

**Submission to the Scottish Government Health  
Department in response to its public  
consultation on a Patients' Rights Bill for  
service users of the NHS in Scotland**

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This submission is made on behalf of the group of individuals who attended a consultation event organised by Gengage and the Genetic Interest Group on 9<sup>th</sup> December 2008. It does not necessarily represent the views of either of these organisations.

We are happy for the contents of the response to be made available to the public via the Scottish Government library and website. We are also happy to be contacted in the future in relation to this consultation response.

## 1. Summary

This paper brings together the views of more than sixty participants who attended a consultation event organised by Gengage and the Genetic Interest Group (GIG). The event took place in Edinburgh on 9<sup>th</sup> December 2008. Gengage has put together this report on behalf of the participants and presents it to the Scottish Government in response to its public consultation on a Patients' Rights Bill for service users of the NHS in Scotland. It aims to reflect the points which participants made during the course of the day and does not represent the views of either Gengage or GIG. GIG will be submitting a separate document which reflects the view of its organisation.

### 1.1. The consultation event

At the event, participants were invited to discuss the consultation document on a Patients' Rights Bill for service users of the NHS in Scotland. Both Gengage and GIG have a particular interest in healthcare genetics as did many of the participants. The participants were encouraged to consider the particular implications of the bill for healthcare genetics within the context of their wider experience of the NHS.

### 1.2. Description of discussions

For the purposes of describing the discussions, the main comments which participants made have been grouped under four headings and the key points in each section have been summarised below. The wide range of issues which participants raised and the points they made is described in detail later in this paper. An appendix is also provided at the back of the paper which indicates which of the consultation questions were addressed by participants and whereabouts in the paper further details about their views can be found.

Participants made the following points about the bill and what would need to happen to see it become a reality. They felt that the bill should:

#### **Create a partnership between patients, their families and carers, patient organisations and the NHS**

- The NHS should address the concerns which sometimes prevent people from complaining.
- There should be a "no blame culture" and mistakes should be learnt from.
- Patients and their family and carers want to work in partnership with the NHS but time and opportunity must be given for this to happen in practice.
- The support of an advocate can be very valuable to a patient and should be a right in the bill.
- The expertise and knowledge which patients and their families often have of their condition should be valued.
- NHS staff should also be included in decisions about service provision.
- Information about the NHS and how it works should be provided to patients.

## Recognise the individual and their specific needs while also working with families

- Waiting time guarantees should allow sufficient flexibility to meet the individual needs of patients with genetic conditions.
- The right to appropriate specialist services and a specialist opinion, even when the condition is very rare, should be included in the bill.
- The needs of all service users should be met with dignity and respect. The barriers which different cultures, languages and disabilities can present must be overcome.
- It is important to communicate with families and carers as well as patients. Where the patient is a child, he or she should also be included in discussions about care.
- Participation should be a right not an obligation.
- The bill should recognise that there may sometimes be conflict between the rights of one individual and those of another family member and make specific reference to genetic information.

## Deliver care which is equitable

- Transport and other improvements need to be made to ensure that patients who live in more rural parts of Scotland enjoy the same access to services as those living in the major cities and towns.
- Healthcare professionals should be competent and have up-to-date training; “you can have the right to anything but if the healthcare professionals don’t have the appropriate skills then that right is meaningless.”
- Information should be provided for all patients to help them understand and manage their condition including those with rare conditions.

## Provide a holistic care package

- The bill places emphasis on a patient’s rights in a hospital setting. More reference should be made to the rights which patients need in other areas such as social care, education, employment, relationships and housing.
- For care to be safe and effective it must be “linked” or “threaded” together. It is essential that there is good communication between professionals who work together to provide a package of care for each individual patient.
- Many participants were keen to have a named contact that they could go back to if they had any questions and who would help coordinate their care.
- Safe and effective care should not be a right but a given of NHS services.
- The psychological and emotional as well as the physical needs of a patient should be addressed.
- Providing medical information about a condition at the time of diagnosis isn’t enough. Patients need to know where to find practical information which will help them to manage their condition on an on-going basis.
- It should be easy to feedback positive experiences as well as complain.

## 2. The consultation event

This report records the discussions which took place at an event organised by Gengage and the Genetic Interest Group (GIG) on 9<sup>th</sup> December 2008. The event was held in central Edinburgh and organised both to mark the launch of Gengage and the GIG Patient Engagement Network and to give those with an interest in healthcare genetics the opportunity to comment on the Scottish Government's public consultation on a Patients' Rights Bill for service users of the NHS in Scotland.

### 2.1. Participants

More than sixty people took part in the event. The majority of participants were patients, their families and carers and representatives of patient organisations with a particular interest in genetic conditions. A number of NHS staff members (mostly, although not exclusively, from clinical genetic services), university academics and laymen with an interest in genetics also attended the event.

### 2.2. Structure of the day

At the start of the day, Fiona Montgomery from the Scottish Government Health Department gave participants an overview of the bill. Participants then discussed in pairs, then small groups and eventually with the whole room what aspects of the bill they liked, if there were any aspects of the bill that they didn't like and if they felt there were any issues that were missing from the bill.

In the afternoon, participants took part in a "world café" where participants moved between tables to discuss three of the eight rights in the bill or whether any rights might be missing in detail. These table discussions took place in three half-hour facilitated, small group discussions. Throughout the afternoon and morning sessions the facilitators took full notes of the discussions which have been collected and presented in this report.

### 3. Description of discussions

The facilitators' roles were to keep the conversations going and involve all those who wished to speak, while making limited interventions to allow participants to discuss whichever aspects of the bill they wished. During the event it became clear that there were a number of themes emerging across the tables which had implications for the bill both in terms of its content and implementation. This paper reflects the four major themes which emerged in the day's discussions.

Throughout the day it was evident that participants welcomed the opportunity to contribute to the consultation. They saw this as an opportunity to share their experiences and thereby improve the experiences of all. In general, participants saw it as helpful that these rights were recognised and hoped that the bill would improve the experience of NHS users.

As part of the morning's discussions, one group asked whether the new bill would duplicate existing legislation. They felt that it was important to place the bill in the context of existing legislation and to ensure that it doesn't become an additional burden on the NHS.

In spite of the general support for the bill, there were concerns about its implementation. Participants wondered how the government was going to make sure that it "has teeth" and that its content is enforced. They did not want to see it become a document which gathers dust on the shelf nor a mere tick-box exercise.

#### 3.1. Create a partnership between patients, their families and carers, patient organisations and the NHS

Many participants expressed a wish to see healthcare professionals, patients, their families and carers and patient organisations working in partnership to manage and treat conditions. There was a strong sense from patients that they often had a great deal of expertise about their condition which they would like to see valued and used by the healthcare professionals treating them. They wished to work as an equal partner in discussions and decisions about their health and that of their families.

Participants spent a considerable part of the day discussing the poor experiences they had had in the NHS, not so much to do with the clinical care but bad communication and information. It was suggested that the NHS could easily develop case studies of good and bad practice to give staff ideas on how best to communicate and provide information at the time of diagnosis. A number of examples of bad practice, identified by participants, are given below:

- Being re-assured that nothing was wrong and then getting the diagnosis that something was amiss

- Not being given the information as soon as it was available
- Giving diagnosis on a Friday afternoon and leaving patients with no-one to talk to about their concerns over the weekend
- Giving diagnosis by letter rather than being told personally, sometimes many years after their initial consultation
- Professionals making off-the-cuff remarks without realising that they may upset patients

This desire to work in partnership came through in many comments, with participants agreeing that “communication has to be a two-way street” and that what they wanted was “communication that’s in partnership.” There was also a feeling that more could be done to make the relationship between the patient and healthcare professional more equal which was reflected in comments such as “information empowers people.”

<b>Respect</b>	<p><b>Recognise that patients can sometimes get angry with good cause or that their distress can be misunderstood as anger</b></p> <p>Health workers can sometimes wrongly interpret patients’ distress as anger, especially when the patient cannot speak good English. Patients do get angry, sometimes with good reason, if they are suffering and think they are not being listened to. It was felt by some participants that the bill needed to acknowledge this.</p>
<b>Safety</b>	<p><b>Learn from mistakes and avoid a blame culture</b></p> <p>An NHS staff member commented that a “blame culture” is damaging to the trust that needs to exist between the patient and health worker. It can also mean that mistakes go unnoticed and that they are not made use of by learning how to avoid them in the future. It is, therefore, important to respect and listen to complaints and make sure there is a “no blame culture.”</p>
<b>Communication</b>	<p><b>Value patients’ and their families’ expertise and knowledge of their condition</b></p> <p>Participants felt that patients, particularly those with genetic conditions which are often rare, can offer knowledge and expertise of their condition which is not always fully used by the healthcare professionals treating them. There is sometimes an assumption amongst healthcare professionals that patients have no knowledge of their condition and even a sense of resentment when patients have found information for themselves. This point was illustrated by one participant who explained how he, as a parent, knew that his children often got chest infections. He, therefore, asked if they could have the flu jab. However, because an increased tendency to get chest infections was not a known aspect of the condition, the doctor dismissed this piece of information. Parents should feel that they can voice all their concerns and observations and not be ignored. There also needs to be a change in attitude so that patients don’t feel “[they] are damned if [they] do and damned if [they] don’t” take responsibility for improving their own knowledge of their condition.</p>

### Provide information about the NHS and how it works

Participants recommended that information should be provided to explain the NHS and how it works to service users. A number of examples were given of how this would benefit both patients and the NHS.

- Specialist nurses have an important role and do a great job but a lot of people don't know what they are there for. It would be helpful to communicate their remit and role to patients.
- Sometimes people are referred to genetic counselling but do not attend. This can be because no-one has explained why they should attend and they fear having yet another person interfering in their lives.
- One participant mentioned a recent study which showed that people from socially deprived backgrounds don't attend appointments because they don't understand why they've been referred. The cost to the NHS of these wasted appointments and to the patients of not receiving the care they need was discussed.
- "You can only access something which you are aware exists"

### The right to an advocate should be included in the bill

The benefits of advocacy for patients when they are in a potentially vulnerable and confused situation came up a number of times and in relation to various aspects of the bill. It was thought that the inclusion of a right to the support of an advocate could prove a useful addition to the bill. Both NHS staff and patients agreed that advocacy can help a great deal in ensuring that patients are treated with respect. However, the potential need for advocacy must be recognised in advance so it can be arranged. A patient's notes should flag up if advocacy is likely to be needed. Advocates can also provide support for the patient after the event which can be useful in helping them get over any trauma that has occurred.

### Create "forums" which allow patients and the NHS to work in partnership

When asked, participants were happy with the bill giving patients the responsibility to provide information about their history, current treatment medication and alternative therapies directly or through their family, carer or other nominated supporter. However, they felt that it was important that patients be given the "forum" to do this. There is a need for time during a consultation to allow information to be given and for healthcare professionals to help patients say things which they may find difficult; patients sometimes don't know how to say what they need to say. It was also felt that patients were often asked to repeat a lot of information when this might not be necessary.

## Participation

### **Include NHS staff in decisions about service provision**

Individuals from the NHS felt that they were often not given sufficient opportunity to participate in decisions about service provision and that much of their expertise or insight into service provision was consequently wasted. They felt that decisions about service provision should involve all who have an interest in the provision of healthcare services, including NHS staff.

## **3.2. Recognise the individual and their specific needs while also working with families**

“Professional health workers sometimes see a condition, not a whole person.”

A patient

The nature of genetic conditions, particularly when they are rare disorders, means that patients often have very specific needs to be met. Participants repeatedly raised the importance of adapting services to meet these individual needs and not to make patients “fit in” with a particular method of service provision.

Alongside this, participants made the point that “genetic conditions are family conditions” and that there was a need for services to work with families as well as the individual patient. This raised questions which are perhaps particular to genetics where respecting an individual’s right to confidentiality may actually breach the rights of their family members to receive care.

Participants welcomed the acknowledgement in the bill that care should be responsive to the individual circumstances of a patient and highlighted a number of areas where they felt more work was needed to ensure that this right was respected. A number of groups of patients were specifically mentioned by participants as individuals who would benefit from the NHS giving more consideration to their particular needs.

## Access

### **Include access to appropriate specialist services and a specialist opinion in the bill**

For patients with genetic conditions, it is important that they receive access to specialist professionals. This should not just include doctors but also other healthcare professionals such as specialist nurses, physiotherapists and occupational therapists. Patients need to be given a choice about whether they see professionals in their local area or travel to receive a more specialised opinion. Services need to be integrated.

Linked to this, participants talked about a need for honesty from clinicians about their own limitations. They did not expect all clinicians to have an expert knowledge of genetics, particularly when some conditions are so rare, but wanted honesty about the limitations of their knowledge. They also looked for recognition that patients may have a degree of expertise to share. Without this they felt that their opinion of the individual clinician was lowered.

### Allow sufficient flexibility with waiting time guarantees to meet the individual needs of patients with genetic conditions

The waiting time guarantee was welcomed as it would mean that patients didn't wait too long to be seen by specialists. However, it was felt to be important that patients still received choice about how and where to receive care and that the quality of that care was not compromised in order to meet the waiting time guarantee. NHS staff members expressed concern that a twelve week timescale could be unrealistic in genetics because of the need to compile a family history. It was felt that these timescales were positive for NHS patients in general but that a number of issues would need to be addressed to make sure they were of benefit to patients with a genetic condition. The issues were:

- It can take a long time to run genetic tests.
- Some patients may choose to wait longer in order to be seen more locally.
- Patients are not always looking for treatment but for management.

Without recognition of this difference, there was thought to be a danger that waiting time guarantees could be counter-productive and that patients might lose out.

### Treat patients with learning difficulties with dignity and respect

Patients with multiple learning difficulties are not always respected by health workers (including GPs) and their dignity can be ignored. It should not be assumed that because a person has a learning difficulty they can't understand what it said to them. This situation could be improved if staff were trained to understand better the reality and complexity of some genetic conditions and their impact on cognitive ability. Patient passports can and do help, and should be more widely used. Members of staff need to be trained to use them effectively.

### Recognise different cultures

There has to be an appreciation of a patient's culture when treating someone with a genetic condition, such as recognising different attitudes to marriage and having children. For example, mothers from communities with a tradition of cousin marriage should not be blamed for having a second child with a disability. The bill needs to recognise that people from different cultures and backgrounds can present with illnesses that may be rare in Scotland and difficult to diagnose but which are perhaps common in other countries, for example sickle cell anaemia. Conditions shouldn't be ruled out just because they are rare. Effective services still need to be provided. There also needs to be cultural awareness amongst staff and training e.g. about taboos in other countries.

### Include the right to an individual existence

The section about safe and effective care should make better reference to respect and in particular the right to have an individual existence. Patients should be supported, whenever possible, to live in a way which makes them as independent as they can be given any difficulties they may have.

### Healthcare professionals should make sure that patients and their families *understand* information

Patients sometimes have difficulty taking in information particularly if they have learning difficulties. It is, therefore, important not just to communicate but to make sure that information has been taken in and understood. People with learning difficulties may have parents with learning difficulties – so where does the help come from for them? The voluntary sector can help meet this need. Participants identified the terminology used by professionals as a barrier to understanding. This is not an issue restricted to genetics but applies across specialties. There is never enough time allocated to explain fully what is meant by a term.

### Overcome language barriers

Problems with English can lead to difficulties. Some health professionals are not aware that they shouldn't use family and friends as interpreters or that they need to make sure that the interpreter has the right dialect or gender. This group of patients need to have the confidence not just to say "yes, yes, yes" but to question. Healthcare staff members need training so that they use interpreters effectively.

### Communicate with families and carers as well as patients

It can sometimes be difficult for healthcare professionals to communicate with carers rather than patients when a patient is not able to communicate for themselves e.g. with dementia. Barriers to this should be removed. It was also suggested that more could be done in the bill to recognise the rights of carers.

### Involve children in discussions about their condition and care

It is important to make sure that children are communicated with in a way which meets their needs. Decisions are often made about the care of a child with a genetic condition without talking to the child himself. The assumption can also be made that the child has a learning difficulty when he doesn't. There is a need to use and value play as a means of communicating with a child. Children's hospices are a good example of how this can be done e.g. Rachel House Children's Hospice in Kinross and Robin House Children's Hospice in Balloch. Children have a right to be respected.

### Allow time to give information

A healthcare professional felt that "professionals do a better job when they have the luxury of time, then they can provide more individualised information. Unfortunately, due to time constraints getting the right information is more likely when people have the confidence to keep asking." A parent of a child with a genetic condition also commented that "[she knew] if [she] hadn't been so persistent we still wouldn't know the cause of [her] son's condition'.

### Match the information given with the needs of the individual patient

Some people seek more information than others and “not every patient wants to have all the information.” One NHS staff member commented that she needs to identify the level of information which an individual needs and do her best to meet it appropriately. A patient agreed that “One size doesn’t fit all” and another that medical professionals are right to filter information and give patients what is useful. It was also felt to be important that families who were less forthcoming weren’t pushed aside. Participants suggested that:

- The current process used by cancer services to provide newly diagnosed patients with the information they need should be considered as a model for patients with genetic conditions.
- A database of support services, specialist providers and information resources should be created for healthcare professionals to use to access information: “they [healthcare professionals] can’t be expected to carry all of this in their heads.”

### Participation should be a right not an obligation

While many patients welcomed the right and opportunity to participate in decisions about their own care and about the services they use, participants thought that some may find it an unwanted burden. In particular, the extent to which patients prefer to leave decisions about their care to the relevant professionals will vary: some may prefer simply to tell doctors or other experts to decide as they see fit; others may wish to be involved in decisions about certain aspects of their care but not others; while some will wish to play a very active role in all stages of decision making. It is, therefore, important to make sure that while patients are given the opportunity to participate in decisions about care, they should not be forced to make decisions when they feel unable to do so. It is also important to involve families, carers and other professionals when necessary.

### The bill should recognise the complexities of the consent process

Obtaining informed consent can sometimes be difficult particularly in genetics where care can take place over many years. It is important that the bill recognises this complexity, two examples of which were offered at the event:

- Genetic medicine is changing rapidly and new techniques for diagnosing conditions which previously couldn’t be diagnosed are being found. It is, therefore, possible for years to pass by between a patient being seen for the first time and then contacted to be told that a test now exists for their condition. Patients need to be made aware that they may be contacted again years in the future and given the option of deciding if they still want the information at that point.
- The question of genetic testing in children is complicated. On the one hand, if a parent refuses to have a genetic test for their child, it may prevent clinicians giving the child suitable care. On the other hand, genetically testing a child for a condition such as Cystic Fibrosis may result in the child being burdened with the knowledge that they are a carrier which they might not want.

### Allow time in the informed consent process for patients to consider their decision and ask questions

Participants agreed with the inclusion in the Patients' Rights Bill of informed consent as a key element of a patient's participation in decisions about his care. However, it was felt by some that it could be difficult to achieve truly informed consent in reality for a number of reasons:

- Patients may be reluctant to admit when they do not understand information given to them for fear of appearing stupid.
- The information provided may not be the information which patients themselves feel they need in order to make informed decisions about their care.
- Patients may need time to make sense of large amounts of complicated information given to them at one go, particularly when also coping with the emotional stress of a new diagnosis.

Patients need to be provided with the right information (as described elsewhere in this document) and given the time to think about it, so that they are completely happy with their decision. They also need the option to ask further questions before taking a decision.

### Recognise that there may sometimes be conflict between the rights of one individual and those of another

Participants made the point that "genetic conditions are family conditions" and that there was a need for services to work with families as well as the individual patient. This raised questions which are perhaps particular to genetics where respecting an individual's right to confidentiality may actually breach the rights of their family members to safe and effective care. For example, if the NHS is treating a patient for familial arrhythmia and does not communicate with his relatives about the condition, the lives of those relatives could be put needlessly at risk. Measures should be put in place to ensure that, where it is deemed appropriate, medical services will share otherwise confidential information with nominated others, be they relatives, carers or peers. Healthcare professionals need clear guidance about when and how they should do this. The publication of case studies alongside the bill to ensure that there is clarity around this matter would be welcome. It is also important that the bill recognises that there are circumstances such as those described above where a person's right to confidentiality may need to be infringed.

### Make specific reference to genetic information

The proposals make no specific reference to genetic information in the section about privacy and confidentiality. This is a new field and one in which there are few precedents. As has already been mentioned, it differs from other medical information in that it is not only relevant to the patient who is being treated but potentially also to their whole family. The bill should make specific reference to genetic information and to how it should be managed by the NHS.

### 3.3. Deliver care which is equitable

Throughout the day, there was frequent mention of ensuring that all patients receive the same quality of care no matter what background they have. This idea of equity was mentioned in relation to many aspects of NHS service provision, which are summarised below. Inevitably, many of the issues participants raised were to do with equity of access to NHS care.

The participants discussed both physical and social barriers to patients accessing care which might mean that not all patients received the same quality of care as others. They also discussed issues to do with rare conditions. Participants felt that more could be done to meet the needs of patients who have rare conditions and require specific information and support to help manage them.

#### Access

##### **Improve travel and transport arrangements to get patients to hospital**

At present, patients can only claim travel expenses when they are on benefits. Families on low incomes but not on benefits can have real problems in paying for transport to get to appointments. Travel expenses should be paid for, for more patients, to ensure equity of access. Public transport to hospitals should also be improved and better integrated. This might have the added benefit of easing demand on the limited number of parking spaces sometimes available and the cost of parking.

##### **Maintain quality of care when providing services in rural areas**

Transport can be a major problem in the more remote parts of Scotland. The NHS needs to provide services in a way which ensures that quality does not reduce the more remote a patient finds his or herself. Video-linking can be a good way to address this. This technology can also be used for training and networking for staff and not just patient consultations. Video-linking can also be used for interpreting which gives a patient immediate access to an interpreter. However, it may mean that the patient does not get the same level of support that they might get if an interpreter were to be there in person.

##### **Ensure there is good access to GPs**

There is a lack of ready access to GPs and also insufficient flexibility. More should be done to improve access to GPs. This might include introducing some new working practices such as telephone consultations which were thought by participants to work well.

##### **Improve physical access to and within NHS buildings**

Disabled access needs to be throughout a building and not just at the front door. There is often an assumption that stairs won't be a problem for patients except perhaps orthopaedic patients. The NHS needs to look at access to clinics and GP surgeries in general to make sure that they are all fully accessible by patients with disabilities.

<b>Access</b>	<p><b>The right to access to medication and treatment should be included in the bill</b></p> <p>One patient described the difficulties that they had had in accessing oxygen despite the fact that it was available on the NHS when a company supplying the gas pulled out. The right to medication should be included in the bill and made explicit. Patients should have the right to access the most up-to-date drugs available and not be left taking older, less effective drugs.</p>
<b>Safety</b>	<p><b>Ensure that the Scottish Patient Safety Alliance does its job</b></p> <p>Although participants felt they had an inadequate understanding of the Scottish Patient Safety Alliance to comment fully, they did wonder if this organisation asked the right questions or had sufficient power and authority to ensure that care is safe.</p>
<b>Information</b>	<p><b>Provide information for patients with rare conditions</b></p> <p>Given the rare nature of many genetic conditions, patients sometimes find that healthcare professionals don't have the right information at their fingertips. The voluntary sector provides information and support for patients, their families and carers but, at present, patients often come across this by accident rather than through recommendation from a healthcare professional. It would be helpful if healthcare professionals could point patients in the direction of information they might find useful. That said, the limitations of information and support which is available through patient and other voluntary organisations should not be seen as a substitute for the NHS, particularly as they don't exist for all conditions; both are needed.</p>

### 3.4. Provide a holistic care package

Patients with genetic conditions often have a variety of needs when it comes to their care. There was a strong sense from participants that they would like the NHS to do more in terms of co-ordinating their care and helping them through what can often be a complicated process. It was also felt that more could be done by the NHS to ensure that there is continuity of care, with information being passed between the many healthcare professionals who might be involved in a patient's care.

A recurrent theme in the day's discussion was a desire for more personalised care for patients with genetic conditions. The rarity of many genetic conditions may mean that the number of patients in the whole of Scotland with a particular condition is only a handful. Care packages need to be designed to meet these patients' needs in the same way as a patient with a much more common condition.

Another theme which came through on the day was around the complexity of many genetic conditions. Many genetic conditions affect various parts of the body and can require expert medical care from numerous specialties. There was a sense from participants that they would welcome greater help from the NHS in coordinating this care.

Finally, participants talked about the need to address not just the physical requirements of a patient in terms of medical care but also their other needs such as social care, housing and education. It was also felt to be important that care met the psychological and emotional needs of a patient.

## Access

### **Include a right to respite care in the bill**

Genetic conditions can often be complex and a patient can need a great deal of care from his or her family. It was, therefore, suggested that there should be a right to respite care to offer families who are caring for someone with a genetic condition the opportunity for a break from their responsibilities. The reintroduction of convalescence homes was suggested and might be a way of addressing some of this need for respite care.

### **Provide self management courses for patients with long-term conditions**

It was suggested by one participant that self management courses for patients with long-term conditions might be of benefit. The expert patient programme which is provided in England was offered as a possible model, although a note of caution was expressed that this was very good for patients on the programme but perhaps less so for those who were not.

### **Healthcare professionals should be competent and have up-to-date training**

It was thought to be important that all healthcare professionals are adequately trained including those working in the community. Without this healthcare professionals can deliver ineffective care because they don't have a good enough understanding of the condition. One participant made the point that "you can have the right to anything but if the healthcare professionals don't have the appropriate skills then that right is meaningless." Such training needs to be adequately funded.

## Safety

### **Link together all the care a patient receives**

Safe care means that all the care a patient receives is somehow "linked" or "threaded" together. This is particularly the case for patients with complex conditions who have many problems and issues which need to be addressed in a holistic manner. Providing multidisciplinary care is essential and healthcare professionals should be encouraged to "join forces" and work together. Patients should be provided with a package or pathway of care which addresses their needs, including access to a specialist service when wanted. The use of audits is a way of identifying any weak links in the chain of treatment. Similarly, talking to parents or perhaps shadowing a family might help.

### **"Should this be a right? Should it not be a given?"**

The fact that safety should not be a right but a given of NHS services was raised by a number of participants.

**Safety****Social care should be fully integrated as part of a care package**

There is too great a focus in the bill on the hospital setting and infectious diseases rather than the social care issues more often encountered by genetics patients. In a number of the groups' discussions, the focus of the bill on the medical setting was commented upon. It was felt that more reference should be made to the rights which patients need in other areas such as social care, education, employment, relationships and housing.

**Flag up allergies and adverse reactions effectively**

Patient notes need to highlight any allergies or adverse reactions. Paper records can sometimes be problematic as they can get lost. The use of online records might help to avoid this and to ensure that any allergies or adverse reactions are drawn to the attention of healthcare professionals.

**Communication****Address the psychological and emotional as well as the physical needs of a patient**

Some participants thought that more could be done to address the psychological and emotional as well as the physical needs of patients and that this would make sure that patients received more holistic care. It was suggested that this aspect of care should be included in the training of all healthcare professionals. It was also suggested that access to psychologists could be included as part of clinical genetic services.

**Ensure there is communication between professionals**

Patients with genetic conditions often need care from a number of specialists to cover the various symptoms that they have. Some participants felt that clinicians can sometimes "fit in" your condition to their specialty and only look at the symptoms that relate to that specialty rather than coordinating care with that of other specialists. Participants raised lack of communication between professionals and between different services as something which really reduced the quality of their experience of care. It was suggested that communications would be improved if there was a single case manager to co-ordinate and communicate between the different services. There was strong support for a single point of contact for all health services: one person you could always phone.

**Information****Provide the right information at the right time**

Patients were keen to have access to the information they wanted at the right time: "Knowing the faulty gene isn't the information I need. What helps is good treatment for the condition." Patients, their families and carers didn't just want medical information at the time of diagnosis but on-going practical information which would help them to manage their condition. One patient commented that "after diagnosis, it was like the door was shut." Current websites provided by the Scottish Government do not function effectively as a portal to support groups in Scotland. There should be a website which is a central point and easy to find. It should provide a list of genetic conditions which you can then click on to find the appropriate support services. A patient suggested that if this was on the internet, it need not be based exclusively in Scotland. Information should be provided about prevention as well as treatment.

### Information needs to be managed – it doesn't just happen

The information which is provided needs to be thought through in a joined-up way by the NHS. It was suggested by an NHS staff member that an information card or checklist for healthcare professionals to give to patients with rare conditions when they are diagnosed might help ensure that they received all the information they might need.

### Work should be done in the community to encourage full participation from all parts of the population

Active steps should be taken to help patients, particularly those with rare genetic conditions, access relevant healthcare and participate fully in decisions about their care. An example of a rare genetic condition where support which reaches out into the community would be of particular value is sickle cell anaemia. Scotland is home to a growing population of immigrants from sub-Saharan Africa, significant numbers of whom suffer from sickle cell disease and related haemoglobinopathies. The patients and their families can be unfamiliar with the healthcare services available to them and many have only limited English. Community organisations would offer a means of providing such assistance as they have relevant knowledge of patients' circumstances, language abilities etc. Moreover, community organisations are very knowledgeable about rare medical conditions like sickle cell disease.

### Participation in research should be considered as part of the right

Some participants who were involved in medical research discussed the difficulties they can sometimes have in involving patients in research activities because of stringent (perhaps over stringent) application of laws around data protection and confidentiality. It was felt that this might be overcome by including a right to agree or disagree to be contacted about being involved in clinical research. This was supported by some patients, with one describing how the loss of family members to a condition meant that she wanted the opportunity to participate in medical research and prevent others suffering.

### Address the concerns which people sometimes have about complaining

People are sometimes reluctant to raise concerns about safety and feel anxious about complaining. This is particularly the case where they need to continue to see the healthcare professional. Participants were unsure where to go to raise concerns about their treatment and were nervous that it would become a lengthy and formal process. Some participants felt that it was important that patients and their families knew what to do if they had a complaint from the outset of their care rather than having to find out when they actually needed it. The process needs to be clear and accessible. One participant also highlighted the help that independent support and advocacy workers could bring in helping individuals such as himself understand the complaints procedures, reduce the amount of time it might take and give them the confidence to complain.

### **Adopt existing good practice in managing concerns more widely**

The Patient Information Centre at the Edinburgh Royal Infirmary was highlighted as an example of good practice in this field. It offers three different ways to initiate a procedure, a booklet in many languages and a patient liaison officer. It attempts to resolve matters as soon as possible. This was felt by the participant who gave the example to be an effective model for managing concerns.

### **Make it easy to feedback positive experiences as well as complaints**

One group had a detailed conversation about the right to independent support and redress and was unanimous in agreeing the importance not only of raising a grievance but also when the experience of receiving care has been positive. The participants felt that being given a formal way in which they could feedback these positive experiences was of equal value as it would provide the healthcare professionals/services involved with a more balanced view and ensure good healthcare provision is maintained.

### Specific responses to consultation questions

The information below identifies when specific questions in the Scottish Government Health Department's consultation document on a Patients' Rights bill for users of the NHS in Scotland were addressed by the discussions outlined above.

	Page no.
<b>Question 1: The right to Access</b>	
Do you agree with the inclusion of these entitlements and responsibilities?	
<b>Do you agree that there should be a 12 week in-patient and day case waiting time guarantee as proposed in this paper from 2011?</b>	
➤ Allow sufficient flexibility with waiting time guarantees to meet the individual needs of patients with genetic conditions	9
<b>Is there anything you would like to add to the right to Access?</b>	
➤ The right to access to medication and treatment should be included in the bill	14
➤ Include access to appropriate specialist services and a specialist opinion in the bill	8
<b>What do patients and/or the NHS need to do to make this happen?</b>	
➤ Improve travel and transport arrangements to get patients to hospital	13
➤ Ensure there is good access to GPs	13
➤ Improve physical access to and within NHS buildings	13
➤ Maintain quality of care when providing services in rural areas	13
➤ Provide self management courses for patients with long-term conditions	15
<b>Question 2: The right to Respect</b>	
Do you agree with the inclusion of these entitlements and responsibilities?	
<b>Is there anything you would like to add to the right to Respect?</b>	
➤ Recognise that patients can sometimes get angry with good cause or that their distress can be misunderstood as anger	6
➤ Recognise different cultures	9
<b>What do patients and/or the NHS need to do to make this happen?</b>	
➤ Treat patients with multiple learning difficulties with dignity and respect	9
➤ Make sure that there is not a "blame culture"	6

**Question 3: The right to Safe and Effective care****Do you agree with the inclusion of these entitlements and responsibilities?**

- “Should this be a right? Should it not be a given?” 15

**Is there anything you would like to add to the right to Safe and Effective care?**

- Social care should be fully integrated as part of a care package 16

**What do patients and/or the NHS need to do to make this happen?**

- Learn from mistakes and avoid a blame culture 6
- Ensure that the Scottish Patient Safety Alliance does its job 14
- Healthcare professionals should be competent and have up-to-date training 15
- Flag up allergies and adverse reactions effectively 16
- Link together all the care a patient receives 15

**Question 4: The right to Communication**

Do you agree with the inclusion of these entitlements and responsibilities?

**Is there anything you would like to add to the right to Communication?**

- Address the psychological and emotional as well as the physical needs of a patient 16

**What do patients and/or the NHS need to do to make this happen?**

- Create “forums” which allow patients and the NHS to work in partnership 7
- Value patients’ and their families’ expertise and knowledge of their condition 6
- Overcome language barriers 10
- Communicate with families and carers as well as patients 10
- Involve children in discussions about their condition and care 10
- Ensure there is communication between professionals 16

**Question 5: The right to Information**

Do you agree with the inclusion of these entitlements and responsibilities?

**Is there anything you would like to add to the right to Information?**

- Provide information about the NHS and how it works 7

**What do patients and/or the NHS need to do to make this happen?**

- Healthcare professionals should make sure that patients and their families *understand* information 10
- Allow time to give information 10
- Match the information given with the needs of the individual patient 11
- Provide information for patients with rare conditions 14
- Provide the right information at the right time 16
- Information needs to be managed – it doesn’t just happen 17

## Question 6: The right to Participation

### Do you agree with the inclusion of these entitlements and responsibilities?

- Participation should be a right not an obligation 11

### Is there anything you would like to add to the right to Participation?

- Include NHS staff in decisions about service provision 8
- The bill should recognise the complexities of the consent process 11

### What do patients and/or the NHS need to do to make this happen?

- Allow time in the informed consent process for patients to consider their decision and ask questions 12
- Work should be done in the community to encourage full participation from all parts of the population 17
- Participation in research should be considered as part of the right 17

## Question 7: The right to Privacy

Do you agree with the inclusion of these entitlements and responsibilities?

### Is there anything you would like to add to the right to Privacy?

- Recognise that there may sometimes be conflict between the rights of one individual and those of another family member 12
- Make specific reference to genetic information 12

What do patients and/or the NHS need to do to make this happen?

## Question 8: The right to Independent support and redress

Do you agree with the inclusion of these entitlements and responsibilities?

### Is there anything you would like to add to the right to Independent support and redress?

- Make it easy to feedback positive experiences as well as complaints 18

### What do patients and/or the NHS need to do to make this happen?

- Adopt existing good practice in managing concerns more widely 18
- Address the concerns which people sometimes have about complaining 17

## Question 9: Other Rights

### Are there any other key rights which you think should be included in the Patients' Rights Bill?

- The right to an advocate should be included in the bill 7
- Include the right to an individual existence 9
- Include a right to respite care in the bill 15

What do patients and/ or the NHS need to do to make this happen?