

PATIENTS COUNCIL NEWSLETTER

January 2018

NEWS, VIEWS AND COMMENT FROM THE ROYAL EDINBURGH HOSPITAL

Patients Council Meeting – 25 September 2017

We had a huge turnout for our Guest Speaker, Sean Harper, Consultant Clinical Psychologist, NHS Lothian. Sean explained that arts and psychological therapists have been working closely together to introduce therapeutic activities to adult acute inpatients, then Kate Pestell briefly informed us about the art and music therapies which are now available on wards in the new Royal Edinburgh Building.

Sean told us that service users, carers and staff all wanted improved access to therapeutic activities for in-patients. The model they've been using for the past four years includes training in psychological therapies for multi disciplinary staff, staff support such as reflective practice, access to individual psychological formulations and therapy, and to groups, to create a more therapeutic environment. All recognised diagnoses were included. From June 2014 to April 2016, they worked with 99 patients, spending 397 hours on individual sessions and 185 on groups sessions, each stand-alone, in three therapy groups. Themes which have emerged include emotional acceptance (OK, it'll pass) and change from self-harm to self-care. Patients found it helpful. There was a small reduction in depression and anxiety, still maintained at the six months check up, but less reduction for psychosis. There have been fewer readmissions. Self-efficacy improved - people became more confident at managing their conditions and this strengthened over the six months. They experienced fewer IHTT and A&E episodes than the control group.

1.5 FTE permanent psychologist posts and 0.6 arts therapists have been created across the REB wards but there's a long way to go before a full biopsychological model is adopted. Collaborative research and a large definitive trial are needed.

Our questions covered protected time for nurses; choice of treatment between psychology and psychiatry (we need to influence the Scottish Government here); continuity of therapy into the community and lack of community resources; the human right to psychological therapies; long waiting lists; the importance of early intervention (instead of restraint/injections which are so traumatic for patients that they, as well as staff, need debriefing afterwards).

Annual General Meeting – 27 November Angela Dias spoke about the recently competed Age In Mind project which focussed on growing older with a mental health condition. They gathered information and used it to form Change Networks which tackled issues such as self-stigma, family, power of attorney,

diagnostic overshadowing, and age-

event at the Scottish Parliament!

capping of services. They even held an

We presented our Annual Report which highlighted three main pieces of work – the advocacy contract tender process, the opening of the new hospital, and Stories of Changing Lives III. We elected Safina Bibi, Martin McAlpine, Stephen Muirhead, Alison Robertson and Patricia Whalley as full members of the management committee and presented flowers to Patricia who is standing down from the Chair's role which she has filled so ably for the last 3 years. Many, many thanks, Patricia!

Stories of Changing Lives III

In her evaluation of the project, our project worker Katherine McMahon concludes that "The project was extremely successful on many counts: it produced a diverse range of high quality outputs, with a high number of participants who were often deeply engaged. The different ways to engage with the project - whether as participant or audience member - have made it more accessible, as well as creating a lot of interest in the Stories of Changing Lives series. The creative approach offers a different way for people to engage with each other, providing emotional connection which supports compassion and understanding. The book and film will be used in training at the hospital.

The Stories of Changing Lives Project would certainly benefit from further volumes, particularly as the Royal Edinburgh Hospital is in a period of significant change. Further work could be used to ensure that patients' voices are heard in the process, as well as chronicling their experiences of the process." Thank you, Katherine, for an amazing job!

Group Advocacy

At our December group advocacy meeting in Braids ward, patients discussed the different models of care they had experienced in various wards over the years. They compared and contrasted the different approaches used and degrees of freedom allowed throughout their admissions. Some felt that in recent times, the level of restrictions being applied to them had actually increased; that wards had become "stricter" over time, especially in regard to the granting and removal of passes; they talked about often feeling they were being punished for breaking the rules.

This led on to a discussion about human rights and the dispiriting sense that services on the ground seem to be moving in the opposite direction to the new human rights ideas proposed in documents like the UN Convention on the Rights of People with Disabilities (UNCRPD). Instead of a shift away from the use of compulsion, patients tell us they feel more subject to force than ever before. Failing to recognise our fundamental human rights to autonomy and self-determination, the system creakily insists on using out-moded ideas of substituted decision-making via the Tribunal system. We should be moving towards a situation where the role of services is to support us to make our own decisions about what care and treatment we want, or even whether or not we want it at all. Many patients do not feel this is happening.

15 years ago, Scotland patted itself on the back about the then new Mental Health (Care and Treatment) Act, proudly claiming to have one of the most progressive human rights approaches towards mental health in the world. 10 years ago the UNCRPD changed the landscape dramatically and arguably Scotland has failed to keep up with the advances in human rights thinking. Other countries have been more innovative and bold: For example, in Tromso, Norway, patients now have the option of medication-free in-patient treatment, all based on the central principle that patients should have the right to choose/not choose their treatment.

There are admittedly some reasons to be hopeful—both the National and the forthcoming Edinburgh Strategy for Mental Health and Wellbeing extol the virtue of recognising our human rights, while accepting that a 'sea-change' will be required to get us there.

Have a look at our website

www.rehpatientscouncil.org.uk

Lots of information about the Patients Council and links to other interesting items

www.facebook.com/rehpatientscouncil/

twitter.com/rehpatients

The Royal Edinburgh Hospital Patients' Council

The Patients Council is an independent collective advocacy project for people who use or have used the services of the hospital. We provide a forum for common issues about mental health treatment and care and represent patients' interests in order to improve services. We hold general meetings every two months. To get involved with mental health issues from the service-user's viewpoint, contact our staff.

Telephone: 0131 537 6462 **Email**: <u>info@rehpatientscouncil.org.uk</u>

Write: The Patients' Council, Royal Edinburgh Hospital, Morningside Terrace, EH10 5HF

Our Management Committee

Martin McAlpine, Stephen Muirhead, Alison Robertson, Patricia Whalley

Co-opted members:
Cathy Robertson, Isla Jack,
Safina Bibi

PATIENTS COUNCIL MEETINGS 2018 2 – 3.30pm, The Hive

29 January

19 March

28 May

23 July

24 September

26 November:
Annual General
Meeting

1.30 – 3pm with refreshments

History of the Patients Council

A few of our members have written a history of the Royal Edinburgh Hospital Patients Council highlighting some of our activities since 2000. Please contact us for a copy.

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The Royal Edinburgh Hospital Patients Council is a registered charity
Scottish Charity No SC021800
Our offices are between Outpatients and Mental Health Tribunal in the ADC
www.rehpatientscouncil.org.uk

All patients, former patients, staff and visitors are warmly invited to attend

PATIENTS COUNCIL MEETING

from 2.00-3.30pm on

Monday 29 January in The Hive

Guest Speaker

Professor Alison McCallum NHS Lothian Caldicott Guardian

Proposal by NHS Lothian to add patients' psychological records to TRAK