Scottish Government Call for Views on the NHS Charter of Patient Rights and Responsibilities – See Me Scotland response

See Me is Scotland's national programme to end mental health stigma and discrimination. Our vision is to enable people who experience mental health problems to live fulfilled lives.

We are working to change negative behaviours towards mental health, by creating a movement for change, bringing people together all over Scotland who are all passionate about tackling stigma, to work as one. Currently we have nearly 10,000 people signed up, including supporters, volunteers and champions, who are leading the way in making real changes in communities across the country.

We want to change the culture around mental health so people feel confident enough to speak about how they are feeling and can ask for help if they need it, without the fear that they will be stigmatised and discriminated against. To do this we are targeting key settings where people face stigma and discrimination: in health and social care, workplaces, education, and in their local communities.

1) **The Charter of Patient Rights and Responsibilities was first published in September 2012. Does it in your view continue to accurately summarise the rights and responsibilities of everyone who uses the NHS in Scotland? If not, can you suggest what needs to be reviewed and updated?**

How does the Charter fit with the Public Bodies (Joint Working) (Scotland) Act 2014 – for instance in the explanation of the NHS in Scotland, do the terms 'NHS services' and 'NHS staff' also refer to those services that are commissioned and governed by Integrated Joint Boards of Health and Social Care Partnerships? How is the Charter enforceable on multi-disciplinary teams consisting of NHS and Local Authority staff (e.g. OTs and social workers) – is it only enforceable on those that are hosted by the NHS?

These pertinent questions suggest to us that the Charter should be updated to reflect the spirit of the health and social care integration, and the changed context within which it will now need to operate. It could also be clearer about the fact that these rights exist not only within acute settings, but also for those who receive treatment or support within community-based services. Thusly, in the spirit of the legislation, the language should be altered in order to reflect that it is about people who access services and support and not patients.

We would also echo the Health and Social Care Alliance Scotland's response encouraging the refresh to reflect the updated National Care Standards (now titled the Health and Social Care Standards[1]), the remit of which have been extended, in order to best use the existing learning from their development and the on-going learning from their implementation, and to also highlight the recently refreshed NHS Scotland complaints procedure within Feedback and Complaints.

Finally, we feel that this is an ideal opportunity to highlight the positive aspects of feedback, that it can be used for continuous improvement, including in real-time, and that new mechanisms exist for this such as Care Opinion[2].

2) Do you consider the Charter effective in raising awareness of the rights and responsibilities of everyone who uses the NHS? If not, how do you think it could be made more effective?

Through the work of the Scottish National Action Plan for Human Rights (SNAP) and Declaration, and from the experiences of people with lived experience, we know that more needs to be done to raise awareness of rights in ways that are accessible to people. Furthermore, part of this activity should practical suggestions for how these rights can be realized, how to access mechanisms for redress if rights are not upheld – including light-touch immediate mechanisms, and other more serious ones, and which ombudsman-like bodies can be approached should these initial formal mechanisms fail. Other reported barriers include people not having access to appropriate information, low levels of literacy, and limited understanding of what to do should they feel their rights are not being considered.

Staff within health and social care also report uncertainty and nervousness around the current rights agenda, as quite often they do not have a comprehensive understanding of their role as duty bearers. Another issue is that within mental health, and unfortunately often due to stigma and discrimination, staff tend to take a safety-first or risk-averse attitude, and thus tend to infringe upon the rights of the people they are treating or supporting.

Another issue is that staff are often fearful of human rights leading to legal cases, and thus this can act as a barrier to people speaking about their rights. Compounding this, is that a key issue that has been raised by people with mental health issues is that often human rights can be seen as othering as opposed to empowering, and thus lead to further risk-averse treatment and acting as a barrier to collaborative conversations and care.

We were encouraged by recent work by the Mental Welfare Commission to raise awareness of rights, both from a person receiving care and a staff member's perspective, in producing their Rights in Mind toolkit[3] – a comprehensive guide to

---

[1] http://www.gov.scot/Resource/0052/00520693.pdf

[2] https://www.careopinion.org.uk/

[3] http://www.mwcscot.org.uk/media/367147/rights_in_mind.pdf

rights within mental health care, accompanied by an infographic that highlights at which points of an individual's journey through the system particular rights may need to be accounted for. This also mentioned the Charter of Patient Rights and Responsibilities.

The current policy context within mental health, public service reform, health and social care, and community empowerment, all set out the need to implement a human rights-based approach. However, currently there is a general acceptance of the value of the PANEL principles[4] but limited understanding of what that means in practice. Particular issues exist in respect of Accountability – how duty bearers can be held to account; Legality – in respect of what is the process for recourse should a person identify with their rights not being met, and; Participation –the extent to which service design and delivery is truly person-centred rather than being system driven.

The emphasis on participation in the earlier charter could be increased to focus on individuals directly shaping, commissioning and influencing service responses – ensuring that services and wider ecosystem around them wrap around the individual.

Issues relating to equity of access and experience of services still remain. We know marginalized groups and individual have less positive experiences of services – including those with severe and enduring metal health issues. People with mental health difficulties also face enhanced difficulties in accessing services, and it is clear that parity of esteem does not exist. Furthermore, 9 out of 10 people with experience of mental health issues experience stigma and discrimination[5].

It should be our ambition to move human rights to a place where they are intrinsic to practice rather than being seen as a difficult but pre-requisite add-on, and persuade people who are undecided about human rights that they are relevant, useful and applicable to everyone.

We feel there should be a national awareness campaign conducted with the wider public regarding not only the Charter, but human rights in general, as in our experience, people have limited knowledge of the applicability of human rights (including their right to the highest attainable standard of physical and mental health) and how they can be effectively realised.

Relating to the Charter and its associated documents specifically, we feel that "Caring and Consent" should make it clearer that the information is also based on the Mental Health Care and Treatment Scotland Act 2003, and include appropriate upfront information about the legal rights that a person and their carer has e.g. a right to an independent advocate and legal services

---

[4] http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

[5] https://www.time-to-change.org.uk/mental-health-statistics-facts

3) **In what way does the rights and responsibilities set out in the Charter currently influence (i) the delivery of care and support by your organisation (ii) organisational improvement?**

Human rights are embedded into the design and delivery of See Me – See Me plays a key role in challenging perceptions, prejudices and inaction across the system. A core element of See Me's approach is to empower people to understand and assert their rights. This can be seen through previous work with Voices of Experience and Scottish Recovery Network, to develop the Rights for Life Declaration and Change Agenda. This highlighted the rights that people should assert and also challenged decision makers to uphold this.

Furthermore, we will be piloting a new toolkit, Community Conversations, which aims to make rights accessible to people, particularly those with mental health issues, and through these workshops an updated Charter could be promoted to emphasise that rights are there to be enforced and upheld, and that there are mechanisms for redress if they are not.

See Me's managing partners, the Scottish Association for Mental Health and the Mental Health Foundation are committed to ensuring the Programme is underpinned by the principles of equality and human rights. Part of this is ensuring that people who experience multiple disadvantage and discrimination are amongst the Programme priorities, through an ongoing emphasis on the effects of intersectionality on people's experiences and outcomes.

We work directly with people with lived experience: championing, promoting and respecting their human rights particularly in settings where people with experience of mental health issues face the greatest stigma or discrimination, which includes health and social care services.

We support staff and partners to understand and apply a human rights-based framework as an integral part of our Programme in Health and Social Care, Workplaces, Education and Communities.

We are working directly with SNAP's Health and Social Care Group to support greater and wider implementation of human rights within and across health and social care settings as part of the SNAP Action Plan.

4) **Does your organisation currently promote the Charter as a means of raising awareness of the rights and responsibilities of everyone who uses the NHS? What opportunities do you see for your organisation to support the promotion of a refreshed and updated Charter in future?**

As stated above, See Me developed Rights for Life with partners, which set out an agenda linked to the Charter but specifically focused on the experience of people with mental health problems and mental ill health. It lists 8 rights for people affected by mental health issues[6]

Ideally there would be an increased synergy between the Charter and those with lived experience of mental health – this would mean embedding the Rights for Life priorities within the Charter to reduce duplication, guidance and expectation on service providers.

An updated Charter could then be promoted through our volunteer network, which includes people with a specific interest in health and social care. They could use the Charter in their influencing work around the design, delivery and evaluation of services, and also promote it through their own extensive peer networks, thus reaching many often seldom heard groups, including those facing multiple discrimination.

If you have any questions or would like more information on this response, please get in touch:

Wendy Halliday, *Assistant Director of Programmes*

- Email: wendy.halliday@seemescotland.org
- Telephone: 0141 530 1032

Benjamin McElwee, *Health and Social Care Policy and Practice Officer*

- Email: benjamin.mcelwee@seemescotland.org
- Telephone: 0141 530 1128

- See Me Scotland
  51 Brunswick St
  Glasgow
  G1 1UZ

---

[6] https://rightsforlife.org/the-declaration-2/declaration-text/