



## Service users and carers information

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**The views of people with lived experience on  
supported decision making  
and people with a mental illness  
- some practicalities**

**Mental Welfare Commission for Scotland**

**July 2019**

The following paper reflects the voice, experience and opinions that people with lived experience and carers, as individuals and as groups, provided for the Commission's forthcoming work on supported decision making. 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 consulting about**

We asked if people who are very ill, and might get detained, can make their own decisions. We wanted to know whether, and how, they can be helped to do this.

### **Who we asked**

We asked 195 people in fifteen focus groups.

### **What we found out**

#### **Can people make decisions at such times?**

Most people said that there are times when some people cannot make particular decisions, and may need them taken by other people. They felt that this can be necessary to keep people alive, and avoid negative consequences such as homelessness or prison.

Some people who had been extremely ill told us their decision making ability was profoundly damaged at these times. However, some people said that they can sometimes make reasonable and sensible decisions, even when very ill or distressed; but the way they are treated and regarded can stop them being listened to, and having their views respected.

#### **How can people be supported to make decisions?**

People spoke about the advantages of making advance provision for how they would like to be treated when they are well. This might be through advance statements, or named persons, power of attorney or crisis planning.

The way that the staff concerned with people's care approach them and view their ability to decide about their treatment is crucial. People find it most helpful to making their own decisions when staff are respectful, sensitive, and supportive, rather than when they are dismissive or patronise people. Staff should start with the assumption that people can make their own choices and decisions about their lives, unless it becomes apparent that they cannot.

Having a trusted person who knows the person well can be key in knowing how much risk they can take, and how they would like to be treated. A trusted person may be a friend or family member, but equally, for some people, it would be staff who support them. Some people may have no-one to take on this role.

In order for people to be able to make decisions they need to be in an environment that encourages this. They need to have information provided in a way they can understand so they can weigh up the pros and cons of what is being planned.

Advocacy is also a service people can access, but was only mentioned by one group.

#### **Systems approaches to making decisions for ourselves**

Many of the groups we approached said that key to avoiding decisions being taken out of their hands is the need for commissioners and policy makers to provide enough resources and services to help prevent people getting seriously ill. These need to have

a preventative function, provide day to day support if needed, respond to crisis and also provide a safe place for people to go. This would help to prevent people relapsing and becoming extremely ill. In this way people are much more likely to be able to continue to make decisions in their own right, because they have enough support to stay well.

## Introduction

In late 2017 and early 2018 the Engagement and Participation Officer (Lived Experience) at the Mental Welfare Commission had conversations with fifteen focus groups on supported decision making [*for definition see Appendix A*], and how this might work in reality when people are acutely ill or distressed. He also had individual meetings and interviews with a number of people with lived experience.

The conversations involved 194 people in fifteen focus groups in:

- Wick – with Caithness Mental Health Support Group
- Thurso – with Caithness Mental Health Support Group
- Inverness – with HUG (action for mental health)
- Fort William – with HUG (action for mental health) and Support in Mind
- Aberdeen – with the Aberdeen Carers Support Group
- Dundee – with Bipolar Dundee
- Dundee – with Dundee SUN
- Perth – with PLUS Perth
- Edinburgh – with Bipolar Lothian
- Alloa – with Klaksun
- Bathgate – with West Lothian Involvement Group
- Glasgow – with Restart (Maryhill)
- Glasgow – with Restart (Bridgeton)
- Glasgow – with Bipolar Glasgow
- Dumfries – with UCI and Kaleidoscope – Support in Mind

The vast majority of people involved were people with lived experience, but a very small number of workers also participated, as well as some carers.

We had previously had discussions with people with lived experience and carers on capacity, detention and supported decision making, around a year ago; a report of which can be found on the Mental Welfare Commission website. We wanted to follow up and find out from people just how and if people could make or be helped to make decisions when acutely ill and at risk of being treated against their will (substitute decision making).

The conversations resulted in three main themes:

- Whether people can make decisions when acutely ill, and whether compulsory treatment is sometimes needed.
- What can be done to support people to make decisions and participate in care, when very ill and at risk of compulsory treatment.
- What could avoid the need for compulsory treatment.

During these months six people also spoke in some detail about their own experiences, and how they felt services had changed for them to enable them to live a life relatively free from detention, and sometimes hospitalisation, in contrast to

the past where this was more common. Some of these accounts are included in the boxes to illustrate the points people made more generally.

## Can people make decisions when acutely ill and is compulsory treatment sometimes needed?

*"I think it was spur of the moment. It was an overwhelming feeling of not coping and not wanting to be around, it was about dramatically going downhill which was not like subsequent depressions.*

*I just didn't want to be in the present, I had all the lethargy and was hardly eating, I wasn't interesting in things, I don't think the overdose was life threatening but I also don't think it was a cry for help.*

*I know my husband needed help and got the nurse straight away. I can't remember the journey to hospital, I needed someone to intervene. I don't think my husband even knew I was suicidal, it was quite weird.*

*At that time I am not sure if anything could have been done to help me make decisions. I remember at that time just staring at the water when with friends; nothing made sense but because I was with them there was not the possibility for me to act on how I was feeling.*

*It would have needed a skilled person to pick up on subtle signs from me that I was this ill; my husband was used to me being apathetic and not doing things and probably couldn't see how ill I really was."*

Whilst we were not particularly looking for another debate about the pros and cons of compulsory treatment, this inevitably became a part of the conversation.

People spoke strongly in favour of the need for detention and substitute decision making in 14 of the focus groups with 49 comments recorded that compulsory treatment can be needed.

In four of the groups people were unanimous in saying that compulsory treatment is sometimes needed, with some people being very indignant that anyone could consider otherwise.

- *"They are not the people who have been homeless as a result of this."*

People felt that there can be a need to intervene against a person's will to keep them safe, or other people safe, because their judgement can be so impaired that they cannot take some decisions for themselves.

Some people who had been detained felt that there can be times when they are extremely ill, when they are completely incapable of making decisions, and struggled to understand how supported decision making could occur at such times, unless it was carried out in advance.



*“The section was put in place because: I could not control my racing, malfunctioning brain; those around me – friends, family, colleagues – were out of their depth at keeping me safe at home; my young children would have been exposed to bizarre risky behaviour on their mother’s part (e.g. cooking soup on the hob, then being distracted by my next all-absorbing project, and burning the pot; or driving erratically).*

*Moreover, hospital staff were unable to contain me initially as I escaped the premises, in nightwear during snowy weather, with no money or phone.*

*Holding me under section meant that staff could watch my movements more closely.*

*It also meant that I was safer, as were the public – e.g. having little sense of risk at the time, I could have walked in front of a car and endangered more lives than my own.”*

It was mentioned by some people that without compulsory treatment some people would be likely to end up in prison, and that with treatment more people would be able to **live better and more dignified lives.**

- *“When I was really psychotic – I was paranoid to the point that I wouldn’t speak to health professionals, I thought they were spying on me – I was very ill for ten years – then built up a world where my world did not mesh – I do not think any responsibility should be given to you at such times.”*
- *“A friend called about me and I refused to let them in but they kicked the door down and took me to [hospital]; in retrospect that needed to happen.”*
- *“Having decisions taken for us can protect our dignity.”*
- *“I think they were right to section me in hindsight.”*

When talking about substitute decision making and supported decision making, four people in four groups said strongly they were against all compulsory treatment, and people in three groups said that despite being ill they can still often take decisions about their care and treatment, and that often the opposite is assumed.

It was also mentioned that being forced to do things against someone’s will can make them angry and upset and, in contrast, being able to make their own decisions makes people feel better about themselves.

All the groups mentioned the trauma and pain that detention can cause, and ways in which this can be improved, especially to give people more say and autonomy than they presently have.

*"I can make decisions for myself nowadays and know when I am ill and need to stop doing various things. This needs to be respected, however I can imagine that there are people who get in a space where they are no longer able to make decisions.*

*Sometimes it can be necessary to section some people, but it can be done unnecessarily and has caused me incredible damage in the past. One of the major flaws in the system is that we can be sectioned and because of this can worry hugely about if we will be sectioned and when we might be released from it.*

*In fact sectioning is always traumatic and people who have been sectioned because of severe mental illness have also nearly always been traumatised in the past. There is a need to deal with the inevitable re trauma that sectioning also causes people."*

It was also mentioned that the treatment by, and attitudes of, staff can make it harder to make decisions and make it harder to be listened to; that not being able to make decisions was not always about illness or impaired judgement, but about the way the system people found themselves in responded to them.

*"I feel that practitioners need to be aware of the 'nocebo effect'. We all know about the placebo effect but when doctors or other care givers hold negative ideas about us or our prognosis it can have a very powerful and deleterious effect.*

*People will live up or down to expectations quite often and it is up to everybody to hold the highest degree of hope and positivity about a patient's ability to heal. This is particularly important when people have been through the trauma of having their rights removed and being detained against their will."*

One group wondered whether a person with a mental illness, especially if they have capacity, should be able to make a decision to die because the illness is so severe; saying that people with a physical illness can refuse treatment and hasten their death and therefore this might apply to people with a mental illness too.

In another group it was stated by one person that anyone who is determined to die will do so whether detained or not.

One person in one group believed that it was possible to provide community facilities which completely stop the need for hospital or detention, and that such places have been demonstrated to work effectively.

- *"Even though I took the tablets and was up to high dose I could make decisions."*
- *"If they give you more medication then you cannot speak and then they talk to you as if you are daft – some can understand and others can't."*

*"There is the balance between being acutely ill and wanting to die and having compulsory treatment; which seems right and proper and wanting to die and having an illness but also having capacity.*

*An assessment of someone's life can show that they do not see the way they live as acceptable and in this case when they have capacity they should be able to choose to die.*

*With the first one where someone has the chance of recovery to an acceptable standard, then intervention should occur even where they are not happy about it but if, ten years later, that same person has judged that their life is absolutely awful: a sort of 'I have been through this so many times, I no longer want medication and want to be left to die.' But how do you know if someone has the capacity to say this?*

*It is not an either or thing, but sometimes it might be unreasonable for people to go through the pain again and again and again.*

*It can be very blurred; personally I do have faith in clinicians being able to make some decision as to someone's mental state.*

*They will not always get it right but I would worry if they were not able to make a fairly accurate judgement of a person's capacity and illness."*

## What can be done to support people to make decisions and/or participate in care when very ill and at risk of compulsory treatment?

### The approach and attitude staff take towards people in distress

*"I take my medication on a PRN ['pro re nata'; taken as needed] basis when I feel I need it and have worked for many years with a consultant psychiatrist. He knows me well and has established a good relationship which has enough boundaries to make me feel safe.*

*He is non-judgemental and not sexist which is important to me. He is happy to live with a degree of risk that other people have tended not to be. He has also agreed with me that some of the ways I have been treated in the past by psychiatry have been abusive, which is important to me.*

*I have managed to remain free of being sectioned for many years due to this approach but there have been times when it has been close; there was one time when I was high and out on pass and was wanting to go to the school my son goes to and my son was worried about the impact that would have. At that point he told me that if I walked into the school then he would have no choice but to section me and this was enough to stop me.*

*Key to avoiding times when I would probably have been sectioned is the relationship that I have had with my psychiatrist and GP who are both experienced and have known me for many years.*

*I need a person who is strong in themselves: my psychiatrist will share aspects of his life with me and show his reaction if I surprise him with some of my experiences but he is bombproof. I never have to worry that what I say or do might harm him."*

People felt that one of the key ways of helping people take decisions when distressed, and in avoiding compulsory treatment, rests in the way staff approach people who are ill, and that staff attitudes towards them can also be crucial. This was raised in 13 groups.

10 groups said that sometimes the attitudes and automatic assumption of power and superiority by some staff made it difficult for people to want to engage or participate in treatment or decision making, or for staff to pay attention to people's wishes. This can occur in small acts or in their reaction to crisis, which may traumatise people.

- *"When they keep typing when you are talking – show that they care about you."*
- *"A lot of people are suspicious if you are seen as mentally ill and cannot communicate with you because of this. This is a part of how you can be treated in hospital."*

- *“On one to one – I was on this and – it got in a bad state and was shouting and raving five nurses got a hold of me and injected me – they should not have done that – they should have talked to me civilly.”*

*“Sometimes it is seemingly small things, like one time when I was, at last, managing to relax in a relaxation class in the hospital and a nurse burst loudly into the room and ordered me back to the ward unnecessarily and in a very unpleasant fashion. Or another time when I wanted to go out on pass and some of the nurses who knew the father of my son said “What about him, if she goes on pass?”*

*And yet my psychiatrist had enough faith in me and my level of illness to say I had every right to go on pass and that if my relationship with him was unhealthy and involved domestic abuse that was an area of my life where I had a right to make choices and had little to do with illness.”*

People wanted staff to recognise that people are likely to be scared, and that they should be approached gently and with empathy and with a belief that, generally, people can make decisions about their care and treatment.

This fact, that people may not be able to make decisions in some areas but can in others, and that this should be respected and expected, was a strongly-held belief by some people.

- *“It was so painful and demeaning, they did need to keep me in hospital to keep me safe but my opinions on these were belittled and ignored. Some of my opinions were out there but no one talked to me about my delusions.”*
- *“Sometimes people say there is no point in speaking to us ... they do not think you are in a state to talk.”*

They wanted staff to know that compulsory treatment will be traumatic, and that to help people engage, they need to speak with them about what has happened. They felt that key to helping people with decision making were: friendliness; good communication skills; and an attempt to reduce power imbalances.

In addition, staff need to explain what is happening and why, and do the basics of asking people what they want, instead of assuming they know what people need or that they will automatically understand what is being said to them. Alongside explaining what is happening is the need to create a humane and respectful environment.

- *“If they ask who you would like contacted for you that may be a start.”*
- *“Treat you with dignity and respect.”*
- *“Treat you like a person.”*
- *“Get to the bit of them that is still in there - like make eye contact – be gentle, be friendly, show them that they don’t need to do it.”*
- *“Being listened to and taken seriously.”*

*“Perceptions are skewed in mental illness, but you are wed to these perceptions because they are all you have; that is your only mode of access to understanding the world and yourself.*

*Staff should appreciate that, perhaps try to follow the patient a little in his/her logic, try to understand it, and only then gently suggest to them a more normalised perspective.*

*Essentially staff should be open-minded, good listeners, and not be overly dismissive of ways of seeing that are at odds with the norm – all this, while keeping themselves and their advice grounded.”*

Two groups also raised situations where people seek help when in crisis, or need to express themselves in certain ways, and instead of being listened to they are dismissed and turned away. When people do not feel that their distress or need for help is being acknowledged, then supported decision making cannot easily exist because people feel that their feelings and opinions are being ignored.

- *“I think it is bad; my friend was crying her eyes out but they just turned her away – they didn’t care – I have always been treated when I need it – they like to use judgement a lot but that can be subjective – for instance that suicidal threats are not serious.”*

In contrast, some people made the point that when some staff do reach out and connect with them that the whole experience becomes better and decisions become easier to take and agree on.

- *“There is one nurse that really rang a bell with me. She said ‘I am your nurse for the day, I can see where you are just now and I will go away but I will definitely be back at 11.00.’ She explained the reasons. Some nurses say that and do not turn up when they say they will. She understood my condition.”*

*“I was high and in need of a hospital bed but they were insisting on unnecessary assessments and procedures which were really upsetting, when all I wanted to know is that there would be a bed available for me.*

*The nurse who was dealing with me was unpleasant and authoritarian. Eventually I demanded to see a doctor; he listened to me when I asked to be given a specific nurse as my key nurse, who had been very good in the past, instead of this nurse. He said that he would try to make this happen but in return he wanted me to agree to try to work with the nurses and to work to get better. I agreed.*

*The new nurse was amazing and did the first ever cost benefit analysis of my bipolar and helped create the first proper care plan for me that I had seen. He was very dignified and approachable.”*

One group mentioned the need for staff to seek out the positives in people. With this approach, prospects can be better but so can attitudes and a sense of partnership and an ability to make decisions together.

- *“What are your interests? Hobbies? Skills? Find all this out: what will keep people in their recovery journey?”*

The more that staff are able to create an environment where people feel that they are on a shared journey rather than being told what to do, the more likely it is that decisions can be taken that suit the persons needs and desires.

- *“I don’t think there should be meetings about us without us in them.”*

One group also made the point that people with lived experience may have a responsibility to be open and honest with staff as well, in order that they can have an idea of how to treat them.

Some people were also open about the fact that they do not get on with other people, and that accommodation may need to be made for this. Another group felt that certain professionals tended to treat them better than others, and that this learning might be incorporated into training.

- *“It is hard to judge; a CPN doesn’t know what is on your mind and if you don’t tell her she will never know.”*
- *“Every time the police came when I was suicidal they were far better and respectful and human than half the nurses.”*

In summary, many groups felt that in order for people who are acutely ill to make decisions and participate in or control their care, staff need to approach them assuming that they can usually grasp what is happening, and need to avoid doing those things that may cause patients to feel alienated or powerless or inferior.

The more that staff can develop positive relationships with patients, the more inclined those patients will be to co-operate. It will also be easier for staff to find out how people are really thinking, what they actually want to do, and want to have done to them.

Supportive decision making may be as simple as introducing humanity and calm into fraught situations.

*"But I did not have control, I have never been so angry in all my life at being told what to do, but my mind was illogical, impractical, unrealistic. Some part of me knew some of the things I wanted to do were impractical and stupid and shouldn't happen and I had no idea how awful I was at phoning people at all hours of the day and night or of the demands that I was making on friends that I should never have made.*

*Looking back I am sure I was psychotic; it was real but not real. I had a thing about Nelson Mandela and wanted to go to South Africa for his birthday party and thought a stranger on the ward was really famous; things like that, but I could still make all sorts of decisions including some about my treatment.*

*In some ways it is just obvious: most people nearly always know which areas we do not have capacity in when we are very ill but in order to find this out properly they need to talk to us and be with us and listen to us and find out about what our world is like."*

## **Stating in advance how people would like to be treated, when at risk of compulsory treatment**

When looking at how people can take decisions and have their views taken into account when acutely unwell and at risk of compulsory treatment, seven groups mentioned the value of making advance statements. However one group, while saying that advance statements were a good idea, also had doubts about their value; both in people being able to access them and in them being adhered to.

- *"Check for advance statements and that they are up to date and at the front of your files. They can't find them: this happens a lot."*
- *"Last admission they printed all my information and about the side effects. They gave me the choice of whether I took it or not, and this was in my advance statement."*

One group said that having a crisis card saying what to do and who to contact in an emergency could be helpful as would a buddy card.

The existence of patient passports and powers of attorney were also raised as valuable ways of helping with decisions at these times.

*"I don't always feel able to make decisions about my care and treatment when I am ill and in hospital but I am happy that my Advance Statement is strong enough in these circumstances.*

*In the past I have had trust in the people mentioned in my advance statement. Sadly that wasn't the case due to a breakdown in family relationships when I was in hospital last October but luckily a couple of my close friends stepped in and helped sort this out."*



*"I'll now be updating my Advance Statement as soon as possible – it is important to remember that our wishes can change rapidly as circumstances change as can the people we would like to help us speak out or help with our care.*

*I sometimes struggle with decisions when I get home due to lack of confidence in my ideas. It can also feel very patronising when family, friends or members of staff question my decisions when home.*

*My WRAP Crisis Plan is also pretty clear about how people can help and what the signs are that I need less help in order to take back control and move forward.*

*I try to update my Crisis Plan at the same time as my Advance Statement i.e. post crisis and keep a copy of it attached to my statement. However even when I am very organised and take notes about my care after a crisis, actually updating my advance statement or crisis plan can take some months to do, it is not the first thing you seek to do when you are recovering again, sometimes we can go through a great deal in our personal life during a crisis and it can take a long time to process this."*

## **A trusted person**

*"What I would like now is someone who had been trained to discuss how I was feeling at the time, my thoughts about what I want to happen and if that comes to a negative answer because you can't see past the next hour; to have a meaningful conversation that talks about hope, not to avoid the idea of suicide but to explore that with you and spend time with you, it needs someone who doesn't need to be going off to someone else for their next appointment.*

*You need to be the important person that they are trying to communicate with and help and you need to know this.*

*You need to be able to trust them and gain their confidence and to be able to give them permission to talk to other people who might be able to help you until hopefully you get through it.*

*They need to communicate with the most appropriate skilled professionals about how to take things forward."*

Eleven groups said that one of the key ways of being helped to make decisions is to have a trusted person who knows them well; someone who can both assist them to make decisions because of the relationship that they have with them, and because the trusted person has a good understanding of their wishes, needs, and experiences. Groups also felt that some staff were good at creating a sense of trust, even when the person being treated was not well known to them, and that this was very important.

A variety of people were mentioned who would fit into this category. It could be a friend or family member, or it could be a professional such as a CPN [community psychiatric nurse].

In one group, comment was made that it might be better to have someone who is not in a person's very close social circle or who knows them best to take on this role, presumably because there may be a conflict of interest, or elements of that personal dynamic that could be damaging when trying to ascertain someone's wishes, and to help them to take decisions. Another group said that some people do not have anyone in their life who could fulfil this role.

It was also mentioned that if a worker knows you well they will have a far better idea about whether to intervene or not compared to a worker who has little or no knowledge of the person.

- *"Key is a trusted person."*
- *"It is about trust. I wouldn't trust my family but I would trust my psychiatrist."*
- *"I will not talk to someone I don't know: I cannot open up."*
- *"I can push close ones away and can feel family and friends are better off without me. So having someone that knows you and doesn't talk down to you and have real empathy is important."*

*"It shouldn't be just about compulsory treatment. It is often obvious that a person needs treated and is ultimately glad that they are alive even if they did not agree with the section at the time. It is about being involved in drawing up your care plan or your anticipatory care plan. You need people to get to know you as a person.*

*If you are able to express your usual interests and likes when you are well, for people to know about you as a person and the things you would like them to know. One way is an advance statement and a personal statement: the detail that you think would matter to someone who doesn't even know you, like how to be treated in an emergency. It needs easily accessed.*

*You need someone who knows you well and knows what you are like as a person and what you do and don't want to happen to you. People like this could be contacted to get information about you or to ask what makes you tick or how to approach you and things like that; almost multiple named persons."*

## **Named persons**

Four groups mentioned the importance of named persons; both to help people make decisions and to calm down the situation but also to act as a voice for the person they are a named person for, although that is closer to the role of an advocate than a named person.

In a development of the role of named person, one group suggested that a named person could take decisions on behalf of the person when they were unable to

themselves, bringing the role closer to one of Power of Attorney as is found in adults with incapacity legislation.

- *"I would like to say that if I am unwell and can't make decisions, that they should let my named person take decisions."*
- *"Maybe when you do your advanced statement; do it with your named person so that when you are in a crisis they are aware of what will happen to you and you can trust them. Maybe they should sign it too."*

*"There should be a failsafe for people who spend all their money when they are high; ideally when people are well they would set up power of attorney for when you cannot make basic decisions when you are unwell or an arrangement with the bank not to loan people money when they are unwell.*

*I don't see why banks couldn't be educated enough to recognise that this situation can happen: to try to put a stop on an account if someone's spending follows an abnormal trend, especially if you have told them in advance of illness.*

*But you still need to pay your bills and food, how do we deal with this? Ideally they would be able to say this person is too ill to pay their normal outgoings and therefore it has to be put on hold but how this is resolved a bit later when they are more stable and need control again: how does it go back to normal?*

*It shouldn't be the case that people lose out financially because they are ill. There should be someone who can help with your account and money in these situations."*

## **Dignity**

One group highlighted the need to be respectful of people, even if they appear to be out of touch with reality, and said that this constant awareness is vital to ensuring people are treated with dignity. Again, this approach is likely to make it easier for people to participate and be encouraged to participate. This theme could also be seen throughout the thoughts people had on how staff should approach and think about the people they are caring for.

- *"We can lose capacity; it needs to be formally assessed – my mother used to be a nurse and nurse patients in a coma or nonsensical state but they always said you never know what someone can understand or hear – they could transfer this need for dignity to us."*

## **Information**

When trying to make decisions, five groups said that it was important that people were given the information that they needed about their condition and what was being done to them. If this was done, people would be more likely to participate and more likely to be able to make decisions. People will always struggle to make decisions if they do not know about their diagnosis, or how they are being treated, or how they are expected to behave.

- *“Maybe if they came with knowledgeable stuff about your condition to inspire you to have confidence in them.”*
- *“Remember you will forget.”*
- *“I am diagnosed bipolar and understand but then they diagnosed me with e.u.p.d.<sup>1</sup> too. I thought it was schizophrenia; I said “Can you write it down?” They just gave it me and threw it across the table at me and did not explain that I had both. I was so scared.”*
- *“In hospital explain why and give reasons; don’t just say ‘We will be doing this’. I didn’t even know I wasn’t allowed off the ward.”*

Two groups said that if people work together, maybe to the extent of creating joint care plans that patients also have copies of, then decisions are far more likely to meet a person’s wishes and the person is more likely to be able to take those decisions.

- *“Write it down and keep it in your room to let you know what is happening.”*
- *“Have a Care Plan that you know and agree to.”*

When giving information, people said that it is important to remember that people need to understand what is told to them, in order to use it to make sense of and take decisions about their care. This means considering access issues.

- *“I cannot read properly; they should explain it to you.”*

When giving information, one group said it is also important to let people know about the range of services and supports that are available, rather than just about hospital or community services. If people know what exists then they can both make decisions and possibly also access help that prevents them getting to the point where they may lose capacity.

- *“Simply letting people know what is out there: that if people know about it they will be sent by [service] and that is part of the signposting. It would make a huge difference.”*

## **Advocacy**

One group mentioned the value of being able to access advocacy when trying to come to decisions about their care and treatment.

*“Advocacy is, to me, vital for assisting people to express themselves and make decisions, they have training and skills in terms of listening to what the person is saying and trying to understand, from the person’s point of view, what they are saying and trying to help the person communicate their views and opinions. Because advocacy is independent the individual might trust them more. They listen to the person but can’t make decisions over the person. There is not a power imbalance because they cannot agree to a decision on the person’s behalf.”*

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<sup>1</sup> Emotionally unstable personality disorder

## The Hospital Environment

The way a hospital functions and is built has a major impact on how people feel about themselves, and therefore if they feel able or willing to take part in treatment or in decisions about their care.

One group raised issues about a lack of activity, and also the promise of activity that didn't happen, as a reason that people can become disillusioned with treatment; and another highlighted how difficult ward rounds can be, and yet felt that with some accommodation these could become experiences people maybe benefited from rather than dreading.

- *"In [hospital] they put up ward activities every week but not once do the activities happen – the ward staff never did anything."*
- *"Standing in that queue to get fed: it was like feeding time at the zoo."*

*"The psychiatric ward in the NHS hospital for me felt maternal in some ways. There was during my seven weeks stay there (of which three weeks were under section) a kind of regression to a safe, secure place; I was rendered helpless (like a baby).*

*The section sought to contain my mania and safeguard me and others from my own risky behaviour. It was like being held, while I gathered myself back together, rested and healed. Held, not in the sense of prison bars, but rather that of being held by someone who is looking after your well-being and who considers your well-being important."*

In many ways, the suggestions made in these sections reveal that when we are talking about helping people have as much of a say as they can have in their lives, and in the care they are being given, when at risk of detention, then most of the ideas boil down to simple and basic ways of treating people.

The people we spoke to said that staff should:

- Find out what they want, in advance ideally; develop a good relationship, find people who have a good knowledge of them and what they would want or not want done to them.
- Involve trusted people when it looks like decisions are likely to be taken out of their hands.
- Assume, as far as possible, that people will be able to make at least some decisions, so give them information in a fashion that they understand; and treat them in such a way that they have the confidence to participate; and the faith that as far as they can, the people caring for them will try to respond to the majority of their wishes and needs.
- Where it seems like they are at risk of not being heard, involve advocacy.

## What could avoid the need for compulsory treatment?

These focus groups were all about finding out how people can (and if they can) make decisions when they are acutely ill, and possibly so ill that decisions are likely to be taken out of their hands.

However most groups also wanted to point out that key to supported decision making is the sort of systems change to health services that means that people do not routinely get so ill or distressed that compulsory treatment is a common option for them. People would be able to take decisions and to participate in their care if they had access to the sort of help that means that they do not end up critically ill, with their judgement so impaired that they can no longer grasp some of the world's basic realities.

*"However, several things could have obviated the need for sectioning:*

- 1. Having a better therapeutic relationship with my psychiatrists, from 2010 on. On several occasions I was variously patronised, not listened to properly, judged and treated dismissively. Too much deference to my first psychiatrist perhaps? – an esteemed head of perinatal psychiatry. Had my bipolar condition been diagnosed sooner, I would have had access to Lithium and this would have reduced the chance of my going manic. Further I would not have been give an antidepressant – Venlafaxine – unsuitable for bipolar depression which triggered the mania that culminated in my sectioning.*
- 2. Seeing a psychiatrist more regularly: every 3 months I presented, with depression. No psychiatrist actually saw me high, until I was hospitalised.*

*Better CPN team. While I was fortunate with the nursing staff in hospital, my Community Team was poor. One of the three CPNs I had was good and that was subsequent to my section. It was made clear to me that I was taking up resources and that there were others more in need the team ought to be servicing. On my last meeting with the CPN in [place name], prior to hospitalisation, I again said that I believed I was bipolar and he retorted: 'Stop saying that. Nobody thinks you are bipolar. Only you.' He then discharged me, and in less than 2 months I was sectioned."*

## Getting help before the crisis gets too bad

When looking at supported and substitute decision making, five groups were keen to point out that if services could help earlier, when people were approaching crisis, then many people would not get to the point where compulsory treatment and substitute decision making was becoming a likely option. They also pointed out that crisis plans and relapse plans could all play a part in supported decision making and in reducing the likelihood of compulsory treatment being needed.

- "Last time I was in hospital I was down at A&E, the duty doctor went home then the police came, I was paranoid –I got some swords that were telling me to stab*

*them – next there were hundreds of police – (we [the group] all agree that at these times they should have intervened) - but they should have helped beforehand.”*

## **Prevention**

Two groups said that if services could intervene early in the development of a person’s illness then the chances of it progressing to the point that compulsory treatment becomes likely will be diminished. Making the likelihood of people developing mental health problems in society less, would, for them, be better than having to deal with the end results of mental illness.

- *“If there was early intervention and help before it escalated, maybe we wouldn’t need to have sectioning – if they could pick up on it in teenage years where it often manifests.”*
- *“Our GPs could have a role in prevention with more mental illness training and knowledge of who to refer people to.”*

## **Safe places and protection**

Five groups talked about the need to give people a sense of safety and a safe place to go in crisis, feeling that if they can go to somewhere where they feel safe and looked after, that they are less likely to get into a position where compulsory treatment is needed.

One group said that there are some people for whom there is a need for a protected and safe place in which to live. They felt that some people will never integrate into the community and never be truly in a position to manage. They felt such people may need specialist facilities in which to live and be cared for and some wished that they could have access to such a place.

- *“I need to be kept safe and taken to a place of safety at such times – I need looked after.”*
- *“You need a buffer between admission and crisis: a safe place to go that may avoid escalation; a sort of safe-house with people qualified to understand and listen.”*
- *“People who are distressed and suicidal have presented repeatedly to [hospital] and have not been able to be admitted and have committed suicide because we had no safe place. We need somewhere with beds.”*
- *“Cabins with a sanctuary; by a waterfall with heathy living and therapy and rest and things to do: a place of peace and silence.”*

## **Lack of services and support**

Nine groups said that if we are to avoid compulsory treatment then we need to have adequate community and hospital services in order that people can get the support and care they have a right to.

They highlighted examples of continuing cuts in services and support, and felt that this led to extreme situations that could have been avoided from developing.

- *“The way the NHS is, you don’t get a bed unless you are really ill.”*
- *“Intensive home treatment also sounds great for that but we do not have that.”*
- *“I needed help when I was at home on all this medication; the psychiatrist said ‘We do not have enough CPNs in the team’ – I have no one to treat me.”*
- *“We need access to services in first place – such as a psychologist.”*
- *“Peer support: suicide survivors who can help other people; then you would be more likely to phone someone.”*

### **Self management**

One group felt that another important way of getting to the point of making decisions and avoiding detention rested in the need to have a thorough personal understanding of yourself, your experience and your condition. From this a greater degree of autonomy could be exercised.

- *“It is about having coping strategies.”*

### **Alternative approaches**

One group suggested a couple of ways of dealing with distress that they felt may reduce the likelihood of distress and mental ill health, and therefore the necessity to detain people. These approaches were both about challenging the medical model of treatment and seeing if there were other more effective and humane ways of dealing with distress.

- *“The medics go on the medical model and are constrained by it. It is too easy to say drug someone. Let them sleep, talk to them and give them a safe space but not necessarily in that order.”*



## Conclusion

It is clear from these conversations that the majority of people we talked with believe that compulsory treatment, and therefore substitute decision making, will sometimes be needed; but it is also clear that compulsory treatment can be traumatic and damaging and should be avoided where at all possible.

Some people, when asked about whether they can still make key decisions when acutely ill, strongly believe that there are times when they cannot make any decisions and should not be put in a position where they are asked to do so.

However most people felt that there are many points, even when in extreme crisis, that people can make decisions and should be supported to do so. A key element of being helped to make decisions is the basic good practice people would expect from psychiatric staff in how they approach them and relate to them when they are very ill or distressed, which at its simplest appears to be being approached in a respectful, gentle and compassionate manner.

Apart from this, people felt that a key element of being able to make decisions or to have decisions made in accord with their wishes is to have a trusted person present, ideally someone who already knows them well; or to have trust in the staff providing treatment.

In addition the support a named person can provide and the evidence that can be provided by advance statements, crisis plans, patient passports and power of attorney can all assist in supported decision making.

People in the groups we met were keen to add that they felt that some compulsory treatment was a direct result of a shortage of services, a lack of preventative help, early intervention and safe places to be treated in and live in. They felt that supported decision making would be more likely to be the norm if people were given enough help and support to make crisis and acute illness less likely in the first place.

People felt that if services did not appear to be geared towards just treating people when they can no longer cope but provided the sort of support that meant that people had a better chance of maintaining good mental health, then the need for substitute decision making would decrease and people would routinely be able to make decisions for themselves, with or without support to do so.

## Appendix: Definition of supported decision making from MWC Good Practice Guide – *Supported Decision Making*<sup>2</sup>

### **What is supported decision making**

Supported decision making has no formal definition and different people use it differently. We use it to refer to a process in which any individual is provided with as much support as they need in order for them to be able to:

1. Make a decision for themselves and/or;
2. Express their will and preferences in the context of substitute decision making (for example guardianship or compulsory treatment for mental disorder).

In both cases the purpose of supported decision making is to ensure that the individual's will and preferences are central to and fully respected with decisions that concern them.

Substitute decision for an adult should only happen where there is specific legal authority. The main pieces of legislation that authorise substitute decision making in Scotland are:

- The Adults with Incapacity Act which provides for guardians and attorneys and sets out procedures to authorise medical treatment where a person lacks decision making capacity;
- The Mental Health Act which allows for detention and treatment linked to significantly impaired decision making ability;
- The Adult Support and Protection Act which allows for short term intervention for 'adults at risk'.

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Note from the author: another simpler way of looking at it is that a person who is sectioned or detained has not made this decision, and may be made to accept the decisions of another person about how they are treated – this is substitute decision making.

A person who is helped to come to their own decisions about treatment, and is not detained or sectioned, and has their decisions respected, is experiencing supported decision making.

If someone is detained, and their views are still listened to and respected, then an element of supported decision making exists.

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<sup>2</sup> <http://commissionintranet/Interact/Pages/Content/Document.aspx?id=1597>



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