

Seeking Your Views Consultation

Capacity, Detention, Supported Decision Making and Mental Ill Health

April 2017

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 current 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.

Introduction

Over the autumn and winter of 2016 and stretching forward into 2017, the engagement and participation officers for the Mental Welfare Commission met with with Service User and Carer groups to look at issues around Supported Decision making and Impaired judgement.

This report contains the views of people from:

- Bi Polar Fellowship Scotland Annual Conference
- HUG (action for mental health) - Highland
- ACUMEN – Argyll (Dunoon and Oban)
- ACUMEN - Inverclyde
- Restart in Maryhill - Glasgow
- Restart in Bridgeton - Glasgow
- Bi Polar fellowship - Stirling
- Bi Polar Fellowship – Borders
- Klaksun and STUN - Stirling and Clackmannanshire
- Angus Voices - Angus
- Royal Edinburgh Hospital Patients Council - Edinburgh
- Lanarkshire links
- West Lothian Users Forum

Two hundred and fifty nine people have been involved in the discussions, mainly people with lived experience but family and friends too. Many people have personal experiences of detention but not all.

This is the first of what will probably be a number of reports looking at this subject and related ones. Separate reports will also hopefully be provided of consultations with people learning disabilities and dementia etc.

We passed this report to the groups concerned for any additional comments and to check that it included as far as possible the views of their members. We also had a follow up meeting with a small group of people using an interim version of this report as a basis for discussion.

Background to Capacity and Mental Health Consultation

In the Commission, we are having a look at Capacity as part of our general work and as a contribution to possible future reform of mental health and incapacity law.

There are also increasing National and International conversations around supported and substitute decision making which we would like to have some conversations about.

At the same time, a member of the UNCRPD (United Nations Committee for the Rights of Persons with Disabilities) has also asked us to look at the topic of supported decision making.

We are also aware that VOX (the National Service User Voice) is also interested in the subject of Supported and Substitute decision making.

Why is this relevant?

First of all there is going to be a review of the Adults with Incapacity Act, and the Government has promised to review whether learning disability and autism should still be covered by the Mental Health (Care and Treatment) Act. The Commission and other organisations have said it is time to look at the whole legal framework for making treatment decisions without the consent of the individual.

Secondly the United Nations Committee for the Rights of Persons with Disabilities have issued a general statement saying that all compulsory treatment for people with a mental disorder should stop and be replaced by supported decision making: That lack of capacity is not a legitimate reason to provide treatment against someone's will.

This could be very exciting but maybe alarming – we would love to know what people think: is it sensible to stop Detention under the Mental Health Act in all circumstances? And if we are to give people support to make decisions when they are struggling to do so how should this happen?

It could be by using advance statements, maybe through the help of trusted people such as friends and relatives, maybe through assisted conversations or in some other way. We would love to know what people think and are seeking all points of view.

Capacity and impaired decision making

These are two closely related concepts:

Capacity is defined as

'Whether an individual is able to make a decision at the time when a decision has to be made.'

To demonstrate capacity individuals should:

- Understand broadly what the treatment is, its purpose and nature and why it is being proposed;
- Understand its principal benefits, risks and alternatives and to be able to make a choice;
- Understand in broad terms what the consequences will be of not receiving the proposed treatment;
- Retain information long enough to use it and weigh it in the balance in order to arrive at a decision;
- Communicate that decision.

Significantly impaired decision making (SIDMA)

This is when a mental disorder affects the person's ability to believe, understand and retain information and to make and communicate decisions, it is not the same as limited or poor communication or disagreements with professional opinions.

'... and has been described as a manifestation of a disorder of the mind occurring when an individual's understanding or reasoning regarding the medical treatment for their mental disorder is distorted or impaired, as a consequence of that mental disorder...'

The most common reasons for SIDMA were lack of insight (44%), limited cognitive function (9%) and/or presence of psychotic symptoms (10%) Lack of insight was commonly correlated with psychotic symptoms. Other reasons for SIDMA included presence of severe depressive symptoms or learning disability (20%). Limited cognitive function was the main reason for SIDMA in people with dementia. There was no clear evidence of cognitive impairment being the main reason for SIDMA in individuals with learning disability.'

The Adults with Incapacity Act applies to people who lack capacity. For people to be detained under the Mental Health Act, they must have significantly impaired decision making. If they are detained under the Mental Health Act, they can be given treatment for their mental condition against their will, even if they have capacity at the time to make their own decision about treatment.

People's views: capacity and significantly impaired decision making

Virtually everyone who spoke in the groups consulted felt that people who experience mental illness can experience impaired decision making at some point.

Some people said that they got to such a point that they were unable to make any decisions at all, that the choice between making a cup of tea or washing became something that it was impossible for them to do.

- *You get mixed up about everything – when you are high you want to do everything and when you are low you can't do anything.*
- *I did not know I was ill – it was only when someone else noticed, that I got help – I was hardly eating.*
- *I was thinking I was making sensible logical decisions but I was way from rational decision making. Looking back it was horrific what I was thinking.*
- *Deep depression is an overwhelming sadness that makes you incapable of contemplating your future; you cannot think ahead. You stop cleaning yourself, you can't comprehend what you need to do next; your body is that tired you can't do anything*
- *When I get in that position I can't make decisions – I can't shut the door or put the kettle on – I just sit.*
- *All I want to do at the moment is to sleep and sleep but people say that it is because I am low – I don't make the right decisions.*
- *When I am in a medical state, in a clinical state of mania, psychosis or depression – it is at those times I don't have capacity – at these times I cannot do anything I am hell bent on destroying myself – at these times I cannot make any decisions.*
- *My decision making is far worse when I am depressed. I won't answer the phone or letters etc I didn't do anything around appointments or things I needed to do – in some ways it was worse then – it was more hidden – I wouldn't contact services and didn't have a CPN - you can avoid people and be isolated until it becomes an absolute crisis – I lied because I couldn't bear to be so pathetic –and felt so guilty and inadequate – people assumed I was better than I was.*
- *Anything that is to do with the daily routine – if I go down the way or up the way – if I am losing capacity there is a tell tale sign of not washing or eating or taking medication but clearly evident, I get unkempt.*
- *If I don't engage it is a clear warning sign these are basic things.*
- *I don't think I have ever had long times of incapacity but one of my warning signs is that I will be dressed to the nines – everyone has individual signs of things going wrong.*

A lot of people who had never been in hospital or been detained, also felt that, at times, their decision making could also be faulty and impaired due to their distress or mental illness and that this needed to be taken into account when providing treatment and care for them.

Some people also made the point that capacity or informed decision making is more complex than an intellectual understanding of illness and that it extends to emotional responses to their lives; that a person may actually understand that they are ill but may not be able to adapt their life to this and that their emotional and behavioural responses will betray the fact that they do not really acknowledge or understand their illness despite being able to communicate about it. People also wished to point out that capacity/.decision making varies over time and with the subject being discussed.

- *I was manic a few years ago – on reflection I know I wasn't aware of how unwell I was – but I could make decisions about what to eat and to cook – when I was told not to drive I didn't drive and did agree to use the bus – but clinically I didn't have insight into my illness. Where does this relate to lack of capacity?*
- *Not eating not working – the circumstances you are in too are an element of capacity despite being able to understand.*
- *The capacity to lie or mask things shows enhanced capacity – it is very complex –there is trouble with words like faulty – we need to respect the whole person – when I think about my life I don't like them seeing me negatively: the illness is part of me – people should never make decisions for us but should do them with us – they should know us well – people often don't feel personally understood.*

Very few people gave any account of having their capacity or decision making ability assessed, which maybe raises questions about how people should be involved in such assessments.

- *I am being constantly assessed for my capacity under CTOs; it goes on and on and on – it takes away my human rights – to be told you lack insight or go to the hospital voluntarily and be told you might need to come in and then be sectioned when you don't want to be in.*
- *I was asked what day of the week it is, who is the prime minister? – it wasn't funny.*

People did comment on who they thought should assess their decision making ability. The great majority of people felt that anyone who assesses decision making ability should have some prior knowledge of the person and that without an understanding of the how the person is when they are well they are unlikely to be able to assess them when they are ill.

Many people felt that the best people to know if someone's ability to make decisions was impaired would be people they are close to, especially family members. However many other people felt mental health professionals who have built up a relationship with people would be better.

Some people felt that friends and family can get so close and so involved that they lose the ability to know what is happening to their loved one and some people said that professionals, may have so little time, so little knowledge of the person and be from such a different background to the person they are assessing that their ability to make an assessment is also questionable.

- *Relatives might not be rational either – they can lose perspective.*
- *I don't feel the doctors or nurses have altered their opinion much either – they can have opinions based on the label I have.*
- *Once labelled there can be a credibility issue – you are assessed on the past rather than how you are now.*
- *Family friends will have a good perception around capacity.*
- *It takes professionals who are knowledgeable and experienced.*

Some people question the validity of an assessment of impaired decision making (SIDMA) and do not believe that is an accurate measure of someone's decision making ability.

- *What counts as significantly impaired? It is so wide that you can drive a coach and horses through it.*

Generally people reached a conclusion that a number of people should arrive at an assessment of capacity/impaired decision making and that this could include friends and family as well as a doctor and other mental health professionals.

- *The psychiatrist should decide but they should take into account the relatives opinion.*
- *Care workers or local doctors.*
- *To measure your capacity it should be your CPN or family or a psychiatrist.*
- *A combination of two doctors and next of kin – the doctors who sees you much of the time and next of kin as they know you and will be there for you.*

A few people questioned whether anyone had any right to assess someone else's capacity and felt that anyone who made assumptions about another person's ability to make decisions could be fairly presumptuous.

- *Whose reality is it? Does mine in a housing scheme relate to my doctors in his posh house?*
- *It comes down to what is reality – what reality am I divorced from? Isn't the doctor's view determined by their own version of reality?*

Some people do not acknowledge a medical interpretation of mental illness; they question its validity and the system that allows for intervention and therefore do not accept conventional assessments of decision making or capacity. This is often seen clearly with some members of the hearing voices movement but also with many people who believe that mental illness is actually often a spiritual awakening or experience. Some people feel so powerless because of this that they either feel that they have to conform to a system that controls them or act to avoid it entirely.

- *By gaining insight it is just that we are choosing to agree with the doctor.*
- *It can be seen as a spiritual experience but is seen as a psychotic illness.*
- *There is no room for any wellness in a diagnosis that assumes you are ill.*
- *I don't believe in progressive mental illnesses.*
- *I was sectioned for praying.*
- *Every country has mental illness but different cultures deal with it in different ways - we might not be recognised as mentally ill in some countries.*
- *They may just be standing up against the system.*

Some people feel that if there is to be an assessment of impaired decision making then this should be transparent and standardised.

Should 'sectioning' still exist?

This caused a great deal of discussion, many more people said that detention can be necessary than said it wasn't, often citing their own case or those of their friends or relatives and saying that without detention that person would probably have died.

Judging by the number of people who said that detention was necessary and those groups that unanimously agreed that in some circumstances it can be necessary it appeared that the figure of 87% of people agreeing with the need for sectioning as stated in the report by HUG on the same subject in 2015 was broadly accurate although there may have been slightly more people opposed or unsure of the merits of detention in these meetings than in the HUG ones.

However people opposed to detention had a wide range of opinion and those who agreed with its need also often had many concerns about it.

- *I have no problem with a short term section to deal with an immediate crisis.*
- *I think people should intervene if you are ill and don't know it.*
- *Some patients are so unwell they will not see reason. If we do not make allowances it will be dangerous for me and others.*
- *I do not want people to die because of illness.*
- *I know people who have been sectioned and do feel there is a place for it – some people do not have a level of insight and for their own safety they do need to be sectioned.*
- *A friend of mine was sectioned and it was the best thing that happened for her. It saved her life; her mind had gone completely; she was very unwell. She had asked for help but had had to wait; if she had got help earlier she might not have been sectioned.*
- *If someone is likely to harm themselves or others you need to section them but they must be ill.*
- *If you are not sectioned other people's human rights would be affected.*
- *If a person expresses a concern that you could be a danger to self or others there is a duty of care: then the tragedy may never happen.*
- *A lot of medication is crisis medication. To get you over a hoop if you need it to calm you down from Mount Olympus; it should be compulsory: When I am well I am very well, when I am unwell I am a bastard.*
- *I have been in hospital long term with people who were catatonic and I have seen ECT bring them out of it, it sounds barbaric but it can work.*
- *If it is to save life then autonomy needs to go out the window but not for anything else.*
- *Medication has helped me. I have had help from people who help me with decisions like shopping. I was put in for schizophrenia; they said I had to stay. It was good; I needed treatment and medication for schizophrenia.*
- *In retrospect I welcome being sectioned.*
- *How could we be treated if we lacked capacity if not compulsorily?*
- *If someone has no insight and won't take medication and won't get help – you have to do it.*
- *I am making an assumption that for millennia we have forcibly intervened because we do not like the consequences – we know from many people that forcible intervention saves their lives.*
- *I think forcible intervention was necessary because someone was a danger to someone else; in retrospect he was glad of it.*

- *I'm under a CORA and if it had not happened to me – I spent 4500 days in rehab and not a day was wasted.*
- *When I am depressed I have impaired judgement – sectioning can be good, it forces you into treatment and helps you come to rational thought.*
- *People in prison should be in hospital – if they had help they would not have committed crimes.*
- *Most violent crimes are mental.*
- *With severe depression it can save your life.*
- *Last time I was about to take on about six police officers, I wanted to kill them. It was a good idea to stop me.*
- *The voices are telling you to make the wrong decisions.*

Some people thought that a decision to detain should not be just based on the criteria that currently exist to permit detention but should take into account people's current and past views of their experience of detention.

- *You need to know the views of the user on being sectioned and how they have found it in the past.*

However some people felt that detention was never a good idea and that the imposition of any compulsory treatment inevitably made that very treatment impossible to provide in any meaningful way. A very small number of people said that although they could see how some other people may accept compulsory treatment, that for them the imposition of force or compulsion would be worse than dying as a result of their illness or distress.

- *For me the worst thing is to lose my autonomy.*
- *Even short term detention is wrong.*
- *Because I was sectioned I would never go voluntarily again.*
- *I thoroughly respect the concept of the person – of course I would intervene but I would not force.*
- *I don't think sectioning should happen, not for all conditions for instance side effects of medication: I would rather die than take it – if I was forced to take it I should be in my rights to stop my life continuing.*
- *Stop sectioning I don't think it works unless there is a voluntary element to it – for me it just pissed me off.*
- *If you put someone in confinement they will try to get out and if you don't they relax*
- *By being confined we rebel against it in a way we wouldn't have done.*

People also mentioned the lack of non- medication based therapies for people subject to compulsion, they wanted to see such things as avatar therapy or hearing voices work more widely available and worried that sometimes the threat of detention was used to control people. They also felt that the memory and fear of detention can make people ill.

Some people talked of the trauma of restraint and forced treatment and how in these circumstances it is difficult or maybe impossible to have a dialogue where people have a say or control over what happens to them.

- *Being forced would feel barbaric – it is understandable why I would feel that way.*
- *It is disgraceful when people are restrained and injected.*
- *When you are jagged it is a horrible, horrible, feeling.*
- *They injected me I couldn't stand or walk it was like bricks were hanging from my legs.*

Some people wanted to point out that most treatments for people who are detained are drug treatments which, although many people think are essential, do come with side effects and are often not taken willingly. They also felt that it can be very hard to participate or make decisions when on large doses of medication.

- *Medication can really sedate you: they would restrain me and inject me for being euphoric – what if God did speak to me?*
- *With drugs you are just a zombie and lifeless.*
- *It is hard to get points across if you take medication.*
- *There must be alternatives to medication.*

Some people thought that community treatment orders could be better than hospital treatment and that treatment at home tended to be better than in hospital but they often could not see a reason why they might be treated in the community compulsorily.

- *Having the option of a CTO instead of hospital is better but I wouldn't need it – if I am really ill I need hospital and if I am in the community I would use the crisis team*

Some people did not agree with the idea that people with a mental illness could be detained when they had not committed a crime, feeling that criminal conduct should be the only reason for taking away someone's freedom and some people thought that there should always be a legal process before someone is detained.

- *You need to take responsibility for what you have done – you can't lock someone up if they haven't done anything.*
- *There should be a tribunal before you are detained.*

Some people, many of whom disagreed with many concepts of mental illness, felt that people should take responsibility for their actions and that if they committed crimes as a result should go to jail. They also worried that too many people were unnecessarily detained because a small minority of people either accepted or needed detained. However others disagreed with this.

- *If you are adult then a range of responsibility comes with that – allowing sectioning jeopardises people who can cope without it.*
- *OK you should go to jail.*
- *What makes you assume that it is mental illness there are lots of reasons that people are bad.*
- *This means other people get locked up who do not need locked up.*
- *People should have the right to make bad decisions.*
- *If you don't behave well you should just be in prison.*

Some people felt that being able to detain someone on the basis of mental illness was in itself discriminatory as a particular community is singled out for, what they feel can be abusive treatment.

- *What is the difference between me as an addict and you as a mentally ill person?*
- *Why not do it for other disabilities?*

Some people felt that when they were detained they still had a reasoned and valid point of view when they wanted to refuse certain treatments for mental or physical health and that this should not be overruled on the grounds of impaired decision making.

- *Force feeding is hugely intrusive; they say we care about you. They should do it differently.*
- *Consent to ECT; they say I am not capable; but I clearly do not want it – it is my decision*
- *You lose the autonomy to decide what happens to your body.*
- *The Mental Health Act should just be about care and treatment it shouldn't be about other aspects of your life – it is far too broad.*
- *I have been mad but I know that I didn't want tablets – despite being ill I definitely didn't want tablets.*
- *I worry that my decisions about my physical health will be taken against my will because they say I lack capacity.*

Relatives and carers can agree with the need for detention but may find the experience traumatic and see a very negative effect on relationships.

- *They know and I know that it had to happen. It is extremely upsetting. They take it out of our hands. As a mother I couldn't do it: he was begging not to go but it needed to happen.*

One person pointed out that occasionally they have known people make sure that they were detained in order that they could feel that they had more attention paid to their rights than if they were a voluntary patient.

Some people felt that legalising compulsory treatment was at the root of much of the stigma around mental illness

- *The use of force feeds societies fear.*

Despite most people being in favour of detention most people who had been detained were keen to point out that it can feel degrading and humiliating and result in trauma to people that can take many years to get over. For some people the act of restraint made them feel more ill and more suicidal than before it was applied. Some people felt that with more involvement and control and less force the act of detention would be less traumatic.

- *A five minute discussion with a doctor and then ending up in hospital for a month is really bad.*
- *There is still a punitive approach.*
- *I have been coaxed in and sectioned on the spot – doctors should not have so much power.*
- *Now with CTO's I fear the knock on my door more than anything but if I knew no decision would be made without consulting me first it might be different.*
- *If there wasn't force then I could have been more easily persuaded.*
- *I never self-harmed; I hadn't done anything particularly wrong but I was under the doctor and nurses who I didn't know.*
- *All of a sudden nurses are walking you to the locked ward – it was prearranged.*
- *When I was sectioned I wasn't aggressive or suicidal I was able to make rational ideas and I do not know why I was sectioned.*
- *Sectioning for six months: loads of your rights are taken away.*
- *It is frightening to see it happen.*

Some people also commented on how detention was not always carried out according to procedure and wished that it was.

- *When you are detained it should be approved by the MHO. This doesn't happen enough; it ends up down to just one person's view.*

Some people thought there should be a number of ways of intervening when we have impaired decision making but that this might not always be around detention and force

- *There should be a way of putting a stop to our credit cards when we are high.*
- *If someone was critically ill and suicidal – I don't know what I would do but I would intervene – but I wouldn't dart gun them.*

Supported decision making

This discussion made up the main part of our discussions. In two groups people felt strongly that there are for, many people, points when they are at their most desperate that they cannot make decisions at all and that no amount of support or assistance would assist them along on that route and that at this point it was vital that other people took decisions for them.

Many people were keen to say that decision making and capacity is a variable thing, they felt that often people could not make 'big' decisions or at least those directly connected with their illness when they were ill but that they could make a multitude of smaller decisions. They felt that this was often overlooked and that when people were detained or admitted to hospital that an assumption was sometimes made around control rather than participation and that the presumption should be made that people can usually make decisions about their life rather than that decisions should usually be made for them.

- *We can get to a state where our judgement is impaired; some people have no insight.*
- *Some of the big decisions need made for me – i.e. a friend got me into hospital but you can still make smaller decisions.*
- *If people could acknowledge there are lesser decisions to make; I couldn't hold onto ideas but if they had spent time with me it may have helped but not necessarily.*
- *Sometimes you need to let people make decisions for you.*
- *I could feel unwell and not be able to make decisions – I need someone to make decisions then.*
- *I would have loved someone to make decisions for me.*
- *The question is no capacity and full capacity – but it is a continuum – at some point you can make any decision and at others none and at others anywhere in between.*
- *Decreased capacity does happen to us – we can lose the ability to make decisions.*
- *Even when you are a bit down it can be hard to make decisions.*
- *When I am down my partner makes decisions for me – I won't make any decisions when I am down and when I am high I am reckless.*
- *I still wonder if I would listen to people – if it would work.*
- *My communication is quite bad at these times – I would struggle to write.*
- *I was unrealistic about decisions and spending but there was some logic to it.*

However people did make the point that as they become more well that they get better and better at knowing what they do and don't want and that it is at these points that professionals and others need to consider the importance of empowering them to regain autonomy and to relinquish some of the power that they have taken over them.

- *Giving up your power to make decisions is easy; to get the power back to make decisions is really hard.*
- *There comes a point where we need to be listened to and people need to stop looking after us too much or thinking they need to look after us.*

Some people point out that a ward environment is artificial and that when people are removed from their everyday environment and put amongst other vulnerable people in a place where most responsibilities are taken care of, that it can be very hard to focus on everyday decisions and therefore further damages their decision making ability

Some people felt that even when they are detained there should be an assumption that they are capable of and can make decisions.

- *A change in mind set: they should assume that you can make most decisions.*
- *Empower people to make the decisions that they can.*

Some people said that it is not possible to contemplate supported decision making as a valuable concept if detention remains an option.

- *Supported decision making in tandem with substituted: what meaning is there if they can make you do it?*
- *How can it be a supported decision if there is always an axe hanging over you.*
- *How can you have your say when they inject you.*
- *They should find ways to speak to you before they inject you.*

People also pointed out that in order to make decisions about your care and treatment that people need understandable information provided to them, without it they may struggle to make the sort of decisions they would want or may struggle to be listened to.

Some people felt that if their decision making was seen as impaired that this was more about power and attitude:

- *Can't make decisions can mean that you can't make a decision someone else is satisfied with.*
- *We can be dismissed if we have a mental illness and not be listened to.*

People also said that if they are not able to act on their views and beliefs then people need to make sure that they have their rights explained to them and acted on.

While people mainly talked about needing support for decisions to do with treatment people mentioned that sometimes people need support to come to decisions in most other aspects of their lives, Money and finance was one area that was mentioned especially.

Some people do not want to make decisions and prefer to have responsibility taken away and to feel looked after instead.

- *I would take any help, I would prefer it to be from professionals, I would like to be treated in hospital to be looked after and mollycoddled.*
- *I like people doing things for me, my cooking my ironing, my shopping all the things that keep me going.*

Supported decision making in advance of becoming unwell

There are a number of ways of making provision in advance of becoming ill or losing capacity, however these mechanisms need promoted and encouraged.

A person with experience of legal and financial agencies made the point, after one of the meetings, that the general public are also very poor at making advance provision and that the safeguards below needed promoted sensitively but vigorously as people rarely actively seek to take these actions until it is immediately obvious that they need made.

Advance statements

When people are well they should make advance statements was a view expressed in every group we visited. Nearly everyone knew what an advance statement was, nearly everyone felt that they should have one and the vast majority of people did not have one. People suggested that they should be much more actively promoted than they are and also wished to know more about the evidence that should exist to demonstrate whether they are actually respected and acted on. Many people were unhappy that they were not binding and could be overruled.

- *Whenever you go to the GP it should be automatic to check you have a named person and an advance statement and they should encourage you to make one.*
- *I would like to see advance statements adhered to where possible – mine has been overturned so many times.*
- *Advanced statements are a difficult one, the first responders like the police should have access and that might avoid detention.*
- *I made an advance statement and ECT is not on the cards for me now.*
- *I had an annual review of my mental health and my GP said it would be a really good idea to have one, now we look at it each year and review it.*
- *It can take ages for the system to know that someone has an advance statement; people can forget they have one.*
- *Not every tribunal asks if someone has one.*
- *You can wait until the end of the tribunal for an advance statement to be read which means it becomes a farce.*
- *I don't do advance statements because I trust professionals and I trust my parents to make decisions for me.*
- *An advance statement also makes you face it which you might not want to.*

Power of attorney

People also suggested signing over power of attorney to trusted friends and relatives and some had done so. Some people had made active steps to do something similar but not formally, when they were well. An example being a person who, when high was likely to spend the families savings, she had asked her husband to keep hold of her bank cards and to give her an allowance in order not to put the family at risk. A down side was that there can be an inclination by family members to try to make decisions for people after being given power of attorney, even when they are well and clearly have capacity.

- *I have given my daughter power of attorney over me in case I go into hospital so that she could look after my finances – I need to update it now as she would need to look after my cats – it's the small things that worry me that I would like someone to sort out – silly things that you don't really think about – I wasn't so sure of myself at the time – it only works if I lose capacity but my daughter is now talking about it in present terms - it can damage my trust in her.*

Named person

People also suggested that people take an active part in getting a named person to represent their interests when they are ill and in one case were keen that when they were ill that they were not seen to have capacity to change their named person to another person as had been the case with them.

Personal statements

People also liked the idea of personal statements and some people felt that they should have a similar legal status to advance statements.

Wrap plans

These were suggested as useful tools for helping demonstrate people's wishes and in giving them a say over how they want to be treated

Advance wishes

People also mentioned similar ideas to advance statements such as letters about how they would like to be treated and discussions with people close to them or with professionals about how they would like to be treated. Some people said the very act of creating an advance statement with people providing care for them would in itself be an act promoting partnership and participation.

One person had written letters, in agreement with her consultant, where, if nominated people think she is becoming unwell, she gives them permission to contact her consultant on her behalf if they think she needs help whether she likes it or not. They can be proactive when she won't be.

A person who constantly self harmed made a booklet about what to do (like an advance statement) She talked about dressing wounds and taking her to hospital but not doing more. She talked about different scenarios and how she would like to cope with them. It was a great help to the support team and she is now free of self harm.

'We could have advance statements even when we have capacity'

Paths

A tool in learning disability services is to create a PATH where a graphic representation of a person's goals and the journey to reach them is created alongside a group of people with the person key to it. This was suggested as one way of ensuring people had help to reach decisions and express views.

Recording views

Some people struggle to articulate themselves or to write: by recording their views on 'tape' and being able to play them to professionals they may feel more confident about being heard and could also use them in a similar fashion to advance statements

- *Record what you want to say so that people can understand you when they listen to the tape*

Self management and coping skills

Some people felt that a key element in decision making rested in helping people come to an understanding of their condition, to recognise when they are getting ill and how to cope with different aspects of this experience. By gaining this knowledge people will have more control and more information to participate in treatment.

- *Bi polar self management – feedback is very positive – different strategies and exercises and mood signs; advance statements.*
- *Learning how to prevent highs.*
- *Access to money advice and managing debt due to being high.*

Open dialogue

Early intervention and open dialogue and preventative measures were all cited as key to supported decision making –they and other services can avoid the situation escalating to a point where a person is treated against their will and may not be able to play a part in treatment any longer and are also a way of ensuring that a person's voice and wishes are heard and respected at an early stage. As a situation begins to develop a group of key people would meet to discuss treatment and people's views needs and perspectives

- *A supportive meeting to make joint choices instead of just imposing decisions*
- *Supported decision – similar to a tribunal; around the coffee table: you are unwell we would like to help – open dialogue*
- *You should be asked who you would want to come along: RMO Junior doctor from a different team; You need to feel that you are not alone, You should be able to choose: people you trust*

Who can help with decisions when people are becoming ill and having trouble communicating decisions or being listened to?

Trusted people

Almost everyone said that key to making decisions and being supported to make decisions is being with someone who you know well and who you trust. In most groups trust was the key ingredient when turning to someone for advice over decisions that they needed to make. Unfortunately due to past treatment some people had lost trust in people or had no one in their lives that they felt they could trust.

- *We need to have a good and long relationship with someone you trust and know well.*
- *It is now hard for me to trust anyone.*

Family and friends

A very large number of people said that at critical times in their lives (and other times too) that they trusted their family more than anyone else to both make decisions for them and to help them come to decisions.

In a fair number of cases people said that it would only be a family member who could do this. They felt family members know them when well and when ill and can pick up on signs of illness and poor judgement far quicker and more effectively than professionals. For some people, family are key to helping people make decisions when they have lost some ability to do so. The same was said but to a lesser extent, about friends. People often talked about how friends and family had got people to go into hospital when they themselves were unable to make that decision and how they were subsequently glad of this.

- *My only person I can turn to is my husband – who would speak for me.*
- *I am the first person for my brother; I know him inside out.*
- *I have spoken to the psychiatrist when they haven't been dealing with XXX properly if there are things that need to happen I will tell them based on my knowledge of XXXX we have a bond that works well.*
- *My husband did do things to help me stay safe.*
- *Sectioning is really important – my sister knew what I was going through.*

In contrast, in every group where family was mentioned as a source of help with decisions, they were also mentioned by a small number of people as an impediment: some people were angry with family members who they felt were responsible for them being sectioned, some family members themselves felt hugely guilty about getting a relative involved with services and felt that they should never be a part of any process of detention and some people felt that family members could be too emotionally involved, too stigmatising, too ignorant of mental illness and in some rare cases too damaging to their relatives to be involved. People mentioned that the dynamic within a family could be negatively affected when a family member takes on the role or is assigned the role of carer and that this may take some time to get back to and that if they have a legal role in their relatives care then this is even more likely to happen.

- *My problem was that my mum got involved in the sectioning – my life became her concern; in the end it had already been decided before they saw me.*
- *If they had made it my decision, it would have ruined my relationship with my son.*
- *He still blames me.*
- *It can be frustrating and frightening to be with people in the depths of illness –we can lock them in the house to keep safe.*
- *But families can be complicated – they can call the police in crisis – and off you go.*
- *I kept friendships that I should have left as I was so isolated.*
- *You can have friends that get you into trouble.*
- *Some people can pray on people with a mental illness.*
- *Family can be complicit in detention and may put a great stress on relationships.*

Some professionals can see carers as unhelpful in the process and do not acknowledge the role that they can take.

- *Some nurses see you as the enemy – they do not want relatives in the meetings if they have also had a mental illness in the past.*

Some people said that when they were in recovery they recognised their triggers but when they became unwell they did not have insight. Family and friends could be supported to be involved in care planning so that they are aware of the changes in behaviour which may indicate their loved one is becoming unwell and needs early intervention.

- *They realised and picked up on it – my partner helped and I had made a promise to someone who is no longer here to look after myself – they got me help but were sensitive to how I was feeling.*
- *Family members may need to instigate it because they know us best.*
- *When I was last in hospital I got a lot of help from my mum and dad which helped me a lot.*
- *Friend and family can be a good factor –they know you better than you know yourself: they can bring you back to reality – you can lose responsibility.*
- *I had family and friends and advocacy and a lawyer and the MWC but still it didn't make a difference – I didn't get what I wanted.*

Advocacy

Advocacy was mentioned in every group as a key component in helping people express their thoughts and their views and in coming to conclusions. However in one group it was suggested that an advocacy worker who guides someone to a conclusion they might not have initially held is likely to be in conflict with their primary role of helping them express their views whether these are sensible or not.

Some people also regarded development workers of collective advocacy groups as the ideal people to turn to. However some people are unhappy about the success they may achieve despite the help they get.

Some people felt that they had such a good relationship with their advocates and had so much trust in them that they would turn to them for help in making decisions or expect them to get help for them if they were in crisis.

- *I went to the c.m.h.t. with my advocate; we wrote down what had happened but they still didn't listen. It was discounted because I was ill, I lost trust in the system: they thought I was psychotic so I walked out, it wasn't worth it.*
- *They are more there to put your views forward – not to guide you in decisions.*
- *Advocate – I had one who was good but it stopped when they said I no longer needed one – I would go back if I needed.*
- *Advocacy – in human rights. Your human rights are removed; you need told what they are.*
- *She listens, she is friendly, she is supportive, she knows her stuff, she knows the rules and regulations she is an encyclopaedia.*
- *There is a waiting list for advocacy.*
- *If someone hasn't been around for a while people can go to acumen for help and we can arrange emergency appointments – it allows for help before people are treated against their will.*

Peer groups

Many people were keen for their peers or peer groups to be involved in helping them make decisions, they felt that they could discuss issues with their peers in a non- judgemental and open way which they could not do with professionals.

Some people suggested that they gather a circle of trusted people around them who could all play a part in decisions that were being made jointly for them. However some people felt that activities like this would alter the dynamic of groups that they go to and others said that the very last thing that they would like to do is to share intimate parts of their lives with groups of people.

Some people also felt that peer workers could play a role in this.

- *Your peers; those on who I rely – someone who understands my situation.*
- *Peer support – you know you are speaking to someone who understands – it is different to a doctor who you won't admit some of the things that you do due to stigma.*
- *We all know each other – it helps – we help each other with our decisions.*
- *You can feel like a failure because you can't get out of bed but you can go to a group of peers and not feel that.*
- *Sit down with a peer support worker and talk it all through.*
- *They are a family and a place to I belong to and can speak about my own problems – it's also a positive place you gain your confidence, I can speak out.*
- *Peer support groups – they have a specialist interest = we tend to be on familiar terms with our peers and share experiences – people will notice how you are.*
- *One aspect is the informality – no rules – it depends on good will.*

Support groups

Some people discussed some of the support groups that exist and had variable responses to this, having decisions made by a group of people is the last thing some people want and if they are open to this then they need to be sure of the people in the group, to trust them and know that they have knowledge of the people in the group. However for some people a support group would be the natural place to go for assistance in coming to decisions.

- *Support group – no – no reason to assume they would know what they were doing – I would be unlikely to put myself into a group situation.*
- *Spread the decision making but it needs to be a really good choice of group.*
- *A support group – this is good; get a support group from people in your own circle –you need to trust them and know them. They would need to know about confidentiality.*

Chaplains

Some people have found access to chaplains, and hospital chaplains in particular, are a good way of discussing issues and coming to conclusions and decisions about treatment and their view of treatment

- *They have a compassionate approach to distress and alternative explanations.*
- *They had a chaplain that I would tell stuff to. I stayed in for four months and got used to him.*

Legal assistance

Legal assistance was mentioned in some cases, especially where they have prior knowledge of a person and of their rights. However some people felt that solicitors had been ineffective when representing them at tribunals and also that if legal assistance is given to support people to make decisions then it should be free to all needing it.

- *If you have one that you are in a lot of contact with - generally we have no contact.*
- *If it was about property – you are going to give away all your savings – it may be best to have legal advice.*

Personal assistants and counsellors

Access to personal assistants and counsellors were all accepted as possibilities for making decisions but most people said that they did not have any means of getting access to such people and that their role maybe did not fit neatly into this area of work.

Independent people

Some people said that anyone who plays a part in helping people make decisions and having their views respected needed to be independent of the system.

- *We need a buffer who has nothing to do with hospital.*

Professionals

For some people, the people who provide care to them are the people who they would turn to, to support them in having control, as far as possible, over the decisions being made about them. Doctors, CPN's, Social workers, Psychiatrists, Carers and Support workers were all frequently mentioned.

- *Nobody knows me better than the doctor.*
- *My carer helps me with medication; they take me for coffee and ask me what I want to do: they listen to me.*
- *My head goes fuzzy and there are the voices – my carers help me make decisions.*
- *Support workers: they help me decide things.*

- *Social work: it depends on who they are and what their situation is but they can be helpful.*
- *If I were struggling I would go to a psychiatrist first; I don't have a CPN or any support; I wouldn't have the chance to speak up and tend to shut myself away when I am struggling*
- *I am often quite isolated by the fact of living alone and working alone from home). The only professional who really knows me well is my GP so I would trust her judgement.*
- *C.m.h.t.; if they know you and have treated you when unwell in the past – especially if it is a team member who knows you well and listens to you and has come out to you in the past.*
- *I would go to the crisis team if I could but I would need to be sure they would help me – they tend to tell me to take a long bath.*
- *My psychiatrist is the only option, she is the only person for me even though I don't see her often.*
- *I would just go to A&E in panic, really I need someone to come to my house, when unwell it is really the people that are close to you that need to help you make decisions.*
- *I would rather the nurse on my ward than my relatives.*

Third sector

A few people mentioned people from the third sector as being valuable people to help with decision making.

- *People from the Third sector: Penumbra and so on.*
- *Victim support – they were really helpful – they helped me with my mental health and acted as my advocates and also helped with confidence.*
- *Independent living support: this is where I live; I didn't like them to start with. I turned to them and said I have had a life of having decisions made for me; now you will listen to me – and they did.*
- *They wouldn't dare go against me.*

Circles of support

Similar in some ways to open dialogue was the idea of circles of support that originated in the area of learning disability. People felt that having a group of people that they trust and have chosen to be in their lives could be a good way of making decisions.

- *Circle of people we trust having a say in what happens to us.*
- *Circle of friends – you get a group of people and they decide between you and them what to do if you are having a bad day – you make the decision about who is in the group.*

People's own voice

Some people felt confident of their own ability to speak up and to be heard and would not want other people to be involved in helping them make decisions

- *No one has the right – it should be up to you when you are well.*
- *We make our own decisions.*
- *I have a voice so I don't need help.*

A variety of people

Some people felt that it was important when key decisions were being made or when people were assisting people to make decisions that this was not done by only one person.

- *More than one person to avoid pressure and safeguard you.*

Isolation

Some people said that although they could see the point of turning to trusted friends or relatives to make decisions or going to professionals when things were going wrong that they and many others had no one to turn to for this and that when they were getting into crisis when they may need help with decision making that they did the opposite of seeking help and instead withdrew from contact with other people and services

- *Getting to a crisis point without anyone realising the bubble is going to burst - and then finding nobody really knows me, other than the GP. So can I trust someone else making the decisions?*
- *What about if you have no friends?*
- *If I lived alone I dread to think what would happen.*
- *When you are isolated you have no one to make decisions and don't reach out for help.*

Making it easier for people to participate

Mental Health Professionals and hospital – dealing with attitudes that may hinder decision making

One of the most important areas to people was the subject of treatment of people by professionals, especially when in hospital. This was raised especially by people who had been detained. People often felt ignored, dismissed and patronised or infantilised. They felt that, with the restrictions that accompany detention, that they can feel alienated and almost abused.

- *We can be seen as 'other' and the enemy.*
- *It is like you are misbehaving.*
- *Everything is moved to the lowest level i.e. if one person is sectioned the doors are locked for everyone so in effect everyone is sectioned.*
- *They look at you like you are a two year old – eat your tea, stop staring into space – she did that in the canteen.*
- *When you are in hospital you are in a subservient role – at home they are a guest in your house – being in hospital can make it more difficult to be listened to or to speak up.*
- *Simple things – you need to get permission to make a cup of tea, you need to get the door unlocked – it is like being in prison.*
- *I had a nurse say to me 1:1 'Don't you think you are a bit old for self-harming?'*
- *The police say relax but it makes you react negatively.*
- *To make better decisions for yourself you need training for doctors and nurses in not seeing medication as the answer for everything.*
- *The staff don't have time to listen they just give out medication – medication just makes their job easier.*
- *We need help with trauma and rage – when they saw the rage coming up they would put me in a room and inject me and hold me down. If they could sit and talk me out of my anger and talk about alternatives.*
- *After I went into hospital I was suicidal – but the situation in hospital was what made me suicidal: I was so confined – the blue room with no windows that would open – the barriers they put up like not letting me get a cup of tea – that is what did it.*

They often did not feel people sought out their views in a way that encouraged them to participate or wanted to listen to them. Many people said that when they are in distress that they struggle hugely to communicate or express their views and that this can make it very hard for professionals to help them participate, some people felt that professionals can, instead of seeking out ways to involve them, tend to isolate and marginalise them.

- *Medics can be as screwed up as you – they don't know people the way they used to.*
- *Professionals can be risk averse and frightened of liability.*
- *If hospital could take the fear away I would be less resentful.*
- *Make the hospital nicer places and less scary so that you do not need force to be admitted.*
- *You need to remove the 'them and us' feeling.*

- *We do tend to shut down though – it can be impossible to get a straight answer out of us when we are in hospital.*
- *I go very quiet and can feel ignored and in the background.*

For some people (and in contrast, some other people had nothing but praise for their care in hospital) the atmosphere in a psychiatric hospital and the culture within in it can be such that asking how people can be helped to have control of as much of their lives as possible produced confusion – it was so far from their reality that they could not conceive of how some professionals, even with the training that other people suggested, would be able to involve, communicate with or see them as partners in what was happening.

- *The majority of psychiatrists and nurses are wonderful.*
- *Because I have had an admission I think who I would trust most would be my psychiatrist or someone else in my circle: a CPN or a family member - they may be someone with a medical background.*
- *There can be little privacy and lots of restrictions on the IPCU, but you are there for a reason – for me it is the safest place for me – I feel secure there – it is maybe down to my background and ability to put up with hardship.*
- *The single most important thing is that people need to be aware – young professionals need to see their own biases.*
- *One psychiatrist trusted me to drive when I was well and not when I was ill and then I changed to another one who said I couldn't drive at all.*
- *You can only be so open with people who are not open with you – there is still a barrier that you have to cross – professionals can create a lack of engagement.*

People frequently talked about the basics that made them want to recover or look forward or feel positive about what was happening. This could be as simple as a smile from a fellow patient or a hug from a nurse and seemed to some people to be rare.

- *You can achieve a lot with kindness and compassion.*
- *We need the human touch; I needed a hug: I gave her a hug, the nurse then hugged other people – it was really nice to see her make a connection – it also makes them feel human.*
- *Human warmth, with a cup of tea.*
- *An attractive and comfortable environment.*
- *Make people feel as safe as they can be.*
- *You should sit in a comfortable room where people are talking to you who understand – take away as much power as possible.*
- *Fellow patients; I had shut down – her response to me – she smiled – that gentleness – non- verbal healing for me.*

Some people said that for them to play a part in decisions, people needed to be with them in the place they were, to try to understand them and appreciate how they felt and to genuinely want to know and act on their opinions. They felt that this was a long and intimate process and involved letting people take risks and sometimes fail at the things they wanted to do.

- *It is sometimes their attitude that needs to change.*
- *If there was a change of attitude and use of authority it would make a huge difference.*
- *In hospital the person making decisions for me may be from a different culture and background – they don't know me or what I want.*

- *You need someone to work intensively with you over time to get to know where you are – what you can do and what you need pushed to do.*
- *Somebody who is trained, who you can really communicate with – therapeutic communication – much more difficult when unwell.*
- *Some sort of communication that gives you time where somebody is listening to you and how you are saying things.*
- *It is more convenient if we don't speak.*
- *In hospital a relationship has built up in a journey of being unwell – but over time the nurse has got to know me and what is needed – she now knows how well or ill I am because she knows me.*
- *People relate to a particular conversation that matters to them – these conversations can be crucial – staff can make a difference that they are not aware of.*
- *Being psychotic can be frightening and all over the place – reassurance by people might not be enough – but being calm and with people: a sense of being with you to take away from the sense that you are being punished.*
- *I had a public breakdown and was put in a police cell and not allowed to see family – I couldn't get a hold on reality if I could have seen someone that I could connect with.*

People also felt that there is a need to demystify and help people understand how hospitals work, some people reported being terrified the first time they were admitted or else bewildered and very often ignorant. Some people talked about their confusion when they were restrained because they tried to leave the ward when no one had told them that they were not allowed to.

- *You are not given much of an opportunity to acclimatise –stuffed in a ward; no one walks you through the paces and there is then the possibility of violence from other patients which increases the likely hood of a section.*
- *You have a delusional framework you do not know the legality or the parameters; I was leaving the ward and didn't know I couldn't. I was quickly and forcibly taken back. I didn't know enough to know it.*

Intervention when a person has capacity

This area of discussion caused some considerable confusion which can maybe be represented in two themes. That of assisted dying and euthanasia and those who were suicidal because of mental illness.

Some people said that if a person has capacity and yet is a danger to themselves that ultimately this fact should be respected. They said people determined to die should ultimately have that right and cited Dignitas and the euthanasia debate that currently exists.

- *It's their choice.*
- *The decision must rest with the individual and should be respected.*
- *I feel that people can have had enough.*
- *Euthanasia should be allowed.*
- *Dignitas – you need to be in the right frame of mind for it – I believe in it but not for mental illness.*
- *If I was really ill I would want to go, I want to be able to die if my mental health gets really bad, I don't want to go through that again.*
- *You don't have to be ill to be suicidal – it can be a rational decision.*

- *It is often not obvious if someone lacks capacity – we can make assumptions about this.*
- *If I am allowed to with chemotherapy why not.*
- *Is the assumption that the decision is temporary and that someone can recover?*

They also said that we cannot ultimately prevent people who are determined to die from dying and some people said that some people may find the long term consequence of severe and enduring mental illness so distressing that they can see how this could lead to a rational and credible decision to die but for many people impaired judgement is so bound up with illness that it would be hard to give credence to most decisions of this sort.

- *I was suicidal but my decision was rational and well judged – even now I still feel the same way – I was not listened to I was robbed of the right to make the decision.*
- *If someone has had years of depression and is told that they can't be helped then maybe they should be allowed to die.*
- *What does it matter what we think – it is maybe their choice.*
- *There can be times when we decide rationally to die.*
- *It can be a logical decision i.e. alcoholics can make that choice.*
- *But maybe for some people for whom life is a constant burden it is unbearable – maybe it is their right?*

However many of the people who said death, when judgement is not impaired, is acceptable also said that there need to be services for people who are at risk of harm that are readily accessible and of the type that people want and feel that they need.

A large number of people came from a different standpoint saying that they personally knew many people or had themselves been suicidal (and not detained) and were now extremely grateful that they did not succeed in dying. They felt that many suicides were not actually what the person who died would ultimately have wished for and said that they thought society should intervene when this was a possibility and that they themselves could not personally witness a friend or loved one with capacity go ahead to take their own life.

- *That was my situation – all human life is important.*
- *There needs to be some common sense if someone is about to die.*
- *'Many people acknowledged the pain of feeling suicidal but felt that there should always be help to stay alive as time and healing teach us that there are good reasons to be alive. It was felt there is always a way forward and that is what mental health services help people to work towards. Communication and understanding were thought to be essential especially to the person who is being protected from suicide in hospital. It was agreed that mental health services were necessary and valued as they regularly are "life-savers".'*
- *If someone wants to die they might not really want to.*
- *If someone is suicidal in the short term then someone should intervene.*
- *If you are normal or compassionate: I would have to intervene.*
- *If someone was about to jump –we need a middle of the road approach between ignoring and saving someone – I would try to engage them in conversation which is natural rather than 'don't do that' – ultimately it is their decision.*
- *If the person is stuck and they are swithering it may be a chance to connect and let them know that we care.*
- *If they were suicidal I would section them [even if they had capacity].*

- *I was suicidal – though I wished to die; nowadays I am so grateful that I didn't succeed – I am so glad.*
- *It can be very scary if you are suicidal and left to your own devices.*
- *Sometimes people self-harming are wanting helped – we should ask them what they want and how they want to be helped.*

They also often said that although people were often seen as having capacity that in their view that people who were suicidal very often had impaired judgement that was influencing their actions.

- *I am only suicidal when I am unwell even though I have capacity – I want them to intervene – I would not want to kill myself.*
- *If you get to the point of wanting to commit suicide then you must have impaired judgement – if you are depressed or manic then you will have impaired judgement.*
- *I agree I would not be sectioned but have been suicidal.*
- *When I am unhappy I become depressed and want to die – when I am not I want to live*
- *How many people have attempted suicide and then been pleased they were helped?*

This was reflected in people saying that people may be suicidal, but may also wish for help. They may hope that there could be some reason to stop them dying but at the same time be incapable of accepting help or carrying out coping techniques that they have been taught. There was a feeling by some, that the debate about capacity misses the point to some extent and is more an exercise that looks at intellectual capacity and does not recognise emotional capacity and the mass of contradictions of someone who is aware of the consequences of their actions but not emotionally capable of looking after themselves and may in fact be so determined to prove how bad they are that they do the opposite of what may lead to help and a positive outcome. For this reason they felt that intervention needs to occur and needs to be less judgemental and more humane than it sometimes seems to be.

- *But people can be hoping for help.*
- *People should be given a chance and get support.*
- *You need to give them treatment to help them have hope.*
- *What is it about our services that mean that people lose hope.*
- *How can you assess risk intent and capacity?*
- *The medical profession can put people out when they shouldn't – I know a person who took their own life.*
- *You phone the CMHT and they say they will phone back but in that time you can be dead.*
- *I spoke to someone on the phone and they said 'do you need an ambulance?' and then they said I was ok.*
- *The crisis team – they just needed to know that I was warm and clean –they were dismissive and just said I was ok.*
- *They said if I feel like self harming just to phone back.*

Some carers felt that service users need supported to appreciate the devastation that their suicide would cause to their partner, family and friends. They need to fully recognise that their decision is irreversible.

People also worried about the consequences of permitting suicide if voluntary euthanasia was permitted for people with mental health problems.

- *We should not be a society where pressure is put on you because you are a burden.*
- *It is open to abuse – the system may encourage people to go for euthanasia.*
- *If you feel you are a burden on your family there may be some cruel people who want to get rid of you.*

Legislation

Whilst many people appreciated the chance to talk about the situation that happens when people are judged to need compulsory treatment and how they can play a bigger part in the decisions that are made about their lives. Nearly all the groups were at pains to point to the poverty of community services, the impact of cuts on services and the difficulty of getting a bed in hospital if needed or of getting respite before situations got too difficult.

They also pointed out that the act doesn't even guarantee services for people subject to its orders with one person saying that they were still waiting 18 months after a tribunal instructed that a number of community services be available to their relative, for any of them to be provided.

Some people felt that current mental health legislation mainly dealt with a small number of people for whom compulsory treatment might be justified but that there were a very large number of people with mental health problems for whom services were woefully inadequate, they wished to see new legislation that gave people a right to mental health services and which ensured that those services were provided in such a way that people could access and use them and benefit from them in a way that recognised their opinion of what could help them.

- *There are worse services than before – in the past there were groups and outings and community facilities*
- *The crux to supported decision making is funding*
- *We need social and recreational activity to prevent the need for sectioning*
- *We need a sense of belonging to a safe place where you know people to reduce the need for a section.*
- *Legislation needs to change to give a right to services not just restrictions on people – the key problem at the moment is not being able to get help*

Early intervention and help in crisis

A large number of people pointed out that people would be more likely to be able to participate and have control of the treatment that is given them if they could access it in the first place rather than having to get very ill in order to be given any help. They wanted access to help in crisis and before crisis developed, this would remove some of the need for supported decision making as less people would get so ill that compulsory treatment would be necessary. They also called for more home treatment and the chance to get this without referral. They called for more community groups and activities and more support for young people.

- *Do it before they are likely to be sectioned.*
- *People and family can keep going to the doctors and they don't want to get involved: it can lead to detention or people taking their own life.*
- *Surely people don't have to get so ill that they can't do anything about it? –surely you need help when you need it.*
- *We were promised a place of safety – it never happened – we got the place but there were no staff.*

- *Is someone is very unwell they can end up in then police cell which can be wrong – often it should be dealt with by the CMHT.*
- *When you phone up they refuse to talk to me because I am not on their list – most of us were taken off of their list without being advised.*
- *Last year my brother was in a bad way, he had attempted suicide and was only saved because they tracked his phone – it was horrendous trying to get him into Forth Valley – he was in intensive care but it was terrible trying to get him in.*
- *It is really hard to get into hospital – who makes the decision on who needs a bed? It is now like a production line- hospital puts people back in the community before they are ready.*
- *Just being able to talk to someone and feel listened to can make such a difference and diffuse crisis.*
- *If the support is there in the community you can avoid hospital admission.*
- *'Members felt it was essential to have easy access to the CMHT if you relapse. The CMHT should hold a plan that can be implemented as soon as crisis is identified. The process of having to attend A&E, being reassessed and having to answer the same questions again and again, was highlighted as causing further distress. The need to feel listened to and engaged with when you are in crisis was important as was treatment with dignity and respect.'*
- *The CPNs I saw for an assessment in June said they couldn't help me - despite me having suicidal thoughts.*
- *How many people are fortunate in having continuity of professionals who have continuity in knowing you and helping you get confidence to disclose or make decisions and to recognise when the danger signs are there.*
- *You can wait for hours in A & E to see someone and be referred to psychiatric services, they should have a place you could go first a sort of crisis centre or mental health A&E*
- *There were psychiatric nurses at A&E who calmed me down and got me to hospital.*

Feedback

One group made the suggestion that there should be established feedback mechanisms about hospital stays and especially for people who have been detained: ideally everyone who has been detained should be sent questionnaires or asked for feedback in what helps or doesn't and what they need for a better experience.

Conclusion

The majority of people disagree with the general statement of the UNCRPD to stop compulsory treatment but some people would very much wish to see its statement become binding.

Nearly everyone agrees that people's judgement can become impaired due to mental illness and many wish that this was understood and acted on even when their judgement was not significantly impaired. When someone is assessing capacity or judgement they should ideally know the person well and should involve a range of people who the person also trusts and knows already.

Despite most people agreeing with detention nearly everyone points to the trauma that it can cause people and the negative effect that this can have on treatment.

There are a number of practical ways in which supported decision making can be encouraged including advance statements and power of attorney which already exist and there are many people who can help people make decisions or play a major role in decisions being made, such people are ideally well known to the person and trusted by them.

Some decision making could be enhanced by demonstrating care and compassion for the patient and by services going out of their way to help make a ward understandable, welcoming and less frightening.

Some people think that poverty of service provision puts people's lives at risk and that without investment in appropriate services the mental health act will be less effective and rights based than it should be. They feel this is more important than Supported decision making and also feel that if people could get help when they want and in the fashion that they want they would be fully capable of making decisions themselves about treatment.

An issue that we did not concentrate on was the actual mechanics of helping people to come to decisions when acutely unwell, and also whether people want to make such decisions at such times, or may instead as some people feel wish at critical times to give responsibility away and be 'looked after'. This may merit some further discussion with service user and carer groups in the future

Preliminary discussions with other disability communities indicate that they may have different perspectives and needs; we hope to contact them too in due course.

Appendix

Seeking Your Views consultation

Capacity, Detention, Supported Decision making and Mental Ill health

A discussion on the above paper in a focus group of four people

Four of whom were people with experience of mental health problems and three of whom were family members

January 2017

Introduction

The above paper was written after discussions in late 2016 and early 2017 which contained many points of interest that merited further discussion.

In January 2017 we gathered a small informal group of people to discuss some of these points. These discussions are recorded below, much of the discussion was wider than the specific focus of capacity detention and supported decision making and sought to place it in the context of service provision, stigma and community.

Decision making:

How can we be affected when we are unwell?

In what way are our decisions impaired or affected if for example we are psychotic? And if they are; what aspects of our decision making are affected, is our capacity overall affected or just certain aspects?

Our decisions may be affected if we are moderately depressed or anxious but not subject to compulsion: we may be well aware that we are making 'suspect' decisions but maybe at less risk. How should we or others respond if our ability to act because our feelings about ourselves are impaired by our mental state?

Are there other ways of helping us make decisions at these times, other than by making them for us?

This discussion took a few roots the first of which was that impaired decision making is not always due to mental illness and in fact may be a direct result of the stress that people experience in their contact with the mental health system. The combination of worry about what will happen to you, anxiety about a new and alien environment and lack of information about treatment, services and the condition itself can lead to apparently impaired decision

making which could in fact be solved more readily by giving people time, compassion, trust and care:

- *The Police break the doors down, the mental health system is confusing and frightening, forcible medication may be involved: we need to think about this in relation to any decisions that get made.*
- *I feel very concerned for people who get involved for the first time – i.e. basic information or even general support and knowing what to do and how to get help as it doesn't work.*

In addition people may have difficulty making decisions or participating in care for a number of different reasons; they may be so isolated that they cannot reach decisions or be helped to reach decisions, they may not be able to access help and services may be mainly aimed at extremes of illness.

They may be frightened of getting help and may see illness in very negative terms which again prevents them from participating in services or seeking help before their decision making ability is badly impaired.

This, combined with illness itself, can mean that ideas of supported decision making are hard to see as a key area to work on and are certainly not the answer to many situations where funding, service type, stigma, early intervention and the response from friends and relatives can all be critical to outcomes for the person.

- *How can you make supported decisions when so many people are so isolated – and services are about people either being in crisis or just barely managing? There is an assumption that there is a continuum of services, yet there is not. There are extremes and at these extremes it is hard to get listened to. Also many services are non-existent or poor.*
- *It really concerns me that the people who need the most help don't get it.*
- *You have got to be extremely unwell to get into hospital or just in to the c.m.h.t.: services are decreasing.*

People worry that it is hard to assess capacity or to help people participate and be a part of decision making when often professionals have very limited knowledge of the person that they are treating. With shortages of staff and the increasing use of locums this is even more of an issue.

- *Often psychiatrists may not know what has happened to the person or have knowledge from other members of society or from the police or family – they just see a snapshot of the person.*
- *There seems to be an underlying assumption that people have a care plan, are involved, and have knowledge – but even though I have a psychiatrist I wouldn't say that any of the professionals around me know me well anymore or even that many individuals know me well or that I may be getting unwell. There are so many people who do not have good relationships with family or friends who are so isolated.*

In a wider sense some people worry that difference is not as accepted as it used to be and that what would once have been catered for with little problem, is not any more. They worry that community support and cohesion is decreasing and that in some ways anti stigma

campaigns that seek to normalise mental illness in fact add to the fear people have of people who actually do act very differently. People would like to see more of a sense of community and belonging and for attempts to be made to make seeking help for mental health as ordinary as going to the gym or a health spa, in effect creating mental health spa's that anyone could go to if they felt they needed a bit of picking up and help with wellbeing.

- *Compared to other areas of physical health there are no gym equivalents – no normalisation of mental illness, no just looking after your mental health, just an emphasis on mental illness.*
- *People are also fearful of how people behave if they seem odd –there was a person sat on the stairs in the flats and they said 'I need help' – no one helped; they just phoned the police. More and more the police are being phoned and channelled into the system when really people may need a chat and coffee and some warmth.*
- *People are frightened of odd behaviours and anti- stigma campaigns do not address this; they make people seem normal.*
- *In my community police and others look out for each other.*
- *Services need to learn how to talk to people and how to validate how people feel and also have a community that is accepting of difference.*

There was also a worry that sometimes people can be made too responsible and asked to contribute and participate too much, for some people a sensitive approach needs taken that will provide basic support and which will not concentrate on illness or make people acknowledge that they have a problem

- *People who are in crisis just need to feel secure and helped and may not want to make a decision, but as long as they can be reassured that they can be looked after it can be ok. This is also attached to stigma: some people need to get help without mention of mental illness.*

In addition people worry about some of the impact of the mental health act; key to recovery are things such as friends, family and relationships and the things that people can do and can succeed at. Too often these are neglected when people are subject to detention

- *Whatever we are doing we need to think of the strength of the person and their relationships with other people; we need to keep this going – more effort needs to be made to have an understanding of who the person is instead of barging in using the mental health act.*

Reducing the trauma

We have found that most people agree that detention can sometimes be necessary. However we do know that many people find detention/sectioning hugely traumatic – can we think of ways of reducing the trauma of detention whilst still providing adequate protection for people

We had a number of views on this subject ranging from questioning what gives us the right to intervene to the lack of people available to intervene. We also wondered if decisions to intervene fitted with our own perceptions and wanted to be clear that at any one time we may lack the ability to make some decisions and yet retain the ability to make others.

- *I am bi polar, I have been detained in the past, yes, on reflection, some of the things I wanted to do would have been disastrous but other decisions I could make easily .At*

other times when I have been depressed for months – actively suicidal- my personal safety was more at risk when depressed than when manic – I have been admitted but there was no question of a section or even close obs – it is really weird

We wondered about our varying ability and capacity and questioned when people should intervene. We felt that some interventions would be clearly important to save life and others may be extremely offensive, maybe because the reason for intervention would not warrant such drastic action.

- *I am a tea drinker but when I am a really depressed I can sit for an hour trying to accept or not a tea or coffee rather than saying I drink tea*
- *it should be on how extreme it is – when I haven't been well, I smoke and I eat a whole tub of ice cream at a time, which I would never normally do, but if someone had wanted to take such decisions it away I would be really angry*
- *Sometimes decisions are reasonable but not very logical*

We also had concern about how society treats difference and again came back to when it is sensible to intervene, we talked about people who may have impaired decision making and live more or less happy lives and are accepted by their local community and equally other people who struggle and those who, because of their illness and lack of insight, have been ostracised and alienated by their community. We had trouble deciding what to do in these situations; in some it seemed obvious that to leave someone alone to live their lives as best they can would be sensible whilst in others there was a temptation to intervene even though we knew it may cause irreparable damage to that person and to friends and family.

- *Some people: I know that the things they are saying are very unlikely to be true ... these people go on for years saying this and it makes no difference to their life - they are living a reasonable life – it is only when they are with people who cannot accept this difference that things go wrong – for them it may be quite normal to say these things – they are not normal decisions but does it matter?*
- *This can happen and then they get alienated by the community – my mum gets alienated by the community as a result – would sectioning produce a good result? – possibly*
- *I know a person who lives an eccentric and very difficult life – her capacity is fairly good but she is influenced by her experiences–she does not wish to engage with services and wouldn't – she would never agree to go to hospital, even if it would help.*
- *Where is the line between eccentricity and individuality and illness? And do we have the right to intervene? People will also respond differently to it. What is being offered if you do section someone?*

We discussed reciprocity – the need to give something back to people who have had their freedom taken away and felt that this was paid lip service to. We had a feeling that people assumed that the right to treatment was all that reciprocity implied and yet felt that there was a great deal more to life and the act than this.

We also discussed medication and felt that the main reason people were detained was to give them medication, we wondered if detention would be less common if people were able to refuse medication and yet also were aware that for some people, including those very opposed to it, that medication could sometimes be liberating and give people something of the positives in life that they did not have without out.

- *Reciprocity – what do you give back? It has been forgotten: what do we do for their recovery? – it is so easy to slide into a section – people in hospital are used to it and staff often don't know people.*
- *We need both medication and other things i.e. if you break a leg you need a pain killer and the mending of the leg.*
- *In some cases, medication is needed for insight – to reduce the stress that exists.*
- *When my mum was on medication –she had more friends and more of a life.*
- *Everyone is different we rely too much on medication.*
- *If someone has an unhelpful paranoia and anxiety, then medication may remove the anxiety that they have: just having a talking therapy may not be enough.*

We felt that some people could get ill again; purely due to the trauma they have experienced from previous admissions and the fear of being readmitted and also felt that we should be able to learn from other countries some people believe that Open Dialogue, as pioneered in Finland, has transformed mental health care there; we wondered why we could not learn from things like this.

We also felt that when we look at impaired decision making that there needs to be something available before we get into crisis, something softer than detention but something that we could access and which could reach out to us while we still have decision making abilities but are in the process of losing them.

- *We go from some decisions, that to stop people making them is plainly wrong –to detention – there needs to be something in between – mental health spas and talking treatments – something that can help people maintain mental health rather than proceed to detention.*
- *People can be very fearful of going back to hospital – even the fear can make them unwell – the experience can be so bad – but if you wait too long they go back to the trauma of illness.*
- *If someone doesn't want help but you know they could be helped – there should be some way of intervening and helping that they can accept.*
- *I know what should help me get out of slide into depression –: not ignore calls, not isolate myself and so on. I would need someone I can get on with and someone who could encourage me and nudge me into doing things before I go too far down. – I don't want my husband to do that, It is different – the softer end of services seem to be going.*

We worried that it is harder and harder to access services and that responses can be determined according to how people have been labelled, which may lead to too much help in some cases and very negative experiences in others. We felt that the culture of mental health services was becoming increasingly controlling and clinical with outcomes goals and targets all stopping psychiatric staff from demonstrating basic aspects of humanity, where the main interaction was more to check if someone has a suicide plan than to get to know them as a person.

- *The criteria for help in crisis is getting stricter and stricter.*
- *When my son first got ill, the psychiatrist said 'Don't worry, the police will real him in: he will do something that makes him stick out' – I was really worried he would end up in prison – at first he was eccentric and had no services to 'all or nothing' and his liberty taken away – if people had listened to us as a family - if they had listened to the people who know them well. CPNs may be wonderful but they can assume that they know it all.*

- *We need mental health services to be something that is attractive and something we want to use. It can't be one size fits all.*
- *The system is becoming more cold and controlling and limiting –it is going in the wrong direction.*

We worried that peoples experience in hospital was frequently very negative from leading up to admission and how that was carried out, to right up to discharge and their first few days at home.

We worried that staff could be very busy and could spend more time writing reports and assessments and following procedures than getting to know patients and in so doing create relationships and partnerships and reduce fear.

- *Mechanics of detention: the process of getting there needs to work better – not in the back of a police van.*
- *The more the outcomes and plans, the more the humanity goes.*
- *You need the chance to get to know people – most people are trying to do the right thing but are under so much pressure to reach audit targets or deal with risk assessment that they do not have a chance to understand and build up a relationships.*
- *There are too many cuts.*
- *Hospital is seen as a sign of failure and is not invested in.*

We worried about the ward environment, is it bright clean and homely, the sort of place to make you feel safe and relaxed? Or is it somewhere where you are frightened of staff and patients and have few opportunities to do things together and to talk together. Carers found that patients could be a much better way of finding out how their relative is doing than staff who sometimes have a very limited grasp of what is going on. We found some staff look down on carers visiting and do not have the imagination to encourage the sorts of activities that result in laughter and hope.

We worried that sectioning can be carried out in the hope that it will bring services to some people who would otherwise not have got them and also felt that it should, in itself, be a process that is carried out with love and compassion. With a pleasant and vibrant ward, good relationships between staff, patients and visitors, a culture can be encouraged that takes away some of the trauma of detention.

- *Sometimes people think if we section you, you will get better services –almost as though a pathway is being mapped out for you and you walk along it as there is nothing else.*
- *Environment: is it clean? Is it bright? Are there plants? – make the hospital ward somewhere that is good for your mood –do you have your comforts available and your visitors, do they feel welcome and can you see them easily.*
- *Attitudes – when I first visited – going in, you began to realise what it was like – people were slumped over – I kept going in, and more and more people spoke to me – the staff asked what I was doing. They said that man has not spoken for ages and what was I doing? I was talking! We all went out of the ward and had fun playing ‘mad tennis’ – I thought the staff would like to see it and they said ‘oh no we don’t do that’ ... patients said they would like help with confidence and speaking they said ‘we do not do that’ That they knew best. What they did and what the patients really needed did not match at all.*

We felt that there was a lot of research about what helps people get better and what helps with recovery but that this rarely happens in hospital, we saw changes in service such as

reductions in the use of anti-depressants and reductions in hospital admissions and felt that this was more of a function of finance than need, we worried that most change had to be fought for, often by people with lived experience or their friends and family and that the concept of parity of esteem was just a concept – there was little favourable comparison that could be made between mental health and physical health services .

We felt that hospital staff often had little knowledge about life in the community for patients and what services there are and that their knowledge about whether a patient was doing well or not was solely down to how frequently they saw them as 'in- patients'.

We discussed restraint and observation levels and found them difficult and distressing. Again we felt that with tact and sensitivity they could be carried out much better than they are and that such actions should also be carried out with love and compassion. We discussed such things as medication and some of us felt that if we were going to have to have it anyway we would prefer to be given it covertly than forcibly.

- *I was forcibly injected and one person who was a friend on the ward was horrified at it – I was in a single room and taken forcibly to it to be injected.*
- *Section and restrain with love.*
- *The Nurse was opening and closing the curtains all the time – they did not seem to know how nervous that was making everyone including the patient.*
- *If I were to need medication and I didn't want it – I would be more happy to have covert medication than to be forced – that would be more loving if I were ultimately to get it.*

We discussed trauma and felt that for many of us trauma was at the root of the problems we had developed, we did not wish the services that were dealing with the trauma to be the ones that added to it. Again we felt that relationships are key and the way in which they are developed are key and that one of the key elements of recovery was in having access to family and friends when sectioned and for staff to acknowledge the valuable role that they play in treatment and recovery.

We felt that many services will not intervene until someone is so distressed and ill that they have to be sectioned. We did not agree with this and felt that people needed help that would reach out to them so that even people who strongly disagreed that anything was wrong with them would want to get support from people.

We talked about the numerous hubs in the community that specific groups of people go to, including those with learning disabilities and mental illness, that can be utilised and which can help people access help and gain support and possibly insight and the ability to participate and make decisions before things get too difficult.

We felt that many aspects of community education and community development played a key role in community services and the hope and sense of belonging that people can find and commented that these were increasingly non- existent.

- *The power of psychiatrists - my sister is not well and yet does not see herself as unwell, her mother knows a psychiatrist who said 'keep on piling the pressure till she breaks'. Because she was not visibly ill and could mask illness they couldn't help – it was awful advice but she does need help –we need support workers who can engage at a level people are comfortable with and maybe not bring mental illness into it, try to avoid isolation.*

- *We need people we can go to speak with – to be able to make an appointment easily without it being stigmatising.*
- *80% of older people go to the supermarket for a chat – we could capitalise on this.*

Deciding we have problems making decisions

Who should assess people's capacity? Some people say carers should play a major part in this but also say that some carers are so emotionally involved and sometimes lack so much knowledge of the system and mental illness that they can, on occasion, be damaging in this process. On the other hand some people say that professionals can have so little prior knowledge of our previous life and priorities and wishes that they can also be damaging – how would we resolve this?

We expanded on some of the issues in the report, reaffirming the need for the person assessing capacity to have an understanding of the person that extends beyond their present situation and also repeating the need for family and friends to have a role in this process while acknowledging that, while on occasion, they may not be the best people for this that the presumption should be that they are looking out for the welfare of their loved one and have a good knowledge of that person.

- *'It really worries me about who knows the individual well enough to know what their usual capacity compared to what it is when people are concerned about them.*
- *It may be logical to say my husband – but I am still concerned that some relationships that should be positive aren't and there can be room for manipulation and power.*
- *Mixture of person with scientific knowledge of mental health and someone who knows you well. It should take into account a risk assessment –people should be able to declare an interest – i.e. the relative is not currently planning on getting divorced from the person.*
- *People who present in crisis maybe needing detention – how does someone know how to assess capacity if they have limited knowledge of them?*
- *Carers say how much they have to do when the person often doesn't remember much of what they do do, some people act very positively try to get people help.*
- *It should be the psychiatrist with the assumption that friends and family are looking out for you – with some way of protecting the person from negative influence.*

We also discussed the word 'carer' and the assumptions that come with that role, there was some resentment of it, with 'carers' feeling that it distorted and redefined a loving family relationship, sometimes necessarily, as the relationship had been changed into one in which practical care needs provided but sometimes very negatively by removing assumptions of love and partnership and moving towards ideas of being 'in charge of'. Instead people felt that there should be a sense of partnership and doing things together.

- *It can destroy relationships; you go from being a mum or wife to a carer, just being defined that way, the word carer has implications I don't like; it takes away from the warmth of relationships. Not working alongside them.*
- *Professionals refer to 'carer', they see you as a carer if you are involved regularly with care – while it is more important to see if someone cares about someone.*

- *My greatest happiness was last year when someone I supported, in turn supported me – it was a reciprocal arrangement.*

There was also some discussion about psychiatrists being the people who ultimately make decisions about capacity. People felt that this was a huge responsibility and the automatic assumption of this role may be bad for both person and worker.

People also felt that assumptions about capacity are not necessarily clear cut, that what may appear to be very strange and disordered thinking may actually have a logic to it if listened to carefully enough and that adjustment to this thinking may be more important than imposing the ideas of other people about what is 'right and proper'

- *Anybody making these decisions would have to take so much into account and not base it on other people – how do you make the decision and justify it? And why do psychiatrists make the decision? It has been quite an arrogant profession for some years, by being given the right to make such decisions does it inevitably become arrogant?*
- *Faulty decisions can be logical; if you have got one basic fact wrong at the beginning. This investigation and listening can cure and solve many issues if recognised.*
- *Recognise the reason someone does something which, while not logical, may lead to better reactions – i.e. someone says 'this room is red we can't meet here' then let's not have the meeting in this room today.*
- *Ask more people about what has been going on when assessing.*

Discussion

There are thoughts to combine the mental health act and the adults with incapacity act and make the key criteria for detention to be lack of capacity and not mental illness, what do people think about the two definitions listed above: is one more appropriate than the other?

So:

1. The decisions about compulsion, should SIDMA be replaced by a capacity test?

We discussed this issue and included the idea that legislation such as this is discriminatory if it is based on a disability group but did not reach many clear conclusions.

We felt that people were trying to group the needs of all people with any disability into one homogenous group where any statement applied to all members of that community and felt that this may be unwise; feeling that the particular experiences and needs of people with a mental illness are very, very, different to those of some other groups of people.

We worried that a shift to capacity alone, while maybe positive, because it doesn't discriminate against people with a mental illness, may increase the number of people who end up detained and then wondered about people with addictions and if detention might be a good idea for some of them who clearly seem to have lost capacity. We also discussed some ethnic minority groups whose beliefs in black magic could be deeply harmful to members of their own community and wondered by what right are certain beliefs and actions accepted as reasonable in society and others not.

We also looked at the definition of capacity and felt that many people confronted with the complexity and confusing language and information in the mental health system as well as about mental illness would struggle to be seen as having capacity.

We also felt that an instinctive negative reaction to the control and way that the mental health system works may be seen as a sign that someone lacks capacity when in fact it may be a normal reaction to a challenging situation.

Some of us tended to feel that making capacity instead of SIDMA the main test in legislation would be sensible and some didn't – overall we had no clear or strong view on this

In addition:

A second issue is about *what treatment you can be made to take* if you are detained/on a CCTO. Assuming there is a treatment power in the order (which there almost always is), there is no SIDMA test about the treatment the doctor decides you need. If you don't agree, the doctor can still give you drugs even if you have capacity to decide about medical treatment (provided they follow the safeguards in the Act and respect the principles). (ECT is different – you can't get that if you have capacity and refuse).

- 2. If you are subject to compulsion, should there be a capacity test in relation to the specific treatment you are required to accept – i.e. you should have the right to refuse particular treatments?**

Again we did not have a clear view on this; we mainly talked about medication and the need to have alternatives to medication, we said that any decision to make someone take medication would need to be clearly explained and that most people should be able to understand some of what is being said.

Some of us felt that people should have the choice not to take medication even when detained and some of us talked about the very difficult life some people would have if they were not to take medication if they could refuse it.

We also worried that the effect of medication itself can lead to reduced capacity and that people can relapse when they come off of it not because of illness but because of the effect of withdrawal from medication.