

PATIENTS COUNCIL NEWSLETTER

September 2016

NEWS, VIEWS AND COMMENT FROM THE ROYAL EDINBURGH HOSPITAL

Patients Council Meeting

16 people attended our meeting on 25 July. Our guest speaker was Ailsa Brown, Lead Health Economist, Scottish Medicines Consortium (SMC), which advises NHS boards on comparative clinical and cost effectiveness of new medicines, new formulations, new indications/line extensions. They assess drugs on the basis of safety, efficacy and quality – how much better does this medicine work than those in current use, and is it value for money? Their decisions are published on their website.

Health economists use economic evaluation to balance benefits versus costs to help make tough choices on how to spend the limited healthcare budget. They use a tool called QALY – Quality Adjusted Life Year – which calculates survival gain and quality of life to enable them to compare treatments. Decisions on whether to grant licences are based on economic analysis (is it good value?), the views of clinicians (does it work?) and the views of patients (how does it make you feel?). Increased public involvement enables SMC to look more holistically at what's of value to patients.

We discussed the biopsychosocial model of mental health and wondered if health economists should challenge the primacy of the medical model. We raised questions about the costs of treating the terrible side effects of some psychiatric drugs, other therapies such as psychological therapies, public funding of research and development and how SMC accesses negative information about new drugs. We wondered about the influence of politics although this could be beneficial: political intervention could encourage drug companies to offer a lower price and politicians can represent what people want and can respond to patient pressure.

This was a thoroughly enjoyable, informative and stimulating session – thank you, Ailsa!

Walk a Mile in My Shoes

Everyone who took part in our Walk a Mile at the REH Fete on 19th August really enjoyed it. The route showed people some brilliant places in the grounds of the hospital such as the Glasshouses and the Community Garden. Here's what Chris Young, who led the event, had to say afterwards:

"Hi Maggie and Simon –

thanks again for all your work today - and before today - and the thought you put into the route - and ensuring I had Alison Meiklejohn to walk with.

I had a great time & we had a whole bunch of interesting conversations

Cheers for now - looking forward to the next one."

Community Links and Peer Support Service

The Community Links & Peer Support Service, run by SAMH at The Hive, supports people leaving hospital to manage their mental health and get involved in their local community.

The community links worker signposts activities for people based on their interests and the peer support workers work alongside people to achieve their goals.

Support includes:

- Weekly peer support for around 4 months
- Support accessing learning opportunities, volunteering and employability support
- The option to take part in Health in Mind's MAPS Programme (My Assets and Personal Strengths)
- Access to Edinburgh Leisure facilities for £1

Nina Allinson is the Team Leader. Nicole Carter is the Community Links Worker, James Knight and Juanita Hunter are the Peer Support Workers. Contact them on 46256 or email communitylinks@samh.org.uk.

Group Advocacy

Advocacy is all about supporting people to fulfil their basic human needs and demand their basic human rights, so the Patients Council volunteers began summer at our annual development day by looking at the UN Convention on the Rights of People with Disabilities. This proposes a new paradigm for mental health human rights, with ideas of autonomy and equality before the law at its very heart. We felt we needed to discuss and debate these ideas, in the hope that we can bring them to bear on the group advocacy we do on the wards. Watch this space!

Meanwhile, back on the wards, people continued to tell us that staff shortages remain a problem. The hospital management are fully aware of this situation and explained (at our joint Staff/ Patient Dialogue meetings) that the issue is less a shortage of money, than a shortage of actual nurses applying for the vacant posts. To try to remedy this, our Chair attended an NHS recruitment day which was held in August and aimed to promote the benefits of in-patient mental health nursing to prospective job applicants. Time will tell if this will prove successful, although wards in the new hospital will have a slightly higher ratio of staff to patients, due to overall bed number reductions.

On one of the acute wards, a wheelchair user told us about their difficulties in negotiating the ward, which lacked suitable adaptations e.g. to beds and toilets. Again, the hope is that the new hospital building, due to open early next year, will bring big improvements to accessibility and the ward environment that will benefit all patients, whether physically disabled or not. Patients frequently complain to us about the noise levels on the ward and the lack of quiet areas where people can go for a bit of time out. Our hope is that with everyone due to have their own private bedroom space in the new hospital, this will become a less frequent issue.

In the CAMHS unit, the young people wanted to discuss their human right to an education and the difference between attending lessons in the CAMHS unit to the experience of being at classes in their local school. We were impressed that the patients and staff had decided to set up community meetings to try to come up with solutions to the day-to-day issues that arise on the wards. We were delighted when the unit finally had a TV installed in its purpose-built case, after a few false starts with faulty sets etc.

We also attended an event run by the Scottish Patient Safety Programme (SPSP), which will have a major impact on the in-patient experience of being under observation. SPSP have started an Improving Observation Practice group, which aims to re-write the national policies for how patients are observed in mental health settings. The idea is to blend the needs for safety and therapeutic interventions, with the ever-present imperative to respect the human rights of people with lived experience of mental health issues.

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: info@rehpatientscouncil.org.uk

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

Our Management Committee

Shirley Gowers, Eileen Hay, Albert Nicolson, Martin McAlpine, Stephen Polockus, Alison Robertson, Patricia Whalley

> Co-opted member: Cathy Robertson

PATIENTS COUNCIL MEETINGS 2016 2 - 3.30pm

25 January

21 March

30 May

25 July

26 September

28 November:
Annual General
Meeting
1.30 – 3pm
followed by buffet

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.

To receive the newsletter direct, by post or e-mail, please complete and return this section. I would prefer to receive the Newsletter by post email (tick as appropriate) Name	
Address	Post code
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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 26th September in **The Hive** with

Jane Anderson
Local Unison Branch
Secretary

www.rehpatientscouncil.org.uk