

Individuals' rights in mental health care

**Dawn Griesbach and Jacki Gordon
Griesbach & Associates**

March 2013

Table of contents

- 1. Introduction 1
 - Background 1
 - Aim of the consultation 2
 - Structure of this report..... 2
- 2. Methods 3
 - Consultation participants 5
- 3. To what extent are people aware of their rights? 7
 - The right to be heard and listened to..... 7
 - The right to have information and make choices 8
 - The right to protection from discrimination 9
 - The right to be treated with respect / as a human being / as an individual 9
 - Legal rights..... 9
 - The nature and standard of care 10
 - Rights for which there was a general lack of awareness..... 10
- 4. How well do services respect people’s rights? 11
 - Positive experiences 11
 - The process of being compulsorily detained 12
 - Putting the principles into practice..... 13
 - The rights of carers 14
 - Other issues 15
- 5. What are people’s priorities for action? 16
- 6. Conclusions and recommendations 18
 - To what extent do people with mental health problems know their rights? 18
 - How well are services respecting people’s rights? 18
 - What are people’s priorities for change? 19
 - Recommendations 20

Acknowledgements

We would like to thank Alison Platts, Karin Dowell, Sasha Railton and Sarah Hartley for their help in taking notes at each of the consultation sessions.

We are very grateful for the help of the mental health service co-ordinators across Scotland who helped to arrange the consultation events in their areas, and who invited people from their local groups to attend.

Finally we would like to thank the people who took part in the events for their time and their interest in the subject of the consultation.

1. Introduction

This document is a report of a consultation commissioned by the Mental Welfare Commission (MWC) and carried out by Griesbach & Associates. The focus of the consultation was on exploring the participants' knowledge about, and understanding of, their rights in relation to the care and support they receive from mental health services (hereafter referred to as 'services'). The project also explored participants' views about *which* rights issues require to be addressed most urgently by services and what specific actions they believe services could take to address these issues – to ensure that services develop a greater focus on and respect for the rights of those in their care.

As such, this consultation was commissioned as a first step in a longer process of improving the focus on patients' rights by mental health services in Scotland.

Background

The Mental Health (Care & Treatment) (Scotland) Act 2003 is seen as having brought about the most fundamental change to Scottish mental health law in 40 years.¹ It puts service users' rights at the heart of treatment and care services, and has been described as *one of the most advanced pieces of mental health legislation in the world.*² Under the Mental Health Act, there are a range of legal rights as well as service delivery principles that people with mental health problems are entitled to when they access services. (These are set out in Chapter 2 of this report.)

Since the Mental Health Act was passed in 2003, Scottish Government has continued to bring forward legislation and policies to protect the rights of individuals including the most vulnerable members of society and to enhance the rights of people who have previously been subject to discrimination or unfair treatment.

In the area of mental health, specifically, Scotland's new Mental Health Strategy, published in August 2012, sets out a range of commitments which aim to deliver better, more effective care and treatment for people with a mental illness.³ This action plan emphasises (in Commitment 5) the need for a continued focus on the rights of people with mental illness. The Scottish Government will be working together with the MWC and the Scottish Human Rights Commission (SHRC) to fulfil this commitment.

At the same time, in October 2012, the SHRC published the findings of a three-year project to identify gaps in human rights provision in Scotland.⁴ *Getting it right? Human rights in Scotland* makes the point that although Scotland has a strong legal and institutional framework for human rights, and some examples of positive strategy and policy direction, the actual outcomes for individuals often remain inconsistent.

¹ Ridley, Rosengard, Hunter & Little (2009). Experiences of the early implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003: A cohort study. Scottish Government.

² <http://www.samh.org.uk/our-work/policy-campaigns/mental-health-law>

³ Scottish Government (2012) *Mental Health Strategy for Scotland: 2012-2015*. Available at: <http://www.scotland.gov.uk/Publications/2012/08/9714>

⁴ SHRC (2012) *Getting it Right? Human rights in Scotland*. Executive summary available at: <http://www.scottishhumanrights.com/actionplan>

The report particularly identified the area of mental health care and treatment as an area for improvement.

This consultation was commissioned specifically to get the perspective of people with mental health problems about what specific improvements are needed in this area.

Aim of the consultation

This consultation sought to answer three main questions:

- To what extent do people with mental health problems know what their rights are when they access services?
- How well are services respecting people's rights?
- What are people's priorities for change?

The focus of this study was specifically on NHS and local authority mental health services.

Structure of this report

In the following chapter (Chapter 2), the methods used for undertaking this consultation are described. In addition, Chapter 2 also provides information about the range of people who participated in the consultation.

Chapters 3-5 present the findings of the consultation, focusing on each of the questions listed above in turn.

Chapter 6 sets out the conclusions and recommendations from the consultation.

2. Methods

This section provides a brief description of the consultation events. Events took place in six locations around Scotland. In each location, the intention was to hold two group discussions involving between 5-6 participants each, so that a total of 10-12 people were consulted in each area. Participants were recruited through local voluntary sector support services for people with mental health problems. Most of these services had a local remit for facilitating consultation among their clients.

The time and date of the consultation events were agreed with the service co-ordinator. In some cases, the time / dates were chosen to coincide with a regular meeting time of an existing support group. An information leaflet about the consultation was given to the co-ordinator who was asked to distribute this to potential participants. The information leaflet stressed that participation in the event was entirely voluntary, and that if individuals chose to participate, their identity would be protected.

Discussions were facilitated by the commissioned consultants and ran for between 1.5 and 2 hours, depending on the time each group had available. In addition, a note-taker attended each session.

Discussion focused on three questions, which relate directly to the research questions set out above in Chapter 1:

- What do participants think their rights are when they access mental health services?
- Which rights issues do participants think are not well-addressed by services?
- Which areas should be prioritised for improvement, and what specific changes would they like to see?

As part of the discussion, participants were given a definition of rights, and a list of rights which had been provided by the Mental Welfare Commission (see Box 1). These included the ten service delivery principles which provide the basis for the Mental Health Act as well as four legal rights. The definition of rights used in this consultation was:

Rights are legal, social or ethical principles of freedom or entitlement.

In the first part of the discussion, people were given a number of post-its and asked to note down on each post-it what they thought their rights were – with one right on each post-it. These post-its were then read out in turn and each perceived right was noted onto a flipchart by the facilitator or note-taker. Once everyone had read out all their post-its, they were then given a copy of the list of rights shown in Box 1. These were read out to the participants (in case any had reading difficulties), and the discussion focused on how people's *beliefs* about their rights related to those on the list.

The participants were then asked to say which of the rights issues on the list they thought were not being addressed well by services. The group's priorities for improvement were obtained by asking each member of the group to pick the two rights issues from the list which they felt services needed to address most urgently and to indicate these by placing a sticky dot against these.

Box 1: Your rights

You can expect that services will:

1. Take your past and present wishes into account
2. Make sure you get the information and support you need to take part in decisions. You have a right to make your own decisions where you can. Everything possible should be done to help you do this.
3. Take the views of your carer, named person, guardian or welfare attorney into account
4. Your carers' needs are taken into account and they get the information and support they need to help them care for you
5. Consider the full range of options for your care
6. Give you treatment that provides maximum benefit
7. Take account of your background, beliefs and abilities
8. Make sure that any restrictions on your freedom should be the 'minimum necessary in the circumstances
9. Make sure that you are not being treated less favourably than other patients
10. Take special care of your welfare if you are under 18 years of age

You have legal rights:

11. You have the right to advocacy, to appoint a named person and to make an advance statement about your treatment.
12. You cannot be treated in a way that is degrading or inhuman or causes unnecessary pain or suffering.
13. You have a right to privacy, e.g. having your own private space and belongings and ability to see who you want to see. Anyone who interferes with your privacy must only do this as far as they need to and must do it lawfully.
14. If you are deprived of your liberty, it must be legal and you have the right to go to a court or tribunal to ask for a review. Any court or tribunal must be fair. You have a right to be heard and legally represented. This is the Mental Health Tribunal if you are detained under the Mental Health Act.

This participative method represented a modified form of the nominal group technique. The nominal group technique has a number of advantages over a straight focus group discussion:

- It helps ensure that all members of the group (including the quieter ones) get an opportunity to share their thoughts.
- It allows people time to think in silence (which some people find easier) – and it gives people time to think about what they would like to say.
- It is a more comfortable process for sharing information within a group whose members may not all know each other.

- It provides a easy way of allowing the group as a whole to decide what the main themes are in the discussion.
- It provides a simple method of capturing people’s exact words.

In practice, the format of some of the consultations was slightly adapted. It was important to do so in order to ensure that discussions were not (unhelpfully) constrained by rigidly adhering to a set of ‘tasks’ and associated timings if these were not working well for particular groups or individuals, for example:

- Where groups were larger than had been expected, and so more time was necessary to ensure that everyone had their say; or
- Where some participants struggled to contribute to a task (often through concentration difficulties) but were able to express a view in response to more direct questioning by the facilitator.

This flexibility enabled the facilitators to maintain an outcome-focus – ensuring that the consultations led to the identification of participants’ views in relation to the questions above.

Consultation participants

As mentioned above, events took place in six locations around Scotland. These locations were purposefully selected to obtain a spread of Health Board areas (urban, rural and mixed). In each location, two groups took part in the discussions. The number of participants in each group ranged from 3 to 9. Altogether, 73 people (33 men and 40 women) took part in the consultation. See Table 2.1 below.

Table 2.1: Number of participants in each group

Area		Number of people		
		Men	Women	Total
Area 1	Group 1	6	0	6
	Group 2	4	3	7
Area 2	Group 1	3	6	9
	Group 2	3	4	7
Area 3	Group 1	2	2	4
	Group 2	2	2	4
Area 4	Group 1	3	4	7
	Group 2	1	5	6
Area 5	Group 1	2	6	8
	Group 2	1	2	3
Area 6	Group 1	2	4	6
	Group 2	4	2	6
Total	12 groups	33	40	73

Participants spanned a wide age range. All but two of the participants had a mental health problem and had had contact with NHS services over a long period. The remaining two participants (both from Area 1), were the carer of an adult child with a mental health problem, and a volunteer working with people with mental health problems. Two participants were from black and minority ethnic backgrounds.

No systematic attempt was made to gather more detailed information about participants and their history of service use. This was deliberate in order to keep discussions focused on rights rather than detailed accounts of people's (individual) experiences. However, participants often explained their views on rights by referring to their personal situation and / or experiences. As a consequence, it became clear that many of the participants had had one or more experiences of being detained under the Mental Health Act. In addition, a small number of the participants had complex needs. For example, one had a learning disability, one had autism, and some also had physical disabilities, including hearing or vision loss, dyslexia, communication difficulties and mobility problems.

3. To what extent are people aware of their rights?

This section presents an analysis of participants' comments to the first question in the consultation events: 'What do you think your rights are when you access mental health services?'

It was not unusual for participants to preface their responses to this question by saying that they didn't really know what their rights were, or that no one had ever explained their rights to them. However, while *individuals* were often unsure of what their rights were, the overall *group* response to this question generally identified (or roughly coincided with) many of the rights on the list provided by the Mental Welfare Commission. (See again Box 1 in the previous chapter.) At the same time, participants often stated that they believed that certain of their rights were "aspirational" – that is, they believed they *should* have certain rights, rather than believing that they actually had those rights.

The group responses to the question were remarkably consistent from one group to another, and the most commonly perceived rights focused on a relatively small number of inter-related themes. These were:

- The right to be heard and listened to
- The right to have information (about their care / treatment) and to make choices
- The right to protection from discrimination
- The right to be treated with respect / as a human being and as an individual.

Less commonly, the groups identified:

- Certain legal rights which they have under the Mental Health Act (the right to independent advocacy, to appoint a named person and to make an advance statement, etc.) and rights that they have under the Data Protection Act 1998 (for example, the right to see their own medical notes)
- Rights in relation to the nature and standard of treatment or care they receive.

Individuals rarely identified that:

- They had certain rights when they are compulsorily detained (i.e. the right to ask for a review and attend the Mental Health Tribunal)
- Their carers had rights (for example, a right to have their carer's views taken into account and the right of a carer to have support in caring for someone with a mental health problem).

Participants' comments in relation to each of these are described in further detail below.

The right to be heard and listened to

In response to the question, 'What do you think your rights are?' participants' responses frequently focused on the issue of being *heard* and being *listened to*. Examples of perceived rights offered by the groups included:

"The right to say everything you want to say"

“The right to be listened to properly”

“The right to give your views”

“The right to speak up”

“The right to have a voice”

“The right to make a complaint (to have it dealt with seriously, and to know the outcome)”

“The right to have your choices (or wishes) respected”

“The right to have your opinions taken into consideration”

Such comments were largely seen by participants as coinciding with the first and / or second principles from the list of rights which state: (i) that services should take your past and present wishes into account; and (ii) that you have a right to make your own decisions where you can. These rights are not legally enforceable.

While the right to an advance statement is intended as a mechanism to allow patients to be ‘heard’, it was notable that the participants in this consultation less commonly identified these statements as a right (see section below on legal rights).

The right to have information and make choices

A second major theme arising in participants’ responses to the question, “What do you think your rights are?”, related to a right that people felt they had to be *informed*. In addition, this right to information was closely linked to a right to make *choices* on the basis of the information received. Examples of perceived rights offered by the groups include:

“The right to be informed about all aspects of your care”

“The right to know about the side-effects of treatment – short and long term”

“The right to understand the medication you’re being given”

“The right to have treatment explained and be kept up-to-date”

“The right to know what to expect in hospital”

“The right to information about other services”

“The right to choose what treatment you get”

“The right to have input to my care”

“The right to say ‘no’”

“The right to a second opinion / the right to change your psychiatrist”

“The right to refuse treatment or a drug that might harm me”

“The right to have my rights explained”

Such comments were seen to relate to three of the principles that underpin the Mental Health Act: (i) that services should make sure people get the information and support they need to take part in decisions; (ii) that services should consider the full range of options for a person’s care; and (iii) that services should give people

treatment that provides maximum benefit. Again, these are not legally enforceable rights.

The right to protection from discrimination

A third main theme arising in participants' responses related to the right to be protected from discrimination. These perceived rights often highlighted people's awareness of the stigma of having a mental health problem (and the right to be treated in a non-stigmatised manner), but they also pointed to other equalities issues in relation to which people might be subject to unfair discrimination.

"The right to not be judged" (because they have mental health problem)

"The right to be taken seriously and not fobbed off" (because they have a mental health problem)

"The right to be treated the same as any other patient / as any one else"

"The right to be treated fairly"

"The right not to be treated worse than younger people" (this statement was made by someone aged over 65)

"The right to express my spirituality"

The right to be treated with respect / as a human being / as an individual

One of the most common responses to the question, "What do you think your rights are?", focused on the more general human right that people believed they had, to be treated with a respect. This perceived right was often expressed by people in different ways:

"The right to be treated with dignity / civility / honesty / compassion"

"The right to be treated as an individual and seen as an individual"

"The right to be treated like an adult"

"The right to have my views respected"

"The right to be treated with respect and be believed"

"The right to be safe" (this statement referred to physical safety, particularly in hospital, where some people did not feel safe).

The groups tended to see these rights as related to the idea that people should not be treated in a way that is degrading or inhuman or which causes unnecessary pain or suffering.

Legal rights

In addition to the four main themes described above, a number of less common themes could also be identified in participants' responses to the question: "What do you think your rights are?" For example, few respondents identified their *legal* rights to have an independent advocate, nominate a named person, make an advance statement about their treatment, or appeal to the Mental Health Tribunal regarding a decision of compulsory detention. Those who *were* aware of these rights were generally people who had experience of working with an advocate, nominating a

named person, or making an advance statement. However, few respondents had this experience, or were even aware of what a named person or advance statement was. One individual expressed the opinion that, *“When you’re sectioned, you have no rights at all.”*

Participants also identified some rights which they had under the Data Protection Act, rather than the Mental Health Act. For example, *‘the right to view my records’, ‘the right to confidentiality’, ‘the right to know what information about me is shared with others’.*

The nature and standard of care

Another less common theme in people’s responses related to the nature and standard of care that they felt they should be able to expect from services – in particular, the type of services they thought they needed in order to feel well. For example:

“The right to get services that meet my needs”

“The right to have access to a psychiatric nurse / keyworker / psychologist”

“The right to be admitted to hospital when I feel I unwell”

“The right to a peer support group”

“The right to a recovery service”

“The right to correct support in the community”

“The right to expect punctuality” (from care workers in the community)

“The right to continuity of care”

These perceived rights were often seen by participants as relating to the principle that services should give treatment that provides maximum benefit, not just in the short term (when in hospital) but following discharge and in an ongoing way. These responses indicate that participants do not compartmentalise the treatment / care they receive from statutory services. Rather they see all support services they receive as contributing to their care, treatment, and (potentially) recovery, in a more holistic way.

Rights for which there was a general lack of awareness

It was rare for any of the groups to believe that they had rights which related to the following issues:

- Right to privacy – although occasionally the groups saw the “right to confidentiality” as related to a right to privacy
- Right to appeal a compulsory detention order and attend a Tribunal.

In addition, it was uncommon for the groups to identify that their carers also had certain rights (i.e. to have their views taken into account, and to have their needs taken into account).

4. How well do services respect people's rights?

The second main question this project sought to answer was, "How well do mental health services respect people's rights?" To explore this question, consultation participants were asked to consider the list of rights they had been given and to say which issues they felt services were doing well with, and in which areas services needed to improve.

The individuals who took part in the consultation generally found this question difficult to answer – mainly because they saw the question as too black and white. In addition, the complexity of people's lives and their experience of services made it impossible for them to comment on NHS or local authority services in isolation. Moreover, even where individuals could focus solely on *hospital* services, for example, their comments indicated that there was a great deal of variation in whether people felt that services respected their rights. Participants often made general comments such as: "*Sometimes they do*", or "*It depends on the individual*", or "*Things are getting better.*" Moreover, there was a recognition that services often had to deal with very unwell and challenging individuals and that ongoing budgetary pressures and high staff turnover were affecting the ability of services and staff to deliver high-quality care and treatment.

Participants frequently gave examples from their own recent experiences to support their views. These included examples of positive experiences which illustrated the ways in which services can and do treat people with respect.

Positive experiences

There was general agreement among participants that "*there are some tremendous people in the health service*" who give good information to their patients, who routinely involve them in decisions about their care and treatment and who are prepared to explore options for improving wellbeing.

Participants gave examples of being able to discuss their medication with their psychiatrist and agreeing changes in medication which produced fewer side-effects. One individual spoke of being referred to a third sector support group which helped to improve her confidence. Others felt that their current care packages met their needs well, and that the individuals involved in providing that care were supportive and helpful. Still others spoke about the positive relationships they had with GPs, psychiatrists or psychiatric nurses. Such comments suggested that consultation participants saw positive relationships as closely linked to the issue of rights since those who had positive relationships with their doctors, nurses or care workers tended to feel that their rights were better respected, i.e. that they were active participants in decisions about their own care and that they were treated as individuals.

Notwithstanding these positive experiences, overall, participants in this consultation did feel that there was more that services could do to ensure that the rights of people with mental health problems were protected. Comments tended to focus on a need for improvement specifically in relation to:

- The process of being compulsorily detained and

- The extent to which certain service delivery principles are put into practice by mental health services (in particular, giving people information so that they can take part in decisions about their own treatment and care; offering options in relation to treatment; and giving treatment that maximises benefit).

Other issues were raised less often. However, when specifically asked how well services were addressing the rights of carers, participants generally felt that this also was an area for improvement.

The process of being compulsorily detained

In the main, the individuals who took part in this consultation expressed dissatisfaction about the process of being compulsorily detained in hospital. Participants accepted that there were situations in which people might sometimes *need* to be treated compulsorily to keep them safe, acknowledging that doing so was actually a right (e.g. a right to life). However, they also felt very strongly that the process of keeping people safe should not result in them feeling terrified, degraded or humiliated – which was the experience that many had.

Participants' experiences of being compulsorily detained were linked, in their view, with a feeling that people in this situation are often treated in ways that are degrading or inhuman and which cause unnecessary pain or suffering.

Individuals spoke about the distress they felt at being forcibly and publicly removed from their homes; the feeling of powerlessness which resulted from being restrained and injected with drugs; the fear felt by some that they may be given certain types of treatment against their will (electroconvulsive therapy (ECT) was mentioned); the distress of seeing and hearing other hospital patients being restrained and injected; and their bewilderment about hospital rules and routines.

The experience of acute distress from being detained in a police cell was also highlighted. In addition, some participants talked of experiences of the police man-handling them and threatening them, e.g. that they would be put into a strait-jacket to calm them down.

Some reported that, upon being compulsorily detained, they were not seen by a consultant for several days, and meanwhile were given no information about how long they were likely to be in hospital. This resulted in people feeling extremely anxious about what would happen to their children or their home in their absence, and whether they might lose their tenancy if the rent was not paid. However, attempts to bring these justifiable concerns to the attention of hospital staff often appeared to them to be not taken seriously.

Others reported being given no information about how the hospital ward operated except from other patients. Participants gave examples of the humiliation they felt – or the sympathy they felt for other patients – because they did not realise they could request clean clothes and underwear while being detained in hospital. Others spoke of feeling unsafe because of the mix of patients on the ward (i.e. including some people who were very unwell, or who were being detoxed from drugs / alcohol).

As noted in the previous chapter, few of those who took part in this consultation appeared to be aware of their *legal* rights to have an independent advocate, appoint

a named person, make an advance statement, or ask for a review of a compulsory detention order.

When asked the question, “How well do services respect people’s legal rights?” few of those who had a recent experience of being compulsorily detained could recall anyone explaining their rights to them, and it was rare for any of the participants to say that they had experience of successfully appealing against a detention order. Furthermore, participants in this consultation suggested that if someone *had* read their rights to them upon admission to hospital when they were acutely ill, they would have been unlikely to take in or act upon this information. Even among the relatively small number of participants who *knew* what their rights were, most reflected that they were far too ill at the time they were detained to be able to ask for assistance from an advocate, or to request a review of the decision to admit them to hospital.

Such comments highlight the inherent difficulty of ensuring that people’s rights are protected when they are being compulsorily treated – even though there is a good legal framework in place to enable this to happen. These comments also raise questions about when is the correct time to inform people of their rights, whether people need to have their rights explained to them on more than one occasion, and how best to support them to claim their rights.

In contrast to the largely negative views that people had about the process of being compulsorily admitted to hospital, examples were given of more positive experiences of being admitted to hospital in a planned way. One individual recounted an occasion when she had become increasingly unwell, and she was given a choice by a CPN with whom she had a positive relationship. The choice was to either go into hospital voluntarily, or to be compulsorily admitted. This individual recognised that she was being given no choice about whether to go into hospital. However, the process felt less fraught and more positive than a compulsory detention because it seemed from her point of view to be a planned admission.

This example was unusual, however. More often, participants said they often knew they were becoming unwell but found it difficult to arrange for admission to hospital when they felt they needed it – until they were so unwell, they had to be admitted in a crisis or through a detention order.

Putting the principles into practice

The other areas in which participants in the consultation felt there was a need for improvement were in relation to being given a “full range of options for your care” and being given “treatment that provides maximum benefit”. These comments tended to relate to care provided both in hospital and in the community. As mentioned in the previous chapter, these two principles were often linked in the minds of participants, and in further discussion, it became clear that these issues were also closely linked to the idea that people with mental health problems should have information in order to be able to be involved in decisions about their own care and treatment.

Some individuals commented that they were often given information about a specific treatment (in particular, medication) which was recommended by a psychiatrist, but they were not always offered an alternative. In such cases, people felt they had no real choice or opportunity to be involved in decisions about their own care. There was an acknowledgement that the mental health team may be the best judge of what

treatment will provide maximum benefit, and for the most part, people were willing to trust the experts in this matter. At the same time, however, people did not feel empowered to question or challenge decisions taken by medical professionals, even when they did not feel happy about them.

Participants in all groups recognised that for some people, coming off medication may not be an option. Nevertheless, people felt that other therapies (e.g. talking therapies), could be used positively alongside medication to achieve maximum benefit. However, these were reported to be seldom offered, or to be offered for only short periods of time.

Participants in some groups expressed concern about the idea that services should be expected to take their past, as well as their present wishes into account. The point was made that services were sometimes slow to recognise and acknowledge that people had changed and were recovering, particularly in cases where there had been a history of substance misuse.

Some individuals recounted experiences in which they had complained (either about the way they had been dealt with in hospital or in the community). However, they were often not believed because they were considered to be unreliable, which left them feeling dissatisfied about the outcome of their complaint. Others chose not to complain at all (including in cases where they felt they were being bullied by staff) for fear they would be seen as trouble-makers. This was particularly an issue for people as inpatients when they worried that complaints might result in less favourable treatment. These issues compounded their sense of disempowerment.

The rights of carers

As noted in the previous chapter, it was rare for participants in this consultation to be aware that their carers had certain rights: i.e. the right to have their views taken into account, and to be given information and support to help them in their caring role. However, when asked specifically how well services were taking into account the rights of carers, participants saw this as an area for improvement.

Those (few) who had some experience of nominating a named person generally had more favourable experiences in this respect. However, it was more common for people to report that their carers were often excluded from discussions and decisions for reasons of “patient confidentiality”. At the same time, participants felt it was correct that services did not *assume* that patients would be happy for information about them to be shared with their relatives without their consent. One individual talked of the distress and sense of violation experienced when a family member was given details without the patient’s consent as this had a marked impact on the nature of their subsequent relationship.

There was some confusion on the identification and process of involving carers. In particular, some participants believed that if an individual had not nominated a named person, then their next of kin would automatically be considered to have the

role of named person. However, others pointed out that this was not their experience.⁵

Other issues

Some respondents made comments about other types of services, including support services in the third sector, housing support services and the police, and suggested that these types of services should also be required to respect the rights of people with mental health problems. Again, these views indicate that people do not see statutory NHS and social services in isolation, but rather see other community-based services as integral to their care and support package.

There was also a sense among some participants that the rights of people with mental health problems (and indeed other disabilities) were continually being eroded by government policies such as welfare reform, which were resulting in the loss of entitlements and support services.

Another issue raised less frequently was that some participants felt that they should have the right to smoke on hospital premises when being detained since, in that time the hospital ward was effectively their home.

⁵ According to the Mental Health Act (Scotland) 2003, if a “named person” is not nominated, an individual’s primary carer is considered by default to be their “named person”. If the person has no primary carer, their nearest relative would be considered as their “named person”.

5. What are people's priorities for action?

The third and final question this project sought to answer was, "What are people's priorities for action?" In particular, which rights issues do people feel need to be addressed most urgently by services.

Across all twelve groups, the rights that were prioritised by participants in this consultation were the following:

- "You cannot be treated in a way that is degrading or inhuman or causes unnecessary pain or suffering."
- "Services should make sure you get the information and support you need to take part in decisions. You have a right to make your own decisions where you can. Everything possible should be done to help you do this."
- "Services should consider the full range of options for your care."
- "Services should give you treatment that provides maximum benefit."

In relation to the first point, there was a feeling that services needed to do much more to demonstrate that they were treating people as individuals, with respect and dignity. Participants re-iterated earlier points made in the discussion that service providers should "*treat people as people, not as illnesses*".

The latter three points, as previously discussed, were often seen by participants to be linked to a more general idea that people should have the right to be actively involved in their own treatment and the management of their condition. This includes being heard and listened to, and making available to people with mental health problems a wider range of services – both NHS and community-based – which provide support and / or therapeutic benefit.

It was also a general feeling across all groups that action needed to be taken so that people with mental health problems are better informed about what their rights are.

Beyond this, participants in this consultation made few other suggestions about specific actions that services could take to improve their focus on rights in these particular areas. The suggestions that *were* made included the following:

Suggested actions regarding compulsory detention and treatment

- Formal procedures should be reviewed in relation to the use of restraint, compulsory treatment / injections, and the process of forcibly removing someone from their home. Less public methods should be used as much as possible, not only to protect the dignity of the individual being detained and treated, but also to reduce the alarm and distress caused to other acutely ill patients in hospital who may witness others forcibly restrained.
- There should be a change in the timing of telling people about their rights when they are compulsorily detained. This shouldn't happen just once, but may need to happen several times over several days as people cannot always take in the information when they are acutely ill.

Suggested actions regarding the delivery of services in hospital

- A list of patients' rights should be displayed prominently in hospital wards.

- In hospital, a member of staff should take responsibility for explaining to newly-admitted people what the ward rules and routines are. Again, this may need to happen on more than one occasion or over several days, so that people have time to absorb the information and are given an opportunity to ask questions. Alternatively, an information pack could be given out to people when they arrive in hospital which they could read (or be given help to read) when they want to.
- There should be greater use of peer mentoring, particularly in hospitals. The participants in this consultation suggested that they often learned more from others in the same situation, rather than from professional staff.
- Talking therapies should be made more available – not only in hospital (some participants said there was not enough “talking time” with the nurses in hospital) – but also after a person was discharged home. This was linked to another suggestion that it was important for professional staff to spend time with patients, especially at the early stages of a mental illness, when people are confused and frightened about what is happening to them.
- There should be the option to change from one psychiatrist to another. People consider that it is important to establish a trusting and therapeutic relationship with a psychiatrist.
- Hospital staff should be given training to understand what the rights of their patients are.
- Staff (both in hospital and in the community) should ensure they have read a patient’s advance statement (if there is one) and be more proactive in asking people about these.

Suggested actions regarding the nature of care and support in the community

- People should be put in contact with support groups in the community as these provide a safety net, help people gain confidence and encourage people to get out of their own houses.
- Care workers should show up for appointments on time, rather than expecting people to wait in all day for them.
- Service providers should have more of an appreciation for the whole person – and provide the type of help / support for people to enable them to live more independently. One specific example was that if a particular treatment had a side-effect resulting in weight gain, then services should be in place to counteract that side-effect (i.e. gym passes).
- Service providers need to allow people to move on. It is unnecessary to keep bringing up events from the distant past.
- Service providers should ensure that people have support systems in place in the community when they are discharged from hospital. Some participants suggested that it was often left up to them to arrange support in the community, rather than having a discussion with anyone about what support they needed.

One participant suggested simply that services should always focus on and plan for recovery.

6. Conclusions and recommendations

The purpose of this consultation was to answer three questions:

- To what extent do people with mental health problems know what their rights are when they access services?
- How well are services respecting people's rights?
- What are people's priorities for change?

Each of these questions will be considered in turn. However, it is important to note that this was a relatively small-scale study which sought the views of people in six different areas of Scotland, and as such, was commissioned as a step in a wider process of insight gathering.

The study did not seek the perspectives of service providers. Therefore, we cannot draw firm conclusions about the extent to which statutory services in different parts of Scotland are, or are not, respecting the rights of their patients / clients.

To what extent do people with mental health problems know what their rights are?

The findings indicate that very few of the individuals who took part in this consultation knew what their rights were. This was the case even among those who had experience of being hospitalised, including through compulsory detention, because of a mental health problem. This finding was surprising in view of the fact that people were recruited to take part in the consultation through mental health support groups. No information was gathered about the frequency with which participants actually attended these groups, nor indeed the extent to which these groups were facilitated. However, it might be expected that overall, individuals involved in such groups would be **more** informed about their rights than people who are not, that is, the general population of people with mental health problems.

It is worth noting that not *all* of the participants in this consultation had little awareness of their rights. At a group level, the participants in one area of Scotland appeared to be very well informed about their rights. The particular group through which these participants were recruited has a very active member engagement programme. In addition, this group frequently participates in national mental health policy-making initiatives. In other groups, it was striking that those individuals who could articulate their rights most clearly often had some sort of service provider role (either currently or previously) as well as a service user role. Examples included a volunteer advocate, those with carers' roles and those involved in the delivery of other types of services (i.e. non-mental health services).

How well are services respecting people's rights?

In relation to the question of whether services are respecting people's rights, the individuals who took part in this consultation suggested that positive changes have been made in recent years. However, participants often linked their (recent) positive experiences to good relationships with particular care providing *individuals*: that is, those who tended to feel they were consulted about their care and that their views were taken into account usually attributed this to the good relationship they had with

an individual doctor, nurse or care worker. As many said: “*It depends on who you get*”.

The findings of this study indicate that there continues to be considerable variation in the extent to which people with mental health problems feel that their rights are respected by statutory services. Specifically, people who took part in this study from around Scotland consistently voiced dissatisfaction with the *process* of being compulsorily treated / detained – although not the *principle* of compulsory treatment / detention, which most believed was necessary in situations where people had become very unwell and could no longer care for themselves. The *process* of being detained was frequently described as inhuman and degrading.

It is notable that very few of the individuals who took part in this consultation had any experience of exercising their legal rights to independent advocacy, to nominate a named person, to make an advance statement and to ask for a review of a decision regarding compulsory treatment. As mentioned above, most were simply unaware of these rights, and could not recall having had them explained by anyone.

The other areas about which people consistently expressed dissatisfaction were in relation to: (i) being given sufficient information to be able to take part in decisions about their care / treatment and (ii) being given options other than (or in addition to) medication. Participants perceived that because they were being given only one option (that is, medication), they questioned whether services were addressing their right to treatment that provides maximum benefit.

In many cases, the experiences recounted by participants could be viewed as *neglect* of people’s rights, rather than *abuse*. However, it should not be the case that the protection of a person’s rights “*depends on who you get*”.

What are people’s priorities for change?

The participants in this study saw the main areas for improvement as follows:

- Actively involving people in discussion and giving people choices: Although some of the people who took part in this consultation suggested that they were routinely taking part in discussions and decisions regarding their mental health and wellbeing, others clearly felt that they were not being listened to or heard. However, more importantly to them, they felt they were neither involved in discussions about, nor given much in the way of choice (or even input) in relation to their treatment.
- Respecting people as individuals: The participants in this consultation wanted to be viewed as individuals first and foremost, not as mental health patients or as ‘service users’, but as people. Participants called for greater support to lead a good life irrespective of their mental health problems. In doing so, they highlighted the need for more recovery-focused support that addressed their holistic (not just mental health) needs and which actively involved them in the process of their care. Those who had experience of such support, most commonly provided from third sector organisations, valued this highly.
- Protecting people’s dignity in those situations where they cannot exercise decision-making power: Participants accepted that when they were acutely ill,

others would have to take decisions for them. However, their main concern in these situations was that their human dignity was respected.

While not specifically identified by people as priorities, the fact so few people knew about their legal rights under the Mental Health Act suggests that these should also be seen as priority areas for action.

Carers' needs for information and support were also not prioritised by the groups because there were very few carers participating. However, among the carer participants, this was seen as a high priority.

Recommendations

The main recommendation to be made from this study is that **there should be better information available to people with mental health problems and their carers about their rights**. The systems and legal entitlements (e.g. independent advocacy, advance statement, etc.) which have been put in place to protect people's rights through the Mental Health Act are not well understood by those whom they are intended to benefit. At present, the law requires that information is given to people about their rights at the point at which they are compulsorily detained. However, the findings of this study suggest that people need to be informed of their rights on more than one occasion during their stay in hospital, as they are often too unwell when they are admitted to be able to take the information in.

This information should be made available through a variety of ways, such as leaflets in primary care services, psychiatric units, discussions with hospital staff, or a statement posted in a prominent location in hospital wards. Such information should highlight not only legal rights but also the wider suite of rights that services should be respecting (as detailed previously in Box 1). The Charter of Rights for People with Dementia and their Carers in Scotland might offer a useful starting point or template for this.⁶

At the same time, a leaflet or a statement of rights by itself is insufficient: people need to know what their rights would look like in practice. There is a need for rights to be brought alive by giving people examples that they can relate to.

In addition to a need for information, there is a need for patient and carer education. It is recommended that the Mental Welfare Commission explore options for the development and delivery of this type of education. One way of doing this might be to work together with the third sector to develop a short educational session for people who are involved in support groups. This should complement written information such as that described above. While this type of education is perhaps already being delivered by some third sector organisations, the findings of this study suggest that this is not widespread.

⁶ See <http://www.dementiarights.org/charter-of-rights/>

In addition (and if feasible), attention should be directed to reaching individuals who are not in touch with support groups, e.g. through the development of podcasts and signposting people to these.

Regardless of the mechanism (or mechanisms) used, it is important that **information and educational material should make use of the same language people use themselves to refer to their rights**. In relation to this, the Mental Welfare Commission may wish to refer to the quotes provided in Chapter 3 of this report. In addition, this material should be tested out with the people for whom it is intended – i.e. people with mental health problems – prior to having it rolled out.

While there is evidence from elsewhere to suggest that services in Scotland have improved their focus on the rights of their patients over the past few years,⁷ the findings of this study suggest that there is still a great deal of variation, and there needs to be ongoing training of staff about this issue. There are obvious links between the rights agenda and the recovery agenda, particularly in relation to empowering people to be actively involved in decisions about their care and working with people to support their own goals. In view of this, **the Mental Welfare Commission could usefully strengthen its links with the Scottish Recovery Network (SRN) and identify opportunities to address shared agendas**. The Scottish Recovery Indicator, in particular, may offer a useful tool, with some refinement, which services could use to reflect on how well they are doing not only in recovery practices but also rights-based ones. In addition, the SRN has played an important role in supporting the roll-out of WRAP training (Wellness and Recovery Action Planning) at a local level. Among other things, WRAP helps people with crisis planning – including the preparation of an advance statement.

Other very practical suggestions for changes in the way services are delivered in hospital and the community have been made by the participants in this consultation, and are listed in Chapter 5. Not all of these suggested changes are within the remit of the Mental Welfare Commission. However, it is suggested that the Mental Welfare Commission should consider which of these suggestions it may be able to implement, or incorporate into its inspection work.

⁷ Griesbach, Russell, Lardner & Gordon (2010) *Evaluation of the Scottish Recovery Network*. Scottish Government. Available from: <http://www.scotland.gov.uk/Publications/2010/12/16111855/21>.