About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. It brings together almost 2,000 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

Introduction

The ALLIANCE worked with the Committee to organise an informal evidence session on the morning of Tuesday 21 March, to give people living with long term conditions, disabled people and unpaid carers the opportunity to express their views on NHS governance directly to members. This response is informed by the discussions during the 21 March session, as well as supplementary comments provided by members of the ALLIANCE’s Involvement Network. Our response will focus on questions 2 and 3 posed by the Committee.

2. Are patient and service users' perspectives taken into account in the planning and delivery of services?

Given the breadth of this question, it is unsurprising that it elicited comments spanning a wide range of contexts, from people’s reflections on the extent to which their views had been considered in the delivery of their own care right up to perspectives on the level of public engagement in national service planning and redesign.

Comments from ALLIANCE members highlighted the following issues.

Communication support needs

Ensuring that individual communication needs are met is central to enabling people who access support and services to make informed decisions and play an active role in decision-making around their care.

Despite this, we heard from one member about a hospital based situation in which their relative’s hearing impairment was not sufficiently recognised and addressed by
staff during a key decision-making ward visit. As a result, the person was without their two hearing aids which they were reliant on for clear communication, and therefore had no opportunity to effectively participate in the decision-making process relating to their care in this instance.

The Patient Rights (Scotland) Act 2011 gives all people the right that the health care they receive will “encourage them to take part in decisions about their health and wellbeing, and provide them with the information and support to do so”\(^1\).

**Power of Attorney**

There will be situations in which the person directly accessing medical care is unable, either permanently or temporarily, to give consent to treatment. We heard feedback of an example relating to this situation, where it was felt that the person’s role and status as an appointed Power of Attorney was not recognised and acted upon by staff involved in their relative’s care.

As an unpaid carer, the individual recognised that they had a great deal of information to contribute regarding changes that they had observed in the cared-for person’s condition, but despite requests to take part in ward discussions and multidisciplinary meetings, they felt excluded from assessments and decision-making. In their perspective “the power of attorney might as well have been a doormat en route into the hospital.”

In summarising the provisions of the Adults with Incapacity (Scotland) Act 2000, the Mental Welfare Commission for Scotland states that where a person has “a welfare attorney or guardian with the power to give consent (or refuse consent) to your treatment . . . . the doctor should consult the attorney or guardian before treating you”\(^2\).

**Independent advocacy**

Building on the point made above, there will be situations where people require support in order to make sure that their voices are heard and their views are taken into account in healthcare decisions.

The Scottish Independent Advocacy Alliance’s (SIAA) response to the Public Audit and Post-Legislative Scrutiny Committee’s recent call for evidence highlights the positive impact that the Mental Health (Care & Treatment) (Scotland) Act 2003 has had in strengthening advocacy provision and ensuring that there is independent advocacy provision in every Local Authority. The Act identifies that every person

with a mental disorder (as defined under section 328 of the Act\(^3\)) has a right to independent advocacy and the Act places a duty on local authorities and the NHS to ensure that such services are available.

However, the SIAA also states that often the funding that advocacy organisations receive is insufficient to meet local need, leading to significant variations in advocacy provision across Scotland. The response also draws attention to extensive waiting lists where sometimes people are required to wait many weeks to see an advocate and are therefore unable to readily benefit from the important preventative role that advocacy can play.

**Proposed service changes**

At the other end of the spectrum, we heard concerns from a representative of a support group in relation to their recent experience of being involved in a proposed service change. Their experience of the process led them to feel that “engagement and consultation is merely a tick-box exercise and the results are made to fit a decision that has already been made”.

Specific concerns were raised about the timing and transparency of meetings. Comments highlighted that one public engagement meeting was held less than 24 hours before the option proposal meeting, and despite requests for meeting minutes and written answers from officials to be produced, these were not made available.

**Engaging with ‘seldom heard’ groups**

In examining the question of whether the perspectives of people who access services is taken into account in the planning and delivery of services, the ALLIANCE encourages the Committee to specifically consider how services engage with people from groups which may be characterised as ‘seldom heard’.

This is because despite everyone having the human right to the highest attainable standard of health, the existence of health inequalities in Scotland indicates that the right to health is not being enjoyed equally across the population.

The ALLIANCE recently worked with NHS Health Scotland, the University of Strathclyde’s Centre for Health Policy, Glasgow Homelessness Network and the Mental Health Foundation on a participatory action research project\(^4\) examining what the right to health means to people who face inequalities and may struggle to access

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\(^3\) The term mental disorder includes any person with a mental illness, a personality disorder or a learning disability. People with dementia and acquired brain injury are also covered by the Act.

support, specifically in this case people with experience of homelessness, and women refugees and asylum seekers. The research revealed that human rights felt far removed from participants’ reality, but for different reasons. Participants highlighted encountering discrimination and were also clear that their experiences impacted on their mental health, but it was largely believed that this was overlooked by the services they interacted with, or treated inappropriately.

3. Do services treat people with dignity and respect?

Respondents commented on the inherent difficulty in trying to give a definitive answer to this question. We heard that for many people, their perspective will be based not only on their own personal experience of accessing healthcare services, but also on those experienced and discussed by their family and friends. Additionally, they noted that their view on a particular ‘service’ could often be very strongly influenced (either positively or negatively) by the behaviours of an individual member of staff or team.

“Like all walks of life, the NHS has its share of staff that make you wonder why on earth they are in that profession. They appear to not only hate their job/colleagues and members of the public, they behave inappropriately making colleagues/patients/everyone uncomfortable or upset. This is more than balanced out by the amazing NHS staff you will come across. Staff members that are renowned for going above and beyond expectations. They not only care for you/your family in respect of your medical condition but they have an ability to show compassion and empathy whilst always treating you with the greatest respect and dignity.” ALLIANCE Involvement Network Member

The ALLIANCE welcomes recent initiatives taking place within NHS Scotland aimed at further embedding person centred care and encouraging more meaningful conversations between people who provide health and social care and the people, families and carers who access health and social care. Two examples include the ‘What matters to you?’ and #hellomynameis campaigns.

As with all campaigns of this type which seek to influence culture and working practices, sustained effort will be required to ensure that these approaches become embedded as ‘business as normal’. For example, one unpaid carer highlighted that during their relative’s hospital stay, unknown members of staff would frequently congregate around the bed to discuss the person’s private health details, without making any effort introducing themselves to the ‘patient’ first. The unpaid carer was then able to make use of the recently installed ‘What matters to you?’ notice board to

5 http://www.whatmatterstoyou.scot/
6 https://hellomynameis.org.uk/
write a polite reminder to staff to introduce themselves to their relative before starting any consultation.