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 2010
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Dear Reader,

I am pleased to present this report of our engagement with almost 1,000 people across Northern Ireland regarding their perspectives on future priorities for health and social care.

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 their public services. The fact that so many people took time to give us their views is a testament to the interest they have in 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 Department of Health, Social Services and Public Safety (the Department) 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 protecting the numbers of “front line” staff (particularly nurses), increasing waiting times, care of the elderly (particularly domiciliary care), and 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 2011 and beyond.

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 940 people took part in this process; 579 individuals completed a short questionnaire in “one to one” interviews during street consultations and 361 took part in small group discussions.

The opinions and needs of patients, service users, carers, communities, and, the general public (people) 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.

Most participants were unaware of the “Priorities for Action” (PFA) targets. However, once these were explained to them, participants expressed a desire for the public to be better informed about the targets, and, the performance of the Health and Social Care Trusts in achieving those targets.

Each individual was asked to suggest three priorities. This generated approximately 1,700 responses. The top ten priorities identified by both individuals and groups were then identified as follows:

1. the protection of front line staff – particularly nurses;
2. dealing with increasing waiting times for hospital inpatients, outpatients, diagnostics, and GP appointments;
3. care of the elderly including domiciliary care;
4. developing appropriate mental health and learning disability services;
5. the need to secure public funding for health and social care;
6. access to local services including Accident & Emergency and outpatients services;
7. access to, and quality of, GP services;
8. access to, and quality of, cancer care;
9. improving the quality of communication between staff and patients/service users; and,
10. the rising costs of prescription drugs.

Almost three quarters 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.

There was diversity of opinion among those who felt that targets were not important. However opinion did centre on a number of themes including the potential for targets to become the focus of delivering services rather than the quality of outcomes for patients and service users; and, for targets to put undue pressure on front line staff, particularly doctors. Some people felt that targets may be counter productive and that valuable resources are required to monitor them.

The report makes a number of recommendations to the Department and key decision makers. It will also play a significant part in the development of the 2011/12 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 was established on 1st April 2009, to provide 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 targets for health and social care reflects the opinions of people who use the services.

In the period from August to November 2010 representatives of the Patient and Client Council met with people across Northern Ireland. What follows are their responses to questions asked about priorities for future target setting in health and social care.

In 2009, the Patient and Client Council carried out a similar exercise. A copy of the 2009 report is available from the Patient and Client Council’s website www.patientclientcouncil.hscni.net or by telephone request (0800 917 0222). The 2009 report 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 full implementation of carers’ assessment;
- the application of standards and targets;
• 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” document in 2010 and the Commissioning Plan 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 the 2009 report.

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, change and develop in the coming years. The Health and Social 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 the health and social care services;
• produce a report based on what people said;
• use the findings in the report to inform “Priorities For Action” for 2011 and beyond; and,
• raise awareness of the work of the Patient and Client Council.
Given the current debate in relation to expenditure for public 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 Minister for Health, the Department and the Northern Ireland Executive.

“The Health Service here is excellent....”
2.0 Our Approach

To capture the views of people 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 17 street consultations including public events such as the Ould Lammas Fair and the Mela festival. We met with people in shopping centres and GP surgeries and we organised 24 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.

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 940 people took part in this process; 579 individuals completed a short questionnaire (See Appendix 2) during one-to-one consultations and 361 took part in small group discussions. In addition to the specific questions asked, people took time to share with us their stories and experiences.

Meetings were organised in each of the five Health and Social Care Trust areas, including meetings with members of the Patient and Client Council Membership Scheme as well as the voluntary sector and community groups across Northern Ireland.

This report presents the findings of this exercise.
3.0 Our Findings

579 individuals completed the questionnaire and 361 took part in small group discussions. This section summarises their responses.

The small group discussions gave an opportunity for more in-depth conversation 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 three questions (Appendix 2).

The 3 questions asked in the PFA questionnaire were:

1. Were you aware of the PFA Targets before we met?
2. 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 2011 and beyond?
3. Do you think targets are important to the delivery of health and social care and if so why?

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:

<table>
<thead>
<tr>
<th>WHEN WE SAY:</th>
<th>WE MEAN:</th>
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<tbody>
<tr>
<td>“few”</td>
<td>10% of the people or less;</td>
</tr>
<tr>
<td>“some”</td>
<td>11 to 25% of the people;</td>
</tr>
<tr>
<td>“many”</td>
<td>26% to 50% of the people;</td>
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<tr>
<td>“the majority”</td>
<td>51% to 75% of the people; and,</td>
</tr>
<tr>
<td>“most”</td>
<td>76% + of the people.</td>
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3.1 Awareness of the Targets within “Priorities for Action”

“Were you aware of the targets before we met?”
Of the 579 individual respondents, 155 indicated some awareness of the use of targets in health and social care. 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. 412 people were unaware of the targets and 12 made no response to this question.

![Figure 1](image)

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.

“No – The targets are not well enough advertised”
3.2 Priorities for 2011 and Beyond

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

Each individual was asked to suggest three priorities. This question generated approximately 1,700 responses. Of these responses two thirds (1,151) of the issues identified were represented in the top ten priorities. Figure 2 below presents the top ten responses and the notes which follow provide an explanation of each.

Figure 2

![Bar Chart: The People's Top 10 Priorities]

Peoples Priorities:
1. The Protection of Front Line Staff, Particularly Nurses
2. Concern About Increasing Waiting Times
3. Care of the Elderly, including Domiciliary Care
4. Developing Appropriate Services for Mental Health and Learning Disability
5. The Need to Secure Funding for Health and Social Care
6. Access to Local Hospital Services, including A&E and Outpatients’ Services
7. Access to and Quality of General Practitioner (GP) Services
8. Access to and Quality of Cancer Services
9. Improving Quality of Communication Between Staff and Patients/Service Users
10. Rising Cost of Prescriptions
People’s Priority 1 – The Protection of Front Line Staff, Particularly Nurses

People were concerned about the need to protect front line staff, and in particular nursing staff. In total 226 identified this as a key priority. They expressed the opinion that there should be a greater focus on strengthening numbers of nursing 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. They expressed a strong opinion that management costs, administration and so called “bureaucracy” should be minimised to ensure that front line services are protected.

“Ensure that all nurses are fully qualified… and we do not have trainees taking care of serious cases”

“Protect front line services…..”

“Bring the matron back”

People’s Priority 2 - Concern About Increasing Waiting Times

People are concerned about increasing waiting times. 210 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 elderly people in treatment rooms).

Groups raised concerns regarding increasing waiting times for hospital treatment, diagnostics and GP appointments. 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 review appointments were particularly on the increase. They stated that it was becoming easier for the GP to make another referral for a first appointment, rather than wait for a review appointment.
People’s Priority 3 - Care of the Elderly, Including Domiciliary Care

179 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; and, better partnerships with the community and voluntary sector. They felt that nursing levels should be enhanced to ensure adequate support for people who require feeding in both hospital and community settings. They also expressed the need for good discharge planning from hospital, increased respite and day care and better support for older people in rural areas.

In small group discussions the majority of people were concerned about care of the elderly in both acute hospital and community care settings. Suggestions regarding priorities for this programme of care took many forms. Many people spoke of the need to ensure that the most vulnerable people had help with feeding in hospital, in care homes, and in their own homes.

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. People related stories of domiciliary care being provided in time slots of 15 minutes or less, with staff being under pressure to deliver personal care and / or nutritional support in that time. Some people expressed the opinion that care workers often undertake additional unpaid work to complete the care in their own time. Some people also expressed

“Reduce waiting times for vital appointments – including scans....”

“GP waiting times for appointments – and waiting when you get there.”

More staff required to ensure follow up appointments are put in place.”
concern regarding the appropriate nature of the care provided; for example; they recounted stories of elderly people being put to bed at 6.00 p.m. each evening, and, being left for several hours between “toileting” calls.

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.

“Improvements in the care of the elderly i.e. cleanliness, nutrition. Creating and maintaining a dignified and caring service..”

To improve services for older people’s services in the North Down area due to growth in this area”

“Improve community support for dementia sufferers and carers.”

“The Ward Sister should always be on the ward – not in an office and ensuring that staff are available to feed the elderly”

“Elderly care needs looked at - domiciliary care is very hit and miss, most people getting this would be lost if didn’t also have family support”

People’s Priority 4 - Developing Appropriate Services for Mental Health and Learning Disability

There was strong support for developing appropriate services for mental health and learning disability. 113 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 Bamford recommendations, increased promotion of good mental health, protection of vulnerable adults, continuity in care, an increase in alternative therapies, more specialist nurses, support for dementia patients and their carers, and improved day opportunities and respite. They also expressed a desire for improved Inter –
Departmental working in areas such as supported living, transport and day opportunities.

In small group discussions the majority of people felt that the Department should prioritise services for people with mental health problems. In particular, they expressed a desire to see an emphasis on promotion of good mental health and early intervention/prevention. They expressed concern about the issues which impact upon emotional health and wellbeing of young people; particularly the impact of drug and alcohol abuse.

Some people expressed a desire to see an improvement in out of hours services for people with mental health problems. Others felt that professional staff underestimated the impact of depression. In particular people expressed the desire for:

- more activity based therapies (in in-patient settings);
- the full implementation of the “Card Before You Leave” scheme;
- more community psychiatric nurses; and,
- more training and support for accident and emergency staff.

In addition, some people expressed concern regarding the need for services to recognise and respond appropriately to the mental health needs of children who experience or witness domestic violence.

People also expressed concern regarding support for adults and children with learning disability and carers. They felt that many service users and carers live independently with little practical or emotional support. Concern was expressed for improved support for elderly carers, and improved access to emergency hospital care for adults with a learning disability.

The people were encouraged to learn that the Minister for Health has openly acknowledged the need to make this programme of care a key priority.

“Implement the Bamford Review recommendations.. particularly for adolescents.”

“Increase the provision of mental health services in the community.”

“Equality of treatment for mental health and learning disability.”
People’s Priority 5 - The Need to Secure Funding for Health and Social Care

Concern was expressed about a potential reduction in the budget for health and social care. People felt that there was a need to “ring fence” funding for health and social care in light of any proposed public sector funding cut. 100 people identified funding as a key priority. They wished to see greater accountability for existing funding and to be assured that money is not being wasted unnecessarily on inappropriate use of services such as accident and emergency, prescription drugs, and, high management costs. They expressed a desire for extra funding for specific services such as domiciliary care, respite care, children’s services and specialist teams including cardiac and stroke.

“There shouldn’t be any reduction in funding for health”.

People’s Priority 6 - Access to Local Hospital Services, including A&E and Outpatients’ Services

99 people identified the need for access to appropriate local hospital care in their area. There was support for centralisation of very specialist services. However, they wished to have reasonable access to accident and emergency care, minor injuries, maternity services, diagnostics and outpatients clinics. People who live in rural communities feel particularly vulnerable as a result of the perceived erosion of local services. This is particularly the case for people who live in the South West.

“Pre-natal care should be provided locally.

“Keep services local so people don’t have to travel”

“Better access to neurologists locally”
People’s Priority 7 - Access to and Quality of General Practitioner (GP) Services

People expressed concern about access to, and, the quality of GP services; and
access to GP out of hours services. 72 individuals identified this as a priority. In
particular, they wished to be able to access their GP more quickly, have more
appropriate appointment times to ensure a better quality consultation. They
highlighted a perceived need for better training for GPs in specific conditions
including chronic neurological problems and women’s conditions. They also felt
quite strongly that GPs should work extended working hours including evenings and
weekends and that local GPs should be involved in out of hours service. People in
the South West 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 hour’s 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.

There was a strong desire to improve access to a named GP. This was particularly
the case for people with mental health problems.

“More availability of GP doctors – times not suited to the working man.”

“There are 6 GPs in this town – not one of them works a minute past 5 o’clock”

“Male GPs need more training on female complaint issues”
People’s Priority 8 - Access to and Quality of Cancer Services

59 people identified access to and quality of cancer services as a priority. In particular, they wished to see faster waiting times for diagnostics and treatment. They also identified a desire for:

- better emotional support for cancer patients and the terminally ill;
- improved transport for patients who have to travel long distances for treatment;
- improved screening for breast and prostrate cancer; and,
- better support to enable the terminally ill to remain in their own homes.

“Better and quicker diagnosis for cancer patients.”
“More services for cancer patients”
“Quicker treatments for all people with cancer”

People’s Priority 9 – Improving Quality of Communication Between Staff and Patients /Service Users

People are concerned about the quality of communication. 54 people identified this as a priority. This took many forms including:

- poor staff attitudes affecting communication;
- problems associated with Doctors whose first language is not English;
- lack of information about services and specific conditions;
- the need for training in "people skills" for doctors; and,
- better communication between and across services.

In group discussions, without doubt communication between patients, service users and carers; and service providers was a major concern. They expressed concern that staff had neither the time to explain what was happening nor to listen to issues which they raised.

There was a widely held opinion that one part of the service did not seem to communicate with another and that professionals also did not seem to communicate with each other. They reported lost notes and diagnostic reports but most often
frustration that they did not see the same person twice; whether in the GP surgery, the hospital outpatients department or in community services.

Some patients with long-term conditions told us that they had made up their own hand held patient record with photocopies of test results and correspondence to help prevent unnecessary repeat visits to hospital outpatients because of incomplete records.

People reported having to give their full history every time they met someone. Not only was this repeated telling of their story distressing for some people it created a sense that the service was not joined up enough to plan and deliver a coherent programme of care based on a sound knowledge of the patient.

Some people raised concerns regarding the employment of doctors where English wasn’t their first language to provide out of hours services. They reported problems in communicating clearly with doctors and this was a cause of great concern for patients who often perceived that their problems had not been well enough understood.

Some patients whose first language is not English expressed concern regarding the centralised interpretation service. To access this service you must be referred by a GP. However, they experience difficulties in making an appointment with the GP in the first instance. They expressed the view that there should be greater access to local interpreters.

Many people expressed the view that professional staff including doctors and nurses should be more effectively trained in ‘people skills’. For example, some people felt that staff should be trained to deal more appropriately with issues such as domestic violence. We were told of instances where nursing staff would ask a patient about potential domestic abuse in the presence of the patient’s partner.

Lack of communication and partnership working between health and social care departments and other government departments was also highlighted as contributing to problems with service delivery. This was particularly the case for people with
physical and learning disability who require support from several departments. For example, one young lady told us that when she left school one Department took away her communication device and it took the local health and social care Trust 18 months to assess her need and provide her with an appropriate replacement device. This meant that for 18 months she was left without a voice.

“A lot of resources are wasted… we need better communication between departments”

“Listening to people and communication skills”

“Patient information – records/files – should be more careful with people’s files – lost information causes stress and longer waiting times”

**People’s Priority 10 - Rising Cost of Prescriptions**

People are concerned about the rising cost of drugs in health care. Many people express a desire to see a re-introduction of prescriptions charges for those who can afford to pay.

“Put a minimum charge on prescriptions again.”

“Target a reduction in cost of drugs.”

“Free prescriptions only encourage abuse of the system.”
3.3 Other Priorities Identified

Priorities Identified By Individuals
It is important to note that many other priorities were identified by individuals and while it has not been possible to list everyone individually, the table below presents a list of those identified by 10 individuals or more.

Table 1

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<th>Priority</th>
<th>Number of People</th>
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<tbody>
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<td>Control of Infection in Hospitals</td>
<td>32</td>
</tr>
<tr>
<td>Health Promotion and Prevention</td>
<td>29</td>
</tr>
<tr>
<td>Services for People with a Physical Disability</td>
<td>29</td>
</tr>
<tr>
<td>Access to “NHS” dentistry for children, the unemployed and pensioners</td>
<td>25</td>
</tr>
<tr>
<td>Quality of Access to Maternity Services</td>
<td>23</td>
</tr>
<tr>
<td>Child Care / Children’s Services</td>
<td>22</td>
</tr>
<tr>
<td>Transport – Including Community Rural Transport and Ambulance Services</td>
<td>18</td>
</tr>
<tr>
<td>Appointment Systems</td>
<td>12</td>
</tr>
</tbody>
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Priorities Identified By Focus Groups
A range of other issues were raised in some small discussions groups and the most frequently mentioned ones are summarised below;

Transport
Access to and the cost of transport to services is undoubtedly becoming more of an issue for people on low incomes and those who reside in rural communities. Many people expressed the view that changes are made to services without taking account of the financial implications for patients and the practical capability of getting to these services. For example, some mental health patients explained that changing the location of outpatient services from one town to another would mean that they could no longer afford to attend these services.
The Patient and Client Council is currently undertaking a surveying of the experience of people who live in rural communities regarding health and social care. Early indications show that people in rural areas are very concerned about transportation to hospital and GP appointments; they often rely on neighbours or costly taxi services. A full report of our Rural Voices project will be published during early 2011.

**Nursing care**
Some people expressed the desire to “put the nurse back into nursing”. They wished to see a greater emphasis on practical nursing skills such as feeding, and personal care of vulnerable or frail patients. They wished to see Ward Managers / Sisters have greater authority at ward level. They felt that there should be better training for nursing staff in the care of people with specialist needs, including people with Dementia.

**Dental Care**
People wish to see an improvement in access to so called “NHS” Dentistry, and an improvement in out of hours dental care.

**Carer Assessment**
Many people expressed concern about the lack of assessment of need for carers. They stressed the need to implement legislation and relevant regional policy on carers’ assessment as a matter of priority.
3.4 The Importance of Targets

People were asked “Do you think targets are important to the delivery of health and social care and if so why?”

453 individuals responded to this question. Figure 3 below presents their response and the notes which follow summarise the reasons given.

Figure 3

Almost three quarters 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 and a standard against which services must deliver. They expressed the view that targets have improved the responsiveness and accountability within the services. They particularly value the reduction in waiting times in recent years.

There was diversity of opinion among those who felt that targets were not important. However opinion centred on a number of themes including; the potential for targets to become the focus of service delivery rather than the quality of outcomes for patients and service users; and, putting undue pressure on front line staff particularly doctors. Some people felt that they may be counter productive and that valuable resources are required to monitor them.
In group discussions the majority of people felt that targets were important and should be maintained. They felt that they were necessary to ensure accountability within the system. However, many people expressed the view that the monitoring should include a qualitative element with a particular focus on the quality of outcomes for patients, clients and carers.

“Yes, they give everyone something to work towards.”

“Yes, you’re not forgotten about!”

“Broad targets are beneficial but I feel it can be detrimental to patient health if target hitting is the number 1 priority. At times targets can be reached but this cannot be the driving force of the NHS. The focus should always be the PATIENTS”.

“Targets are important, but not as important as real human values and respect and common sense in working with citizens”.

4.0 Conclusions

The questionnaires and group discussions have highlighted a range of issues across health and social care. The report sets out the priorities which 940 people have identified for health and social care in Northern Ireland.

The fact that people gave of their time so readily is a testament to the fact that they care deeply about health and social care services.

This report presents a number of common issues that patients, clients, carers and communities feel strongly about and want to be represented in future decision making in health and social care:

- People are largely unaware of the specifics of “Priorities for Action” targets. However, once these are explained to them they support the targets and seek greater participation in the target setting process. They want to be involved in the decision-making process and feel that important decisions should be made with them;

- People wish to see funding for health and social care in Northern Ireland ring-fenced during potential funding cuts;

- People identified as priorities a range of services for which PFA targets already exist. These include care of the elderly, mental health and learning disability, waiting times, GP services, cancer services and domiciliary care. The Department, the Health and Social Care Board and the Public Health Agency must consider how best to make the realisation of these targets a reality for patients, service users, carers and communities in Northern Ireland;

- People seek assurance that in the face of any spending cuts there will be protection of frontline caring staff, particularly nursing staff; and,

- People are concerned about a wide range of issues relating to communication.
5.0 Recommendations

There is common ground between the priorities people have said they wish to see and those within “Priorities for Action” for 2010 and beyond. The current “Priorities for Action” already sets targets for many of the issues raised such as communication, waiting times, domiciliary care, carer’s assessment and respite packages and sets strategic direction aimed at improving and developing community and home based services.

Taking this into account, but recognising the themes that emerged from their actual experience we further recommend the following:

- In face of potential public sector funding cuts people are concerned that services should not be reduced and that the Department should strive to secure “ring fencing” of funding for health and social care.
- The Department should take cognisance of the impact on services and the delivery of targets of any erosion of front line staffing
- The Patient and Client Council should continue to work with the Department to ensure that mechanisms are developed so that patients, clients and carers should be fully involved in decisions regarding the planning and delivery of health and social care.
- The Department, the Health and Social Care Board and Trusts should take steps to ensure that the legal requirement for every carer to have an assessment of their needs carried out is fully implemented. 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.
- The Department should set further standards for communication and pay particular attention to patient concerns around fragmented services and the reported lack of continuity in care.
- 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.
The Department should review standards and targets regarding discharge from hospital for older people to ensure effective involvement of all stakeholders at an early stage.

Following on from the implementation during 2010 of a new target in the older people’s programme of care regarding the right to have an individual care plan which they hold personally, the Department should implement this target across all programmes of care in 2011.

The Department should fully fund the continued implementation of the Bamford Action Plan.

The Department should implement patient/service user held records for people with long term conditions, rare diseases and complex physical and learning disabilities; and where appropriate these records could be held by carers.

The Department should work with the Patient and Client Council to develop and implement a clear plan for meaningful reporting of patient and service user experience as a means of monitoring performance. This is necessary to complement the more quantitative data gathered.

The process of engaging with the public in the setting of priorities should be further developed with the Patient and Client Council in 2011 and beyond.

The Patient and Client Council will actively work with Health and Social Care organisations to monitor progress on the implementation of these recommendations; and will report openly to the public.
List of Street Consultations 2010

Air Show, Portrush
Antrim Hospital, Outpatients Department
Ard’s Hospital, Outpatients
Ballymena Health Centre
Banbridge Care Centre
Bloomfield Shopping Centre
Dunne’s Stores, Enniskillen
Grove Health & Wellbeing Centre
Health Fair, Omagh Library
Lammas Fair, Ballycastle
Mela Festival, Belfast
Oaks Shipping Centre, Dungannon
Saintfield Health Centre
St. George’s Market, Belfast
St. Mark’s Parish Centre, Newtownards
Westwood Shopping Centre, Belfast
World Mental Health Day, South Eastern Health and Social Care Trust
List of Small Discussion Group Meetings

Alzheimers Carers Support, Newcastle
Belfast Carers group
Cedar Foundation
Cheers Youth Group, Ballymoney
Chinese Welfare Centre, Belfast
Cullybackey Senior Citizens Group
Epilepsy Action
Equality 2000
Hilltown Senior Citizens
M.S. Society
Mental Health Group Antrim
Mindwise Downpatrick “Monday Night Club”
Patient & Client Council Membership Workshop, Newtownards
Patient & Client Council Membership Workshop, Ballymena
Patient & Client Council Membership Workshop, Dungannon
Patient & Client Council Membership Workshop, Lurgan
Patient & Client Council Membership Workshop, Newry
Patient & Client Council Membership Workshop, Omagh
Patient & Client Council Membership Workshop, Belfast X 2
Prospect Citizenship Group
Strabane & District Caring Association
Toome Ladies Group
Women’s Information Group, Belfast
Young Stroke Moving On
Priorities for Action Questionnaire

1. Were you aware of the PFA Targets before we met?
   ___________________________________________________
   ___________________________________________________

2. 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 2011 and beyond?
   a. ________________________________________________
      ________________________________________________
   b. ________________________________________________
      ________________________________________________
   c. ________________________________________________
      ________________________________________________

3. Do you think targets are important to the delivery of health and social care and if so why?
   ___________________________________________________
   ___________________________________________________
   ___________________________________________________
Remember you can contact your local office on

**Telephone 0800 917 0222**

or email **info.pcc@hscni.net**

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**South Eastern Area**
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