



Consultation Response

Charter of Patient Rights and Responsibilities

June 2012

Key Points

These points are discussed in detail in the body of LTCAS' response.

- LTCAS is concerned that the Charter does not currently extend into social care provision and therefore the rights of people with long term conditions are likely to be inadequately protected.
- A comprehensive strategic framework must be developed to support the Charter and ensure that people enjoy the rights set out within it.
- There is currently a lack of independent advocacy provision in Scotland, which is essential to ensuring the rights set out in the Charter are implemented effectively. Measures to address this issue should include sustainable funding of the third sector to ensure that third sector organisations can continue to provide and increase their independent advocacy services.
- People should be provided with support to access suitable transport when appointments are arranged for them outside their health board, which should be arranged to be as close as possible to where the person lives.
- The right to start to receive an agreed inpatient or day case treatment within 12 weeks of agreeing to it must also apply to follow-up appointments and ongoing care.
- LTCAS supports the provision of accessible and clear information

about conditions and available support and the third sector has considerable expertise to support the health service in this. NHS staff should adopt a self management approach to providing this, including working with the person to make decisions about their care and routine signposting to third sector self management support. To ensure this, staff must be provided with appropriate training and again the third sector can play a key role in delivering this.

- The Charter should ensure that NHS staff make sure the person is well aware of and informed about high quality independent advocacy services as well as helping to arrange the support.
- In order to strengthen a person's 'right to clear communication about their care and treatment from NHS staff', the Key Information Summary should also be used for people who require out of hours services. Additionally, people should be able to securely access information (such as test results), and provide information (for example home monitoring of symptoms) more easily.
- The current barriers to self management in hospitals, such as people not being allowed to continue their self management regimes, need to be addressed to allow people to enjoy their right to be treated with respect.
- It is important that the onus to achieve safe and effective care does not fall too heavily on the individual. To ensure that this does not happen, NHS staff must interact with people, involving them in decisions about their care, support and treatment at every stage.
- NHS staff should proactively provide people with information about the role of Independent advocacy services and the role of the Patient Advice and Support Service (PASS) in assisting people to make their views heard and/or to raise concerns or complaints.

1. General Comments

- Long Term Conditions Alliance Scotland (LTCAS) welcomes the introduction of a Charter of Patient Rights and Responsibilities to help strengthen the rights of people who use the NHS in Scotland.

People's rights must be at the heart of the care and support

delivered by the NHS. It is imperative that the NHS supports human rights, independent living and citizenship in order to ensure that Scotland achieves the Quality Strategy's ambition for a person-centred NHS, with mutually beneficial partnerships between people, their families and those delivering health care services; and that ultimately people with long term conditions are empowered to live fulfilled lives.

People living with long term conditions are particularly vulnerable to infringements of their human rights as they face a number of barriers (including medical, physical, social, economic and cultural) to securing their rights. This Charter of Patient Rights and Responsibilities will therefore help to ensure that their rights are fulfilled and respected. It will help to make clear what people's rights are, what experiences people should expect from the NHS and what to do when standards fall below these expectations.

- However, LTCAS is concerned about the lack of joint and coherent action taken by the Scottish Government to help secure the human rights of people who also receive social care. The Charter does not currently extend into social care provision. People living with long term conditions frequently receive care and support from both health and social care and it is therefore vital that social care is also rooted in the values and principles of human rights. The current Scottish health and social care integration agenda provides a valuable opportunity to ensure that the Charter also evenly applies to social care and that people with long term conditions receive good quality, holistic care and support in every aspect of their lives. In response to the Scottish Government's consultation on adult health and social care integration, LTCAS and other third sector organisations will call for a much firmer human-rights basis than the current proposals reflect.
- The Charter must be supported by a comprehensive strategic framework to ensure that people can fully and consistently enjoy and uphold their rights. The correct plans and processes must be put in place to allow people to exercise their rights as laid out in the Charter. This should include support for people to enjoy their rights, such as the provision of independent advocacy; awareness raising; the implementation of a communication strategy; and training for NHS staff.

LTCAS recommends delivering training to NHS staff using the FAIR (Facts, Analysis of rights at stake, Identification of responsibilities,

Review of Action) model which is based on a human rights approach¹. The FAIR model has been used to deliver training to social care staff. Evaluation of the Scottish Human Rights Commission's *Care About Rights* projects demonstrates the value that a human rights-based approach can bring to care and support services. Between 800 and 1,000 care workers and managers have received training using the FAIR model. Using this approach assists social care workers to involve service users, their families or their advocates in decision-making and deliver more personalised services, thus helping to shift the power balance in relationships between providers and users².

In terms of making the Charter available to people, LTCAS suggests that the NHS works jointly with the third sector to disseminate the Charter once published and communicate the rights contained in it to people. Third sector organisations frequently work closely with the people that they support. They are therefore well placed to effectively communicate to people their rights and responsibilities when using NHS services as set out in the Charter and to distribute copies to them.

The strategic framework should also include plans for monitoring and evaluating the Charter. To ensure that the Charter is embedding people's rights effectively when they use NHS services, (in that people are understanding and enjoying these rights) the NHS must carry out regular monitoring and evaluation of the Charter and adopt a robust plan for this. Such action to measure the Charter's success should be carried out more than at least once every five years, as stated in the Charter's supporting consultation document³. Every five years is not an adequate level of review and thus a much more frequent period of review, such as an annual review, along with ongoing improvement activity, will ensure a more robust approach to scrutiny.

- Independent advocacy services are vital to ensuring that the rights of people with long term conditions are enjoyed. They provide a crucial tool to realising many of the rights set out in the Charter.

¹ *Personalisation and Human Rights: A Discussion Paper*, Chetty, Dalrymple and Simmons, The Centre for Welfare Reform
<http://www.scottishhumanrights.com/application/resources/documents/Finalpersonalisation2012.pdf>

² Ibid.

³ *Consultation on Charter of Patient Rights and Responsibilities*, Scottish Government (2012) <http://www.scotland.gov.uk/Resource/0039/00390990.pdf>

However, there are currently insufficient levels of independent advocacy services available in Scotland to ensure an effective implementation of the Charter. Recent research carried out by the Scottish Independent Advocacy Alliance highlights the lack of independent advocacy service provision in Scotland. Nearly all participants in the research (95%) reported an increased demand for their services over the last two years, but the majority of participants (84%) did not feel they had sufficient funding to meet their overall demand and 11% had closed projects, usually as a result of the non-renewal of project funding⁴. After participant organisations were asked to identify the three main challenges they anticipate for their organisation over the next 12-18 months, most of the challenges identified related to meeting the increasing demand for their services, and maintaining a high quality service in the absence of a corresponding increase in funding or support from funders⁵.

Thus this lack of independent advocacy provision needs to be addressed. Action taken to address this issue must include increased support for third sector organisations which provide independent advocacy, as they are a main provider of high quality independent advocacy services. The NHS and local authorities must therefore take a strategic approach to sustainable funding of the third sector to ensure that third sector organisations can continue to provide and increase their independent advocacy services.

2. Access

- The Charter states that 'you have the right that your local health board will assess the local community's health needs' which 'means it will not necessarily be able to provide every treatment for every patient'. The result may be that treatment is instead offered in another health board, requiring the person to travel relatively far to access treatment. People living with long term conditions may receive treatment regularly. Thus appointments outside the health board should be arranged to be as close as possible to where the person lives and the person should be provided with support to access a suitable form of transport.
- The Charter lays out the right to start to receive an agreed inpatient

⁴ *More for Less? Independent Advocacy — More demand, less funding SIAA research into delivering advocacy in the recession*, the Scottish Independent Advocacy Alliance (2012) http://www.siaa.org.uk/images/books/1112sia08_moreforless.pdf

⁵ Ibid.

or day case treatment (subject to some exceptions) within 12 weeks of agreeing to it. LTCAS welcomes this right, however this right must also apply to follow-up appointments and ongoing care. This is required as people with long term conditions may be pushed back to the end of the waiting list if the treatment time guarantee does not apply to ongoing healthcare.

- If people with long term conditions are eligible to register with a local pharmacy to access the Minor Ailment Service or the Chronic Medication Service (or both), they should be made aware of this by their GP. They should be given information to find out more about these services in accessible formats other than only leaflets, such as spoken form, in order to ensure those people with communication difficulties, sensory impairments, learning disabilities or low levels of literacy are made well aware of these services.

3. Communication and participation

- LTCAS fully supports the right to be informed, and involved, in decisions about health care and services as this is essential to ensuring that people can understand and enjoy all of their rights in relation to the NHS. LTCAS welcomes the point in the Charter which states that 'if you have a long-term condition, NHS staff should make sure you have clear information about your condition in a way you understand' and the point relating to the provision of information about support that is available from the NHS and other relevant agencies such as local authorities and the voluntary sector.

The proactive provision of accessible and clear information about conditions and the support available is essential to health outcomes. This must therefore be accompanied by routine and consistent signposting to the wealth of self management support provided by the third sector, as it provides a range of highly-responsive, person-centred and holistic support. An example of such support is the 'My Condition, My Terms, My Life' Campaign (run by LTCAS, funded by the Scottish Government)⁶ which aims to help improve public understanding of what self management means for people living with long term conditions; and encourage people living with long term conditions, and the people who support them to adopt a self management approach. Another example is the ALISS (Access to Local Information to Support Self Management)

⁶ *My Condition, My Terms, My Life*, LTCAS <http://www.myconditionmylife.org/>

Project which is based in LTCAS and is working closely with LTCAS member organisations to make self management support and information accessible to all⁷.

- LTCAS strongly supports the provision of support to manage conditions as set out in the Charter. However, in support of this statement the Charter states that 'for example, staff should **tell you** how and when to take your medication, how to control pain, and how to access other services that could help you'. It is vital that NHS staff work with a self management ethos in which they work with the person to make decisions about their care and support, rather than as the expert 'do things to' people or 'tell' them what to do.

The necessary cultural shift is already underway to move from traditional 'health deficits' approaches to 'asset-based' approaches such a self management. This shift needs to be sustained through a number of supporting mechanisms, such as the Quality Strategy⁸ and the 'My Condition, My Terms, My Life' Self Management Campaign, to enhance understanding and capacity among practitioners and ensure people are routinely given information and signposted to relevant third sector support. This will support people with long term conditions to become the leading partner in the management of their conditions, working in partnership with practitioners and making shared decisions.

- In order to enhance a person's 'right to clear communication about their care and treatment from NHS staff', as set out in the Charter, it is crucial that the Key Information Summary is effectively and widely rolled out across all services of the NHS and is not only used for people who require out of hours services.
- People themselves also need to have greater access to, and ownership over their own medication and data. Individuals should be able to securely access information (such as test results), and provide information (for example results from home monitoring of symptoms) more easily. People across Scotland should have consistent access to systems that allow them to exchange information using the internet, television or phone in order to improve communication channels about people's care and

⁷ ALISS <http://www.aliss.org/>

⁸ *The Healthcare Quality Strategy for NHSScotland*, Scottish Government (2010) <http://www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf>

treatment.

- While LTCAS agrees that people should take some responsibility for their own health and should ask questions if they do not understand anything (as set out in the Charter), it is extremely important that NHS staff carry out their responsibilities in informing the person about and making them aware of their care, support and treatment at every stage. They should help support the person to exercise their rights and take responsibility for their own health and care. This should especially be the case for people with long term conditions who, for a variety of reasons, may lack the capability to ask questions or for information; or fear doing so. Additionally, in order for people to communicate well with NHS staff about their health, condition(s), medication and any related issues, staff must be provided with appropriate training to listen and communicate effectively. This training should aim to embed the use of self management approaches into the everyday practice of NHS staff.
- In relation to people speaking up for themselves, LTCAS feels that the point in the Charter on people's access to independent advocacy could be strengthened to help support or give people's views and ultimately support them to exercise their rights. The Charter should therefore ensure that NHS staff make sure that the person is well aware of and informed about high quality independent advocacy services as well as helping to arrange the support. This should include regular signposting to independent advocacy services provided by the third sector.

4. Respect

- The Charter states that 'you have the right to ask for your needs and preferences to be taken into account' and 'health boards are committed to taking such matters into account wherever they can'. This right must be upheld in relation to respect for people's self management regimes when they are in hospital, particularly for people living with multiple conditions. Where a person with multiple conditions is being treated in hospital for one condition, management of their condition is often undermined⁹. People report not being allowed to continue their self management regimes, for example only being able to access their medications at specific

⁹ *Living with Multiple Conditions: Issues, Challenges and Solutions*, LTCAS/Healthcare Improvement Scotland (2011)
http://www.ltcas.org.uk/download/library/lib_4e858df323e51/

times according to the hospital's routines, not theirs¹⁰. These barriers to self management in hospital settings need to be addressed to allow people to enjoy their right to be treated with respect.

5. Safety

- LTCAS is in support of a mutual NHS which involves shared rights and responsibilities. It is important, however, that the onus to achieve safe and effective care does not fall too heavily on the person. NHS staff must interact with people, involving them in decisions about their care, support and treatment at every stage. They must take the time to ask the individual if they understand everything and have any allergies in relation to medication and treatment, instead of expecting the person to always raise these issues themselves. By working together in this way, NHS staff will ensure that they deliver truly person-centred care.
- Improved communication between different professionals to share information appropriately for the benefit of the individual, through for example, the implementation of the Scottish Government's e-Health Strategy¹¹ and effective rollout of the Key Information Summary beyond out of hours services, will reduce the need for people with long term conditions having to repeat the same information each time they deal with a different professional. This will lead to the provision of more safe and consistent information, care and advice.

6. Comments and complaints

- In this section of the Charter, it is stated that 'you may ask to have an independent advocate to help you give your views' and that 'you have the right to independent advice and support in making a complaint'. It is essential that NHS staff proactively provide people with information about the role of independent advocacy services and the role of the Patient Advice and Support Service (PASS) in assisting people to make their views heard and/or to raise concerns or complaints.

¹⁰ Ibid.

¹¹ e-Health Strategy 2011-2017, Scottish Government (2011)
<http://www.scotland.gov.uk/Resource/Doc/357616/0120849.pdf>

About LTCAS

LTCAS' vision is for a Scotland where people with long term conditions enjoy, not endure, full and positive lives, free from discrimination and supported by access to high quality services, information and support.

LTCAS is the national third sector intermediary for a range of health and social care organisations. LTCAS has over 220 members including large, national support providers as well as small, local volunteer-led groups. Many NHS Boards and Community Health and Care Partnerships are associate members.

For more information

www.ltcas.org.uk