WILL AND PREFERENCE AND THE MENTAL HEALTH ACT.

THE VIEWS OF 86 PEOPLE WITH LIVED EXPERIENCE OF MENTAL ILLNESS OR AS CARERS OF PEOPLE WITH A MENTAL ILLNESS.

draft

EXECUTIVE SUMMARY

What we were trying to find out

We were trying to find out people's opinions on how important it was to abide by the will and preference of people when they are very ill and also how to find out what that will and preference is, both when well and when ill.

What we did

We met 85 people in group meetings of people with lived experience and/or carers of people with lived experience at venues across Scotland and held focus groups at these meetings at which this discussion subject was one of the ones being discussed. We were not able to ask all of the questions that were suggested due to time constraints and also because in some meetings people found the questions too difficult to answer. We held one interview with one person on the same subject at the same time as the meetings. We wrote up the meetings and sent them out to the groups we met to check they were happy with our record and then compiled these notes into the following report but anonymised some of the quotes used, to avoid identifying anyone.

What we found out

We found out that as far as possible, people wanted their will and preference to be abided by when reaching decisions about their lives and treatment. However most people felt there could be times when these views were overruled. Reasons for this would be because they posed a risk to themselves or other people and because their judgement was impaired and because the actions they were carrying out were leading to a much poorer quality of life.

Impaired judgement was quite critical in this context. When discussing a person's right to die, although some people were against this in every situation, many people felt that, just as a person with a physical illness could refuse potentially life saving treatment, so should a person with a mental illness where they have made a considered judgement about the quality of their life. However, where their mental illness was clouding their judgement, especially if they were delusional, most people felt that people should intervene and take decisions for them.

People worried about giving more autonomy to people about the care and treatment that they get when it is already hard to access services and worried that giving choice when the possibility of choice was often largely absent would make life even more difficult than it presently is. They felt that decisions such as this need to be seen in the context of services provision and access to help in crisis.

When finding out what a person's will and preference was, people felt that finding out from their 'well self' what they would want is the ideal way of abiding by their will and preference and used advance statements as a key mechanism to do this. However they saw problems with this. Some people had no faith in advance statements because they could be overruled and yet other people felt that there were circumstances in which they should be overruled; for instance if an advance statement asked someone to act illegally or the actions it included would harm other people.

Despite seeing advance planning as key to decisions about their treatment, many people were aware that uptake of advance statements is extremely low and therefore they might not be the answer they appear to be.

A small number of people felt that advance statements could be expanded into a new broader statement of will and preference about many aspects of a person’s care treatment and their wider wishes in their life but again, doubt was expressed about how such a document could be made effective.

People felt that establishing a person’s will and preference was difficult even when well and that it could change and shift rapidly, especially as people are getting ill.

They wondered if people’s opinions when very ill and expressing bizarre beliefs and opinions were too readily discounted and thought maybe with more time and interpretation professionals could come to a better understanding of what people wanted. However they also felt that when people are very ill it can be almost impossible to come to a clear understanding of how they would want to be treated, especially if contrasting their ‘ill’ wishes with their ‘well’ self.

People were especially conscious that many people would not engage in treatment decisions because they did not believe they were ill and therefore the concept of treatment would appear to be meaningless to them. In these situations some people thought it was better to act in someone’s best interests but had some confusion as to who would interpret best interests and what these might be. Some people felt that their relative’s ability to make decisions was so impaired that if they were left to decide on their treatment they would be exposed to great risk that may lead to death.

When looking at best interest people also wanted the damage that can occur when overruling someone’s opinions and wishes be taken account of in any decision to act against their will. Despite this some people had a strongly held opinion that at certain times in their lives they need other people to take decisions for them.

Some people thought that friends/relatives/informal carers are in an ideal position to interpret what a person’s will and preference is, especially when they have been ill for some time, however others did not agree with this. Some carers of people who are on compulsory treatment orders felt very uncomfortable about interpreting their relative’s will and preference and also felt that their relative would not confide in them and did not know or want to express what they wanted and that what seemed an ideal way of obtaining their ‘real’ opinions might be less effective than it at first seems. However the point was made that decisions about the treatment and life of an individual almost always have an impact on other people and such people, often friends and family, should have a say at such points.

People thought that some professionals would be very good at knowing what their wishes and desires would be and did not see any conflict in gaining opinions in this way, however other people said that for some people, care providers are, in their eyes, their enemy and relying on their opinion would not be at all helpful.

Time was seen as a mechanism to help a person arrive at what their will and preference really would be but it was also mentioned that compulsory treatment lasting a number of years may be the only way in which some people can come to terms with and accept that they have an illness that benefits from treatment.

When assessing a person’s ability to make judgements there was some scepticism. Some people felt that professionals may have assumptions about their ability to do so that were at odds with reality and worried that differing values and ways of acting of people from different communities and cultures may not rest easily with people making assessments. People talked about the importance of establishing a relationship and treating people with respect and sensitivity. Some people wondered how anyone could assess their judgement making ability when they were very unclear about what they themselves felt and wanted and wondered if their peers may be in a better position than others to do so.

A few people wondered if people were allowed to take more risks, even when ill, if this could be a catalyst for growth and transformation despite the danger contained within this.

Lastly it seemed that few people saw major changes needed in legislation around compulsion and only a very few people supported the UCRPD’s general statement about legal capacity. However many people felt being sectioned was a traumatic event and many people saw a need for a change in culture and service provision and wanted help when they needed it and when their friends and relatives saw it was needed. They wanted services that they would want to use and which saw them as people with unique needs and wishes.

Some people wanted to point out that legislation on issues around life, choice and liberty will always be full of dilemmas and will never be just right.

INTRODUCTION

In the autumn and winter of 2019 and 2020 the engagement and participation officer (lived experience) for the Mental Welfare Commission held a series of meetings with advocacy and support groups for people with lived experience of mental illness and/or lived experience as carers.

A number of subjects were discussed but one of the subjects for discussion was about how to find out a person's Will and Preference about their care from people with a mental illness both when well and when ill and likely to be subject to compulsory treatment.

Some ideas for questions were supplied by Jill Stavert from Napier University and some from Colin McKay from the Mental Welfare Commission but as this was one of the later discussion topics of the meeting and because some people found the subject overly complex; conversation and discussion was less focussed than it might have been. It was a rare meeting in which most of the questions were answered.

However eighty six people participated, most of whom had experience of detention and hospital admission, either personally or of that of friends and relatives.

The notes of the meetings were checked with each group and quotes used have been anonymised in order not to identify anyone.

The groups involved in this consultation were:

- Bipolar Highland
- West Lothian involvement group
- Angus Creative Minds
- Bipolar West Lothian
- Carers and Relatives Alliance Edinburgh
- Healthy Minds Network Dundee
- Hope Kitchen Oban
- HUG (action for mental health) Inverness
- Moray Wellbeing Hub Elgin
- Moray Wellbeing Hub Buckie.

OVERARCHING ISSUES

When looking at legislation and changes that might be made, some people had some general points to make:

Some people thought that ideas of reforming legislation along the lines of the UNCRPD (United Nations Committee for the Rights of People with Disabilities) hope to minimise or stop compulsory treatment on the grounds of mental disorder was very idealised and unrealistic and struggled to understand why such an organisation was suggesting this.

Some people felt that that creating set standards for assessing such things as impaired decision making/capacity or ways of treating disabled communities of people were risky. That despite the desire for consistency and its seeming attractiveness that this was not a realistic or sensible goal to have.

There is no way in the world in which decisions like this can be standardised.

The difficulty is how do we create a universal rule when each act is so personal and has such different consequences? We need something that is mouldable in capturing that but that can still apply to everyone

And some people felt that the wish to have a definitive answer to legislation as complex, grave and important as this was misguided.

We cannot remove all dilemmas; there is a desperate wish to do this. Some things should always rightfully be a dilemma.

There is no perfection here for these issues

WAYS OF FINDING OUT WILL AND PREFERENCE AND ISSUES TO DO WITH THIS.

The following is a list of different issues connected with finding out and abiding by people’s will and preference listed roughly by how frequently they were mentioned.

ADVANCED PLANNING

Many people immediately said that advance planning when well, would be a very effective way of giving an indication of what their views are about how they wanted to be treated and helped or not when they become ill.

Most people mentioned the value of advance statements, but people also mentioned crisis plans, powers of attorney, personal statements and a statement of Will and Preference.

Despite this there were many different aspects to the conversations we had.

Some people felt there was little point in advance statements because they could be overruled and that sometimes the way they were overruled was so traumatic that they had consequently lost faith in mental health services.

Many years ago they injected me and in my advance statement I had said I would take drugs orally but not be injected but they picked me up; threw me on the bed and injected me. You lose all your trust if they do that.

Other people felt there could be a need to overrule an advance statement especially if it would negatively affect other people or ask people to carry out actions that are currently illegal.

People were very keen that a written, understandable, explanation of why an advance statement had been overruled should be given to them and also that there was ongoing monitoring of the reasons that advance statements were overruled.

They also felt that it would be good to see the variation in overruled statements from different psychiatrists.

This did not mean that the reasons for overruling a statement could be set and formalised but that people would like to know how and why such things might vary from person to person.

Other people felt that sometimes people did not have the ability to create a valid advance statement despite not being acutely ill at the time.

People also pointed out that although advance statements seemed to be an ideal way of saying how people wanted to be treated, that uptake of them was still extremely poor.

Regarding a statement of will and preference there was mention of how a person would write one and whether everyone would be capable of this, and that maybe if people could not create such a statement themselves, that this might be helped by the assistance of an advocate or someone who knows the person well.

Again, just as with advance statements, there was some scepticism about how to enforce a statement of will and preference.

People expressed some disappointment that they had experience of having their opinions discounted, especially when seen as psychotic but also said that referring to the opinions of their ‘well self’ was a very good way of dealing with the issues they face when ill.

THE NEED FOR COMPULSORY TREATMENT

Inevitably people returned to the rights and wrongs of being detained and made to undergo treatment.

There were varied views but the great majority of people felt that people could, at some points, need detained. Even people who felt that they had been detained unjustly felt that sometimes compulsory treatment was necessary.

Some people felt that if their relative had been treated compulsorily then they would not have died or even if they had just been able to get treatment they would not have died.

X wasn’t sectioned. He knew that was the only way he would be safe and they refused and he died.

Other people had witnessed very successful use of the Mental Health Act and were glad it exists.

When contemplating the idea that there might not be compulsory treatment as we currently know it, and considering the UNCRPD committee’s general statement there was the following comment:

I have seen people who need to be in hospital for their and other people’s protection, that is just craziness.

A very, very, small number of people were totally opposed to compulsory measures because they had experienced them themselves.

I would not trust someone with power of attorney over me or guardianship. I have no reason to trust any of them.

WILL AND PREFERENCE: FOLLOWING IT, FINDING OUT WHAT IT IS

People had a lot to say on this subject. People had some difficulty with the idea of finding out what a person's will and preference is and only rarely did they think it was an easy task to find out people's views were, even when 'well.'

Many carers said that their relatives struggled to speak with them about what they wanted and were reluctant to tell anyone what they wanted and sometimes did not know what they wanted. They also said that people's views on what they wanted could change rapidly and that this could cause difficulties.

She needs someone to push her and prod her because she is not able to say how she wants treated.

A lot of people will not have that conversation because they cannot face it.

My daughter will not talk about it at all.

Real will and preference. How do you see it? Some illnesses give a will and preference that are not what they would want if they were well. [They] would need treated with psychotic drugs to reveal what they really want.

There are many people who are too unwell to know they need to engage and who are not getting help – really they do not know what they are choosing

People also said that what may appear to be will and preference was variable and what might appear to be a clear vision of what people wanted may not be the case at all, especially if people are psychotic and also if influenced by addiction and addictive substances. However they also said that there can be a great deal of confusion in interpretation. The view of a carer on what is illness-induced might be accurate but maybe not always.

It is damn near impossible to do; someone may have been harbouring a wish to do something for years but as they get ill they are more likely to carry out that action. It can need intervention that stops people from getting into a terrible situation. I have seen people left so long that they are living inside a cupboard and in a terrible state. Was that choice? It was illness.

Think of the gender identity debate. I remember a young psychotic man who met a lot of gay guys and was questioning his identity. His mum was very strong that that was illness. I don't know what he really was. How do you work this out?

The only way possible now would be to put him on a CTO and get him into hospital, off drugs and stabilised on medication; then he might see the benefits of treatment.

They also said that care should be taken with how people are approached when trying to find out what someone wants; that this should be respectful and sensitive.

If it will not cause additional harm then respect those views but make sure it does not escalate. You need to validate as much as you can. As far as possible don't tell them what to do. Have a discussion; try to find out why they are saying it.

Work with the individual and work out positive risks and needs. Build relationships, get to know people.

They also said he was making a personal choice. I had seen him earlier in the day and he had pointed into the trees and got upset at the bodies he saw hanging from them; he was asking why they had been killed. They said he had capacity; he was psychotic and living rough.

When looking at following and respecting the will and preference of people, there was a clear view that if people had expressed an opinion then, as far as possible, this should be followed but with caveats regarding what the opinion and wish is.

Most people felt people's preferences may need to be overruled if those wishes were going to damage the person or other people.

I imagine if you are well, if, in that case, they want a certain person not involved that should be respected as far as possible.

Sometimes you don't want a certain drug or person and that needs respected. If it becomes a danger then your decision needs overruled.

Do we take a choice a person makes as a right in itself? Or according to the outcome? If it was in the outcome it would be seen as bad, publicly, if someone died as a result of impaired decisions.

Last time I was unwell there were police; two ambulances and they said "You can go to hospital or the cells." In hindsight I didn't know how unwell I was. I can make decisions but I am not sure that they are wise. At the time I will say "I am fine." and other people know fine I am no well.

Attention was paid to the idea about how medical interventions should not do harm and should be beneficial, it may be necessary to intervene against someone's will but equally the distress of ignoring a person's opinion, however irrational it may appear to be, needs to be included in this process. It may be that ignoring a person's seemingly bizarre beliefs could cause so much damage that the benefit that might be gained from overruling the person is lost.

Many carers reflected on the views of their relatives and felt that their relatives would have opinions on treatment, for instance about stopping medication, but that if this were listened to, their relative would inevitably end up in hospital again or die as a result of this.

However some people felt these were difficult decisions and that treatment was not always beneficial and what may seem to be a poor decision might not be. Others felt that people's preferences changed as they became ill and that this was not helpful in providing care.

It would be signing their death warrant if their wish not to take medication was respected.

If someone is unwilling; my sister was on tablets and unfortunately she decided to stop taking them and became very withdrawn and would have discussions with me every day about why I hated her. It went on for years. Once she became unwell it was more difficult to treat or get back to how she was. If she decided not to take meds she would end up back in hospital and with the police.

He wouldn't want the pills at all; they turn him into a zombie.

This worries me. If they have a named person fine. If they are not well they can take the named person off when they are getting ill and that can cause all sorts of problems.

Other people said that weighing up people's will and preference was a delicate balance and that sometimes if people are left to their own devices they become deeply distressed and vulnerable and not to intervene could be very neglectful.

People who are unwell and don't want their depot. Beforehand they were Christian and yet on the ward they were praying to Allah. I get the need to respect will and preference but where does neglect come in as a result?

People talk about rights to freedom and autonomy but people should also have the right to treatment and health and some sort of quality of life – we have a duty of care to people who don't think they are ill and won't take treatment but are living a terrible life.

HOW FAR DOES WILL AND PREFERENCE GO?

Discussion around the idea of giving as much weight to a person's will and preference as possible inevitably led to discussion about what should happen if someone wanted to die or was at risk of dying due to the thinking their mental illness produced.

People had mixed views on it. Some people thought that if someone wanted to die then they should have the right to do so and other people thought this should never be permitted, however strongly a person wished this.

I don't think they should let you die even if you have wanted to for a very long time.

Who are we to stop a person from ending their lives?

In between these thoughts were other opinions. There was a feeling by some people that if someone had experienced mental illness for many years and had made a considered decision that life was no longer worth living, perhaps because of the pain their illness has caused them, then that should be possible if their judgement is not impaired. Almost everyone seemed to think that someone who had impaired judgement, for instance due to delusional thinking, and was likely to die as a result of this, should be prevented from doing so.

If someone knows the best what needs to happen for them; for instance you have been plagued with it all your life, maybe you should have the right to die but not if you are unwell at the time.

Some people are so out of their heads that they do not have a choice. They might die when they shouldn't.

Some people felt that the idea of agreeing to the choices a person might make as a result of illness would lead to a right to die which would create its own difficulties and debate.

The extrapolation of 'et the person decide' is that you would assist anyone to suicide; this is very difficult.

PEOPLE'S BEHAVIOUR AND DECISION MAKING ABILITY WHEN ILL.

Most people felt that there is a need to listen to what people want to do even when they are ill and appear to have impaired judgement, but equally most people felt there was a need to intervene when people's behaviour was a risk to other people or to themselves.

People need to know what you want to happen but need to be able to overrule it.

However there were some variations around this. Some people feel that they act in ways they wouldn't normally when ill and need prevented from doing so.

Other people worry that it is possible to discount people's opinions because they are expressed in such a way that people assume they make little sense when instead more effort should be put into interpreting what someone wants, despite the apparently strange ways that they are expressing themselves. Some people feel that the label of a mental illness means that their opinions can be automatically discounted.

Others need people to accept that they were not responsible for the decisions they were making when their judgement and behaviour is impaired.

Could someone be using psychotic language to explain what they really think? Do we come to hasty conclusions?

I can do crazy things.

The spending sprees are horrific and put me bankrupt and make me suicidal. Now I have to go onto Universal Credit to prove I am ill. They are awful; they say they don't believe me. Because I live on my own; I have the computer and no support to stop me spending.

Because I have a mental illness I am not allowed to say how I want to be treated

However despite most people seeing a need for intervention, the degree to which this happens and the degree of restriction concerned some people.

A lad who goes around. I have seen him laid back and also quite volatile. Other times I have seen him putting bricks through neighbours' windows and the other day he came past the van, threw his bike down, marched up to the van and I locked the doors. He stood there and stood and stared at me. Eventually he walked off; I don't know what would have happened if I was out the van or if he was near someone who he could attack. Does he know to stop? But when he seems to be on medication he seems ok. But I wouldn't say being in hospital is appropriate as everyone needs a right to freedom.

People also felt that people do lose the ability to make decisions when they are unwell but it is not always clear what decisions they can make and what they can't.

When acutely ill you are often unable to make decisions about how you should be treated

If your thoughts are all over the place they need to do intervention

From a carers point of view there was the belief that, when unwell, some people make decisions that are not good for them and that, as carers, they can be in a better position to interpret how they need to be treated.

If he had to be sectioned he would not want to be in hospital. When he was really unwell he actually does not care about himself; just wants home and in school but I care. I just want what is best for him.

It is a downward spiral, how will it end? They say he needs to do something in order for them to intervene. Do we really need to wait for him to carry out his threat to kill XXX, who he says is a paedophile?

People also raised the issue of dementia where peoples' decision making ability is undoubtedly impaired and wondered how much credence should be given to the decisions they are making. They also witnessed people with dementia who did not understand what was happening to them and because their preference was respected seemed to suffer more than necessary.

What about dementia? Say they say "I can live alone" and yet they can't?

A friend's mum with dementia broke her neck….. She was crying with pain but did not understand that the medication helped her. It was so painful to see her refusing medication that would have helped her. She is still in pain and is still refusing treatment.

THE CRITERIA FOR MAKING DECISIONS FOR OTHER PEOPLE

In some groups people discussed what the grounds should be for intervening in the decisions a person was taking and most people said that this was, to a large extent, dependant on the risk a person was posing, as well as how ill they were. There was a feeling that society decides what level of risk is acceptable. Some people felt risk to other people was more important than the risk people pose to themselves. There was also a wish that the label a person had did not influence the decision to intervene.

Another issue people raised was around benefit, for some people there is a balance that might need to be struck between quality of life and quantity of life and for others there may be merit in treating someone against their will because their life is greatly improved even though they are not aware of it. In this situation some people felt acting in the person's best interests outweighed their expressed views.

What about the quality of life for people coming off medication? Would the quality of life be better when on medication because it is supporting their life even if they do not recognise it is supporting them?

BEING IN CONTROL

Far from wanting to be in control at all times, in some groups people said that when they were ill they wanted other people to take control for a time while they were making poor decisions, especially when people were spending money in ways they did not normally.

I want to leave my husband at such times : now my CPN will tell him and he will take my card and he will agree to speak to her and seek support for himself.

Then you wake up and say "What have I done?" You need someone to take decisions for you.

When you are ill it is good if people do things for you and stop you spending

Not doing anything can be much worse than intervening

In one group the issue was not so much about taking control but when and how to pass it back.

There is a dilemma at home. I find myself taking control of XX's life almost being a bit bullying. My concern is that I need to take control but beyond that point you need always to say when to back off: not should you control or not? But can we back off; having controlled?

CARERS' AND FAMILIES' VIEWS

In the context of intervention many carers said that they knew when someone was getting ill before anyone else did and that they were very used to not having this knowledge acted on.

No one looks at the whole picture or listens to the family.

I am not invited or welcome at case conferences and have no chance to let them see the picture of the person he once was.

People also talked about family and carer rights in the context of decision making and illness. They will be affected by decisions made around treatment of a person and decisions about will and preference and should therefore have a say in what happens.

The person who has a mental illness does not necessarily live in isolation to everyone else and other people who will be affected by decisions made for, about or with them should have some say in those decisions.

If I am expressing wishes for myself in treatment and that would be harmful for a carer; should my wife be able to say "I can't have him home because it will damage me?"

However there are times when it is impossible for family to speak to each other in a meaningful way due to the effects of illness.

He still won't see me and thinks I am a clone and that I should talk to him telepathically.

OTHER WAYS OF FINDING OUT WILL AND PREFERENCE IF A PERSON IS UNABLE TO SAY WHAT THEY WANT

When talking about other ways of finding out what a person's views are, especially if they are currently acutely ill and it is difficult to be certain about what their 'real' views are, many people said that the ideal people to speak to were informal carers who will have an in depth view of the person, their wishes, preferences and needs.

If you have discussed it with your carer and they know your thoughts that could be really good.

Your carer will also know what you want and should be consulted.

However some carers and some people with lived experience had other views. In their experience it was almost impossible to find out the views of their relatives, or they felt their relatives would be unwilling to tell them. They could be too close to the situation to give a balanced view or in some families the dynamic might not be healthy enough to rely on their views.

Often we do not know what they would want.

Often they do not want to tell us or go there.

They do not think they are unwell and so can't talk about treatment.

It doesn't sit well; us saying what they want; we are maybe too close to it.

I can't speak to my son about his illness, only mundane things, I don't know what he wants.

Consider the health of the relationship – is it coercive or violent?

There were other people who might also be in a position to give an opinion of a person’s will and preference and these often included the professionals in people’s lives. Despite the assumption that professionals often have a conflict of interest in helping express a person’s will and preference a fair number of people had a great deal of trust and faith in the ability of their care providers to convey and respect their views.

Your lawyer, carer, GP will know what you want

I can’t fault my GP. It depends on your relationship with them and how much you trust them and how well they have tried to get to know you. I have a really good relationship. Locums don’t know. It depends on how much you confide in them and how much time they have and whether they want to listen to you

Maybe a CPN who could make decisions for you which might take out the over involvement or personal bias. Maybe [some distance] enables them to see the facts better.

I say more to my counsellor than my family

However for some people, people providing services are the last people they would trust to work with let alone help with deciding on their will and preference;

The nurse said he has a very limited awareness of his circumstances and that he would visit the homeless hostel and leave him a letter and maybe this would get him to engage but he is suspicious of him and sees him as the enemy – we know this won’t work and time is limited now in getting help for him.

He doesn’t think he is ill so when they say he needs to want to engage they are not making sense; why would he?

Lastly there was a feeling that some people had no one in their life who would be in a position to give insight into their will and preference and in this situation there was a suggestion that looking at people’s blogs, personal statements or diaries might help guide people to an idea of what their will and preference might be.

I have told my family what I would want but not everyone has that

THE COMPARISON WITH PHYSICAL ILLNESS AND DIFFERENT CULTURES

In a few groups people made the point that people with physical illnesses are able to make seemingly illogical decisions and that these are respected. People did not see why this shouldn’t be the case if people have a mental illness.

We don’t do this if someone refuses chemotherapy

Three years ago I convinced myself I should take my own life. I looked at the pros and cons. I can see from this distance that it wasn’t logical. I had attempted a couple of times before and stopped myself. If you can allow them to do things when they are in great physical pain then you should when they are in mental pain.

If the voices are part of your pain and you need it to stop then you should have the right to stop living even if that is from mental illness.

I don't think it is entirely logical (physical and mental) Why can't people with a mental illness go to Dignitas? People who want to die because of the impact of physical illness is often due to the impact on their mental health

They also said that people from different communities can appear to act in illogical and harmful ways, according to people who are not part of their community, and that their beliefs are still respected. They went further and said that what may be seen in one culture as a sign of illness would not be considered as such in another and therefore what right did other people have to act against the expressed wishes of another person?

What about Jehovah's Witnesses? Why do we not stop them?

What about people who will not take a blood transfusion which will save their lives?

DECISION MAKING IN THE ABSENCE OF SERVICES

In a few groups people were keen to relate legislation to service provision. First of all if people are to have more autonomy over the decisions that they make then there need to be sufficient services to support people. In the absence of services and with increased autonomy to act in potentially damaging ways people worried that people would die.

Without services people would die. It sounds really scary.

They said "Either she harms herself or you; otherwise there is nothing we can do."

How many times have people been turned away from hospital?

They can assess someone but there is nowhere they can go to for help, the hospitals are full and often turn people away – people will just end up in prison.

They also recounted times when, as carers, they have had to seek help for relatives and have not been listened to or been able to access help. The threshold is when someone's decision making is so impaired or the risk so great as to justify intervention. They felt that the reality is already that people do not get the help they need and if this threshold also disappeared then even more people would get into critical states. They felt that this combination would lead to greater intervention by the police.

They also felt that the current state of service provision was already so poor that people had very limited services and choices which raises the question of what will people be able to access if they are free to make decisions about what services they want to use and yet there are very limited options about the support they can get.

…they have to threaten to kill other people or threaten to kill themselves and then you need to call the police out. It shouldn't get to the point that you have to call the police.

They often are not prepared to do anything. It is often as though professionals need to see for themselves and will not listen to the carers who have been telling them what is happening

I kind of agree with him that all he is offered is meds and I am kind of angry about this. I would like him to have …..

We need to be person centred and person led; not having to fit every aspect of mental health diagnosis criteria. We need services for people to go to and we need a culture in services that mean people will want to go to services and we need legislation that gives a way of scooping up people who do not know they are ill.

SOCIETAL AND PROFESSIONAL ATTITUDES TO PEOPLE'S DECISION MAKING ABILITY

In a few groups people queried how people assessed and worked with people who may have impaired judgement. People felt that in society people could interpret behaviours they were uncomfortable with as illness and that some mental health professionals may be seen as more skilled in assessing people than they are; the power and status they have, may actively work against finding out and assessing people's views and judgement.

There is a thing about assuming doctors are infallible. The idea that someone could take decisions even though they are psychotic and the decisions dangerous sounds surprising and refreshing and gives food for thought. It is empowering

Psychiatrists; all they have is how a person reacts but they might be right and they might be wrong. There are times a patient can be right. Sometimes you are right but are told you are not respectful.

People also felt that they themselves, often had little idea of how they were feeling or thinking and acting and therefore questioned how professionals might do this when they had even less access to their inner world. They also felt that the interests of the NHS, carers and society may be at odds with the interests of people with lived experience but that this was not necessarily justified.

In my 20s I enjoyed my life but it was very risky. Who decides? Who works out the emotions and what we want? We can't sometimes, so how can someone else do something so complex? When we cannot explain the pleasure or pain we are in or how it is affecting those we love? And how do you marry this with the NHS and what they want and expect? How do you manage what parents want? How do you manage your knowledge and expectation of professional carers?

An additional point people made is, that people's decisions are often a reflection of the culture that they are a part of but as people experience mental illness they could benefit from seeing how different societies and cultures live and react to the world and that this may change the choices they make. Different generations may also have different values and ways of seeing the world that also need to be respected.

The judgement of ‘conventional’ society needs to take account of the values and beliefs of other communities.

Government creates the society that means people end up in prison… it is only when we see other cultures and ways of living that we can make choices for our existence and what we do…lived experience impacts a lot on our values.

There are generational changes to our values.

TIME TO TAKE DECISIONS

There were two aspects to this; one being about giving people enough time to come to the decision they would be more likely to want to make if they were well.

Can you delay a decision by whatever means so that they can get to a better place to make the decision they want to make?

The other aspect to time was the fact that it can take some people many years to get to a place where they gain insight and acceptance of their condition and find ways of engaging in treatment and therefore managing an independent life. This can depend on the quality of care being provided and the state of mind of a person and may again involve taking decisions for another person.

At the end of the day it is about when does the penny drop to let people accept treatment. I fought three years for that at three tribunals… It took three years for something to click to make her stop drinking and it has all got better since then. There was a lot of careful handling by the psychiatrist and the team with 5 different specialists. It is about the penny dropping.

TREATMENT

In a couple of groups people talked about the quality of life when treatment is insisted on. The side effects of medication may be intolerable for some people and, in the past, some long term treatment options such as hospital stays could be barbaric.

The effect of treatment on quality of life needs to be taken into account when decisions are being taken for someone.

POLICE INVOLVEMENT

In one group there was considerable discussion about the involvement of the police. Some people, who are clearly getting ill are left in the care of their family until the police need to be called and on some occasions the involvement of the police has been life saving.

There was a feeling that this shouldn’t have to happen.

She doesn't have insight when unwell and is left to her family. She ends up with the police because she becomes aggressive. The police were nice but shouldn't have to deal with it.

At the time, for a long time I wanted to die. If it wasn't for the police I wouldn't be alive.

PEER ASSESSMENT OF DECISION MAKING

People reflected on the value of peer involvement in this process, especially around someone's ability to make decisions. They talked about how alienated they can feel and yet how connected they can feel when they find someone who understands.

You need more people who have a mental illness to be involved in working out someone's decision making ability. I find it difficult to explain something I don't even understand myself. Trying to talk to someone who hasn't had that experience is incredibly difficult. They look you in the eyes and they clearly don't or do know.

OTHER ISSUES RAISED IN THE CONSULTATION

Rights	*The presumption should be that you have your rights and not that you should have to claim them.*
Responsibility	By stepping back from providing someone's care and making decisions for them some people find that people can, after all, look after themselves
Intervention can have a good outcome	*Two years ago, she took psychosis out of the blue; she was shouting and swearing. She was arrested and taken to the police station. They realised she was ill and she went to hospital. She is now back working and getting on great.*
The growth that can occur when allowed to live with risk	*Whose definition of risk are we going with? How do we define risk? There are different levels of risk. Sometimes my actions could be a risk to others or me but putting myself through that risk and by recognising it I can grow and develop.*
Faith in services leading to poor outcomes	*You can accept and accept treatment and never reject it and end up in a bad place.*
The effect of stigma on compulsory treatment	There was a feeling that as stigma decreases that people will be more willing to seek help and that this will in turn influence the need to use compulsory measures. The earlier and the more willing people are to get treatment the less likely compulsion might be needed.

The balance of listening to the individual and intervening – where does recovery lie?	*Recovery is personal to the individual – how do you marry up the harm of intrusive interventions? You need to look at least restriction and benefit. Freedom of choice versus duty of care.*
Training to ensure consistent approaches	*To avoid a decision being arbitrary regarding a psychiatrist's judgement. For instance different psychiatrists will be more risk averse than others. Is there training and professional development to discuss these issues to make it less arbitrary? It should also be informed by service users.*
Debriefing and finding out the effect of compulsory treatment on people	*When they have denied a service user their wishes seek out feedback afterwards*
Involving other people in decisions	*If you are making a horrible decision about someone else it should not be just you that makes it.*
Establishing will and preference when a person has been unwell for many years	*To get to that stage you should be able to go that far back to say that is what he would have wanted or rather what he would not have wanted. If you have been with someone long enough you know.*
Being sectioned is traumatic and frightening	*When I was sectioned it was horrendous. It happened just after I had been C sectioned for my baby. I thought they would do the C section again when they said I was sectioned*
Trying to work out what to do when people have well established set views that would be damaging is a very difficult issue to address	*If you do not have the means to change the person's outlook it is very hard indeed.*
The need for safety	*Keeping people safe is very important*