Patients Council, Royal Edinburgh Hospital

**ANNUAL GENERAL MEETING 2023**

**2.00-3.30pm-Monday 27th February -In-person**

**MINUTES OF A G E N D A**

**Paul Harvie in his role as Vice Chair began the meeting by welcoming everyone, pointing out the Code of Conduct and confirming that copies of the previous year’s minutes & new agenda were on the chairs. We also said hello to our current Chair, Stephen Muirhead, who although unable this time to join us in person is happily joining us over Zoom, connection permitting!**

**23 people attended the meeting, 4 apologies were received.**

**We then introduced Alison & Kathleen; Karen Martin, who was originally hoping to do a presentation with Alison has sadly had an emergency; as such we welcomed instead Kathleen from the Mental Welfare Commission as a Carer representative who has kindly agreed to step in.**

**The question posed to begin the presentations and discussions was- ‘Can we and should we work together to advance our Human Rights?**

**Alison’s role today is to speak about the Scott Review, her experience on it and the future direction that collective advocacy could go in. The Scott Review was set up in 2019 by the Scottish Government – (a previous one was carried out in 2000) – to review mental health within Scottish Law. This review was chaired by John Scott QC (now KC!) and was specifically tasked to look at rights of people with disabilities, covering many areas such as Adults with Incapacity, accountability, individual and collective advocacy, disability and previous MH Acts.**

**The government had given the review a particular remit to investigate and make recommendations about- the finished document was 924 pages long! John Scott QC when asked if it could be reduced refused – although it is vast, he feels all the relevant sections were important and necessary.**

**Alison sat on the review until it was finished in March 2021; lived experience and human rights were at the heart of each topic which was carefully examined.**

**Areas covered included collective advocacy, empowering people to recognise and use their human rights, support, monitoring and the evaluation of services in a bid to look at how services can be improved and changed for the better.**

**The review offers a set of recommendations to the Scottish Government which in turn puts the focus on various groups in the city e.g. the local authorities, IJB, etc, to implement future changes to services by offering things like improved training, support for all and the encouragement that there should be a legal duty to provide things like collective advocacy freely.**

**The report also reinforces our right to take our concerns to the Mental Welfare Commission, and for the Courts to award legal and financial support so that people can access justice.**

**The role of lived experience in the future was discussed; it could include lots of work; the review also raises the need to generate concepts, frameworks & how things should be carried out with a view to change.**

**We have a role to play in helping to implement current and future change, both individually and collectively. Our role could be to participate, come forward, and refuse to take no for an answer!**

**At present, Scotland seems keener than England to implement positive change; although the UK government signed the European Convention of human rights in the 1950’s, England is trying to change things like the right to protest generally and to restrict access to human rights. The UK has also ratified the United Nations Convention on the rights of persons with Disabilities-2009- (UNCRPD).**

**It is felt that we should be involved in setting up monitoring and complaint systems as well as more involvement in the training of medical students. (We have been involved in undergraduate training but this could be increased).**

**Education is another area which we could expand more in; we are ahead of things as we currently offer a human rights-based training programme in the form of MORE-P; we have three educators in the audience today!**

**The role of mentoring and peer support has been shown to be useful, we need multiple voices in various areas including those of the media. There are still sadly barriers to people taking part- stigma and any repercussions do still exist.**

**It is felt that the authoritative approach needs to change; this should be offered alongside a whole range of other options; the idea that a pill can solve everything for everyone is outdated and incorrect.**

**Tech can also be a barrier to people being able to access services, this can also be limited on the wards with unreliable internet access.**

**Alison also highlighted the improvement of financial arrangements for those with health issues and how various cultures work differently. Restrictions in accessing services relating to where you live, (i.e. the Highlands!) also play a part in recognising and implementing your human rights!**

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**Kathleen said that although she had not read the whole Scott review it clearly raised some very important questions! As mentioned before, Kathleen has kindly agreed to step in at the last minute and to offer a view from the Carer perspective as she has extensive experience in that area!**

**Kathleen said that she was aware that the Patients Council and advocacy services have had involvement with the area of Carers as many people with mental health issues have carers to help support them and also many carers have themselves mental health issues! She also highlighted how important it is that existing organisations work together to help improve things. At present the Patients Council is also in partnership with the Edinburgh Carers Council (along with AdvoCard) so naturally we have had many dealings with them over the years.**

**The review has highlighted many gaps in the current system, both for adults and also children who may also be in immediate crisis if things get even worse.**

**Kathleen explained that among her many roles in life she is a carer and mother to five children all of which have their own mental health issues. This has naturally given her not only a personal insight into the current system but has widened her working knowledge in that area.**

**Kathleen said whether in working with children or adults the importance of staff awareness training was paramount even if they were up against time or financial restrictions. Most families do their best to be supportive and only share when appropriate but one of the biggest issues can still be a breach of confidentiality leading to a loved one being detained. Sometimes liberty has been taken already – families can be placed in a difficult position – sometimes it can be beneficial to include families but sometimes not…. If a family member does report concerns, sometimes specialists can’t or won’t share supportive information. The issue of confidentiality needs to be improved generally; if staff do breach this they could be sacked. Things in Forensic Services seem a bit further ahead. In the User/Carer/ Staff dynamic there are 6 principles to try and involve people…Kathleen visits care groups all over Scotland and is continually asking the question of what would assist the person affected, sometimes not much other than medications are offered which are often not working and not the answer for many people…If services were better organised this would not only help those with mental health issues but also many carers who could see their own mental health improving…**

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**Q) – Advance Statements- Sometimes they can work but not always…It can be hard to get them changed; a new psychiatrist cannot just dismiss what a previous one has put in place…What does Kathleen thing of them?**

**A) Advance statements do slightly worry her. She feels personal statements are ok – she did think that advance statements were just about treatment but obviously if a person’s needs change they can be limiting…**

**Some people are arguing for more information on them but also quicker ways of updating things if requirements change.**

**Q) As a former Chair – It is great to offer a holistic approach for every patient- whether that’s psychiatry or talking therapies etc, but sometimes the only care people have is the family itself…. maybe we should take it back to the basics! Worth pointing out too that if patients were not here staff would not have a job….**

**- Historically there is a bit of division between users & carers; patients want a family life, relationships in some form are very important, sometimes there are conflicting ‘needs’ between what the patient wants and what the carer thinks they need!**

**-The word ‘user’ was played out years ago…’lived experience’ has perhaps replaced this…it’s important that we can choose to call ourselves what we want…**

**-In Article 8 of the Human Rights Act itself it states the right of a private and family life…**

**Q) – From my own experience, labels are not always beneficial…When recently accompanying someone to the doctor, he could tell the doctor wasn’t happy he was there but people have a right to be supported in a way that suits them whether that’s friends or family…It does raise the point that if someone doesn’t have much family or friend what can happen then?**

**A) It is recognised that some people can be in this category, and this is when advocacy services or some form of peer support can be helpful…**

**Q)- You mentioned your sons. Did they have any Occupational Therapy? For some people and especially those who are more creative it can be of benefit…**

**A)- I don’t think they did have this, but may people can benefit from different approaches of support…**

**- What could be the future?**

**- Someone said that they had a 40-year involvement with the REH but even now and after the edition of the new hospital there still isn’t even a café for patients to sit in & if you are visiting you need to get signed in by another patient…So actually you can’t come here…**

**The Veranda Café – (now the ‘Broch’) has not got the access it previously had- maybe posters need to go up to offer slots of 2 hours per week?**

 **-The Mental Welfare Commission posters need to go up too, some patients think they are on side of the doctors…. More friendly posters generally might be helpful…**

**- People need spaces to meet friends and family; family rooms are not always available and not always what is required…**

**There can also still sadly be on entry some very rough treatment with handcuffs, no beds available & being driven to St Johns Hospital in Livingston which for a lot of people is quite far away and not always easily accessible…**

**- Someone said they left the hospital in 1995 and were not even given any information on how to keep well, Ballenden House has also changed, it can take a huge amount of time to see a psychiatrist which is also made worse with people retiring then not being replaced…**

**Maybe the Mental Welfare Commission should have increased powers to make more government recommendations on how things can be improved? It doesn’t seem that in the last 20 years that things have moved much further ahead.**

**We thanked Alison & Kathleen for their extensive speeches and everyone for a very interesting discussion in which I think we can agree that many useful points have been raised!**

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**\*\*\*BREAK- 10 MINUTES\*\*\***

**(Sections 2-5 – 5-15 minutes)**

1. Notes of the Annual General Meeting on 28th February 2022-

2nd paragraph Stephen Muirhead not Chair yet, appointed in March Not January- ***To be amended!***

1. Annual Report and Financial Report-**Available freely**
2. Election of members of the Management Committee- Alison, Edward and new member, Lewis- Explained procedures & respective roles, also new responsibilities of employers, both able to nominate themselves, still an Unincorporated Charity so we need to become a SCIO in the future, - **all voted in.**
3. Date of first meeting of new Management Committee –

 **6th March 2023**

1. A.O.C.B- (**35 minutes**)
2. ­– Patients Council Updates- We have a new consortium of the Patients Council, CAPS and AdvoCard- (previously the Patients Council, AdvoCard and the Carers Council)

We are looking to recruit 2 people – one FAB – (Finance, Administration & Business) Officer and another MORE-P worker…

**Thanks to all our volunteers who have stayed and the time and effort they have given; we are always looking for more people to assist us!**

1. – Patients Council Future- SCIO/Future Name Change?/Updating of Constitution- We need to create a new constitution to give new trustees more legal protection….Stories of Changing Lives 4 – new project?- lived experience- led research is the biggest thing…we have so far produced two Patient Experience reports….People are posting lots of lived experience quotes on twitter…We will hopefully aim to get a new Constitution drafted in the next 6 months…
2. – Member’s Issues- Voting

Are we going to do advocacy in prisons in the future? We have won the Core Advocacy Contract for the next 5/7 years….For the first time this will also include the area of Drugs and Alcohol….there have been discussions about extending to prisons….AdvoCard offer individual advocacy at present in the prison service but there are no collective advocacy groups there…We would need more funding and another worker to do this but perhaps we need to put in place our more immediate priorities as per our existing contracts. We need to deliver on the group advocacy because if we don’t our contracts could be removed!

We discussed how human rights in terms of mental health are very important, without them being recognised it can lead to the increase of coercive treatment, loss of liberty, being locked-up against your will, even more stigma, standards of healthcare slipping; people with mental health issues should always have the main say in what’s happening to them…

It was highlighted how even things like offering patients ‘dignity packs’ which have at least the bare essentials someone might need especially when entering the hospital unexpectantly can make a difference.

We talked about how other competitors who made a bid for the contract we won may only offer a basic phone service & this is clearly not sufficient for many people. Signposting to other areas and forms of information is helpful; many people are having lengthy waiting times to access services; there is also a greater need for bereavement services to be accessed- maybe the MORE-P team could add this into a scenario to discuss in their existing training?

Things can always get in the way of any future progress e.g. unpredictable events –(pandemics) and any changes that may happen after a General Election. Our second project - MORE-P (Mind Our Rights Education project) was started by ourselves during Covid.

 We feel generally the main focus to take things forward in future should be from a human rights-based approach and from a lived-experience perspective!