Secure Funding for Health and Social Care	Mental Health and Learning Disability Services
6.	Access to Local Hospital Services, including A&E and Outpatients’ Services	Health and Social Care Staffing Levels
7.	Access to and Quality of General Practitioner (GP) Services	Access to GPs and Primary Care
8.	Access to and Quality of Cancer Services	Children’s Services
9.	Improving Quality of Communication Between Staff and Patients/Service Users	Reducing the costs of Administration and Management
10.	Rising cost of prescriptions	Quality Assurance of Health and Social Care Services

The report makes a number of recommendations to the Department, the Health and Social Care Board, the Public Health Agency and key decision makers. It will also play a significant part in the development of the 2012/13 work plan for the Patient and Client Council.

1.0 Background and Purpose

1.1 The Patient and Client Council

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.

1.2 What is the purpose of this report?

The purpose of this report is to help ensure that the process of setting future direction for health and social care reflects the opinions of people who use the services.

In the period from June 2011 to November 2011 representatives of the Patient and Client Council met with people across Northern Ireland. What follows are their responses to questions asked about priorities for the future of health and social care.

In 2009 and 2010, the Patient and Client Council carried out a similar exercise. A copy of these reports is available from the Patient and Client Council's website www.patientclientcouncil.hscni.net or by telephone request (0800 917 0222). Both reports made a number of recommendations regarding issues such as:

- the involvement of patients, service users and carers in decision making regarding community based health and social care;
- the need for everyone receiving care at home to have a care plan which they hold personally;
- the need for standards in communication; and,
- the need for public information regarding targets and performance against these.

Some of these recommendations were subsequently reflected in the “Priorities for Action” documents in 2010 and 2011 and the Commissioning Plans of the Health and Social Care Board and the Public Health Agency. The Patient and Client Council will continue to work with the Department and key decisions makers to achieve full implementation of the recommendations made in these reports.

1.3 Why is this report necessary?

“Priorities for Action” is one of the most important documents produced by the Department each year. “Priorities for Action” sets out the key targets for the Health and Social Care Board and the Public Health Agency which plan services and for the Health and Social Care Trusts which deliver services. These priorities decide how services will be delivered, changed and developed in the coming years; they can be accessed at the Department’s web site at www.dhsspsni.gov.uk (search for Priorities for Action).

The Health and Social Care Board continuously monitors the performance of each Health and Social Care Trust (Trusts) against the targets, and reports regularly to the Minister of Health and his Department. The Board and Trusts can then take corrective action to address any unmet targets.

1.4 What are the aims of this project?

The aims of this project were to:

- make people aware of the targets and their content;
 - engage people in a meaningful way;
 - ask people what their priorities would be for health and social care services;
 - provide people with an opportunity to have their say on the future of health and social care;
 - produce a report based on what people said;
 - use the findings in the report to inform decision making for 2012 and beyond;
- and,

- raise awareness of the work and role of the Patient and Client Council.

Given the current debate in relation to the review of health and social care services, the Patient and Client Council is of the opinion that there has never been a more important time to bring the voice and views of the people to the Northern Ireland Executive, the Minister for Health, the Department and the Health and Social Review Care Review Team.

2.0 Our Approach

To capture the views of the public the Patient and Client Council met with people in various settings across Northern Ireland. We spoke to people on a one-to-one basis during street consultations including public events such as the Portrush Air Show, County Shows, Belfast Pride, the NI Ploughing Championship and the Mela festival. Questionnaires were issued through the newly formed Patient and Client Council Membership Scheme. We also met with people in shopping centres and doctors' surgeries and we organised 20 small group discussions with members of the public and community groups across Northern Ireland. A list of all the venues is contained in **Appendix 1** of this report.

From our experience during 2009 and 2010 we knew that it was more difficult to obtain the views of men. Therefore this year we made a very specific attempt to encourage men to participate in this survey. We also provided an opportunity to capture the views of some ethnic minority people whose first language was not English. In addition we wrote to over 900 churches and faith based groups and asked them to encourage their communities to participate in the project.

The opinions and needs of people are wide and varied. Despite the broad range of opinion which exists there are many common themes in relation to issues affecting health and social care in Northern Ireland.

A total of **3,461** people took part in this process; 3,238 individuals completed a short questionnaire (See **Appendix 2**) during one-to-one consultations and 223 took part in small group discussions. In addition to the specific questions asked, people took time to share with us their stories and experiences. This report presents the findings of this exercise. Questionnaires were translated into seven languages (Polish, Slovakian, Lithuanian, Latvian, Russian, Romanian and Bulgarian) and 83 respondents completed questionnaires in these languages. Many respondents whose first language was not English chose to complete the questionnaire in English. Whenever required Patient and Client Council staff and respondents were supported by interpreters.

The small group discussions gave an opportunity for more in-depth conversations regarding the issues. Each discussion followed a similar format. A representative of the Patient and Client Council gave an introduction to “Priorities for Action”. This was followed by a discussion around the questions (**Appendix 2**).

The questions discussed were as follows:

1. Are you aware of the “Priorities for Action” Targets in Health and Social Care?
2. Do you think targets are important to the delivery of health and social care? If YES, why do you think they are important?
3. In light of the proposed reductions in funding for health and social care, if you were the Health Minister what would your top three priorities be in health and social care in 2012 and beyond?
4. How do you think health and social care services could save money?
5. Do you think that patients, their families or carers should be asked to contribute towards the cost of health and social care?

Given the nature of the group discussions it has not been possible to assign numbers, percentages or weightings to quantify the numbers of people who raised specific issues. However, as a general guide the following definitions will give the reader an indication of the frequency of occurrence during group discussions:

WHEN WE SAY:	WE MEAN:
 “few”	= 10% of the people or less;
 “some”	= 11 to 25% of the people;
 “many”	= 26 % to 50% of the people;
 “the majority”	= 51% to 75% of the people; and,
 “most”	= 76% + of the people.

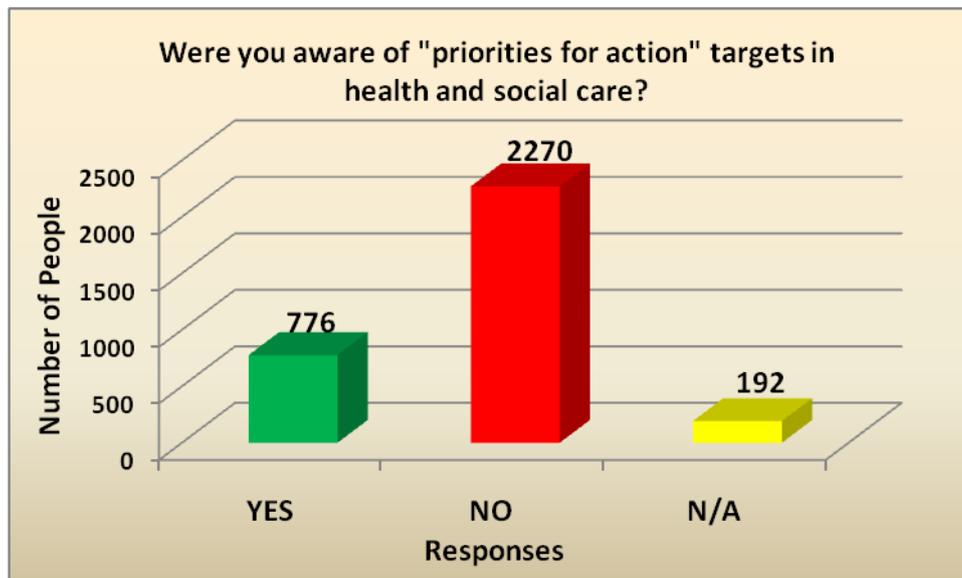
3.0 Our Findings

3.1 Awareness of the Targets within “Priorities for Action”

Q1 “Are you aware of the “Priorities for Action” targets in health and social care?”

Of the individual respondents; 776 (24%) indicated some awareness of the use of targets in health and social care; 2,270 (70%) were unaware of targets; and, 192 (6%) did not respond. During “one-to-one” conversations it emerged that this awareness could be largely attributed to media coverage. During focus group discussions, people were aware that there had been significant improvements in waiting for some operations, e.g. the reduction in waiting times for a hip replacement.

Figure 1



In the discussion groups most participants were unaware of the targets. Some people were vaguely aware and a few had a good understanding of the targets. Most participants expressed a desire for the public to be better informed about the targets and the performance of the Trusts in achieving those targets. They expressed a wish for the Department to publish information about the targets in an accessible manner and for there to be greater public participation in the development of targets. There was some concern that targets should not be misused.

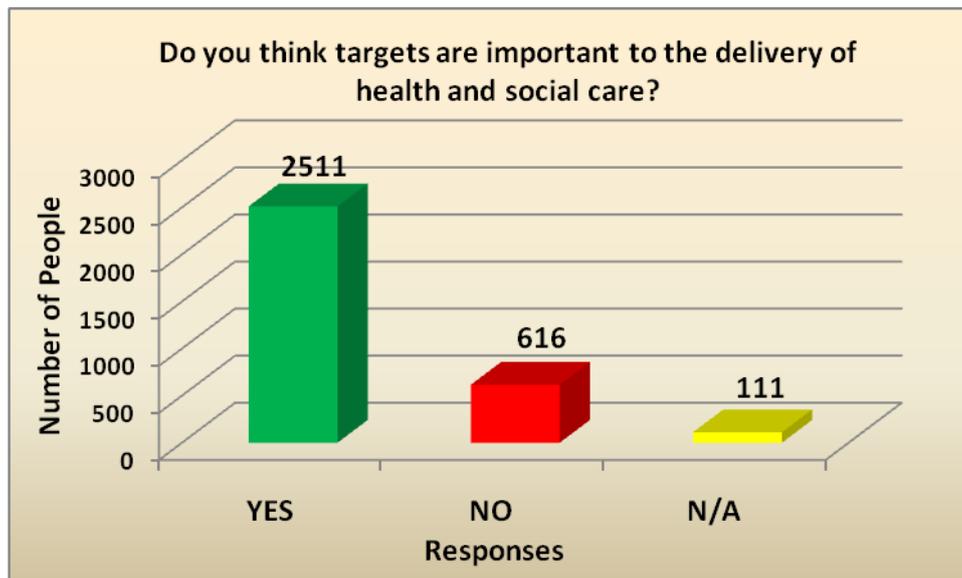
“Dr’s can sometimes concentrate too much on targets.. as long as the right numbers of people are seen in clinics then patient care isn’t as important.”

3.2 The Importance of Targets

Q2 “Do you think targets are important to the delivery of health and social care?”

Of the individuals who participated in this survey 2,511 (77.5%) said targets were important, 616 (19%) said they were not important and 111 (3.5%) did not respond. Figure 2 below presents their responses.

Figure 2



Of those who said “yes” 1,996 (out of 2,511) gave a reason; 861 people felt that targets provide important goals against which the performance of services can be measured, 574 people were of the view that targets improve the care and experience of patients, 333 people were of the opinion that they greatly improve waiting times, 123 people thought that targets ensure accountability, and 105 indicated that they provide an opportunity to save money.

In group discussions there was strong support for targets and clear accountability, as well as assurance of a minimum standard of care.

“The service is not accountable. It knows or wants to know everything about service users but is unwilling to tell service users about itself..”

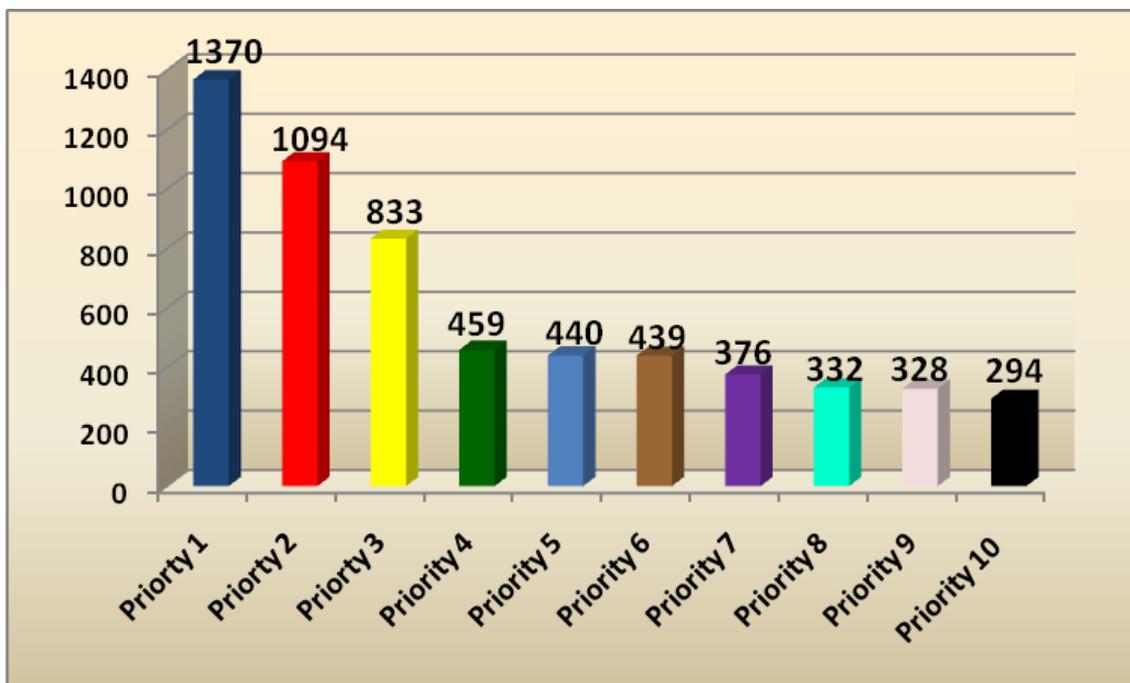
They expressed concern that increasing waiting times could result in a reoccurrence of the situation several years ago whenever patients had to wait for years for some operations. They were concerned about the impact this has on the patients quality of life.

3.3 Priorities for 2012 and Beyond

Q3 “In light of proposed reductions in funding for health and social care, if you were the Minister, what would be your top three priorities in 2012 and beyond?”

Each individual was asked to suggest up to three priorities. This question generated approximately 8,534 responses. Of these responses 5,965 (70%) of the issues identified were represented in the top ten priorities. Figure 3 below presents the top ten responses and the notes which follow provide an explanation of each.

Figure 3 The People’s Top 10 Priorities



- Priority 1 Access to and Quality of Hospital Care
- Priority 2 Care of the Elderly (Including Care in the Community)
- Priority 3 Waiting Times Hospital Care and Treatment
- Priority 4 Cancer Services
- Priority 5 Mental Health and Learning Disability Services
- Priority 6 Health and Social Care Staffing Levels
- Priority 7 Access to GPs and Primary Care
- Priority 8 Children’s Services
- Priority 9 Reducing the costs of administration and management
- Priority 10 Quality Assurance of Health and Social Care Services

People’s Priority 1 – Access to and Quality of Hospital Care

1,370 people identified the need for access to appropriate hospital care as a major issue. They are particularly concerned about having reasonable access to accident and emergency care, and minor injuries. People who live in rural communities and older people feel particularly vulnerable as a result of the perceived erosion of local services. In group discussions and in individual responses people expressed concern about the standard of cleanliness in our hospitals, about the feeding and care of elderly patients, and about appropriate use of scarce hospital resources. They were also concerned that patients and family carers are not listened to or involved in the patients care planning.

“Local care – better care.”

“A balanced approach to hospital locations and A & E”

“Bring back matrons into the hospitals – more control of the wards – hygiene and patient recovery”

“Less long waiting times in A&E”

“Utilise and manage A&E service and stop the public abusing it by educating them on what it is for.”

“To improve the quality of care for the elderly in hospitals. The elderly are being treated as second class citizens”

“Make sure all people have access to emergency services within the “golden hour”...”

People’s Priority 2 - Care of the Elderly (Including Care in the Community)

1,094 individuals identified care of the elderly and domiciliary care as a priority. In particular people expressed concern regarding the need for appropriate care in the community to support people to live in their own homes. They also expressed the need for increased respite and day care and better support for older people including those who live in rural areas. Many people spoke of the need to ensure equality of access to services for older people in comparison to younger people.

The majority of people spoke of the need to develop safe and sustainable domiciliary support to enable older people to continue to live independently. People are concerned about the delivery, quality and monitoring of domiciliary care at present. They expressed concern regarding the length of time allocated for care workers to care and the appropriateness of the care provided.

Most groups felt that respite care should be a priority and that there should be emphasis on the quality of respite to enable both carers and clients to have an appropriate break. The quality of respite care for people with dementia was raised as a particular issue. Another priority for this programme of care raised by some people was the need to ensure appropriate discharge arrangements for elderly people leaving hospital. They felt that discharge planning should be more holistic and commence from the time of admission with timely involvement of the individual, carers, and community and primary care services.

“Caring for the elderly needs to be a priority.”

“Nursing home care should be free. Patients homes should not be sold to pay for their care”

“I want to be looked after in my old age and I don’t want it to cost me and my family a fortune”

“Better and more dignified care for older people – to look after our older generation”

“ 15 mins is just not long enough to wash and dress someone”

People’s Priority 3 - Waiting Times for Hospital Care and Treatment

People are concerned about increasing waiting times. 833 individuals identified this as a priority. This included waiting times for elective in-patient and out-patient treatment, diagnostics, accident and emergency, equipment and primary care (such as waiting times for GP appointments).

Groups raised concerns regarding increasing waiting times for hospital treatment, and diagnostics. They welcomed the initiatives made by the Department in this

regard, and felt that these should be sustained and improved. Some people spoke from their experience that waiting times for operations had a serious detriment on their quality of life; affecting both their physical and mental well being.

“Reduce waiting lists for referral appointments in order to identify conditions earlier and prevent the need for many treatments later on.”

“Reduce waiting times for operations and specialised care”

“Get an appointment with a doctor without having to wait for three weeks”

“Reduce the waiting times for medical procedures and after care.

People’s Priority 4 - Cancer Services

459 people identified access to and quality of cancer services as a priority. In particular, they wished to see shorter waiting times for diagnostics and treatment. There was a strong wish to see more research into the cause and treatment of cancer. They called for improved speed of diagnosis, surgery and treatment.

“Cancer research and screening for the younger generation as they are often told that they are too young to have cancer.”

“Cancer diagnosis and treatment. More investment in specialist nurses and doctors in this area of medicine”

“Move quicker from cancer diagnosis to completion – I have had 2 experiences where the consultant being off in the summer has been very detrimental to the standard of care”

People’s Priority 5 - Mental Health and Learning Disability Services

There was strong support for developing appropriate services for mental health and learning disability; 440 individuals identified this as a priority. Particular suggestions were made around ensuring equality of treatment for people with mental health problems or learning disabilities. They wished to see a move forward with the full implementation of the recommendations of the Bamford Review. People expressed concern regarding the increasing level of mental health problems which have been exacerbated by the economic downturn. In particular they identified a need to focus

on support for young people and the elderly, including their carers. People wish to see increased promotion of good mental health, support for people with eating disorders, protection of vulnerable adults, a focus on suicide awareness and prevention, continuity in care, an increase in psychological therapies, more specialist nurses, support for dementia patients and their carers, and improved day opportunities and respite. In small group discussions there was particular emphasis on the need for continuity of care to support people in recovery.

“Mental health issues still have stigma attached to them – more resources to help mentally ill patients in the community.”

“Reduction in suicide, alcohol and drug deaths in young people.”

“Mental Health - putting the Bamford proposal into action. NI has a high suicide rate. The recession, unemployment and cut backs in benefits are adding to mental health problems”.

“Eating disorder – mental health”.

“Continuity of care is important to help build a relationship with the person who is helping you to recover from an illness.”

People specifically stressed the need to support children with learning disabilities and their families, including those children with Autism Spectrum Disorders. They also wished to see improved support for vulnerable adults who live in the community, including better housing and day opportunities. They also felt that it was difficult for those with rare conditions to get the support and understanding they needed.

“Vulnerable individuals MUST be protected ... learning difficulties must be protected. Hitting such groups will inevitably be seen as weak government and will be challenged.”

“Special needs – services for people with learning disability (only seen social worker 2 (times) in 3 years.”

People's Priority 6 - Health and Social Care Staffing Levels

People were concerned about the need to secure adequate staffing levels to maintain safe services, and in particular medical and nursing staff. In total 439 identified this as a key priority. They expressed the opinion that there should be a greater focus on strengthening numbers of nursing and medical staff with more power being given to the ward manager/sister. They perceived that there were skills shortages in both hospital and community settings; and a lack of specialist nurses to deal with conditions such as brain injury, Parkinson's disease, Motor Neurone Disease and Multiple Sclerosis.

People expressed the need to focus on training staff to provide safe modern services. They felt particularly strongly that nurses should return to more practical hands on nursing and be relieved of the burden of administration.

Some concern was expressed about the quality of nursing care and the need for staff to be more caring, compassionate and for them to listen to and involve patients and their carers more in decisions affecting their care.

“More Parkinson's disease specialist nurses and district nurses.”

“Employ more nurses with more practical hands on experience rather than academic qualifications.”

“Get matrons back. Teach nurses to treat patients as they would treat their own families”

“Staff training – there needs to be more effort put into train staff to have more compassion”.

“stop pampering consultants so they don't want to work out in the sticks”

“my daughter's consultant is really good. He takes time to go through everything with her.”

In group discussions there was much emphasis on need for training and information for staff to help deal with people with disabilities and those with very specific needs, such as transgendered adults, so that they could deliver more person centred care.

People's Priority 7 - Access to General Practitioner (GP) and Primary Care Services

People expressed concern about access to their GP, the Out of Hours GP and the services they provide. 376 individuals identified this as a priority. In particular, they wished to be able to access their GP more quickly, have more appropriate appointment times and ensure a better quality consultation. They also felt quite strongly that GPs should be available after working hours including evenings and weekends and that local GPs should be involved in Out of Hours service. They repeatedly suggested that primary care teams should be encouraged to provide minor injuries services. People expressed particular concern about travel times to Out of Hours services.

In group discussions many people expressed concern regarding access to GP services. They wish to see better arrangements for home visits for vulnerable people. The majority of people are concerned about GP Out of Hours services. Some people feel that it is too difficult to get to the Out of Hours service without a car. Many people expressed a desire to see local GPs provide a service over an extended working day and at the weekends.

Some people with a learning disability felt that GPs were not trained appropriately to listen to them specifically. Some individuals with mental health problems expressed the view that GPs dispense anti-depressants too readily without offering any alternative. Others thought that there is a need to train and educate primary care staff in the treatment of alcohol and drug addiction and that current approaches discourage individuals from seeking help.

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.

“Make use of GP surgeries and GP for minor injuries.”

“GPs – need to be better informed about new medicines”

“Better access to services through GP practices”

“the world now works on a 7 day basis... doctors should be doing this also. Things such as evening clinics and Saturday surgeries would be a great advantage to the public and would help relieve stress on the service.”

In group discussions some people also expressed a wish for better education of GPs in the diagnosis of lesser known long term conditions as many go for years without a diagnosis.

People’s Priority 8 - Children’s Services

While some of the other top 10 priorities were similar to those identified in 2009 and 2010, children’s services was new this year. 332 people identified this as a major priority. Their responses covered a wide range of aspects of children’s services including:

- The need to improve child protection
- Improved childcare for the very young
- Paediatric medicine and surgery
- Support for children in foster care or in children’s homes
- Early intervention and prevention for children and young people
- Diabetic clinics for children
- Support for children with special needs particularly at major transitions.

“Childcare – Social Services are terrible.”

“Preventative children’s service – “early years” social care”

“More needs to be spent on the young as they are our future”

“Paediatric services – maintaining the counselling service”

The care of newborn babies was a particular concern for women whose first language was not English.

People’s Priority 9 –Reducing the Costs of Administration and Management

People were concerned that health and social care services had too many staff employed in administration and management. 328 people identified this as a priority. They expressed the view that there is an over provision of administrative staff and managers and that this has the potential to take scarce resources away from so called “front line” staff.

“I would most certainly have a cut at staff in health centres. There is too many non-clinical staff sitting around.”

“Remove managers at the top and replace with staff who have worked in the areas and therefore know how to address the problems”

“Less paperwork/bureaucracy – more actual care of patients”

“Reduce bureaucracy in management of hospitals etc and over staffing at clerical level”

People’s Priority 10 – Quality Assurance of Health and Social Care Services

Quality of care featured strongly in the individual responses. 294 people identified this as a priority. They sought:

- A return to more patient / service user focused care;
- Improved independent evaluation of care in our hospitals;
- Improved quality of basic nursing and medical care;
- Improvements in nutritional care;
- Improvements in cleanliness; and
- Improvements in staff training in communication skills.

“Improve the quality of basic nursing care in hospitals especially of the elderly.”

“Raise the standards of nursing and medical care in our hospitals – greater accountability costs nothing”

“Ensure services are patient centred, equitable and sustainable”

In group discussions, concern was also expressed about variation in quality of care across health care settings. Examples cited included;

- inadequate pain relief in maternity care;
- inadequate provision for patients with long term conditions
- patients who are in prison;
- issues around patient / service user confidentiality, and
- inadequate diagnostics leading to poorer outcomes.

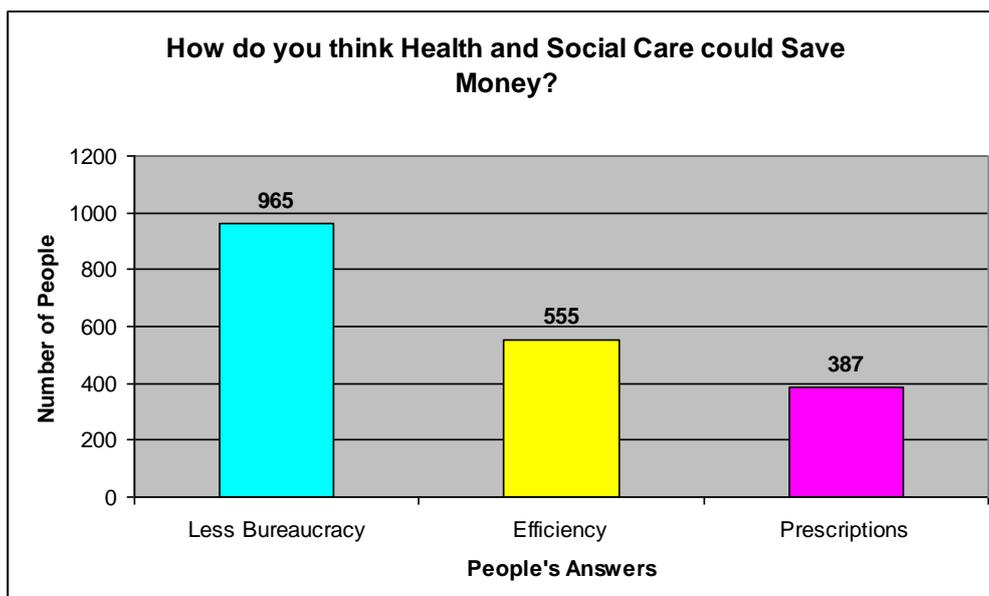
3.4 Priorities For Saving Money in 2012 and Beyond

Q4 “How do you think health and social care services could save money?”

People found this question challenging and 2,845 (87%) individuals responded. There were 29 suggestions in total. However the majority of responses (1,907 (58%)) focused on three suggestions as illustrated in Figure 4 below.

965 people felt that bureaucracy in the services could be reduced, 555 people suggested that there should be a greater focus on improved efficiency in service delivery and 387 suggested reintroducing prescription charges.

Figure 4



“Everybody could pay a little bit for prescriptions.”

Some people also spoke about the need for: greater centralisation of specialist services; greater emphasis on health promotion; less reliance on agency staff and locums; more involvement of volunteers; better staff training; better communication; better information on when to use or access services and better involvement of patients and their families.

3.5 A View on Contribution Towards the Cost of Care

Q5 “Do you think that patients, their families or carers should be asked to contribute towards the cost of health and social care?”

When asked if patients, their families or carers should be asked to contribute towards the cost of their care, 917 (26%) individuals answered “Yes” and 236 (7%) answered “No”. The majority of respondents did not answer this question.

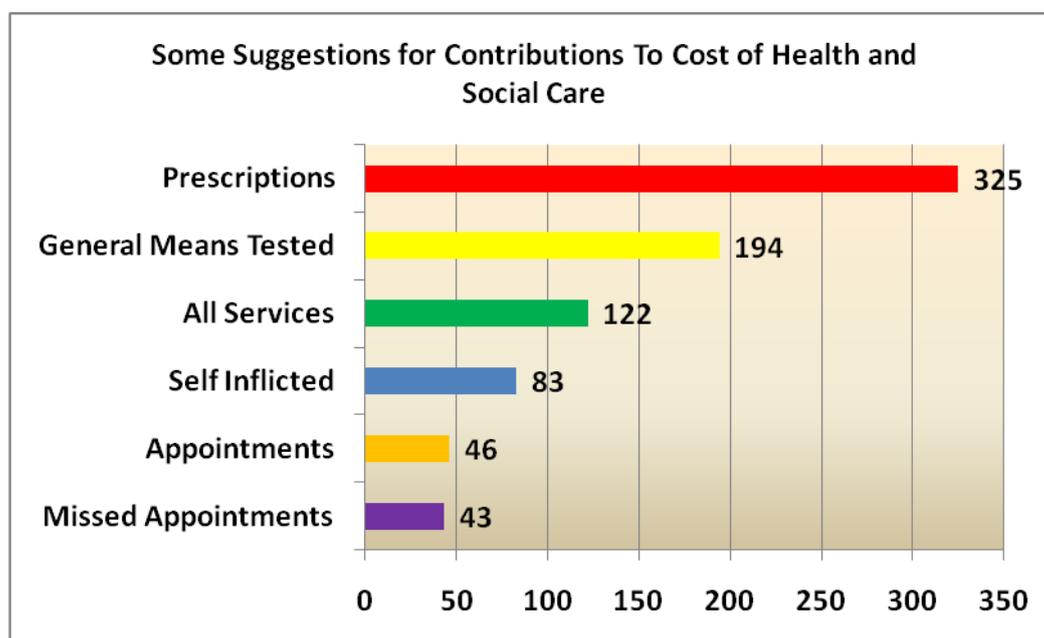
Respondents who answered “Yes” were asked to tell us which services they thought people should be asked to contribute towards; most respondents focused on six areas as follows:

- 325 people thought they should contribute towards the cost of prescriptions for drugs;
- 194 thought that some services should be means tested;
- 122 thought that people should make a contribution towards the cost of all services;
- 83 thought that people should pay if their problem was self inflicted – for example: alcohol or drug related;
- 46 thought that people should make a contribution towards the cost of doctors or outpatient appointments; and,

- 43 thought that those patients or service users who miss appointments should contribute towards that cost.

It should be noted that migrant workers and some ethnic minority groups raised the issue regarding the level of charges which they incur for both hospital care and medication. They also stated that it was difficult to access free interpreting services.

Figure 5



* It should be noted that only 26% of people responded to this question; therefore the numbers are lower.

In group discussions, people were equally divided on this issue. However, some people felt strongly that services should be free at the point of delivery as people already pay taxes and it could create a blame culture, e.g. for smokers or the obese.

3.6 The People

This section provides some basic demographic information regarding individual respondents.

In June 2010 it is estimated there were 1.7 million people living in Northern Ireland; with 21.2% being children (aged under 16) and 17.1% males aged 65+ and females aged 60.

Health and social care services in Northern Ireland are provided through six Health and Social Care Trusts. There is a single Ambulance Trust for Northern Ireland and the remaining services are provided through five Trusts which cover a specific geographical area of the region.

Table 2 below details the population and the number of individual respondents by Health and Social Care Trust area. Each area office within the Patient and Client Council was given a target of 400 respondents per area and this was exceeded by all teams. However, we found that many of the people we spoke to in the greater Belfast area did not reside there and therefore the number of respondents who are residents of the Belfast area is lower. This is an issue which we will address in future projects. 290 respondents did not specify the geographical location.

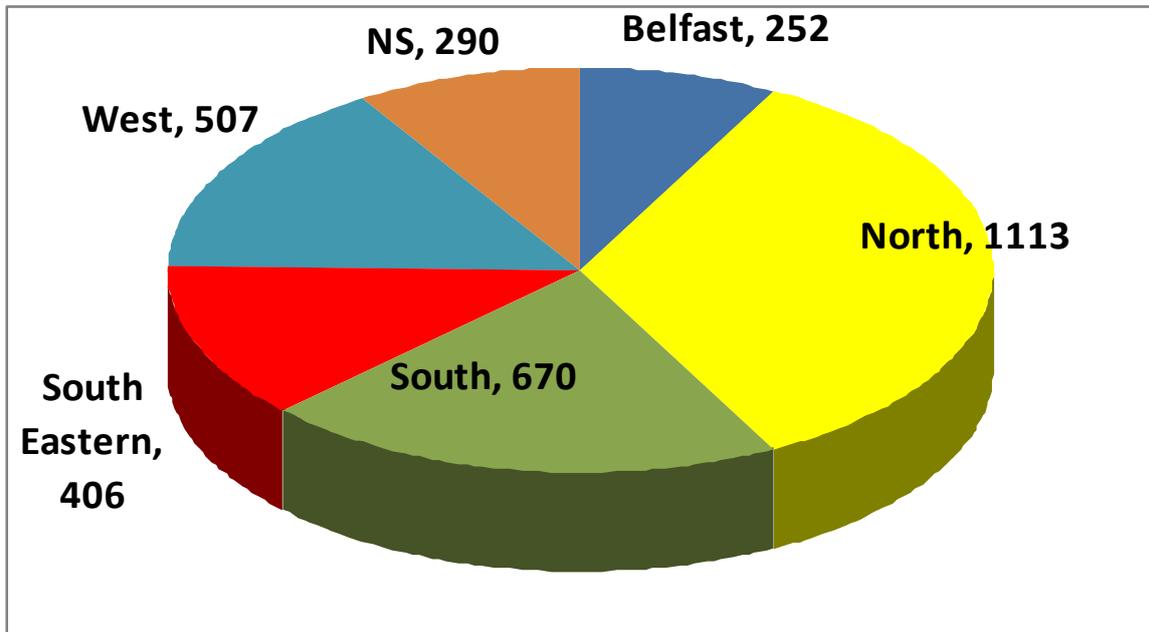
Table 2 – Individual Respondents by Health and Social Care Trust Area.

Health and Social Care Trust Area	Population 2010 *	No. of Respondents
Belfast	335,774	252
Southern	358,647	670
South Eastern	346,794	406
Northern	458,746	1,113
Western	299,431	507
Not Specified		290
Total	1,799,392	3,238

* Source of population: <http://www.nisra.gov.uk/demography/default.asp136.htm> as at 7/11/2011

Figure 6

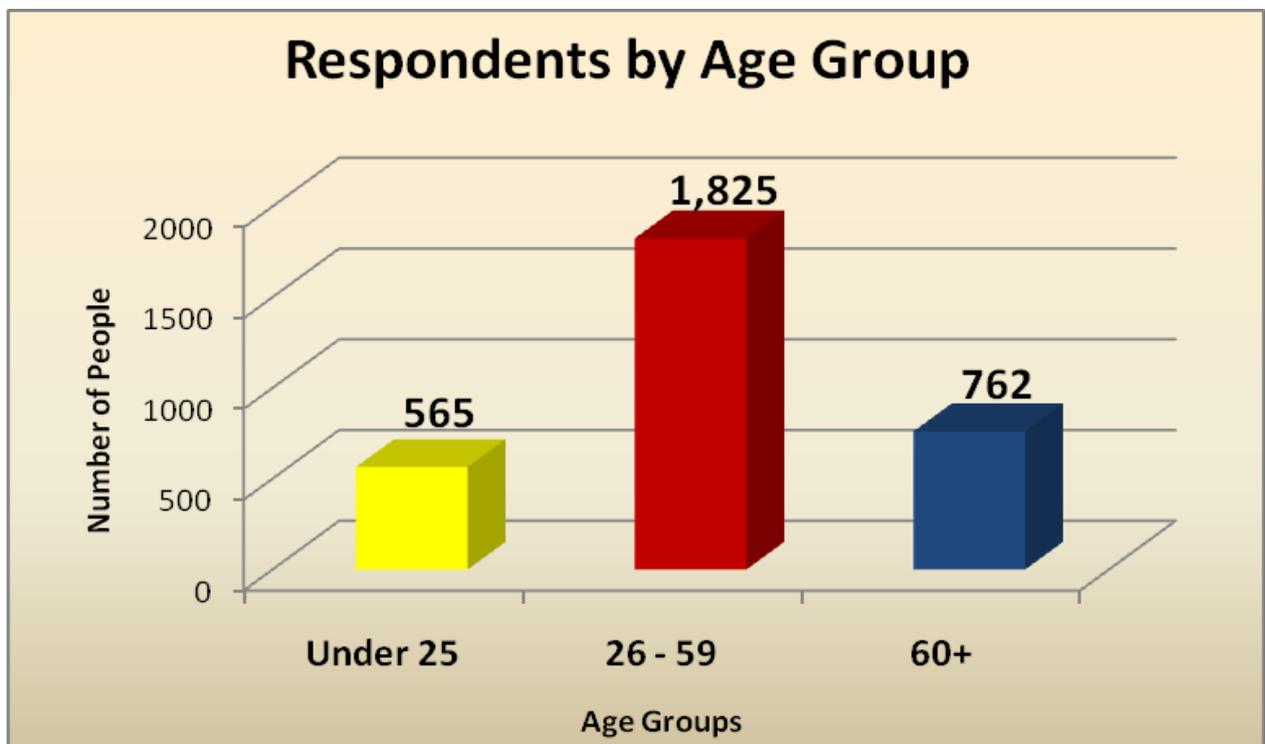
Breakdown of Individual Respondents by Health and Social Care Trust Area.



* NS = Not specified

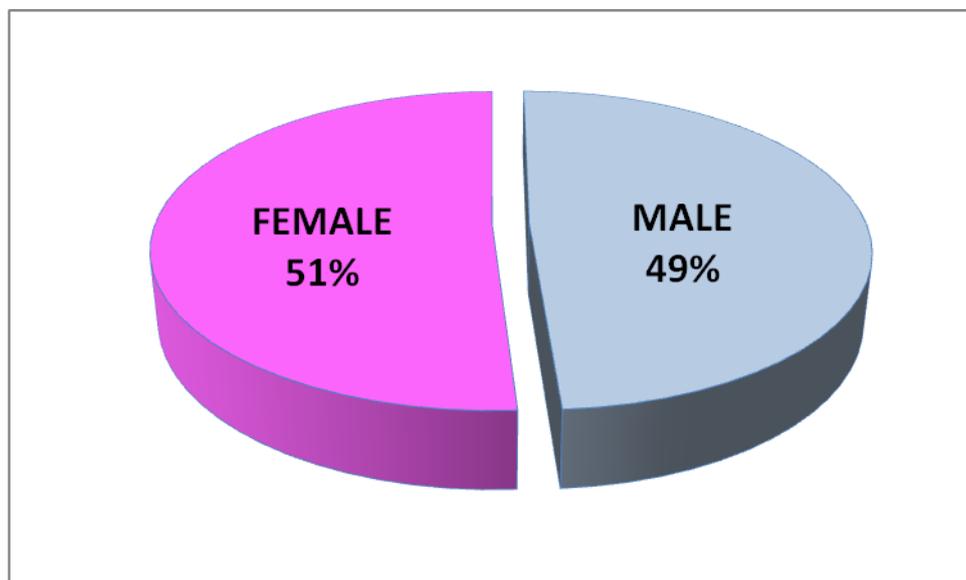
Figure 7 below provides a breakdown of individual respondents by age group.

Figure 7



Based on our experience in 2009 and 2010 we knew that it was more difficult to engage men in these discussions and therefore this year we worked diligently to ensure that we involved more men in the project. Figure 8 below illustrates that we achieved our objective with almost equal involvement of male and female respondents.

Figure 8 – Gender of Respondents



4.0 Conclusions

The Patient and Client Council was established in 2009 to provide an independent voice for patients, clients, carers and the public in health and social care. One of the key functions of the Patient and Client Council is to ensure that the Department and other decision makers listen to and act upon people's views.

Over the last few years we have created numerous opportunities for that voice to be heard and as a result significant changes to the way health and social care is delivered have been made.

We have produced 27 reports which have been compiled from over 18,500 contacts with patients, clients and carers and the general public on a wide range of issues relating to health and social care. Last year "The People's Priorities" was used widely by decision makers to help shape their plans and to bring about new standards and system changes.

This year "The People's Priorities" is more extensive than before and presents a very important measure of the key priorities of patients and clients, their carers and the general public. We would urge the Minister, the HSC Review Team, the commissioners and other decision makers to use this information to inform their decision making processes.

The report sets out the priorities which almost 3,500 people have identified for health and social care in Northern Ireland. The questionnaires and group discussions have highlighted a range of issues across health and social care. The themes which emerged this year had definite similarities with those identified in previous years. This year children's services were new to the top ten priorities.

Over the last three years, even if patients and carers have not been fully familiar with the targets, when they have been explained to them they support the targets and seek greater participation in the target setting process. People would be greatly concerned if there was any attempt to remove or reduce targets as they really value the improvements that have come about as a result of the target setting.

Across all the priorities there is a strong concern about quality of care. This is particularly true of hospital care and the standard of care provided by staff, especially nursing staff. There is a clear message for decision makers and staff across the services about the need to get it right when it comes to basic nursing care, staffing levels, care of the elderly in hospitals, hospital cleanliness, nutritional care and communication.

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.

For the third year in a row people have highlighted concerns regarding the provision of care in the community for elderly people and vulnerable adults, particularly the level and quality of domiciliary care.

Across the priorities identified access to services was a central theme. People are seriously concerned about lack of access to primary care and GP Out of Hours services. They also expressed a lack of clarity regarding where they should go in a crisis.

Patients and carers want to be reassured that they can have reasonable access to advice, a professional opinion, and care and treatment when they need it. People and their carers want to be involved in the decision-making process about their care and treatment and feel that important decisions should be made with them.

Some people indicated a willingness to contribute to the cost of services. This is particularly the case with regards to a charge for prescriptions. There is a clear desire to have the cost of administration minimised and to have increased efficiency.

5.0 Recommendations

The Patient and Client Council urges the Minister of Health, the Department, the Health and Social Review Team, commissioners and key decision makers to address the key messages coming from patients, service users, carers and communities. The following recommendations are based on major themes that surfaced repeatedly throughout the survey responses:

- 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.
- 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.
- 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 Department should report on an ongoing basis to the general public about targets, how they are monitored and the performance achieved by health and social care organisations.
- Any decision to remove or change the targets implemented as a result of the Department's documents entitled "Priorities for Action" should be openly communicated to patients, service users and their carers; and that they should be involved in the setting of future targets and standards against which the performance of health and social care organisations are measured.

- 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 Department and the Commissioners should communicate with the public regarding the level of investment in administration and management required to deliver health and social care services and consider how to reduce costs and improve efficiency.

List of Events/Engagements for Questionnaires

Group/Venue	Group/Venue
200 churches	Market Square, Lisburn
Ardoyne Women's Centre	Meadows Shopping Centre, Portadown
Air Show	Men's Health Clinic (Holywood Arches)
Allstate NI	Moy Park / O'Kanes
ALMAC, Portadown	Musgrave Park Hospital
Antrim Show	Newry City Centre
Ards Shopping Centre	Northern Ireland Ploughing Championships
Ards, Downpatrick	Oaks Centre, Dungannon
Armagh Market	O'Neill's Sports
Armagh Show, Markethill	Park Centre Shopping Centre
Asda, Downpatrick	Portadown Health Centre
Belfast City Hall - PCC Trailer	Quayside Shopping Centre, Derry
Belfast City Hospital Information Stand	RNIB - Community Connections
Belfast MELA	Royal Hospital Information Stand
Belfast PRIDE	Rural Community Network Event, Dungannon
Bloomfield Shopping Centre	SE Roadshow, St Patricks Centre, Downpatrick
Buttercrane Shopping Centre, Newry	South Tyrone Hospital
Castlewellan Show	SRC Freshers Fairs X 5
Chest Heart and Stroke Event,	Strabane County Buildings
Community Festival, Portadown	Stranocum Friendship Group
Connswater Shopping Centre	Supervalu, Dungannon
Craigavon Area Hospital X 2	Supervalu, Omagh
Dalriada Festival	TADA event, Jethro Centre, Lurgan
Drumhaw, Lisnaskea	TADA Information Day, Milford
Fermanagh County Show	Teeamore, Derrylin
Foreglen, Dungiven	Tesco, Craigavon
Foyle Meats, Derry	Thackery, Limavady
Gortmore, Omagh	The Shambles Market, Armagh
High Street Mall, Portadown	Tyrone Farming Society Showgrounds
Lagan Valley Hospital	Ulster Hospital
LT Conditions Inf. Day, Enniskillen	UN Day for Older People-Cultra
Lurgan Town Centre	Wrightbus

Small Discussion Group Meetings

Action Mental Health Service User Group

Action on Hearing Loss

Age NI Group

Ballymena Inter Ethnic Forum

Braintime Service User Group, Thompson House Hospital

Carlisle House

Cushendall Luncheon Club

Dee Street

Disabled Children and Young Peoples Participation Project

Dungannon West Recycled Teenagers (Older Persons Group)

East Belfast Community Health Workers Group

Headway Belfast

Learning & Sensory Disabled/Mental Health

Mental Health

NIACRO Adult Group

Parkinsons Support Group, Omagh

Physically Disabled

Public Babymatters

Renal Patients Group

The Oyster Club – Support Group for Transgendered Adults

Waringstown Craft Circle Women 50+

Patient and Client Council

Your voice in health and social care

Priorities for Action Questionnaire 2011

Q1 Are you aware of the "Priorities for Action" targets in health and social care?

Yes

No

Q2 Do you think targets are important to the delivery of health and social care?

Yes

No

If YES, why do you think they are important?

Q3 In light of proposed reductions in funding for health and social care, if you were the Health Minister what would be your top three priorities in 2012 and beyond?

1 _____

2 _____

3 _____

Q4 How do you think health and social care services could save money?

PLEASE TURN OVERLEAF

Q5 Do you think that patients, their families or carers should be asked to contribute towards the cost of health and social care?

Yes

No

If YES, please tell us which services you think people should be asked to contribute towards:

Q6 Please tell us the first part of your postcode, or nearest town/village:

Q7 Which age bracket do you fall into?

25 or Under

26 to 59

60 or Over

Q8 Are you:

Male

Female

Thank you for completing this questionnaire

STAFF USE ONLY						
B <input type="checkbox"/>	N <input type="checkbox"/>	S <input type="checkbox"/>	W <input type="checkbox"/>	SE <input type="checkbox"/>	HQ <input type="checkbox"/>	BMG <input type="checkbox"/>

Remember you can contact your local office on

Telephone 0800 917 0222

or email info.pcc@hscni.net

Southern Area

Quaker Buildings
High Street
Lurgan
Craigavon BT66 8BB

Western Area

'Hilltop'
Tyrone and Fermanagh Hospital
Omagh BT79 0NS

South Eastern Area

1st Floor, Lesley House
25-27 Wellington Place
Belfast BT1 6GD

Belfast Area

1st Floor, Lesley House
25-27 Wellington Place
Belfast BT1 6GD

Northern Area

Houston's Mill Site
10a Buckna Road
Broughshane
Ballymena BT42 4NJ