

2nd Progress Report

August 2009

On the Human Rights Indicators and Benchmarks of the PIPS-Greater Shankill Bereaved Families Rights Group

Executive Summary



EXECUTIVE SUMMARY

This Progress Report details the second round of monitoring of the PIPS-Greater Shankill Bereaved Families Rights Group's Human Rights Indicators and Benchmarks. The four main areas of concern highlighted by the group to monitor were:

1. Follow Up Care

The current monitoring shows an increase of 7% from the first round of monitoring to 20% of patients who received a follow up appointment within a week. 33% of these patients received a 'Card Before You Leave' with the date and time of their next appointment, a 29% increase from the first monitoring. Whilst there has been progress on this indicator it has not met the benchmark set by the group.

2. Access to the Complaints System

Progress on this indicator has been retrogressive with a reduction in the percentage of dissatisfied patients accessing the complaints system from the 31% in November 2007, to 14% in September 2008 to 6% in the current monitoring in May 2009.

3. Information from GPs about Conditions and Medication

Progress on this indicator has been significant, with 58% of patients expressing satisfaction with information provided about their condition and 65% with information about their prescribed medication. The benchmark for one year, however, of 70%, has not yet been met.

4. Participation of Service Users in Decision-Making

There has been only slight progress on this indicator since the baseline surveys were conducted in November 2007, with a 2% increase to 22% of service users feeling involved in decision making.

The results have been mixed; progress has been made with the Minister for Health making the Card Before You Leave System a Priority for Action and agreeing to its implementation by October 2009 but progress on real and meaningful participation of service users in decision making has worryingly, shown no sign of improvement.



Sections and Contents of this Report

1. Introduction

2. Progress to Date

3. Conclusion

Introduction



1. Introduction

The PIPS-Greater Shankill Bereaved Families Rights Group is made up of individuals who have either been bereaved through suicide or who are themselves/have a member of their family suffering from serious mental illness. **They use a human rights based approach to argue for changes in access to and delivery of mental health services in Northern Ireland.**

The changes the group advocates were chosen through a development programme with the Participation and the Practice of Rights Project (PPR). As part of this process;

- A broad set of issues regarding mental health services in Northern Ireland were identified using a human rights based approach. These were issues that government is already obligated to change given existing international and local policy standards.
- The group carried out surveys to prioritise issues in order to determine which ones their campaign should focus on.
- Finally, they developed a reasonable timeline for improvement on these issues, in line with international policy standards

Human Rights Indicators and Benchmarks

Human rights standards require government to ‘progressively realise’ people’s economic and social rights – i.e., the standards require that services get better over time. Accordingly, the group set human rights indicators and benchmarks for change that measure, both, whether services are actually getting better, and whether the human right to the highest attainable standard of mental health is being achieved.

Timeline of Major Steps in the Group's Campaign

- In **November 2007**, the group presented these human rights indicators and the results of their surveys to an International Panel of human rights and mental health experts.
- In **February 2008**, the panel published their findings about the group's human rights indicators. They validated the group's work and recommended practical changes from government in line with their obligations.
- In **September 2008**, the group published their "First Report on the Progress of Human Rights Indicators". This report showed retrogression or no change on 4 of the 5 human rights indicators the group had highlighted.
- In **May 2009**, the group held an event at Stormont Parliament Buildings to highlight the importance of meaningful participation in public decision-making. The event marked the end of their second monitoring of human rights indicators and benchmarks.

This **Progress Report** details the results of this second monitoring of the groups indicators and benchmarks. It also provides an explanation of the process-based human rights indicators presented at Stormont in May.



Progress To Date



2.1 Follow Up Care

A timely follow up appointment after discharge from hospital provides a lifeline for mental health patients contemplating suicide or self harm.

- **Baseline surveys** (November 2007) showed only 13% of mental health patients were receiving a follow up appointment within a week, as required by national policy.
- **In line with international human rights obligations, the group set benchmarks for the delivery of these public services to be improved.**
 - **In 6 months**, 45% should have a follow up appointment within a week.
 - **In 1 year**, 90% should have a follow up appointment within a week.

The group recommended, as a first step, for the Department of Health to implement a ‘Card Before You Leave’ appointment system. This would ensure patients had the date and time of their next appointment before they left the hospital.

This recommendation was endorsed by an international panel of mental health and human rights experts. It was also one of the key recommendations to the Minister for Health from the Northern Ireland Assembly’s Health Committee Inquiry into the Prevention of Suicide and Self Harm in May 2008.

Research & Policy Context for Mental Health Follow Up Care

-Statistics from the Department of Health show 66% of post-hospital discharge suicides in Northern Ireland occur before the first follow-up appointment.

-NHS Guidelines require that people discharged from hospital with severe mental illness or who are at risk of deliberate self-harm be seen at a follow-up appointment within a week.

-International human rights law requires “timely access to...mental health treatment and care” and states that the “absence of an effective referral system is inconsistent with the right to the highest attainable standard of health”.

First Monitoring

In September 2008:

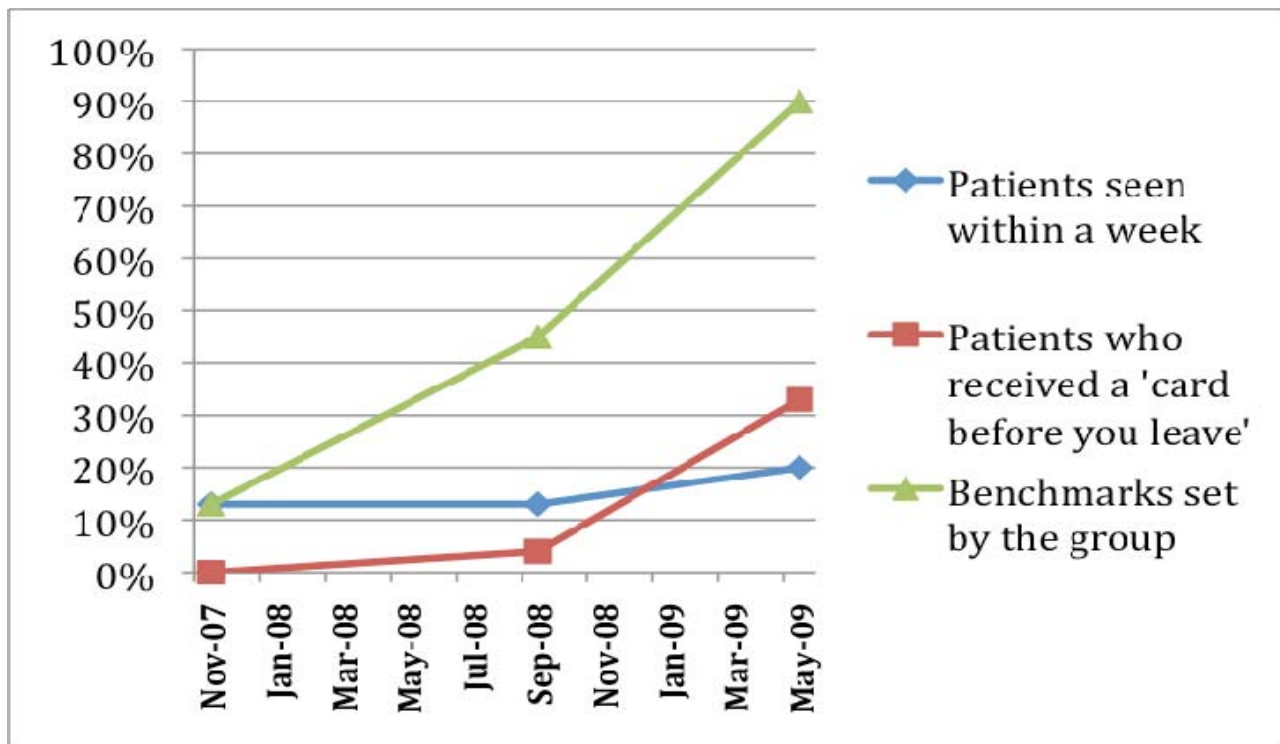
- Only 13% of mental health patients received a follow up appointment within a week.
- 4% received a ‘card before you leave’ with the date and time of their next appointment.

Current Monitoring

In May 2009:

- 20% received a follow up appointment within a week.
- 33% received a ‘Card Before You Leave’ with the date and time of their next appointment

While there is progress on this indicator, it has not met the benchmark set by the group.



Since November 2007, there has only been a 7% improvement in patients receiving an appointment within a week. This is all the more discouraging given the recently announced increases in suicides and self-harming among young people in Northern Ireland. The PIPS-Greater Shankill Bereaved Families Rights Group welcomes the Ministers decision to make receiving an appointment within a week a Priority for Action for the upcoming year. The group is keen to ensure that these commitments by the Minister translate into real change on the ground for the most vulnerable of service users.

Next Steps

- **Regional implementation of a ‘Card Before You Leave’ Appointment System should be complete by October 2009.**
- **Service users should participate meaningfully in the development of standards for the implementation of the ‘Card Before You Leave’ Appointment System.**
- **Minister for Health Michael McGimpsey and the Northern Ireland Assembly’s Health Committee should meet with the PIPS/GSBF Rights Group and receive regular monitoring reports on the progress of the ‘Card Before You Leave’ Implementation Board.**

2.2 Access to the Complaints System

An effective hospital complaints system provides invaluable information about the state of health services. It provides information on where the services require improvement and where resources can be efficiently spent. It should offer effective and speedy redress for problems encountered.

- **Baseline Surveys** (November 2007) showed only 31% of dissatisfied service users accessed the complaints system.
- **In line with international human rights obligations, the group set benchmarks for the delivery of these public services to be improved.**
 - **In 6 months**, 45% of dissatisfied mental health patients should access the complaints system.
 - **In one year**, 55% of dissatisfied patients should access the system.

This indicator was endorsed by an international panel of mental health and human rights experts in November 2007 as a reasonable and necessary timeline for change.

First Monitoring

In September 2008:

- Only 14% of dissatisfied mental health patients accessed the complaints system.
- **This showed significant retrogression from the baseline results in November 2007.**

Current Monitoring

In May 2009:

- 6% of dissatisfied mental health service users accessed the complaints system.
- **This is yet another significant retrogression from September 2008 and from November 2007.**

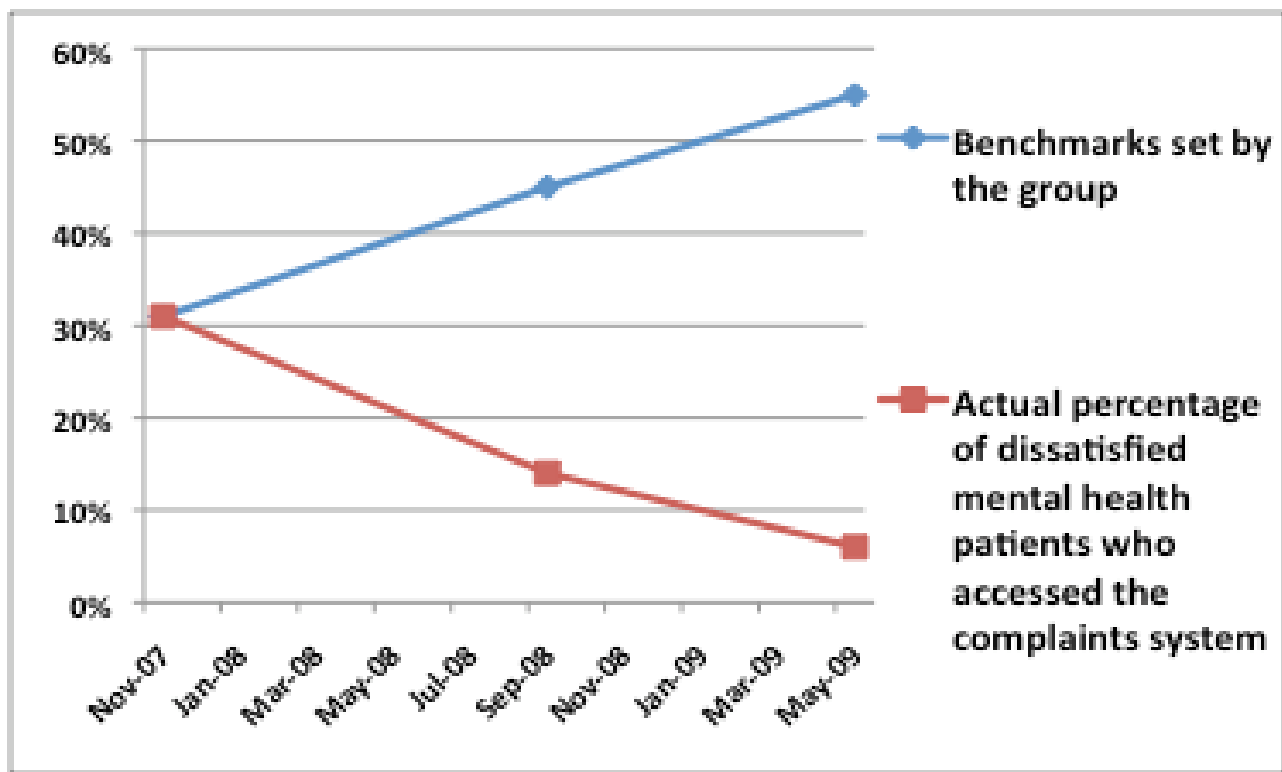
The benchmark for this indicator has not been met, and there has been retrogression during each monitoring period since November 2007. This represents a failure of the health service to take advantage of patient experience as a way to constantly improve services as required by human rights law.

Research & Policy Context for Access to the Complaints System for Mental Health Patients

-In February 2009, the Healthcare Commission in England and Wales issued a report 'Spotlight on Complaints' which recommended that where a complaints system was changing to put greater emphasis to local resolution (as in Northern Ireland), Boards of Health Trusts must ensure that general learning is taken from specific complaints and is embedded into the system of care for the future.

-Local guidance from the Department of Health states that service users should be "made aware of their right to complain and given the opportunity to understand all possible options for pursuing a complaint."

-International human rights law states that patients are entitled to an "accessible, affordable, timely and effective" administrative remedies when their right to the highest attainable standard of health is



While the Department of Health has developed a new complaints procedure, meetings held between the department and members of the PIPS-Greater Shankill Bereaved Families Rights Group have led to concerns about the new system. While the new procedure includes a set of standards which highlight the importance of participation and learning, it provides little guidance for Trusts on how these should be implemented. Arrangements for how service users are involved in decisions are left for Health Trusts and Boards to make. It is not apparent that lessons have been learned from past mistakes. A fact sheet about the details of the new complaints procedure is available at <http://www.pprproject.org/>.

Next Steps for Government and for You

- **The Minister for Health and the Northern Ireland Assembly’s Health Committee should receive each Health and Social Care Trust’s detailed plans for ensuring full participation of service users in the implementation and monitoring of the new Complaints System.**
- **The Department of Health and each Health and Social Care Trust should provide specific information on what mechanisms are being used to monitor the participation of service users in the implementation and monitoring of the new Complaints System.**

2.3 Information from GPs about Conditions and Medication

Lack of awareness about the symptoms of mental illness as well as about potential side effects of medication has had devastating results for patients and families in North Belfast and beyond. GP are often the first point of contact for those with mental illness and an informed intervention at this point allows service users and families to learn about their condition and equip themselves to move towards recovery.

The group set two indicators in relation to information provided by GPs.

- Service user satisfaction with information provided about mental health conditions;
- Service user satisfaction with information provided about prescribed medication.

Research & Policy Context for Information Provided By GPs

-Promoting Mental Health strategy requires development and delivery of Depression Awareness Training for GPs.

- Protect Life, Northern Ireland's suicide prevention strategy, makes suicide awareness and prevention a priority for all "front line health service staff."

- The International Panel of mental health and human rights experts found that the Minister for Health should take "decisive action to ensure that all general practitioners do take the required training course".

-International human rights law states that patients have the right to seek and receive information concerning health issues.

Baseline surveys (November 2007) showed:

- 36% of service users were satisfied with information provided about mental health conditions.
- 38% were satisfied with information provided about prescribed medication.

In line with international human rights obligations, the group set benchmarks for the improvement of these results.

- **In 6 months**, 45% of service users should be satisfied with information about their condition. 50% with information about their prescribed medication.
- **In 1 year**, 70% of service users should be satisfied with both information provided about their condition and about their prescribed medication.

Both indicators and their benchmarks were endorsed by an international panel of mental health and human rights experts in November 2007 as reasonable and necessary timelines for change.

First Monitoring

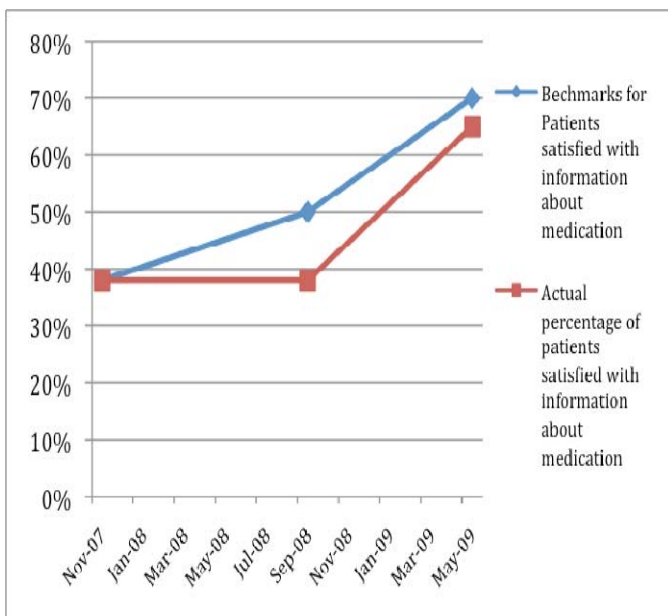
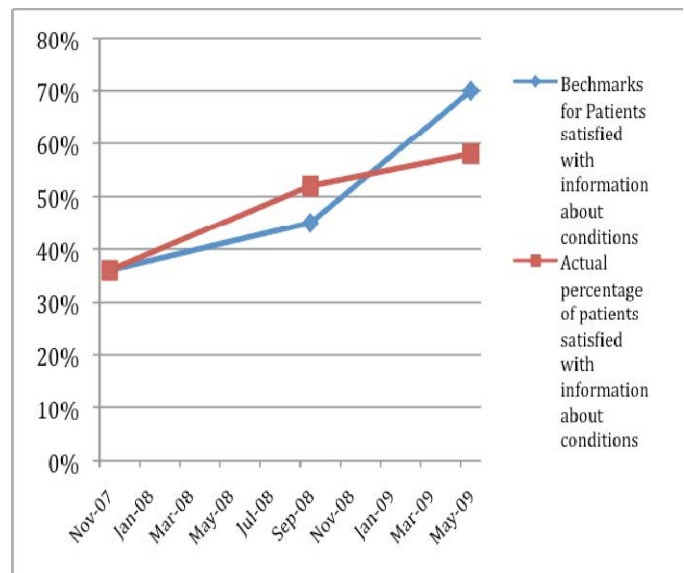
In September 2008:

- 52% were satisfied with information provided about their condition. 38% were satisfied with information about their prescribed medication.
- **The government met the first of the two indicators during this monitoring period.**

Current Monitoring

In May 2009:

- 58% were satisfied with information provided about their condition. 65% were satisfied with information provided about their prescribed medication.
- **This monitoring period has shown significant progress on both indicators. The benchmarks for one year, however, have not been met.**



Next Steps

- **It should be mandatory for all GPs to undertake training about broad-spectrum mental health conditions, so that there is not an inconsistency in provision between GPs who have recently been trained and those who have been practising for years. International standards are unequivocal in stating that appropriate training for health personnel is of comparable priority to a minimum core obligation on government. (Article 44 (e), General Comment No. 14 on the right to the highest attainable standard of health.)**
- Service users should be involved in the proposed Regional GP training advisory board as they are best placed to assess whether changes are happening on the ground.

2.4 Participation of Service Users in Decision-Making

Meaningful participation of mental health service users in decisions about the planning, implementation and review of mental health services is critical to ensuring the effective and efficient use of public resources.

- **Baseline Surveys** (November 2007) showed only 21% of mental health service users felt involved in decision-making (these individuals rated their involvement between 4 and 10 on a 1-10 scale).
- **In line with international human rights obligations, the group set benchmarks for these figures to be improved.**
 - **In 6 months**, 35% of those surveys should rate themselves as involved.
 - **In 1 year**, 50% should rate themselves as involved.

This indicator and its benchmarks were endorsed by an international panel of mental health and human rights experts in November 2007 as a reasonable and necessary timeline for change.

First Monitoring

In September 2008:

- 20% of mental health service users felt involved in decision-making.
- **This showed slight retrogression from the baseline results in November 2007.**

Current Monitoring

In May 2009:

- Only 22% of the mental health service users surveyed felt involved in decision-making about mental health services.

Research & Policy Context for Participation of Mental Health Service Users in Decisions

-Northern Ireland's suicide prevention strategy, *Protect Life*, identifies participation and engagement with mental health service users and bereaved families as a guiding principle.

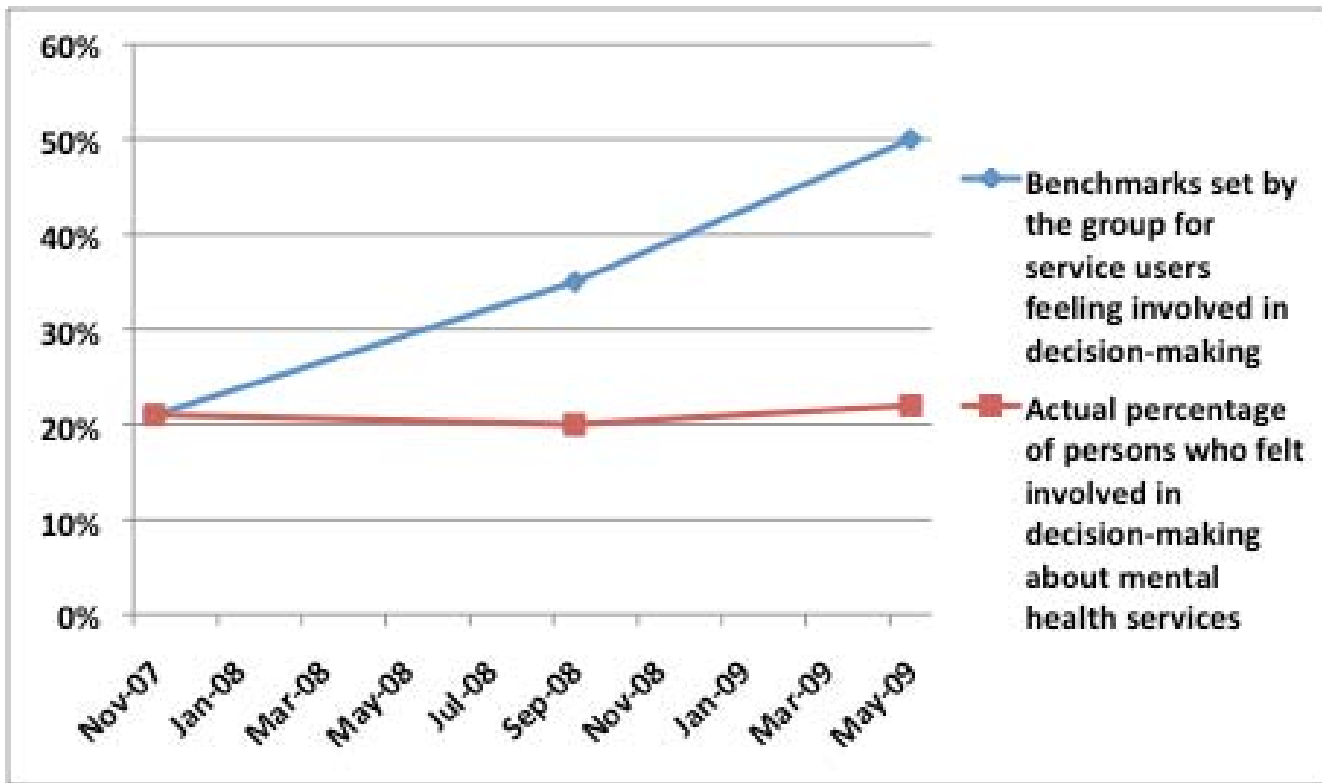
-The Bamford Review emphasizes “the importance of service users and carers as partners in service planning, development, delivery and monitoring” of mental health services and policy.

-International human rights law requires people affected by decisions to be involved in “setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health.”

- **The group's most recent monitoring in May 2009 has shown very slight improvement since September 2008. However, this is again, negligible.**

The benchmarks for both 6 months and one year for this indicator were not met.

In November 2007, the international panel of mental health and human rights experts recommended opening dialogue between the government and the group as a first step towards facilitating “active, free and meaningful” participation. The minister's appointment of a senior departmental liaison for the group began this process of dialogue and accountability. But much more must be done to facilitate meaningful participation with other mental health service users across Northern Ireland.



The minister has taken further steps to involve mental health service users on the ‘Card Before You Leave’ implementation board. The group will be monitoring the significance and effectiveness of this participation over the coming months.

The group has begun to develop a set of process-based human rights indicators that will be monitored against their experience on the ‘Card Before You Leave’ implementation board. These can be found online at <http://www.pprproject.org/images/documents/mh%20participation%20pamphlet.pdf>, alongside the group’s recommendations for how other groups can contribute to this process.

The group hope that through their work on these indicators they and other groups can create standards that will make participation meaningful for mental health service users across Northern Ireland.

Next Steps for Government and for You

- **Consider evidence of how effective process-based human rights indicators have been for the implementation board of the ‘Card Before You Leave’ Appointment System. If it has been effective and encouraged good practice and meaningful engagement, use this learning to begin to mainstream these sorts of indicators across the health service.**

CONCLUSION

Since November 2007, the PIPS/GSBF Rights Group has been engaged in an innovative process of using human rights to set standards for how mental health services in North Belfast should be delivered. The need has never been greater. Statistics have shown that despite a spend of over £6 million per year on the suicide strategy, suicides in Northern Ireland rose from 242 in 2007, to 282 in 2008.

Over the monitoring period, the Department for Health and its service delivery agencies, met only one of the benchmarks set by the group – on the issue of information from GPs on mental health conditions and medication. The other issues of follow up care, the complaints procedure and the participation of service users in decisions about the services they receive, all failed to meet the benchmarks set by the PIPS/GSBF Rights Group. The indicator monitoring access to the complaints system saw significant retrogression over the monitoring period.

In May 2009 the PIPS/GSBF Rights Group held an event in the Long Gallery, Stormont to report on their work to date. The event was named ‘From Pillar to Post’ which reflected the group’s experience of working towards a small change that would save lives, namely the Card Before You Leave appointment system, recommended by the panel of Mental Health and Human Rights experts in November 2007. The group have been gratified by the Minister’s decision in August 2008 to implement this system, despite the Department previously saying there were no plans to do so. They also welcomed the Minister’s decision to make a Priority for Action, the standard that all patients discharged from hospital (who require a continuing care plan in the community) should be seen at a follow up appointment within one week.

The work of the group to date has highlighted to them the importance of government’s commitment on participation to be translated into reality. It is vital that government facilitates service users to be able to participate in decisions that affect how they and their families access mental health services, ensure their quality and are able to make changes when mistakes are made. This is not only required under human rights law, it is a core commitment of the Minister for Health made through the Bamford Review and through the Protect Life Suicide Prevention Strategy. Furthermore, it has enabled the introduction of a simple measure which could ensure that patients remain tied into services at the most vulnerable time, and as a result, also makes good sense.