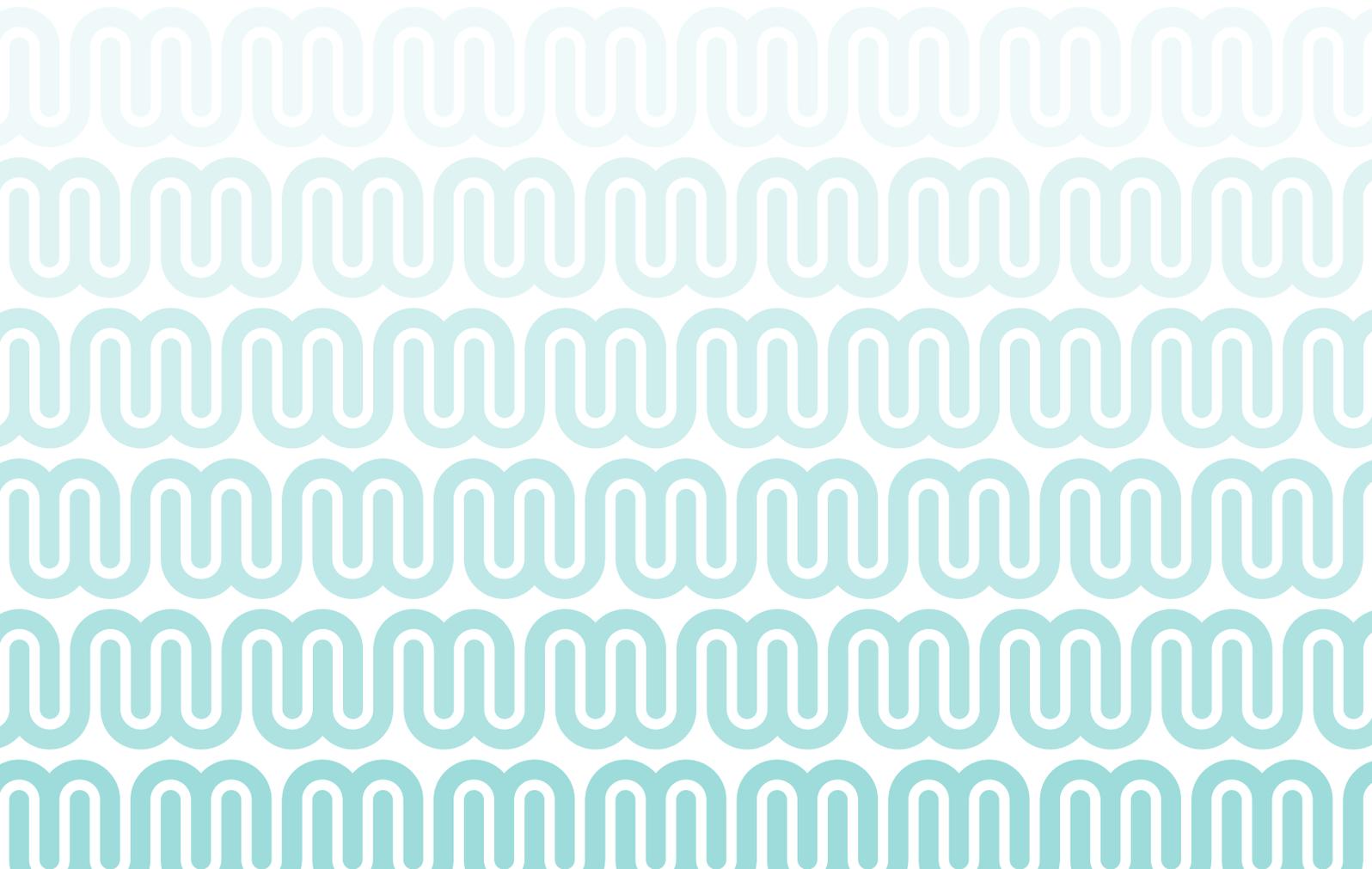




mental welfare
commission for scotland

Service users and carers information



**The views of people with lived experience
of mental ill health and carers**

**The purpose of a psychiatric hospital
and some of the elements that are appreciated
and those that are not**

Mental Welfare Commission for Scotland

July 2019

The following paper reflects the voice, experience and opinions that people with lived experience and carers provided for the Commission around the purpose of psychiatric hospitals. It will inform our work and future reports on this subject but is not, in itself, an expression of the Commission's views on this area.

Service user and carer groups may want to use the stories and opinions gathered, but are requested not to state that they are an expression of the Commission's policy or opinion.

We are very grateful to all people with lived experience and their friends, relatives and/or carers who have contributed their experiences to this project. These are essential to the work we do and our philosophy of involvement and participation.

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Summary

What we were asking about

We were trying to find out what people with lived experience and their friends and family members think a psychiatric hospital's purpose should be.

Who we were asking

We asked 205 people in 16 focus groups across Scotland: mainly people with lived experience of mental illness, but also friends and family members and a very small number of workers, who happened to be present at meetings.

What we found out

We found out that when people are ill and need a hospital admission that they want a safe place to go to and be looked after. Sometimes they want treatment and medication and sometimes they want a chance to find peace, to be cared for and looked after: to get a break from the responsibilities of coping in the 'real world.' A chance to just 'stop'.

They want to be around loving compassionate people who will listen to them, and help them talk about the things they want to talk about without judging them.

They want things to do and places to go outside of the hospital, especially the natural world.

They want support from their peers, but also from staff. Many people prize the sense of community and belonging that existed in some hospitals some time ago.

They don't want to feel frightened, or to feel too controlled, but equally some people do not want so much freedom that they can take rash decisions about their safety. They don't want to face meaningless rules; instead rules should fit their needs. They want to be sure that they have their rights and needs protected.

Some people would like to be separated from people with addiction issues, and not to have to worry about being exposed to illegal drugs or alcohol on the ward.

On a practical level, people want a pleasant environment, good food, and adequate facilities and support for visitors and families. They want to feel that they will get better, and benefit from the stay, and do not want to be bored. They want admissions that last as long as they feel they need them. They want to be able to participate, and to have a sense that they might heal and recover. They don't want to be moved constantly and want to be sure that there is continuity and consistency in their care. They don't want the weekends to be too empty, and don't want to be scared of the thought of admission, or ignorant of what might happen to them during their hospital stay.

Some people would like to see alternatives to hospitals: therapeutic spaces for people in crisis and people who need to retreat from the world. A small number of people worry that a concentration on hospital care can detract from the non-institutional care that they might prefer.

The reality is that some people's experience does not fit these desires, but some other people have said that care and hospital treatment has improved over the years and that generally they get the treatment and respect they want.

Introduction

Over the summer autumn and winter of 2017 and the spring of 2018 the Engagement and Participation Officer (Lived Experience) travelled around Scotland meeting advocacy groups, and visiting places where people with lived experience and carers gain support, to find out some of the issues that are important to people.

He met 205 people, in 16 focus groups; mainly people with direct lived experience of mental illness, but also friends and family members and a very small number of workers.

Part of the conversations that were held, were around what the purpose of a psychiatric hospital should be. This discussion topic was inspired partly because the MWC regularly visits hospital wards across Scotland, and it seemed like a good idea to see what people who have been, or might become, patients actually thought the purpose of a hospital admission should be, and what is important to them about an admission to hospital.

We did not carry out any prioritisation exercise with groups but did gather the thoughts people had under common themes and these are grouped on the following pages.

We met with:

- Acumen – Campbeltown - Argyll
- Restart – Bridgeton – Glasgow – Strathclyde
- Restart – Maryhill – Glasgow - Strathclyde
- Bipolar Glasgow – Glasgow - Strathclyde
- West Lothian Involvement Group – Bathgate – Lothian
- Bipolar Edinburgh – Edinburgh – Lothian
- HUG action for mental health – Inverness – Highland
- HUG action for mental health – Lochaber – Highland
- Caithness Mental Health Support Group – Wick – Highland
- Caithness Mental Health Support Group – Thurso - Highland
- Klaksun – Alloa – Forth Valley
- Bipolar Dundee – Dundee – Tayside
- Dundee SUN – Dundee – Tayside
- PLUS Perth – Perth – Tayside
- Aberdeen Carers group – Aberdeen – Grampian
- User and Carer Involvement/SIM – Dumfries – Dumfries and Galloway

It is worth noting that many of the issues raised by people veered away from the discussion of the purpose of hospital to issues that people had with hospital; both good and bad. However these may also be points of some interest.

What should the purpose of a psychiatric hospital be?

The most frequently mentioned purposes of a psychiatric hospital mentioned in between twelve to six of the sixteen groups that discussed the subject were:

- To provide a safe place.
- A warm compassionate place.
- A place with things to do.
- A place to have someone to talk to and to be listened to.
- A place with access to the outside and natural world.
- A place for treatment.
- A place for respite and sanctuary.
- A place of community and belonging.

To provide a safe space

People said that an important function of hospital is to provide a safe place for people to recover, and to be protected from what they were going through.

- *"A place to feel safe from my rash behaviour – even if it were only for a couple of days, with someone to speak to."*
- *"Keep us away from the public in case we cause any damage or harm anyone else – this should not happen."*
- *"When unwell we may need someone to 'take over' for a short time."*

Despite this being the most mentioned possible purpose of a hospital, there were comments from people that they didn't always feel safe. The reasons included worries about drugs and alcohol on the ward, and fear of theft whilst a patient. People also mentioned worries about restraint whilst a patient, and fears of compulsory treatment. (Although the opposite was also mentioned; where some people felt that compulsory treatment would have meant they were at less risk, and that being free to leave the hospital put them at risk at times when they shouldn't have been.)

- *"If you are sectioned you have no idea what has happened and are more frightened."*
- *"It was dark and horrible and I was scared of the other people, and the people with drugs and alcohol."*
- *"Freedom can be a bad idea because you think you are well; if they had known me they would have not been too quick to let me out."*

However other people felt that hospitals did provide this sense of safety.

- *"Some people have a good hospital experience where they feel to be in the right place, safe, cared for and treated with dignity."*

A warm, compassionate place

People felt that when in hospital they should be treated with empathy by kind, non-judgemental, and understanding staff. It should be a place of love and compassion with some humour and sense of a camaraderie. It should feel supportive and accepting and there should be an interactive atmosphere.

People stated that they did not want to be patronised or ignored and not listened to, and that they wanted to feel that they had a say in what was happening to them, with an implication that this was not always the case at present.

- *“Not say ‘none of this nonsense’ or ‘get back to bed’.”*
- *“Kindness and re-assurance make a difference.”*

Things to do

Having something to do and not getting bored was mentioned. While many people just said that they wanted some form of activity a lot of people mentioned specific activities that they felt were helpful. These included:

- Groups
- Arts activities
- Exercise, bikes, weightlifting
- Pool
- Dances

Some people said that, in reality, there was little to do and that it was hard to get involved in things and that this made their stay feel unhelpful.

- *“The boredom in [hospital] is very high; they get you up at half seven to do nothing all day. I spent a week in [hospital] all the time in my room. No one came to see me and I discharged myself because there was no point.”*

The lack of things to do on the weekends was also highlighted.

Having someone to talk to and be listened by

People said that it was very important to have someone who would listen to them, and who they could talk to, with some of the comments being about how that sometimes did not happen.

- *“You know who is listening and those who it is going over their shoulder.”*

Access to the outside/natural world

People said that it was very important to be able to get outside of the hospital, both because of the sense of freedom this gives, but also because many people welcomed being able to go for walks or to do things in the natural world, such as gardening or walking or just being in the fresh air.

- *“Going out to go shopping with staff then without staff.”*
- *“Chances to walk round the grounds when people are no longer worried we will run away.”*

Treatment

People said that hospital should be a place of treatment. This involves medication, but could also include group work, psychological help, psychotherapy and talking treatments, help around eating and cooking and generally just treatment to help people feel better.

It was again mentioned that some professionals do not work on the weekends, such as physiotherapists and occupational therapists. This was not welcomed, and nor was the fact that it sometimes felt difficult to get treatment. However some people felt that, overall, treatment had improved over the years.

- *“Treatment; medication is a part of it but communication: What brings you here? Why are you where you are? Who are you? What happened? All these are needed too.”*

In another group the main idea that people had about the purpose of hospital was that it was for ‘healing’; whether that is the same as treatment is unclear.

Respite

People said that hospital should be a place of respite; a place to relax and recharge, and be free from the responsibilities of daily living and the reality of the outside world; it should provide a break and a sanctuary.

- *“It was like stop the world I want to get off – it felt like being taken out the world for a couple of weeks to get well without the stress of everyday life.”*
- *“In order to get well and recover – if this poor little brain had a chance to rest it would need a rest and then it will do its own recovering.”*

Some people were aware that hospital usually no longer has a formal respite function. They tended to think this was wrong. One group felt that hospital should not provide this function:

- *“Who needs to be there and who just needs a wee break? – some people do not need to be there.”*

A sense of community

People talked about the need for a sense of community in hospital. Maybe slightly surprisingly, some people compared modern hospitals to ones from many years ago, where some people had prized both the feeling of belonging and the things there were there for them to do.

- *“It used to be fun in the seventies: a lot of good things happened. It doesn’t happen now. There were events: Valentines dances, summer events, go to the Highland games, bonfires. Hospital was never all bad: discos twice a week.”*
- *“In [Hospital] it was very different; you had little privacy but you had to lay the tables for lunch. At least it was something to do; there was cinema and art therapy, in [New hospital] it isn’t like that.”*

In addition, in one group, there was a feeling that, in the past, people may have been more accepted compared to today.

- *“One thing wrong in society is that when I first came to [region]; if you were not good at work there was always some sort of work on farms and places. People knew what he [a man with mental illness] was; communities knew and there was more of an acceptance.”*

Less frequently mentioned, and perhaps less to do with the purpose of a hospital and more to do with what is important within it, in between five and three of the sixteen groups was:

- Being cared for
- A place of sanctuary that is not in a hospital setting
- Peer support
- Enough resources and staff
- Recovery
- Information and explanation
- Person centred care
- Easy access to help
- Food
- Continuity
- Consistency
- A Pleasant environment
- Paid and worthwhile activities to do.

Being cared for

A sense of being cared for and supported was one of the key features people wanted from a hospital

Sanctuary (that is not a hospital)

There were people who preferred to think of an alternative to hospital: places where people could get help in crisis, places accessible to people with a diagnosis of EUPD and places that provide a form of haven and sanctuary as well as places in communities that everyone could use for their wellbeing and therefore maybe prevent some admissions:

- *“A place where people can retreat to, with gardens and kitchens, in a rural environment where people can contribute at the level they can manage where there is alternative therapy and activity, outdoors work and access to some level of recompense for work or equally freedom to stay and contribute or be looked after if you are on benefits.”*
- *“We need crisis centres, safe houses, sleep houses. A much smaller version of hospital with single en-suite rooms with your own personal space, with people to talk to.”*

- *“Mental health centres for each community – places for wellbeing – with activity, massage, coffee. Places to go if you have had an argument or if you feel down or lonely.”*

Peer support

People mentioned the value of peer support: the help that they can get from each other. None of the groups mentioned formal peer support workers, but that might be because few of them exist at present. Some people felt that the support they got from each other could be better than the support from staff, and some people emphasised that although they got support from each other that they still needed help from staff.

- *“Help from peers – the only people that can help is those that have been through it themselves.”*
- *“I find having gone through long periods of depression I find it powerful being around other people with a mental illness; it helps as much as the staff.”*

Having enough resources and staff

People mentioned that there were not enough resources in hospital to get the help they need, and that sometimes it was hard to see staff to get assistance.

- *“Friends couldn’t go for a walk because there were not enough staff.”*
- *“They do not come and sit down with you.”*

Recovery

People said that a hospital should be about wellbeing and recovery

Information and explanation

People said that there is a need to help people understand what the hospital is and what will happen there.

- *“The first thing that should be done on admission is explaining it to you; it is hard enough.”*
- *“Prepare for admission. We are scared and do not know what is going on.”*

Food

People raised the need for good quality food; the need to be able to make your own meals and to be able to have meals brought in if necessary. In one group people complained about putting on weight in hospital.

- *“The right to bring food to the person in hospital. I am not allowed to bring in cooked food. It is the policy; it seems silly. They say it is health and safety.”*
- *“Every time I go in, I put on weight.”*

Person-centred treatment

People talked about their desire for treatment to be based on their own needs, to recognise their individuality.

- *“My perfect thing would be coming in and them asking what I want and us working together on it; rather than a ward round and more meds.”*

Easy access

People said that hospital should be somewhere that they can access easily, and equally there is a need to be able to gain access to community services when they feel they need them.

- *“If you go to A&E you get a row off the triage nurse: they say you should go through your GP; but it is 8 at night and they say it is up to our doctor if they will refer you – you can wait there for hours.”*
- *“You shouldn’t have to wait hours and hours to be assessed.”*
- *“Access to mental health is quite difficult; getting help when you can see someone is unwell is difficult. He sees the psychiatrist every 8 weeks. There is not enough time in this.”*

Continuity

People complained of the fact that the doctors that they saw changed frequently. They felt that there was a need for some continuity of staff.

- *“I was in for 6 weeks and had three different psychiatrists: I had two good ones.”*

Consistency

People said that they wanted consistency in treatment both collectively and individually.

- *“In XXX they were not allowed to smoke in the courtyards, but in the wards opposite they were. The women in there saw it and were stressed out, and could see that they could smoke in another ward; they were really angry.”*

A pleasant place to be

People pointed out that the environment of a hospital was important, and that this included such things as the gardens, colour scheme, cleanliness, and should include access to facilities such as swimming pools, as well as the space people have and how secure that is.

- *“When you are living out a plastic bag because you are changing beds, it means you are ready for discharge. You can be sitting all day waiting to see where you will be put.”*
- *“Wellbeing is not honoured when you have to share rooms.”*

Paid and worthwhile activities

People said that it would be good to have work and productive activities to do when in hospital. People wanted both paid work and a chance to contribute

- *“When the Village was open you could put something back in.”*
- *“Jobs with pay.”*

Mentioned infrequently in only one or two groups were the following:

<p>Rights</p>	<p>People talked of the need for:</p> <ul style="list-style-type: none"> • Advocacy • Admission for people with a diagnosis of EUPD • The right to smoke • Training of staff in sensitive procedures such as constant observation • Access to and the use of advance statements • Information and knowledge of rights
<p>Environment</p>	<p>People talked of the need for:</p> <ul style="list-style-type: none"> • Access to mixed-sex wards • Access to single-sex wards • Access to mother and baby units • Access to physical activity and a gym • Access to single rooms • Adequate waiting rooms which are not exposed to the public gaze
<p>Journey through hospital</p>	<p>People talked of the need for:</p> <ul style="list-style-type: none"> • Access to adequate care and support on discharge • Not being admitted for longer than necessary • Getting the right medication • Help with their physical health • Structure to the day and encouragement to do things • To recover at their own pace • Early intervention to avoid the need for admission • Access to alternative therapies
<p>Attitudes</p>	<p>People talked of the need for:</p> <ul style="list-style-type: none"> • Stigma-free care • To be understood: for people to 'get them' • To be able to trust staff and others • To have their opinions listened to • To have a chance of relaxing and enjoying themselves • The chance to be themselves • To have the right mix of people around them
<p>Carers and friends and family</p>	<p>People talked of the need for:</p> <ul style="list-style-type: none"> • Visits from family and friends • Support for carers • Family rooms • Help with the cost of visiting

What people don't want from a psychiatric hospital

The most frequently mentioned thing people didn't want was: to feel frightened and restricted.

People said that they would prefer not to have too much restriction which can, in turn, cause isolation and fear. They do not want to feel that they have done something wrong, be exposed to violence, or feel they are in the equivalent of prison.

- *"Confinement without being able to see your friends or someone you feel comfortable with – this is not always easy."*
- *"You shouldn't be made to feel scared."*
- *"Also violence between patients which was ignored; which was quite a shock."*

Less frequently mentioned was: not just medication.

People said that hospital should be more than a place to get medication; that people did not want to be overmedicated, and did not think that some people should easily get medications to which they could become addicted.

Mentioned infrequently in two or less groups was:

- A wish not to be exposed to drugs and alcohol (which are easily obtained on wards), and for there to be separate wards for people admitted for drug and alcohol problems.
- Less bureaucracy and for care not to be hindered by excessive regulation.
- For prison to take over the function of a psychiatric hospital.
- To feel worse on discharge.
- For too many institutions to exist instead of community and preventative services.



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