

Summary of the Gengage 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

This document summarises the submission which Gengage made to the Scottish Government Health Department in response to its consultation on a Patients' Rights Bill for service users of the NHS in Scotland. The submission 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 9th December 2008. The submission 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.

The full submission can be found in the publications section of the Gengage website at www.gengage.org.uk

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.

Description of discussions

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.