**Royal Edinburgh Hospital Patients Council**

**Annual General Meeting**

The Hive, Monday 27 November 2017

NOTES

24 people attended the meeting.

Apologies were received from Dick, Rosemary and Ruth.

**Guest Speaker**

We were delighted to welcome Angela Dias from the Age in Mind project, who distributed copies of her final report. The project focussed on growing older with a mental health condition, the first time this has been done, possibly because people tended not to live so long in the past, or ended up in long-stay hospitals – community care for older people with mental health conditions has only quite recently become available. Angela gathered information using a variety of routes such as focus groups, questionnaires, 1:1 discussions, and reached out to harder-to-reach groups such as men and people from other cultures. She also met with organisations such as the Patients Council.

Most people who took part had been diagnosed very young, so they knew how the system has changed over the years. Depression was the most common diagnosis. Nearly all participants had worked most of their lives and had used a wide range of services to improve their mental health. Nearly all had experienced stigma and discrimination, often from family members.

Angela used the information to form Change Networks – local networks of people with lived experience and those who share their concerns, working together to tackle issues they identified. They tackled issues such as self-stigma, family, diagnostic overshadowing, power of attorney and age-capping of services. Issues identified included 65+ services being focussed on dementia; fear of losing your place in a service; fear of isolation; lack of access to Self Directed Support; and lack of access to disability related benefits.

Older people with mental health conditions can feel ‘put down’ by health and social care staff – training in mental health for general nurses varies hugely – better nurse education is needed because physical needs are a big part of the lives of older people. Age in Mind gathered evidence of good and poor practice, devised a plan and discussed it with institutions such as NHS and Scottish Government. To highlight family difficulties, they produced a film to show the discrimination some people experience from family members. To assist with fluctuating loss of capacity and the difficulties of the Power of Attorney relationship, leading to the loss of everyday life choices in older age, they devised a Letter of Wishes for use across Scotland alongside Power of Attorney. Workshops helped professionals to understand self-stigma. Stigma can also originate from appearance, race, ‘unpopular’ mental health conditions, long stay institutions, and LGBTI - remember that homosexuality was illegal for most of the lives of people who are now over 65.

Age in Mind contacted heads of health and social care teams, talked to politicians and held an event at the Scottish Parliament. They met the mental health minister, presented to a cross-party group, and were part of the mental health strategy review group. They also trained older people to have a political voice.

Stigma is also experienced from the media, employers and educators, but this is improving. We discussed the stigma people experience just because they are not in paid employment and wondered if employment really ought to trump well-being.

We did not have time to view the film, but enjoyed watching the animation.

**Notes of Annual General Meeting on 28 November 2016**

These were accepted.

**Annual Report and Financial Report**

Copies of the Annual Report were available at the meeting and will soon be available on the Patients Council website. Patricia, who is standing down as Chair having completed the maximum three year tenure, thanked our volunteers and staff, AdvoCard and Edinburgh Carers Council for their support this year, particularly with regard to the tender process for the new Contract with Edinburgh City Council. 2017 has also seen the opening of the new Royal Edinburgh Building – we were involved in the planning of the new hospital from the beginning, and got everything we asked for – ground floor ensuite rooms with views, and courtyard gardens for every ward were our main priorities. Our current office-bearers will be meeting Nicola Sturgeon at the official opening ceremony on 29 November. This year also saw the publication of our new book, Stories of Changing Lives lll, a wonderful piece of work led by our specially recruited project worker, Katherine McMahon, who excelled in both empowering so many people to tell their stories, and working in partnership with other organisations to produce artwork, photographs, a film and an exhibition as part of the Scottish Mental Health Arts Festival. The book and the film are available on our website, or you can pick up a copy of the book at the Patients Council offices.

We noted the 3% cut in funding under the new Contract. We can manage that, but will need to devise creative training solutions and learn to do more with less. At least collective advocacy is still being funded in Edinburgh, both in the hospital and the community. Financially, we are still in credit.

**Election of Members of Management Committee**

Martin McAlpine, Stephen Muirhead, Alison Robertson and Patricia Whalley were re-elected. One new nominee, Safina Bibi, was also elected. Three vacancies remain for service user members. We noted that nomination forms had been completed by two people who unfortunately did not meet the requirement to have volunteered regularly with the Patients Council for about one year prior to seeking election to the management committee. We will encourage them to volunteer with us regularly, with a view to seeking election at a later date.

**Date of first meeting of new management committee –** 4 December 2017

**AOCB**

No issues were raised.