# Research to support the Duty to Review the Implementation of the Mental Health (Wales) Measure 2010

# Qualitative evidence on the views of service users, carers and practitioners

# Part 2 FINAL REPORT: Coordination of and Care and Treatment Planning for Secondary Mental Health Users

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Llywodraeth Cymru
Welsh Government

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**Opinion Research Services**

Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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## Acknowledgements

# Glossary of acronyms

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|---|---|
| ACT | Acceptance and Commitment Therapy |
| ADHD | Attention Deficit Hyperactivity Disorder |
| Beat | National charity supporting people with eating disorders |
| BDI | Battelle Developmental Inventory |
| BME | Black and Minority Ethnic |
| CAMHS | Child and Adolescent Mental Health Services |
| CATT | Crisis Assessment and Treatment Team |
| CBT | Cognitive Behavioural Therapy |
| CMHT | Community Mental Health Team |
| CPA | Care Programme Approach: the main way of assessing and identifying the care needs of people with a mental illness receiving secondary mental health services in Wales up to 2012. |
| CTP | Care and Treatment Plan introduced by the Measure and operational from 2012 |
| CAVAMH | Cardiff and Vale Action for Mental Health |
| DNA | Did Not Attend – referring to service users who do not attend appointments |
| EMDR | Eye Movement Desensitisation and Reprocessing therapy |
| EMI | Elderly Mentally Infirm |
| IAPT | Improving Access to Psychological Therapies |
| IMCA | Independent Mental Capacity Advocate |
| IMHA | Independent Mental Health Advocate |
| LD | Learning Disabilities |
| LPMHSS | Local Primary Mental Health Support Service |
| MHDO | Mental Health Development Organisation |
| OPMH | Older People's Mental Health |
| OT | Occupational Therapist |
| PAMH | Powys Agency for Mental Health |
| PTSD | Post Traumatic Stress Disorder |
| SRV | Social Role Valorisation -The role of SRV is to create or support socially valued roles for people in their society. |
| UAP | Unified Assessment Process |

# 1  Introduction

1.1 Opinion Research Services (ORS) was commissioned by Welsh Government in June 2013 to undertake qualitative research to support the Duty to Review the Mental Health (Wales) Measure 2010.

1.2 Information and data were gathered by Welsh Government from a range of sources to inform the Review including this study, regular submissions from health board/local authority services, health board primary care satisfaction surveys and third sector surveys. Welsh Government was responsible for coordinating all inputs to the Review and for final reporting to Welsh Ministers.

1.3 This study provides qualitative evidence on the views of service users, their carers and practitioners on the implementation of Parts 1 to 4 of the Measure. The findings are presented in four separate reports; one for each part of the Measure and an overall summary report in Welsh and English versions.

1.4 An interim report[1] published in 2014 presents the background and methodology for this study in some detail.

**Part 2: Coordination of and Care and Treatment Planning for Secondary Mental Health Users**

1.5 This part of the Measure requires health boards and local authorities to work in a coordinated way to improve the effectiveness of mental health services. It also requires that care and treatment plans (CTPs) be provided for service users of all ages who have been assessed as requiring care and treatment within secondary mental health services. In brief, care and treatment plans will:

- be developed by a care coordinator in consultation with the service user and mental health service providers;
- be in writing;

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[1] http://gov.wales/docs/caecd/research/2014/140410-support-duty-review-implementation-mental-health-wales-measure-2010-en.pdf

- record the outcomes that the provision of mental health services for the patient are designed to achieve;

- list these outcomes, record the services and/or actions to achieve the outcomes; and

- be reviewed and updated to reflect any changes in the type of care and treatment which may be required over time.

1.6 Underpinning CTP is the concept of 'recovery' and the guiding principle is a belief that it is possible for each individual to achieve goals that enable them to live a fulfilling life despite serious mental illness.

1.7 Full assessments would need to consider the following eight aspects of a service user's life:

a. Finance and money

b. Accommodation

c. Personal care and physical well-being

d. Education and training

e. Work and occupation

f. Parenting or caring relationships

g. Social, cultural or spiritual

h. Medical and other forms of treatment including psychological interventions.

1.8 Statutory duties around Part 2 commenced on 6 June 2012.

**ORS Role and Commission**

1.9 Welsh Government identified their requirements of the qualitative research project in relation to Part 2 as follows:

Assess the experience of service users, their carers and practitioners of the engagement and consultation process in the development, implementation and review of Care and Treatment Plans, particularly in relation to their previous experiences of care planning. For example:

- Do CTPs address the relevant 8 areas of life as set out in the Measure?

- Has the need to address any additional areas of life regularly

arisen?

- Are plans outcome and recovery focussed?
- Is there evidence of engagement and consultation with service users and carers?
- Is there evidence of service user involvement in co-production of plans?

1.10  The findings presented in this report adhere to these requirements.

**Ethical Considerations**

1.11  For this project the qualitative work with service users could not begin until the project team had:

1. Determined whether an ethical review was needed for the study and if so, had achieved Research Ethics Committee approval
2. Gained permission to proceed from the health boards via their Research and Development sections.

1.12  Examination of the Research Ethics Committee decision tool[2] clearly identified the project as 'evaluation', meaning that it was not subject to full ethical review. All seven Health Boards gave their permissions to proceed. In addition, The Government Social Research Ethics Checklist was completed and guided the project throughout.

1.13  All ORS staff involved in the project were fully trained in the principles of medical and social research ethics and, in particular: potential participants' rights to clear and full information about the study; the importance of informed consent; the right to withdraw from participation at any time and recognition that potential harm to subjects takes many forms, including inconvenience and emotional stress. Each participant was required to read full information about the project and to sign a consent form before taking part.

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[2] http://www.hra-decisiontools.org.uk/research/;
http://www.wales.nhs.uk/sites3/Documents/952/RES_Defining_Research_Sept_2013.pdf

**Methodology – Part 2 Focus Groups and Qualitative Interviews**

1.14　Our methodology for this part of the Measure involved a number of elements:

1.15　Thirteen focus groups with service users and carers across Wales: two in six health board areas and one plus a paired interview in another; three qualitative telephone interviews with service users and two written submissions from carers. Altogether, 60 service users and 39 carers participated in these sessions which mainly took place over the period April to September 2014. See Appendix 2 for profiling information.

1.16　Ten focus groups with mental health practitioners, seven individual interviews and 14 written responses involving 97 practitioners across Wales from a wide range of statutory and voluntary sector professions. These sessions were held mainly between January and April 2014 although a few interviews were held in the spring of 2015. See Appendix 3 for more information.

1.17　Nine case studies were compiled - most of them involving several interviews to track their experiences of care coordination over time. The findings from the case studies are incorporated into the general findings where appropriate and the full details are included as Appendix 1 to this report. These case studies provide insights into individual patient experiences of care coordination and care and treatment planning.

1.18　We encouraged participants to engage with the issues and express their opinions and feelings in their own words. Focus group sessions lasted for up to two hours and interviews for about half an hour.

1.19　Although qualitative approaches cannot be certified as statistically representative samples of public opinion, the meetings and interviews reported here gave diverse groups of people the opportunity to be involved. Because the recruitment was inclusive and participants were diverse we are satisfied that the outcomes are broadly indicative of opinion based on direct personal experience. The outcomes reported in this report are, therefore,

reliable as examples of the reflections and opinions of a range of informed people on the implementation of the changes introduced by Part 2 of the Mental Health Measure.

1.20    Verbatim quotations are used throughout, in indented italics, for their vividness in capturing points of view. ORS reports the opinions as given and does not necessarily endorse the opinions in question.

1.21    This Final Report presents the sentiments and judgements of participants about care coordination and care and treatment planning; its implementation, management, examples of good practice and issues arising. The views expressed by participants might or might not be supported by available evidence; that is, they may or may not be accurate as accounts of the facts. ORS cannot arbitrate on the correctness or otherwise of people's views when reporting them. This should be borne in mind when considering the findings. Where possible any such issues are flagged up in the report.

## 2  The Findings: Part 2

2.1  This chapter draws upon the focus groups and interviews conducted with service users, their carers and with mental health practitioners. The findings under each of the specific review questions in the original Welsh Government project briefing document are presented in turn. A summary of the key findings under each question precedes a detailed commentary.

2.2  The findings presented here complement those from the Part 2 patient and carer self-completion surveys administered by the health boards and analysed by Welsh Government to input to the overall Review report.

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**Review Question 1a: Do CTPs address the eight areas of life?**

Assess the experience of service users, their carers and practitioners of the engagement and consultation process in the development, implementation and review of Care and Treatment Plans, particularly in relation to their previous experiences of care planning, for example:

- Do CTPs address the relevant eight areas of life, as set out in the Measure?

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**Summary**

2.3  Very few practitioners made comment on this issue. A few service users and carers felt they had holistic care plans which covered all their areas of need, although many more felt that their plans missed key information under the areas of life. Many participants felt that the plan in itself was adequate but improvement was needed in how practitioners were using it. The tendency for some clinicians to focus on medication only was mentioned frequently and some practitioners and service users felt that it was a weakness within the code of practice that a minimum of only one area of life had to be completed whilst other practitioners considered it appropriate.

**Commentary**

2.4 Some service users and carers felt that their care and treatment plans were holistic and were satisfied that they covered the areas of life that mattered to them:

*I know that for me and my recovery it really was looking at all aspects of my life – it was building good social networks, and hobbies and interests and it was looking at my housing situation and my money and it was about so much more than just the medication.* (Service user)

2.5 However, many others would have preferred more attention paid to the eight areas of life when compiling their plans. For instance, one participant complained that his interests and his relationship were not mentioned on his CTP. Another said that her accommodation had not been fully discussed or accurately represented on the plan because her care coordinator had made the assumption that she was happy living with her parents. Someone else had been worried about her accommodation and yet this area was empty on her plan and also her worries over her neighbours had not been included. Other participants made the following comments about their plans:

*The education and training section was left blank and never discussed in the meeting. (Service user)*

*I think it's easy to wash over things; for there not to be enough information. That is why I became so much more involved to ensure my mother was getting the right care.* (Carer)

*I think that the eight areas of life are very good. I simply think that things would have been better if people had adhered to it.* (Service user)

2.6 Many service users said that their clinicians focused only upon their medication, taking little notice of the other eight areas of life and complained that this was acceptable under the code of practice:

*Where the legality does fall down under the care and treatment*

*plan is that if one of the eight domains is completed then that's the plan – it gives you the option to do the bare minimum.* (Service user)

*Medication might be prioritised because it's an easier way to deal with patients and it may be within the experience of the CPN or psychiatrist more than having to deal with help with welfare or help with accommodation.* (Practitioner)

2.7    Some participants – both service users and practitioners -  felt that social workers as a profession were holistic in their approach and were, therefore, more suited to the care coordinator role; yet the main responsibility for care coordination was falling to CPNs. Many participants suggested, however, that patients should be matched with appropriate professionals for care coordination and that for many the best match would be with CPNs:

*A social worker is trained to be a social worker; a CPN is trained to be a CPN and they're trying to merge the difference – under, oh, it's easier to get nurses, I think. Social workers are particularly good on civil liberties and have a completely different training to CPNs and they are treating them as the same.* (Service user)

*It shouldn't be apportioned about who puts their hand up; it should be done in a way that's most appropriate - who they're being seen most by - but if it's just the culture - CPNs do it.* (Practitioner)

2.8    Many participants felt that putting any care plan together required trained staff with appropriate communication and care coordination skills:

*It requires a high level of communication skills. It requires an ability to listen – and that's fundamental to it in my opinion. It's not a high level of skill to sit and listen to someone for five or ten minutes without making assumptions about their treatment and care. That's what anyone working in any caring profession, be they a six pound an hour domiciliary carer to a high grade consultant/psychiatrist should be able to do.* (Carer)

*There is nothing wrong with the form … don't need to change the system; don't need to change the policies; don't need to change the legislation - what you need to change is the way people are acting and the way people are behaving*. (Practitioner)

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**Review Question 1b: Is there a need for additional areas of life?**

Assess the experience of service users, their carers and practitioners of the engagement and consultation process in the development, implementation and review of Care and Treatment Plans, particularly in relation to their previous experiences of care planning, for example:

- Has the need to address any additional areas of life regularly arisen?

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**Summary**

2.9    In the main, participants agreed that the eight areas of life were adequate for adult service users and many welcomed the structured and holistic approach introduced by the CTP. Some service users and practitioners said that it was not always obvious under which category to include certain information. There were no additional areas of life that regularly arose. There were, however, other frequently mentioned criticisms of the format and these are covered in the next section of this chapter.

**Commentary**

2.10    By and large, participants thought the eight areas of life categories were comprehensive, appropriate and sufficiently broad to encompass all aspects of a person's life. Many participants felt that the format encouraged an holistic approach to care planning which was welcomed and an improvement since the Measure:

*He (service user) likes things structured that way because he's chaotic and he liked the fact that, right, now we're talking about this and sticking to this subject. It benefitted him a great deal.* (Carer)

*It's diverse and it's holistic. It's a really good tool.* (Service user)

*It's a good thing because you cover every single aspect of your life – you know maybe things that you wouldn't consider if you just*

*talked to the person.* (Service user)

*To me it is a really good instrument. It is holistic; it does seep into every part of somebody's life, but the same with everything, it depends how it is used.* (Service user)

*I think my care plan is quite good because it talks about my diabetes and about the day centre.* (Service user)

*I'm lucky that my psychiatrist looks at my care and treatment plan holistically. I trust him implicitly and whatever he decides I go along with.* (Service user)

*I know a service user who's spoken so highly of this that she's filled in all these areas. She has a CPN and a psychiatrist and it's really, really helpful.* (Service user)

*The eight categories really help. Staff are really starting to think about what impact accommodation has on their mental health; their medication; their hygiene … it brings it all together… so if they've written something in the accommodation box in assessment, does it need to be transferred to CTP? Before, this was not necessarily written down in a heading that would prompt the practitioner to put it in the care plan.* (Practitioner)

*I think we are going to the right place both with the format of that care plan and the code of practice that goes with it – you can play with the words forever.* (Carer)

2.11 Only a few service users suggested other areas of life that should be included or made clearer and a few service users and practitioners said they sometimes found it difficult to find places on the form for particular aspects. For instance, one service user said that there was no obvious place on the form to mention that her behaviour was never violent; another that there was no obvious place to include her eating disorder. However, in general, participants said they could fit the issues within the categories on the form. As an example, one practitioner had included self-harming under 'education' as they were educating the service user

around this.

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**The CTP Format – other comments**

Assess the experience of service users, their carers and practitioners of the engagement and consultation process in the development, implementation and review of Care and Treatment Plans, particularly in relation to their previous experiences of care planning.

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**Summary**

2.12 Whilst a standard care plan format was considered to be helpful, many felt that the form encouraged a tick-box, formal approach and some felt because of this it gave the impression of being less person-focused than the CPA: participants would prefer that staff use the form as a guide rather than as a prescriptive document. Several also thought that space for carer and care coordinator inputs should be included.

2.13 Many felt that practitioners should identify short-term, realistic 'goals' with service users in a step by step approach to achieving longer term goals. An ommission, considered to be significant by many, was that there is no section on the form for unmet needs. The format was also considered by many to be inappropriate for young people; people with learning disabilities or for older people with limited capacity.

**Comments**

*A standard format and using the template*

2.14 Some participants said that having a standard format was helpful to assist practitioners in providing continuity and quality support:

*If these plans are done properly in the first place, anybody should be able to stick to them so if a CPN goes off sick and a duty person takes over - if they can be bothered to read it - any of them should be able to do it.* (Service user)

*The provision of CTP and care planning is a welcome and important aspect of the Measure which I feel can improve the*

*quality of services, provided it is used wisely.* (CAMHS practitioner written response)

*CTP has clarified what it is that we've got to do – about confidentiality; it's got a reviewing structure. I think on the whole it's helpful.* (Practitioner)

*There's people with long-standing severe mental disorder, where assessing across the range of different needs is absolutely bang on and just what you need to be able to do it systematically - that's great.* (Practitioner)

2.15    However, many felt that the CTP format encouraged practitioners into a 'tick-box' approach rather than to guide discussions with service users; that the format did not encourage a person-focused approach:

*Sometimes it feels more like a checklist … Most of the time I'm waiting in the room longer than I see my psychiatrist. So, say, they look at your financial situation and say. 'Are you OK?' 'Yeah'. 'Do you still live at home?' 'Yes I do'. 'OK fine'. 'Are you still doing the same things as last time I saw you?' 'Yeah'. 'Ok. Well, I'll see you in another four months' time then'. Most of the time it's like that.* (Service user)

*They are trying to fit the person into the CTP rather than the CTP fitting them.* (Service user)

*I was talking to somebody today and she said, 'I don't like my CTP because I've just been put into boxes'.* (Service user)

*In some ways I would have preferred for them just to have a chat with me – just talk and maybe go through this stuff in a more organic or personal way and then go away and fill it in … and then come back and talk it over.* (Service user)

*I don't think a generic list works. I think it should be established between the care coordinator and the person involved and should be done as a bespoke thing because we're all different.* (Service

user)

*There's more boxes to fill in so they're filled in briefer and it's how much you can fill in, in an hour. That's how much time I was allocated. We went through it in chronological order, got to about point 3 and then we ran out of time so she said she'd fill in the rest in the office. 'Is there anything you want to say on these last six points or whatever?' … and then she took it away and filled it in.* (Service user)

*I would imagine that the clinicians who have written the more creative and engaging CTPs may have trodden more lightly on the form.* (Practitioner)

2.16 Some service users said that they preferred the approach to care planning before the Measure; saying that it was more personal:

*Under the old regime it was done not in a formal manner. But there seemed to be far more covered … they would spend their time on what was applicable and specific to you.* (Service user)

*I think the old CPA did work a lot better … it was a lot more informal and a lot more person-focused … it was more borne from the genus of having a conversation with an individual to find out what was concerning them; what were their priorities and the plan flowed out of that. Whereas when the CTP is done generally now, you start from those stated areas and then if something needs to be added it might be shoved in at the end because there's nowhere else to put it.* (Service user)

*I have the same care coordinator but the plan I had before was more detailed and more clear than what I've got now. This one seems to have more boxes but less information. In the box on finance this one only has one line but there was more on the other one.* (Service user)

2.17 Some service users felt that having to go through all the life areas in one meeting had made them anxious and suggested working on CTPs when service users were feeling well enough or that the

issues concerning them in the here and now should be addressed before moving on to longer term goals:

*They said well, 'what about accommodation?' And I said, well at the moment I have no money; I have no job … at the moment that's impossible for me. I can't start thinking about that and getting worried about that because that's the future. I can't be worried about that at the moment because I'm worried about other things, so that's where it ends. So there's no point in having that on there.* (Service user)

*The form's set out all too clinical – there's no personalisation; there's no personality to the form. I mean they talk about education and finance. When you're in a state they're the last things you want to think about.* (Service user)

2.18    A few participants also objected to the word 'outcome' in the CTP and felt that 'goal' was a better term and that the form should be changed accordingly:

*Talking about 'outcomes' and 'outcome focus', nobody knows what you're talking about, so in our training … that is how we tend to phrase it in terms of short-term and long-term goals.* (Practitioner)

### Management implications

2.19    Practitioners highlighted other issues with the plan: that practitioners were using it for recording, rather than planning; the level of repetition across the various plans and the fact that it had led to a risk averse culture among practitioners and practitioners avoiding the role of care coordinator:

*The CTP is not fit for purpose because we're not using it as a care plan; we're using it as a recording measure.* (Practitioner)

*The feedback we get is: you have the assessment, the care plan, the risk assessment … there is an awful lot of repetition.* (Practitioner)

*Clinicians noticed how other professions and team members had*

*become much more risk averse, 'what if this happens...' and seeking to avoid responsibility for patients.* (OPMH practitioner written response).

*Nobody wants to accept it, nobody wants to be the care coordinator because the minute you are the care coordinator it's your responsibility.* (Practitioner)

*If someone needs a care co-ordinator … they don't want just a doctor who will fill out their medication review and say, 'see you in three months' time'. And that has led to a lot of problems within teams with the consultants hiding behind their colleagues. Consultants don't act as care co-ordinators apart from in the most complex cases. That leads to resentment because you have the nurses with their tightly controlled caseload and you've got this ever expanding pool of people that need a care co-ordinator but aren't getting them. You've got parts of Wales with outpatient loads of six hundred, a thousand or more, and they're being expected to be care co-ordinators. It is a farce.* (Practitioner)

*I see as many of my customers as possible in primary mental health GP support clinics. It's a model that we're not allowed to do because it's outpatients by another name.* (Practitioner)

*I mean the form seems common sense as forms go. I've seen a lot worse but to fill one in is going to take a substantial amount of time. As you're doing that for literally hundreds of people, add that all up; that is a massive chunk of time.* (Practitioner)

### Missing aspects

2.20 Several participants complained that, unlike the previous plans, the CTP template left no space for carer inputs:

*The CTP doesn't include carers and where are we? We are part of the support service for people 24/7. If they are actually doing the caring why are they not part of it? I'm the one who's been supporting my son for 17 years and I'm not included. It's ridiculous. You're missing out that the carer is a resource.* (Carer)

*In three separate recent situations, carers have highlighted to me that the current care and treatment planning form does not give an opportunity for carers to input directly into this form for a family member. They have all cited that in the previous form there was a box for carers' input.* (Practitioner)

2.21 Several service users and carers suggested that the form should have sections for short and long-term goals and detail of the actions required to achieve those goals. They felt that this would guide service users and care coordinators in an approach that marked progress in manageable small steps towards recovery:

*What seems to happen with my Care Coordinator is that they seem to generalise things. So rather than saying I want to come off my meds, they say, I want to make sure I don't go back into hospital. They don't look at the individual actions required to get there. And if it's vague, it's difficult to say that it hasn't been met. I would like more detail really on what the interim goals are to get to the big one.* (Service user)

*(The Hafal care plan) does follow the same areas but it's nowhere near as generalised … for a start the Hafal one is split into two sections – and there's lots of prompts and tips. And you have a long term goal in there and divide it into short steps whereas in this (CTP) there is your long term goal but there's no way of how you're going to get to it.* (Service user)

2.22 Many participants felt that 'unmet needs' was a significant ommission from the template, especially since the lack of resources for support was considered to negatively impact on recovery and service user outcomes. They felt that the decreasing range of support services meant that care coordinators were finding it hard to recommend options for service users in the CTPs and that for this reason, plans were resource-led rather than person-led:

*There's a whole list of problems associated with the care and*

*treatment plan. At the top of the list by a long, long way is the lack of money to provide the care described in the plan. In our son's case, he needed perhaps seeing somebody daily for three hours to do whatever. That need wouldn't have even gone onto the care plan; it would be that we can afford an hour a week so that's what went on the care plan. That happens absolutely with every care plan. It's resource-led 110%. Nowhere on there is there a thing that says 'needs not met' and if those needs aren't met then somebody can say we've got to go somewhere and get them met but that does not happen at all … talking to other carers they say exactly the same thing.* (Carer)

*We have been in various meetings with the CPN, trying to look ahead but you see she's very well-meaning; she understands the situation but she is severely restricted financially. She can't take on our suggestions because there simply ain't the funds there; it's as simple as that.* (Carer)

*We need a lot more creative thought around what we need rather than what the Health Board can afford.* (Service user)

*The other thing is that places like (day centre) are being taken away – I used to go up to the workshop in (place) – it was fantastic. It gave you something to get out and go for but all of a sudden they just closed it and then you go somewhere else and you're there for a while then that closes down.* (Service user)

*Carers actually have spoken to me saying that it's ok having a care and treatment plan but if the services aren't there that can help that be facilitated then what's the point?* (Practitioner)

*To measure what's going on in care and treatment plans doesn't really acknowledge that services have declined in the secondary sector and also in the third sector so it's very difficult to measure something when there are several variable factors.* (Practitioner)

2.23 Whilst a few participants said there should be a section on the CTP form giving contact details for relatives and other significant people

or organisations, others thought that this was already covered in their own CTPs:

*There's nothing about contact with relatives – who is important in the person's life – it's not captured on the CTP.* (Practitioner)

*It gives people to contact if I become unwell and it gives outlines of procedures if I become unwell.* (Service user)

2.24 A practitioner complained that there was no space on the form for care coordinator opinions:

*There is no opportunity to include something which the care coordinator thinks important but the service user does not. This is both a strength - client centred - and a weakness. There is often a lot in the assessment not recorded in the care plan.* (Practitioner, written response)

2.25 A participant complained that respite provision was not included:

*My psychiatrist says I need respite and before the CTPs came in I used to get respite every three months. Now my CTP has come out and it doesn't say respite any more – it says 'holiday' and they haven't got a legal requirement to give you a holiday.* (Service user)

### The suitability of the CTP for young people, older people and people with learning disabilities

2.26 Many participants said that care coordinators working with young people, older people and people with learning disabilities found it challenging to complete the CTP as the adult-focused template was not accessible for these service users:

*There needs to be some leeway for learning disabilities to adapt the template to the type of patient. Also CAMHS and elderly care, dual diagnosis …* (Practitioner)

*The design of the plan doesn't help in encouraging children to take control.* (Practitioner)

*It doesn't make a lot of sense to kids … not in child language ...*

*You're asking us to create a conversation that says, look, this is a very legal looking document but it's your document and you have to put it in your words. It just is a mismatch. It is not child friendly … our own view is that kids quite like the process of being asked and it has formalised that more clearly than would have been the case but to an adult tune …* (Practitioner)

*The format of CTPs is not as well matched to the needs of people with learning disabilities as the previous care plans. Service users and carers may be slightly puzzled as to why the format of the care plan may change from UAP to CTP and then back again (upon discharge from 'secondary mental health services') despite minimal change to the content of the care plan. To be 'LD friendly' CTPs would need 'easy read' and symbols.* (Practitioner)

*CTP is not fit for purpose whatsoever in older adult services. It doesn't look at the complexity of issues around the physical, social and mental health needs … You can adapt it but that's where the time is taken in thinking, now where do I put this? Which domain do I put it in? … We've recently had a huge issue on the ward with falling … where do you put the falling bit in? Is it under cognition; under mental health; is it under physical well-being?* (Practitioner)

*There were comments that clinicians were previously able to produce good quality care plans with appropriate updates and support. The legislation demonstrated a lack of trust and was intimidating rather than supportive … We don't need anything this complicated for our patients. It makes people think the care is going to be better, but in fact we have less time to see people.* (OPMH practitioner written response)

*Team members working with older people struggled to identify any service users who, having seen the documentation, had wanted to be involved in its completion. The complexity of CTP often meant that older people were unable to understand what they were being asked to sign.* (OPMH practitioner written response)

**Review Question 2: Outcomes and Recovery**

Assess the experience of service users, their carers and practitioners of the engagement and consultation process in the development, implementation and review of Care and Treatment Plans, particularly in relation to their previous experiences of care planning, for example:

- Are plans outcome and recovery focused?

**Summary**

2.27 The requirement under the Measure for care plans to focus on recovery and service user outcomes was generally welcomed by participants although they acknowledged that this required significant cultural change which would take some time to imbed in practice.

2.28 Several service users highlighted how the CTP process had helped towards their recovery and that this was most effective when the plan was used as a live document to guide action and monitor progress. Most participants said that little attention had been given to completing their plans with them and acting on them and they believed the way the CTP process had been operated had not delivered for them. Some said that they had seen little difference or a worsening of care since the Measure. Many thought that capacity and resource issues were mainly to blame, along with what they considered to be a limited uptake of CTP staff training.

2.29 Some service users felt that the focus on outcomes had led to professionals having unrealistic expectations of them, particularly in regard to taking up employment, and that this had caused anxiety. A tendency for staff to over-emphasise any positive progress also caused anxiety, making participants fearful that their needs were being ignored or that the service would be withdrawn.

2.30 The concept of 'recovery' in relation to people with learning disabilities and dementia was raised. Some questioned the relevance of the Measure at all for these people, whilst others were adapting the CTP for their service users.

2.31 Some participants also highlighted the need for services to focus on patient outcomes rather than service outcomes.

**Commentary**

*Managing cultural change*

2.32 Most practitioner participants welcomed the Measure's focus on recovery; on reducing dependency and encouraging service users to take responsibility for their own mental health. In this way the Measure called for a complete change of culture for both service users and practitioners in their relationships with one another. They also acknowledged that these changes were challenging for practitioners and service users and would take some time to imbed:

*It is all about culture - even patients have an expectation … 'if I'm really needy they'll keep me on', and there's lots of issues about how disempowering that is for people: 'I'm under a psychiatrist. I can't do this. I can't do that'.* (Practitioner)

*He told me we were making him ill because we were trying to discharge him from seeing his favourite doctor once a year. Now there's no logic behind that but that is about a person's expectations of their own life and you're right we've created it. Sometimes we've spent ten years telling him that he can't manage.* (Practitioner)

*Yes and then you end up with this kind of person, repeatedly using up a lot of time of a service which is actually meant to be targeted at the people that are most unwell.* (Practitioner)

2.33 A few pointed out that even under the Measure and CTP, it would be necessary for care coordinators to avoid creating dependent relationships:

*We're trying to move people towards independence and being competent individuals and yet we are saying, 'you tell me any problem you've got in your life and it's our job to kind of take that on and sort it out for you'. It's a really good way of making people*

*really dependent … and so they're going to stay with us for years and years.* (Practitioner)

2.34      The need to fully engage professionals in this cultural change was highlighted. However, a tendency for practitioners to persist with medical models of care was raised frequently. So too was criticism that the CTP had created an additional administrative burden:

*You can do a care and treatment plan poorly or you can do it well; you can do it holistically or not and if the doctor still leads and still talks about medication and doesn't really give space for any of the other professionals and it's not the care coordinator who's chairing it or there's lots of cultural things that are different depending on that CMHT or that consultant or whatever …* (Practitioner)

*My engagement with CPNs and social workers is far more positive than it is with medics. I think they've grasped the recovery process far better.* (Practitioner)

*The risks associated are that staff see it as an administrative burden and there is no real engagement and focus on recovery and resilience development.* (Practitioner)

### The CTP and recovery

2.35      The usefulness of the CTP as the main tool for communicating and managing the recovery process with the patient was highlighted by some participants:

*It helps create more of an understanding. If you didn't have this then it would be a lot harder to get the information to everyone involved or to the professionals that are involved.* (Carer)

*I don't think you shift huge amounts of cultural expectations overnight. But what you start getting people to do is to think about why they're doing what they're doing and are they really doing it for the best reasons – and I think that's the stuff where the care and treatment plan becomes useful.* (Practitioner)

*I think the whole point of a care and treatment plan is to put a*

*shape on mental health care. You sit with people coming into your service right at the start - we assess them and we develop the care and treatment plan which talks about discharge; talks about relapse; talks about progress; talks about recovery.* (Practitioner)

2.36    Several service user and carer participants highlighted the ways in which their plans were focused on recovery and described real progress towards their goals as set out in their plans:

*In the back of your mind it's reminding you of the goals that you put down. It's helping you mentally to stop going back into that black hole. For me it's like a safety net and I know when I'm not feeling as good as I should I'll get it out and have a read and it just gets me back where I was.* (Service user)

*Yeah, it's gradual … I'm hoping to progress into a bit of voluntary work, and then progress eventually into actual work.* (Service user)

*It did work. I had a good experience of it. It gave me something to aim towards and I thought, I'm not going to get all this done but by the time I was being discharged it was like, well, actually I have done all this. I've been … doing my voluntary work … I'm going back to Uni in September.* (Service user)

*It was very realistic and very focused on how you feel now and what you want in ten years kind of thing – very positively done anyway.* (Service user)

*My current CPNs seem to have a solid established culture of how they work – they do everything the right way. I don't have to worry about anything; if I mention something to them they will just go off and do it. If there's an issue they will try to solve it. If the problem falls without their remit they will signpost and things like that … It enhances my ability to have a better quality of life ... It speeds my recovery up, as I don't have to worry about sorting those things out. If you take away risk and stress factors it is definitely going to help you recover.* (Service user)

*That sort of stuff (setting goals) really helped … From that stage*

*onwards it was achievable goals; in terms of long-term and short -term goals. Well, those long term goals, they probably wouldn't change but those short-term ones have changed drastically.* (Service user)

2.37    Clearly the attitude and approach of care coordinators was crucial to goal setting, action and recovery and participants highlighted some examples of best practice where the CTP was used as a live document and referred to in each meeting to monitor progress towards goals:

*We go through it and if I've got any questions she'll answer them. It's been very good. We did a 'what were my goals' etc; 'what would I like to achieve?; what had I achieved?' and each time she comes we discuss it and sometimes I might have done a little bit more – so I can sort of gauge myself on it, if you like, as to how much better I'm getting.* (Service user)

*That is very, very good because every four weeks we go through the whole list and, 'How is your mental health today from zero to 20?' And I put 18 because it's very good and then they'll ask, 'How is this? How is that?' with a rating and then they can look back through the months … and if it was six they'd act on it ….* (Service user)

*I'm really happy with the care I've been receiving. My CPN is really, really good. She gives me confidence in myself. I think that pretty soon she's going to discharge me because she's pretty happy with me. I feel fine about that. As far as I'm concerned that's real progress.* (Service user)

*I've got to say the care that we're getting has improved immensely, so we have regular CTP meetings; we have regular input from the CPN.* (Carer)

*We are training the practitioners that the CTP should be a live document so that as they're meeting with Mary or Fred on a fortnightly basis they should be reflecting back on the CTP … to*

*look at the small steps they've taken to achieve the goal. Is it working and if it's not, can we change it?... So we want the service users and carers to use it as a live document just as much as if it was a physical problem and the district nurse was coming every day. It's starting to change – you can see that people are changing their way of thinking and the feedback that I'm getting from a lot of the practitioners is that it's not as bad as they thought.*
(Practitioner)

2.38　Some carers said that they supported the idea of the CTP as a 'live document'.

*Patients and carers … measure the service through individual everyday experiences and it is in these experiences that they seek improvement. Where protocols are known to them, they do expect these to be adhered to in practice; care and treatment planning is a good example. It is reasonable to assume that it is seen by the legislators as relevant to improving the mental health service. This is why CTPs should not be seen or considered in isolation from the quality of service, otherwise the plan becomes yet another meaningless item of paper that simply adds to the workload of professional staff.* (Carers – written submission)

*You can put that care and treatment plan in place but if the CPNs are not coming back and forth regularly; are not monitoring and finding out how things are going then things get forgotten, that's what I find.* (Carer)

2.39　Participants agreed that the CTP had to be managed appropriately for recovery and desirable outcomes. Unfortunately, however, many said that the barest attention was given to completing the plans and acting upon them:

*People are promising that they will action items on the CTP which aren't happening.* (Service user)

*It seems like they just cover their own arse really but they don't follow it through.* (Service user)

*Yeah, she goes along and it's (CTP) sent off and put in the drawer and that's the end of that … nothing much comes of it.* (Carer)

*I think the plan is there as something for people to fall back on just in case it hits the fan … crossing the t's and dotting the i's.* (Service user)

*Unless these care and treatment plans are written properly and then followed by the professionals it's just going to undermine the individuals; it undermines the whole process and the whole intention behind it.* (Service user)

*It's so basic, so basic. It doesn't help me in my goals in life. I don't see the point of it.* (Service user)

*If it's written in, it's not adhered to or they just don't put it in there in the first place … So it's a case of we're recognising all these things with these individuals – we're just not really going to do very much about it.* (Carer)

*Your CTP should be empowering you to recover and not just putting you into a box or a sentence. How is this supposed to empower anybody? You need a paragraph or a chapter or a whole book … There are pockets of good practice out there but there's a lot of bad practice.* (Practitioner)

2.40    Many thought issues of service capacity and resources were central to the failure of plans to deliver for service users:

*If you've got a CPN who is severely overloaded, she's on her bike popping in, 'how are you?' Write up, rushes away – she hasn't got time to do an holistic care plan. She hasn't got time to listen and discuss and develop the picture of the needs, risks, strengths etc. which is the key to it.* (Carer)

2.41    A practitioner suggested that service users as well as practitioners needed to be educated in the recovery approach:

*I think the service user has to change as well as the professional because you're saying to somebody, 'think about your life'. In the*

*past it's been, 'this is your medication'. Suddenly we're saying to people, 'what do you want? What would you like to be in six months' time?' And nobody's ever asked them those questions. And that's a big ask. I think it'll be a while before both parties know where we should be going; before that 'working with' (rather than 'doing to') mind-set develops – it's not my care plan, it's not health's care plan; it's our care plan.* (Practitioner)

### Outcomes

2.42    Some participants felt that focusing on outcomes could be stressful when it appeared that professionals held expectations that service users felt were beyond their reach:

*This first of all freaked me out because it's finance and money and when it goes on about the work and occupation bit – it's almost like … this is what I've got to be doing in 12 months. This was something that wasn't in the other one (care plan) which I thought was a lot nicer.* (Service user)

*The only thing that has come back to kick me is because volunteering has been my lifeline – and that was on my plan; to do volunteering for myself; to enjoy it – I had to go to the job centre the other day and the person in the job centre thinks that it is time to take the next step into work … I would find it hard to do a job of work because of the hallucinations ... But sometimes on the care plan you need a bit more space to say, just because I volunteer and I smile when I volunteer, doesn't mean to say I can go out and get a full time job.* (Service user)

*It seems to bother our (son) a lot. Like he should be goal oriented – the illness makes you reclusive and makes you feel as if you're different to everyone else – maybe it could be worded differently – maybe, 'what would make you happy?' rather than goals.* (Carer)

*It's about you listening to us and everything must not be about work. All the courses you see, unless there's work at the end of it, courses don't exist. Some people with bi-polar and schizophrenia*

*get treatment and they can do excellent jobs. It's the people with anxiety and depression that are in the day centres for years. For some reason we're not getting anywhere with them. You'll find that most of those people have had therapies and different things but they haven't worked.* (Practitioner)

2.43   A tendency for practitioners to over-emphasise any positive progress towards recovery troubled some service users and carers especially when they felt their continuing needs were not being addressed or when they feared this 'progress' would be used by practitioners to justify the withdrawal of services:

*And when I'm talking to her she'll say 'How are you doing? You're doing well'. And I don't think sometimes I am doing well.* (Service user)

*She holds me on a pedestal. If I'm doing well, does that mean they are going to withdraw me from the service?* (Service user)

*When we did that care plan, what we saw when we flicked through those pages was that everything was 100% positive. Anybody looking at it would think that there's nothing wrong with this person. I actually had to adjust 14 points … My concern is that if my daughter didn't have me, they would have gone unnoticed and then she would be put in situations she wasn't equipped for, or they would think she was more able than she was.* (Carer)

*They're interpreting things to fit what they want … and they're trying to manipulate the facts. They think that because he's acting a certain way in certain circumstances, that's great – we'll forget about all the other stuff that proves this wrong. They're picking and choosing what they want to fit this Measure and these goals.* (Carer)

*She always flags up what's positive about his behaviour and ignores what I say. So by the time they leave the house the power of what I said, what I wanted to be passed on to the psychiatrist was reduced and they would do nothing. And I was so desperate*

*because I knew they were doing nothing.* (Carer)

*Part of the care plan meeting has been to build up their confidence and give them a rosy outlook on life which is great but it's unrealistic. So it's, 'well you're doing great and you've got this and you're good at that' when they may not be, which is good for the patient but it's very bad for the care plan because what happens is their needs aren't met … We're not asking to be negative … but it's a sense of realism with the patient. Part of this rosy attitude is, 'I'm doing so well, why do I need to (get involved in care planning)?' So it doesn't draw them in and it also frustrates the carers because the carers are saying, 'Hey this isn't how it is. Do you know about our son or daughter?'* (Carer)

2.44 Changing the working practices of staff towards prioritising patient outcomes over service outcomes was considered to be another challenge:

*Where is the evidence that any of this improves outcomes, or quality of care? No-one seems to measure outcomes, just whether paperwork has been completed.* (Practitioner)

*They (care coordinators) are still not doing it outcome-focused though are they? You know, what is their outcome? To have their (medication) every month? That's not an outcome is it?* (Practitioner)

*OTs are normally pretty good at doing outcomes I think because that's their training but care coordination responsibility, by and large, falls to CPNs.* (Practitioner)

*And actually I mean it says about being person-focused but it (Measure) is not; it's process-focused and we need to get back to looking at outcomes, not process.* (Practitioner)

*Yes, you're concentrating on the outcomes of people you know: are they happy with the service that's provided? Has it been effective? And then move towards trying to look at that - not what's been filled in? How much have you put in that box? I mean that's easier to*

*measure because you've either put something in the box or you haven't.* (Practitioner)

### Quality of care and treatment plans

2.45 Participants also called for improvements in the quality of CTPs and realistic and effective auditing of them to identify shortcomings as well as successes:

*It feels that there is trend that they are starting to ask questions that will reveal a failure – historically they would only ask questions that would reveal a success – and you can do that in auditing – you can ask a series of questions, get affirmatives to them all and make a positive report.* (Carer)

*I guess there is a limit to how often you can say 'It's too early yet' but certainly the emphasis with the Welsh Government and the NHS was on getting the numbers done, getting the number of people with care and treatment plans done. So that was important; to get the process and the system in place, but I think most people accept, and Welsh Government definitely accepts, that the quality isn't there.* (Practitioner)

*Difficulties have been experienced in ensuring that LA/Education undertakes their responsibilities for Part 2. The onus for training was put onto health. However, who is auditing their level of compliance and the standard of the CTP and care interventions?* (Practitioner)

2.46 Many participants mentioned the variability in quality of care coordination and CTPs between CMHTs or between practitioners. A participant offered opinions which were echoed by others: that some staff were choosing to ignore the codes of practice or that the poor take up of training was impacting on the quality of service and outcomes for patients. They felt it was the responsibility of management to ensure that the appropriate standards were achieved:

*The people who deliver it are not fit for purpose and, therefore, you*

33

*have to address the causes for their failure to cooperate with the ethos of the code of practice and address that as it occurs … One of the things that has emerged from my experience is that the continuous professional development programme is lip service only … I think the key to the success of this is to have the right sort of lead. You need an assertive person who says, 'Well, we're here. We can either waste our time or we can get on with this. Here's the core that we must address in the next 12 months ... We've all got to meet this standard and move forward to deal with this. I mean, it's done in industry …* (Carer)

*I think there are some people stuck in the old ways. Especially those who have been working in the system a long time are finding it really hard to change. And one of the things that seems to be happening is that some of the people that don't want to change are actually taking early retirement.* (Carer)

2.47    Some service users said that they had seen little difference in the actual care received since CTP was introduced or that care had actually worsened, not directly because of the Measure but owing to general service cutbacks. This was considered to be an important issue since good care was considered to lead to recovery:

*I don't think it's made any difference, but that's not to say I don't think it's not done anything. It's like a benchmark – but I think they need to use it properly.* (Service user)

*No, I've not found it to be that different at all. It's just been giving information to services in order for them to best work out how to help you, but I don't think there's a lot that gets taken from it. It may help other people with practical needs, but when it comes to therapeutic needs it's not that helpful.* (Service user)

*I feel my care is not so good as it was before CTP but I don't think it's because of the CTP. I think it's because my CPN has more on his plate than beforehand. He had to take on a lot more clients. It's*

*come at the same time as the cuts. Caseloads are getting larger …*
(Service user)

*A lot of the carers that I deal with have been through this system for a lot of years so they know that the care and treatment plan changed – they liked the idea of how holistic it is … and it goes into every part of your life… which is great and they've felt and still feel that it is a good way of organising a care and treatment plan but the reality of the actual everyday life doesn't follow through to that. They don't feel there has been any difference from before to now, other than it seems like a good plan to have.* (Practitioner)

2.48 A few practitioners, however, highlighted their best practice in regard to auditing:

*We do our own internal audits already on the quality of the CTPs; looking at whether they are covering the assessment of needs and risks and whether or not the reviews have been done in time; the contents of the CTP – does it make sense?* (Practitioner)

*So the clinicians are actually taking more responsibility of that rather than us and then we're getting the results back in. So that seems to be working quite well.* (Practitioner)

**People with limited capacity and recovery**

2.49 Many practitioners questioned whether the recovery model was appropriate for people with long-term impairments such as dementia and learning disabilities:

*It's not suitable for learning disabilities … it's already set up for adult mental health and they're trying to fit everyone else into it without thinking about what does somebody with a learning disability actually need.* (LD practitioner)

*Clearly, the Measure was aimed at mainstream mental health services where services are health-led and have a specific focus upon the treatment of mental disorders. Learning disability teams, on the other hand, are social care led and have a rather diffuse role in providing ongoing support to people with LD in which treatment*

*of behavioural problems and mental health problems plays only a part.* (LD practitioner written response)

*The Measure has a detrimental impact at times on work with people who have dementia as mental disorder is seen as episodic and services are based on a recovery model … The Measure has not supported improved services for people who have dementia because it was not designed to meet the needs of people who have a progressive illness that requires a multi-disciplinary approach where the psychiatric services may have a limited role.* (OPMH practitioner written response)

*What is the advantage in deeming these people to be relevant patients? Why would we want them to be under this system? Because what we actually have is service-led decision making around whether somebody is CTP or not; it's not needs led … two people sitting next to each other in a nursing home with exactly the same needs, one might be CTP just through a service stream that's led them there … and somebody else might be UAP. So it simply doesn't work.* (OPMH practitioner)

2.50 An older people's mental health practitioner said they were seeking clarification of how to define relevant patients and 'recovery' for their service. Given the increasing levels of dementia patients, the implications for caseloads were also raised:

*If somebody goes into a nursing EMI (home) now, they are placed there because of their mental health issues. They're being deemed at the moment - although we've asked for clarification on this - as 'recovered' once they're settled and stable. But is that really a recovery? Because if you remove them from that nursing home they wouldn't be settled and stable … If somebody's a relevant patient at the time that they're placed in a nursing home, at what point would we consider that, that was no longer the case? If somebody's placed because of their dementia needs in an EMI nursing home, are they always CTP or not?* (OPMH practitioner)

*We're facing a huge challenge and it's the numbers and I think that this (Measure) has made it worse to be perfectly blunt. There is no getting around it because we now have to have discussions and try and work out what we do so we're compliant with what is now law and it doesn't help. Dementia shouldn't be under the Measure in my view. … We should be de-medicalising our services around dementia; we should be modelling our services on learning disabilities.* (OPMH practitioner)

2.51 Older People's Mental Health Practitioners also highlighted the sensitivities around sharing the CTP, a legal document, with patients living with dementia and their carers:

*If you're putting a diagnosis in that the person doesn't have capacity to remember or is unwilling to accept … you have to fluff it up a little bit to make it less provocative and then it demeans it as a document really doesn't it?* (OPMH practitioner)

*Clinicians felt they often had to produce vague assessments which they could get service users to sign. Service users would disagree with such things as 'memory problems' or 'dementia', so such words would have to be removed.* (OPMH practitioner)

2.52 Helpfully, a learning disabilities practitioner gave their interpretation of 'recovery', which was echoed by several others, and which essentially sought to maximise wellbeing for the individual:

*Somebody with a learning disability is not going to get better in terms of learning disability but I think we talk about it in maintaining skills, in ensuring people have still got rights and choices and I think we talk about it more in that person-centeredness way …* (LD practitioner)

2.53 In one area practitioner participants concluded that LD service users should only have CTPs during periods when behaviour was out of control or people were mentally unwell:

*None of ours in the residential houses are on CTP because we know they're safe. They're managed well* (Practitioner)

*In learning disabilities, people with secondary mental health issues and sectioned should be on CTP.* (Practitioner)

2.54   As already mentioned, the CTP form itself was considered to be difficult to adapt for service users with cognitive impairments. Practitioners also believed that introducing an additional system for case management had caused complications:

*Since the mid 20<sup>th</sup> century, LD services have been built around different models – normalisation, SRV, advocacy / self-advocacy. These concepts share much with 'recovery' and pre-dated the recovery model. To date the 'recovery model' has not impacted LD services … The arrival of CTPs in this landscape has caused confusion. Existing systems were not working well in the first place (due to poor implementation and under-resourcing I would suggest) and now LD teams are struggling to decide which individuals on their case-loads should be provided with a person-centred care plan (which is extremely detailed and 'LD friendly') and which should be offered a CTP (which is less detailed, seems less relevant and less 'LD friendly' often). Sadly it seems that many are offered neither!* (LD practitioner – written response)

*What we end up with is people who have complex social care packages and UAP who then come into our service under a separate system. So rather than Part 2 of the Measure being a way of helping us to deliver services with other professionals, it actually makes things more difficult. The majority of our patient group with dementia will have health needs in excess of people of the same age and they have social care needs in excess of people of the same age. So, badging dementia with mental health actually makes things more difficult …* (OPMH practitioner)

2.55   However, in one area, careful planning had led to a system that practioners believed was working well and although it was early days, it was hoped that the changes brought about by the Measure would result in moving away from 'maintaining and supporting

disability' and towards empowering service users:

*I think from a learning disability perspective initially we were like, 'my word, what are we going to do here?', but I think we stalled and said, 'no we're not going to just speed into this. We're going to actually work with our local authority colleagues; we're going to sit down and we're actually going to have an agreement here so everybody understands where we're coming from' and I think that helped us a lot … we've worked with the primary care and we've agreed a definition of criteria of what would be primary and what would be secondary for LDs so we've got that now in place. I think that it has allowed staff to think in more of that recovery model - so that is a positive. So it means that there is more of a thought around enablement and less consideration about holding onto people because they've got a learning disability …*

*So it has empowered staff which, as a direct result, we're hoping will empower service users to be able to make more choices. I don't think we've seen enough evidence to support that yet and I think it'll take some time for that to become more apparent. Within learning disabilities we did come together as a group; as a multi-disciplinary service and that is still evident now.* (Practitioner)

**Review Question 3: Service user engagement and consultation**

Assess the experience of service users, their carers and practitioners of the engagement and consultation process in the development, implementation and review of Care and Treatment Plans, particularly in relation to their previous experiences of care planning, for example:

- Is there evidence of engagement and consultation with service users and carers?

**Summary**

2.56    Some service users and carers highlighted experiences where they felt engaged and involved. They were particularly satisfed when they felt listened to; where the service was responsive and approachable and where they had built a relationship of trust with practitioners. A few believed that this had improved since the Measure.

2.57    However, many felt that their level of engagement was limited: services would not respond to telephone calls; would not inform service users of staff changes; failed to listen to them properly or staff were absent for long periods owing to illness or leave. Some service users felt their complaints had led to unfair behaviour towards them from practitioners.

2.58    Participants also complained about:

- Discharging service users for not attending appointments;
- Making decisions about patients based only on their presenting symptoms rather than taking account of patient notes and the lived experience of the service user and/or their carer;
- Failing to treat service users as individuals;
- Failing to work with carers in the interest of service users;
- Not communicating with service users in their language of choice – including Welsh.

2.59    Stretched staff resources and capacity were considered by participants to limit the potential for service user and carer

engagement.

**Commentary**

*Communications in practice*

2.60 Some participants revealed examples of good practice where services were communicating with them appropriately and working with them in the best interests of the service user. Service users and carers were particularly satisfied if they were able to contact their care coordinator when they needed to and when they felt listened to and understood:

*I feel compared to what was happening 17 years ago that the care that my son's receiving now is far better, because people are listening.* (Carer)

*He (consultant) was a very caring man. He understood what I was talking about. He was very approachable. You could talk to him.* (Service user)

*There was one psychiatrist and one CPN that really did understand him, with his Asperger's and everything, and met his needs perfectly … it was very good. They would listen … they would value my opinion … Some psychiatrists will listen. It's a bit hit-and-miss. The social worker does actually listen to him now, but it's taken a couple of years to get that relationship … You can lump them into two camps: the listeners, who are good; and the ones who don't listen, who are always bad.* (Carer)

*We've got a new social worker - yeah she's brilliant. She's excellent - really good. Because she listens and she understands my daughter. My daughter is much happier.* (Carer)

*The good thing they did say to me was that we do appreciate that you're the expert in you before they knew anything about me and I thought isn't that brilliant cos it's true. That immediately reassured me. I was like, do you know what? That particular person I spoke to does get it.* (Service user)

*The leading principle's that good communication is likely to lead to*

*better outcomes … if you're going to review this thing it should be opened up that good communication is so essential.* (Carer)

*She says, 'give me a ring if you're not well', so you feel as if you have a safety net.* (Carer)

*At least I have access to her number (CPN) and she can send someone – before I used to ring up and I'd speak to the psychiatrist's secretary and she would make an appointment for ten days' time.* (Service user)

2.61    A practitioner highlighted a particular benefit of care and treatment planning: increasing visibility and staff accountability:

*I think the CTP is an excellent service because it makes somebody in the service accountable for what's going on. And if there is poor communication it can be shown up by the care plan. Before it was so vague.* (Service user)

2.62    However, many service users complained of the difficulties in getting in touch with their care coordinator and the services not responding to their requests for contact. For instance, at the time of interview a young person had been waiting two months for some promised information. Others made the following comments:

*In the two months I didn't see anybody I went downhill rapidly. I felt abandoned. As if they'd just dismissed me … and I just thought … they just want me to go and kill myself.* (Service user)

*I've rung them three times and I've got through to the receptionist and she says she's passed the message on to the psychiatrist, but I don't know.* (Service user)

*Part of me thinks – I don't care what's on paper – I just care about you phoning me back when I leave a message and I actually put that on the care plan because it's happened so many times.* (Service user)

*You phone them up and they say yes, they'll get back to you then you go in later that day because you're in town and they say, 'oh*

*they're not in today. They'll be in on Monday'. There's always an*
*excuse. They're appalling at getting back to you. You're chasing*
*them all the time. And then when you do catch them, they're in*
*such a rush and say, 'Oh I've got other cases' and I think well, to*
*you that's another case; to me that's a person in my life.* (Carer)

2.63    Staff sickness and leave were also cited as barriers to making
        contact with services:

*According to my CTP I'm supposed to see my CPN every two*
*weeks but I don't see her because of sickness and stuff.* (Service
user)

*I'm under a care plan but I don't know what the hell's going on*
*because nobody's telling me anything. I had a social worker who*
*came to me at the end of May. I've heard nothing back off her and*
*every time I ring she's either been on holiday or sick.* (Service user)

*I had four weeks in hospital – I never saw my named nurse. I had*
*no care and treatment plan and every time I asked to see my*
*named nurse she was either on leave, she was on nights – and*
*when she was on nights I couldn't talk to her … so I asked, 'can I*
*talk to somebody else?' and they said, 'you've got to speak to your*
*named nurse', so you end up talking to nobody. If that's what*
*commonly happens, then that part of the CTP falls down*
*completely.* (Service user)

2.64    Many service users suggested improvements in the manner in
        which they were treated or spoken to by practitioners. Sometimes
        the simple courtesies were missed. For instance, a learning
        disabled service user was upset by the number of occasions that
        he had turned up to appointments which had been cancelled
        without his knowledge. When he put in a complaint about this his
        care coordinator was angry with him which upset him even more. A
        carer said of this situation:

*If (name) had been informed by a phone call, (name) might have*
*been disgruntled but he wouldn't have been hurt and it wouldn't be*

*so rude – it's about viewing people as human beings.* (Carer)

2.65    This was by no means an isolated example of a complaint being received badly. Another service user complained to the CMHT because his CPN was away for four or five weeks at a time and did not make appointments to see him. He felt that his mental health deteriorated to the extent that he was admitted to hospital because he did not see his CPN regularly. He said that the complaint put him in the consultant's 'bad books' and he remained 'frightened' of him:

*I was a bit furious about that – my illness was getting worse … so, anyway, it got back to the doctor and he said, 'How dare you make a complaint against my team?'* (Service user)

2.66    Other participants said:

*I think what needs recording is that if you have made a complaint you feel that you will be punished … it's a very subtle way of punishing you by withdrawing services.* (Service user)

*And recently he's been dismissed again because he got very angry because somebody turned up to his caravan. He didn't know who they were …* (Carer)

*The CPN that I didn't get on with would never answer my questions … It was one thing fobbing me off after another … general responses that told me absolutely nothing. And I couldn't get a second opinion – that was another thing because a second opinion has to be approved by the person who made the first opinion. So that's not going to happen is it?* (Service user)

2.67    Discharging patients for not turning up to appointments was also an issue of concern to many, especially since missed appointments could be a symptom of illness. This was considered to be an example of services not being person-focused:

*When you're really ill, you tend to lock yourself away and you don't attend these sessions and then you're automatically struck off and*

*that's when you most need the help. Someone should be coming to your flat to check how you are. It makes you feel worthless.* (Service user)

*When you treat people in a personal way, you would text them or phone them - make the effort to go out.* (Service user)

*I'm not quite sure I agree with one DNA and you're struck off and you have to be referred again … I think there might have to be a little bit of leeway with mental health … things don't always go right on the very day they need to be seen …* (GP)

*If someone's not appeared, you think I really must see this person and you put extra effort into it. I suppose the mental health team need to do the same really …* (GP)

2.68    A few participants also complained of practitioners who failed to treat service users as individuals and used terminology which reinforced that view:

*I spend a lot of time with other service users listening to their experiences and there does seem to be a tendency if someone has a mental illness to treat them as if they have a mental handicap … And that patronising attitude is very difficult for people who are in crisis or trying to get their lives back on track. They're more trained to deal with diagnoses and ideas of mental illness which are not necessarily about individuals.* (Service user)

*We're not treated as people. We're treated as a label – as depressive as psychopathic, as sociopathic.* (Service user)

*I've just got a big bug bear about 'service users' … I'm not a service user; I'm a person. … so maybe 'individual' or 'patient' … It's an important point because otherwise the language and everything seems to be designed towards the service and not on the person … it's not designed for us. That's what it feels like.* (Service user)

2.69    According to one participant, making sure that service users were

kept informed about important changes in their care was considered to be a matter of courtesy, involvement and good communications:

*How much does a phone call cost to say, 'I am sorry, for whatever reason this person will not be your care coordinator' and introducing by name who the next person will be so at least you've got some idea of who it is going to be knocking on your door?* (Carer)

2.70  A few service users complained that practitioners failed to take account of their wishes or to listen properly to them:

*But when I had mine (Review) it was a huge meeting and they'd invited my college tutor without me knowing and I wasn't happy about that. Luckily she didn't come.* (Service user)

*She was a psychiatrist. She asked me really personal questions in our first and only meeting. I left feeling a whole lot worse … trying to blame a lot of my problems on my parents … It was weird that she thought that way. She refused to acknowledge my opinion.* (Service user)

*If ever I wanted to change the subject or discuss a topic that I wanted to she had a sort of proforma in her head and we couldn't move off it. Nothing to do with the care plan. It was what she wanted to discuss and I didn't want to hear about her marriages and her divorces … it was inappropriate … She was a very old-fashioned bossy, sort of hierarchical CPN.* (Service user)

2.71  A service user with learning disabilities complained that his new care coordinator saw him infrequently; the meetings were unsatisfactory and his level of involvement in his care and treatment had declined:

*And every time I see my social worker all he talks about is football. He doesn't talk about my head.* (Service user)

2.72  His Gofal support worker (who stayed with him longer than the

agreed time owing to the inadequate support from the statutory sector) said:

*J used to see the previous one weekly – even if they weren't going through a full CTP document, J was very much involved in the planning of his care, whereas now I think he's seen his social worker three times in the last 18 months so J doesn't feel they have any relationship to support his needs.* (Practitioner)

2.73    Many participants felt strongly that practitioners should not make judgements based on presenting symptoms but should read the notes and listen to service users/carers for a full understanding:

*I think the biggest challenge is to get the professionals to look at the big picture not just to look at what they're presented with at that time.* (Carer)

*The way he (psychiatrist) speaks to me when I go to see him I really do not feel since I was passed on to him that he has ever looked at my notes. I can just tell.* (Service user)

*I've worked with people who weren't very good at reading up. If you don't know a patient's history - and I've seen it with my mother - you can prescribe the wrong thing; think something is happening there; completely disregard the carer - whereas if you listen - listening is everything.* (Carer)

*I've had complaints from armed forces veterans who've had PTSD that they're not given enough time to explain exactly what's wrong with them; what their experiences are. One particular person said that he had about ten minutes to try and explain to the psychiatrist what was actually going wrong which was dreadfully little and there appears to be a blockage there … They're not really getting past the first step.* (Practitioner)

2.74    A few participants complained that information on their records was inaccurate or unfair. A carer gave an example:

*12 years ago when M was still poorly, a person came down from*

*(town) to try and get him active. He wanted M to go running, so they set a date. On that date M wasn't well, so he couldn't go running. It was put on M's record that he was unwilling and didn't want any more help. That's still on his file … I was absolutely shocked and annoyed – the psychiatrist told me that today.* (Carer)

2.75 One carer complained of a lack of understanding of people with Asperger's syndrome and this was echoed by a few others:

*I think he (care coordinator) finds us quite frustrating for different reasons. My son is very difficult because of the Asperger's traits … It complicates his mental health issues. There's a very poor understanding of Asperger's generally, because it's just not apparent. He'd go for interviews with people and they'd say 'there's nothing wrong with him'. They have a very literal way of thinking, so you have to be very careful what you say to him. One of the support workers there said 'Oh, you're sleeping your life away', and my son will literally think that he's sleeping his life away. It's really upsetting.* (Carer)

### Staffing issues

2.76 Many participants believed that staff management, working practices and the capacity of staff had a direct bearing on their care and treatment and general engagement.

2.77 Some observed that the multi-disciplinary approach does not always work and could present particular challenges for the care coordinator and confusion for service users and carers:

*Communication seems very inconsistent: some health teams work very well together and with the patient; and at other times it seems like the different workers haven't even met each other. It all seems very random and luck of the draw to me. It could be down to the quality of care coordination.* (Service user)

*There's certainly a raft of problems in terms of getting people to talk to one another – CPNs, social workers, third sector – and not least, not talking to the carer appropriately – and again as in other areas*

*it's patchy and down to the individual practitioner as to how they approach it.* (Practitioner)

*At times the 'care co-ordinator' has no role in delivering an individual's care but there is a view that a professional outside the CMHT cannot be the care co-ordinator. At times the care co-ordinator has no links with the team delivering care.* (Practitioner)

*Doctors in outpatient clinics are referring people into primary services for interventions – unbeknown to the care manager. That's completely against the idea of care and treatment planning. There's a complete confusion in the system at secondary care level.* (Practitioner)

*I do think that we place unrealistic expectations on what the care coordinator can actually achieve, because we see them as the person that will deliver a care and treatment plan and meet all those eight life areas when in fact it's going to need housing to turn up, it's going to need education to turn up, the GP has to turn up. If I was a care coordinator I could happily coordinate a meeting for an individual and invite all the people there but what I can't do is force people to turn up or send in a report or take on responsibility for that individual.* (Practitioner)

2.78   Some also highlighted the issue over professional eligibility for care coordination and welcomed the possibility of Welsh Government reviewing the criteria:

*Part 2 increased the administrative burden on staff; restricting the CTP coordinator role added to this and again undermined certain skilled disciplines.* (Practitioner)

*That was a huge issue. Being such a small service (CAMHS) – there's quite a number that can't be care coordinators – family therapists, psychotherapists … If there had been any thought about the Measure, they would have thought about CTP coordinators being family therapists … because sometimes it's only the psychotherapist that works with them or the family therapist works*

*with the family. In reality the care coordinators in CAMHS never see the kid nor the family.* (CAMHS practitioner)

2.79   The issue of staff continuity arose frequently throughout the study. Forming trusting and lasting relationships with practitioners was considered by service users and carers to be highly important:

*Change of staff, all this change of strategy is driving staff off their heads and patients and carers. You need consistency, someone gets to know someone and that's how you get the best treatment.* (Carer)

*It's having consistent staff; I know when I first worked in mental health when the CPNs had their list they got to know these people. It was consistent, it was a pride to them but if you keep having to swap it's a nightmare.* (Service user)

*And then there's the worry if you have got somebody like that in your life that they're going to move on and leave and then your world could fall apart.* (Carer)

2.80   In relation to this issue of continuity, prison mental health staff suggested that in their area it would be helpful for an individual not to be discharged from the CMHT prior to their stay in prison; that the same care coordinator should remain with an individual before and after the prison stay:

*I think the CMHTs know that it is not good practice to discharge somebody just because they've been remanded into custody … yet they do it anyway.* (Practitioner)

2.81   Similarly, a few practitioners highlighted some confusion over responsibilities for care coordination before, during and after hospitalisation:

*It says in the Measure that care coordination is temporarily handed over – if you look at the code, it's very clear in there … That is not generally being applied – some areas are saying that the community has to maintain care coordination even though that*

*person is on the ward.* (Practitioner)

2.82 A few practitioners highlighted the difficulties of care coordinating for individuals staying at some distance from their services:

*I've a caseload of around about 21 and the majority of those are in funded placements out of area. Under the Measure I have to do a care and treatment plan for these people where in a lot of cases they are just names to me. I don't actually know them. I can't answer their questions or address their needs because they're out of county. I do not have any real active input into their day to day care yet they still have to have a CTP provided by me … The CTP is on (the IT system) but you open it up and it'll say that this person is under the care and treatment of (x) Hospital. There's very little detail other than that because we don't know what their educational needs are, we don't know what their medical needs are … When I attend their CTP reviews after the meeting they then electronically send me the CTP to sign it off to say I'm agreeing with the care that they're delivering and the CTP they've effectively written. If it is a private provider then I physically have got to do that myself. It's just not practical.* (Practitioner)

### *Carers - involvement and consultation*

2.83 Participants said the tendency to work with carers varied widely between practitioners and generally that carers should have more influence and involvement, not only for the wellbeing of the service user but also to benefit the carer. Only a few of our participants related positive experiences of carer involvement:

*The psychiatrist would ring me up and say, 'We're thinking of doing such and such; what's your opinion on it?' My opinion would be actively sought, but that's like an isolated case of a particularly good psychiatrist. I've never had that before.* (Carer)

*My son said, yes, I could see his notes. This woman (social worker) piped up with, 'Oh but there could be legal implications of you seeing them'. And she put it to bed just like that. A person who has*

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*that intention, can just cancel out what a carer says.* (Carer)

*And the carer has to be believed because we can change our behaviour and schizophrenics can behave for the short period of time someone is there and then be unliveable with.* (Service user)

*She (carer) will constantly ring up the CPN and say this is happening and this is happening and I believe this is the trigger for this, this and this and nothing happens. So she has given this information to the professional, they could have acted upon it, they didn't and everything the carer's said has happened.* (Carer)

*So really listen to the people around to get another picture because very often the service user may be a person who wants to impress you; wants to be together; wants to get rid of the label of being under the psychiatrist's care and so forth … and the carer sits there every night trying to calm down this person. So you need to really get the full picture.* (Carer)

*Once a decision has been taken by the care team and you're separate to that, what support is for you as a carer to understand well, what's going to happen next and if it does all go pear-shaped what support is in place? Because I know as a carer I'll be the one picking that person up … trying to sort it out.* (Carer)

*I'm also aware that there could be situations where carers are not doing the best for the individual. So it's a very grey area; it's difficult for them. But nevertheless, they should listen when you're reporting symptoms over and over.* (Carer)

*(To improve the quality of CTPs) you could bring in more information about other people relevant to the plan e.g. carers.* (Practitioner)

*You have some CPNs and social workers who are very inclusive and will sit down and explain the benefits to the service user of having the carer involved while there're others who will just use the confidential barrier to shut the carer out.* (Practitioner)

*There seems to be extremely little that goes to the carer because of course the block of confidentiality that we have isn't it? … I do not find carers really being listened to or worked with in a useful way. I think most carers can be used for the good. I think we need to ditch this idea that every family member, friend, whoever, is a bad influence which still lingers in some places and that you can, by working together, create a much healthier environment and keep people from getting in one crisis after another.* (Practitioner)

2.84    A few participants also thought that carers and service users should be taken more seriously when planning policy:

*There is evidence of the very real experiences of both patients and carers that cannot be dismissed simply as misleading perceptions or anecdotal hearsay. It is not surprising that patients and carers have difficulty in describing their experiences without resorting to personal detail of specific individual situations. As such they can all too easily be wrongly dismissed as lacking objectivity, being less than analytical or having no substance. Taken note of in aggregate, discernible patterns emerge. All who consider the concerns raised by patients and carers - in particular, those professionals who deal in strategy and policy - would do well to remember that 'the devil is always in the detail'.* (Carers written response)

2.85    A few practitioners highlighted the difficult decisions they had to make around whether or not to involve carers. Issues surrounding family relationships and personalities were raised and working with people with cognitive impairments:

*The outcomes have to be set by the patient and if they have a severe dementia, how can they tell you what it is they want the outcome to be? Same for learning disabilities. You should be working with the family but often … the family's outcomes are different to what are considered to be the best interests of the individual, so you have to be careful then about how you are doing that.* (Practitioner)

*There's certainly 5% of cases where I go the other way and not want a carer involved or when I would get the impression that some carer was actively damaging the health interests of the person I was working with – and it is one of those really difficult lines to tread as a professional.* (Practitioner)

*Who do you ask? The kid might say one thing; the parent might say something different.* (Practitioner)

*There are often clear differences between the child and the parent and that can be quite a piece of work. CTP is written as if the child can do everything and that isn't always the case and I should think the same happens with older adults with carers around. It would have been in the case record – in the clinical process and not immediately clear. So CTP raises the clarity for everyone.* (Practitioner)

### Language

2.86    Giving service users the opportunity to communicate in the language of their choice is a clear demonstration of a person-centred and involving approach. However, participants highlighted a range of difficulties and challenges - particularly with accessing translators:

*There's only one worker who does work with mental illness and it's very hard. They're cutting back the services. This particular person who supports everyone in the community – she's almost having a mental breakdown herself. This person has to organise the contact as well as being with patients – when they go to the GP, to hospital, to other places where they need to go …* (Service user)

*What's happening in the ethnic minorities is that patients are taking their husbands and children along with them. You're messing that child's brain up by doing that (if discussing problems of abuse or sexual matters for instance).* (Service user)

*You can't diagnose properly if you can't find the words to describe the symptoms. If there's someone with you who has knowledge of*

*medicine, they can help you with that.* (Service user)

*Access to interpretation services more generally is an issue – the money for it; quality – there are concerns about people being able to communicate clearly. The use of on-line interpretation is not considered to be an adequate substitute by minority communities.* (Practitioner)

*Interpreters cost a lot of money; there's nothing about interpretation that's not a resource issue.* (Practitioner)

*I think we are a multi-ethnic nation, particularly Cardiff, and that needs to be addressed. It's not good enough, having to wait several hours to get an interpreter in or having a telephone translation.* (Practitioner)

2.87    Several service user participants also said that they were not given the opportunity to work with Welsh-speaking practitioners - even in North West Wales – and how it would help them to speak in Welsh. Participants suggested that this requirement should be written into CTPs:

*I have never been offered in Welsh but I have always been brought up by my mother not to be rude. I always speak in English.* (Service user)

*Not many people can speak Welsh in the health service and it's a total disgrace.* (Service user)

*You can decipher it (Welsh) better. You can understand it better.* (Service user)

*Because you think in Welsh, it's hard for you to put it into words in English.* (Service user)

*I can't understand the doctors in the clinics in hospital …* (Service user)

2.88    A participant with learning disabilities explained why she would prefer to speak in Welsh and how the meetings were stressful for her because they were conducted in English:

*I can understand English but not the long words. It would help me in Welsh. It's my first language. If I go to this meeting now (CTP review) and I don't know what they're talking about – I think they're talking behind my back. Every time I go into meetings I ask can I do it in Welsh? There's nobody Welsh there.* (Service user)

2.89  The fact that people tended to revert to their mother tongue when feeling unwell was given as a further reason to offer services in Welsh:

*If I hear him speaking Welsh on the phone then I know that it's likely that he might be starting to get a little wobbly. I believe that we are in Wales. When you're on the wards, there's never the opportunity to have Welsh TV on. There should be more opportunity.* (Carer)

2.90  One participant said that the opportunity to engage with Welsh speaking staff varied by area; she mentioned an example of good practice: a hospital where Welsh was readily spoken and where a Welsh speaking nurse accompanied her to consultant meetings. She said, however, that this was not commonplace. Secondary care practitioners in another area felt that their services were well able to support patients through the medium of Welsh and that this was particularly needed by the oldest and youngest patients. Although the psychiatrists did not speak Welsh, Welsh speaking staff would accompany service users to meetings:

*There are no delays. Staff are readily available. We have Welsh speakers on all the teams.* (Practitioner)

*Not a lot of people ask for it in Welsh apart from some older people and a lot of the children because they only had Welsh up until the age of eight in schools so you can't expect them to talk about their issues and their feelings in English. So you do get that in the primary school age and the parents.* (Practitioner)

2.91  In this same area, the health board was supporting staff to learn Welsh and other practitioners highlighted the intention to recruit

Welsh speaking staff:

*I think it's very patchy which is why I think it's an issue. I mean we've been keen to ensure we can provide a service through our CMHT in Welsh … so we've made it one of our desirable skills - to recruit people who could deliver a service in Welsh.* (Practitioner)

2.92    In an area where the proportion of Welsh speakers was considered to be low, practitioners admitted that there would be issues for service users who requested services in Welsh:

*I think as a predominantly English speaking service and with predominantly English speakers, it would be very easy for us not to perceive a problem, even if there were a problem.* (Practitioner)

*I think most of the information we provide nowadays is bilingual isn't it? But then if we can't follow that up, it's difficult isn't it?* (Practitioner)

2.93    Participants also highlighted the need to communicate more generally with patients using accessible language. This was considered to be particularly necessary for young people and people with learning disabilities or dementia:

*Within the LD service itself the staff are very good … they understand how to communicate with people with learning disabilities but once you start interfacing with other services like the acute sector, that's when the communication starts to break down.* (LD practitioner)

*You will go with the patient and you will get them into hospital and say this is his needs – and there's only three pages of it; it's very basic – this is really important to work with this person and you know it's going to be filed.* (LD practitioner)

*Same for older adults. If you have someone admitted to A&E out of hours and they are known to the CMHT staff on A&E or CDU haven't got access to (IT system) so they're going in blind – on (IT system) you would have all their assessments, how they*

*communicate, what their needs are, medication …* (OPMH practitioner)

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**Review Question 4: Service user Involvement - co-production of plans**
Assess the experience of service users, their carers and practitioners of the engagement and consultation process in the development, implementation and review of Care and Treatment Plans, particularly in relation to their previous experiences of care planning, for example:

- Is there evidence of service user involvement in co-production of plans?

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**Summary**

2.94    Different levels of service user involvement were identified by participants, from no involvement through to 'co-production'. Most explained their level of involvement in terms of the professionalism or otherwise of individual practitioners or in terms of service user awareness of their own rights to being involved. The extent to which carers were involved in CTP production also varied and it was widely thought that the day to day experience and role of the carer was crucial to effective care and recovery and that as a matter of principle and practice, carers should be involved more in CTP production.

2.95    There was also a call for service user and carer involvement in CTP reviews and for person-centred approaches in these meetings and more generally when dealing with service users. The need for care coordinators to undertake training to change working practices in favour of involvement was mentioned by many.

**Commentary**

2.96    One of the guiding principles of Part 2 of the Measure as set out in the Code of Practice[3] is, 'Relevant patients and their carers should be involved in the planning, development and delivery of care and

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[3]Welsh Government, 2012, Code of Practice to Parts 2 and 3 of the Mental Health (Wales) Measure

treatment to the fullest extent possible'. Another is that 'care and treatment should be comprehensive, holistic and person-focused'. This section presents the experience of participants in relation to the principles of 'person-focussed' and 'involvement' in the preparation of their care and treatment plans.

### Co-production of plans

2.97 Most of the service users that were involved in this part of the study were aware that they had care and treatment plans and were questioned about their level of input and involvement. However, participants also believed that many service users were left in the dark about the Measure; their right to have CTPs; whether they had CTPs and if they had them whether they were given copies:

*Another fundamental thing about the Measure is that the awareness is so low that a lot of the time I'm explaining the Measure to people and they don't know any part of it.* (Service user rep)

*He went in to see the psychiatrist and he agreed that V needs to see a CPN and that he was going to try and get him one but he can't guarantee him one. I showed him the piece of paper that showed that V needs a care and treatment plan. I was told that V can't have one because he doesn't have a CPN.* (Carer)

*I personally over the last nine months have worked with over 500 people in secondary care of which I would be very optimistic that 10% would know they've got a Care and Treatment Plan.* (Practitioner)

*Some people have got a care plan and some people haven't so they're still falling through the net.* (Practitioner)

2.98 Whilst most of our service user and carer participants were aware of the role of the care coordinator; who their care coordinator was and their profession (social worker, OT or CPN for example), several of them were uncertain or unaware:

*I don't know, but I presume she is. She does all the sort of*

*paperwork.* (Service user)

*I think the CPN is probably the care co-ordinator.* (Service user)

*I go and do initial support discussions with new referrals and that's one of the questions: 'Do you know who your care coordinator is? What's your input in it?' And it's nil basically, it's nil.* (Practitioner)

*If there is a care coordinator, that term has not stuck with a single carer I've met.* (Practitioner)

2.99   Different levels of service user/carer engagement in the CTP process were highlighted, ranging from no involvement at all to cases where the care coordinator wrote the plan and checked it through with the service user/carer to cases of 'co-production'. Most explained their level of involvement in terms of the professionalism or otherwise of individual practitioners. The following quotations range from negative experiences of involvement to highly positive experiences:

*I never signed mine. It just came in the post and that was it. No-one has followed this up.* (Service user)

*I was seeing a nurse last summer. She arranged a care and treatment planning meeting which I couldn't attend and it went ahead anyway and I was promised by letter that I would have a CTP and I still haven't received one …* (Service user)

*The care and treatment plan has been a bit muddled really. At one point it was forgotten about and not really paid much attention to and another point it was brushed through quite quickly. I've not found it a particularly helpful experience myself.* (Service user)

*I've had people who've said that they've had their care and treatment plan written for them by a psychiatrist and whoever's sent it to them has just said sign this. They felt intimidated that they had to sign it and that if they don't there's going to be repercussions. Their involvement was zilch ....* (Service user rep)

*Hit and miss. Depends on the CPN; depends on the social worker*

(Practitioner)

*I think they are involved, but it's really just a list of who your next of kin is and things like that. There's no thorough breakdown of the patient's past history, or their personal history, or the sort of information that's extremely relevant when you're talking about mental health problems … People usually come back to us and tell us that it was a waste of time.* (GP)

*The CTP was spot on. We'd actually gone through it all and she'd made sure that all the aspects of the plan were applicable to my needs and wants.* (Service user)

*We were really involved from the very beginning.* (Carer)

*He (consultant) does the care and treatment plan with me when I'm there. We discuss it first. He writes down what I say and then at the end I sign it.* (Service user)

*We talked a lot about what should have been on that form and what would actually help me. It was a more friendly approach than a professional. Like she would say what's your financial situation like and she would talk about it with me and discuss if it was likely to change – pros and cons and things like that. Family was more of an in depth issue with me - like personal care and well-being and we talked a lot about that. My thing is I need to open up more about asking for help so we talked about that and put it in my treatment plan …* (Service user)

*We fully participated in the care and treatment plan because the psychiatrist in charge of his case was an excellent psychiatrist … it's like sunlight coming into the room - somebody that's engaging with you - understands the issues; explains the issues; listens to your questions and answers them and he carried that through.* (Carer)

2.100 One participant said that she would have liked to write her own CTP in the first person:

*Why can't I fill my CTP in myself? I know everyone isn't but if I am capable. Why can't I fill it in? … Mine isn't in the first person – it's in the third person. It's my CTP so it should be 'I'.* (Service user)

2.101 Plans that involved patients and carers in co-production were generally considered to be of higher quality than those which were drawn up by the practitoners alone or copied and pasted from pre-existing plans or a prescribed format:

*I've got a really good care plan and I was involved with it and I wrote it together with my CPN.* (Service user)

*I have seen good CTPs … it's not a lot of paperwork – if it's led by the individual it can be a wonderful thing and it can be holistic.* (Practitioner)

*I saw one – it was at a tribunal; an older person's one – and this person had been on the ward for nine months and I asked for a copy of the CTP … and you've never seen anything like it. It had his name on it. It had one word for the interventions and the bit where you say what is the patient's view on this care plan she'd actually put, 'not applicable'. Unsigned and that care plan had been there for nine months and they were happy to take that to a hearing because I don't think they felt any accountability. If they don't do it, 'so what; who's going to tell me off?' Nobody really. What you might find is that people have one on the ward but they haven't been involved with it.* (Practitioner)

*… you do come across CTPs where you think, I can't see anything in here that tells you about this person as opposed to the next person.* (Practitioner)

*What a lot of people did; a lot of services did, was they just simply transferred everything over to the new form which was never the intention. So you are going to have a whole group of people that have care and treatment plans but they are very, very poor.* (Practitioner)

*So it's taking a while to bed down in terms of how you demonstrate that the child has been the major author of their CTP. I think some clinicians work harder and others might say it's a piece of paper.* (Practitioner)

*I don't think the service user and provider collaborate enough to get the CTP right. It doesn't enable us as a tool to carry out good quality care.* (Practitioner)

*… if that group of people (care coordinators) understood engagement with carers a lot of this could be worked through much easier. And where the care coordinator engages with carers is a whole different experience* (Carer)

2.102 A few participants said that having a document where everything was recorded was helpful and gave clarity to all concerned in the care process. For instance, a carer was able to refer to a care plan as evidence during a tribunal. When asked why she had not previously mentioned some issues, she was able to say that they were all in the CTP.

*I have reason to think that they're good (CTPs) It was really useful to have things written down.* (Carer)

2.103 There was some discussion around the signing of forms and some participants thought that only in exceptional cases should CTPs be left unsigned:

*I think the wording needs to be changed – 'may sign if they wish'. Number one it assumes that they will be asked and then it's only if they wish. It's not as strong as it should be.* (Service user)

*All the way along there should be somewhere that says the patient actually agrees with this – that would give the mental health service some knowledge about why they aren't engaging.* (Service user)

*Some teams are being very proactive about making sure that people do sign it unless there is clear evidence that there is an issue around their capacity.* (Practitioner)

2.104 Throughout the study we met service users and carers for whom awareness of their rights to a CTP and their right to involvement in care and treatment planning, had empowered them to make demands on the services, resulting in satisfaction with their CTPs and their own contributions. Many also said that pressure from them had been necessary to ensure that they were fully involved in the process:

*I find through heavy involvement from myself with this, it's now right; I have to keep on top of it all the time.* (Carer)

*I demand from my CPN the issues that are important to me.* (Service user)

*From the point of view of carers, if you want to be involved you can be involved in it but it's very much up to the carer to do it. And it has got better since the CTP. We've got to say we want to come to the care and treatment plan meeting.* (Carer)

*Your views aren't valued until you make such a fuss … and then they think we better do something to shut her up.* (Service user)

*I had to ask for the last care and treatment plan when I was discharged. I said it was out of date to the psychiatrist. They said they didn't have time to do the plan, but I told them I didn't care because it is part of my appointment and I want it done properly – then we did it. If I didn't ask I don't think I would have had one.* (Service user)

*So we have had people saying, 'You don't need a care and treatment plan' and some were saying, 'Well we are entitled because we are in secondary care'. They know what their rights are and they are challenging, and as a result people are taking more notice of that person and they are ending up with a better care and treatment plan but also it is therapeutic to them, their confidence and self-esteem has really improved …* (Practitioner)

***Person-centeredness***

2.105 Throughout the study, the phrase 'person-centeredness' arose from service users, carers and practitioners. This was defined by one participant as:

*Literally putting yourself in that person's shoes and identifying with the struggles and difficulties that they've got in life and not banding everybody together. This is an individual. She's not going to be the same as ten other people with Asperger's or ten other people with mental illness. This is my daughter. This is what she needs and these are the people that should be working with her; this is the understanding that's needed to prevent any further problems.* (Service user)

2.106 Many complained that their experience of the services did not match their understanding of 'person-centeredness'. They complained of insufficent attention to the person in the CTP. For example, someone who was caring for three adult men with learning disabilities and mental health problems said that all three CTPs were identical and she believed they had been cut and pasted one to the other. Another said that her old care plan gave a more rounded picture of her than the CTP.

*How is something which is that rigid and that has to be the same for everybody, how can we then pretend that it's recovery-focused and person-centred? It's anathema; it's just rubbish.* (Carer)

*The CTP process needs to be more person-oriented. When I go to the meetings I always come away feeling relieved that they are over, rather than thinking I've come further.* (Service user)

*It (CTP) came through and the pages were upside down and in the wrong order. If it's about my care and treatment it should be treated with care …. And not just thrown together.* (Service user)

2.107 Some complained that important health details had been missed from their plans. Others said that the CTPs included no personal contact information or the wrong contacts:

*It says in there that if I have a relapse the first point of call is my partner. But he's not my partner anymore. We've not been together for nearly a year now. (Service user)*

*It's very much a standard list of numbers; it's not personalised to me. Because my first port of call should be to my friends and family and that's not recorded on there. (Service user)*

2.108 A few service user participants complained that their relapse signatures were inaccurate. One person's form gave her relapse signatures as 'low mood, self-harming and suicidal thoughts'. However, she believed that by the time she was self-harming and feeling suicidal, it was too late:

*My relapse signatures are more likely to be withdrawing from services, being tearful; being quiet. I think that was filled in for me because I don't remember discussing that … If I've self-harmed it's because I didn't get the help when I needed it. It's the end of the journey, not the beginning. (Service user)*

2.109 Practitioners also acknowledged that important details were often missing from plans including serious issues around safeguarding:

*Something that's cropped up for us several times is the care plans … they're that sparse and there do become quite serious issues around adult protection and often safeguarding will come back to us and say, 'well why hasn't this been detailed in the care plan? Why weren't their mobility needs detailed in the care plan?' Safeguarding is a big issue and we can't reiterate that enough to our colleagues in health but I don't know that they accept that in terms of their responsibilities. (Practitioner)*

2.110 A lack of attention to individual needs could also lead to the same advice being applied to everyone – and inappropriately in some cases:

*In the past they were always trying to motivate her - social workers have programmes to motivate people, no matter how ill they are. These are some of the things they shouldn't be doing. If they've got*

*bad legs or their back's going, they should try and work with them a little bit rather than motivate. They're not understanding the situation, no. There's a basic lack of common sense.* (Carer)

### Carer involvement

2.111 The level of carer involvement in CTPs varied amongst our participants. Whilst some were very involved; others were more distant and this for a number of reasons: patient choice, carer choice or practitioner choice. A few, however, believed that the Measure had resulted in an improvement and that they were more involved under the new system:

*Yes it has changed. In the bad old days I was excluded from the CPA meetings on the grounds that it wasn't protocol to have the carers there.* (Carer)

*We are encouraged to go by our son and we want to go and we think it's the best thing since sliced bread if it's done properly. It's definitely the way forward. We were 100% behind the care and treatment plan ...* (Carer)

2.112 Many carers felt that their involvement in preparation of the CTPs was essential because of their day by day experience and understanding of the service user and their responsibility for providing much of the care included in the plans. They felt that their involvement with the CTP could provide practitioners with the whole picture:

*When that person is really, really unwell sometimes it's the carer that is more aware of that than that person and, therefore, you need to be a strong part of the contingency plan.* (Carer)

*Yes I do try to make sure that I'm there (CTP meetings) because L won't tell them. She'll tell them bits but she won't tell them the nitty gritty.* (Carer)

*The majority of people with serious mental health problems are going to have a huge trust issue with anyone professional and they're not going to want to speak in their entirety so that's where*

*the carers can have such a voice for them.* (Carer)

*I wish I could have written this (CTP). I'm not saying I'm better than anybody else, but I've got a much better knowledge of my daughter's needs compared to anyone else … If I could have written it, I think it would have been a lot more useful. I didn't realise we could have that much input.* (Carer)

*Care and treatment plans do not contain or recognise the 100% input by family 24/7.* (Carer)

2.113   However, many practitioners, service users and carers complained that carers were insufficiently involved in the CTP process or that arrangements for CTP were made without considering them. A written response from a practitioner included the following points:

*Carers being told about CTP meetings at the last minute, making it difficult for them to attend, or have advocacy/support present …*

*Feedback from CTP meetings is poor, carers are not given minutes of action points from the meeting until months later, and often do not receive a copy of the report.* (Practitioner written response)

2.114   Several complained that care coordinators used 'patient confidentiality' as a way to exclude carers:

*I was told my partner couldn't be there for confidentiality reasons. I've met a lot of carers who have said the same thing.* (Service user)

*The principle of confidentiality is so profoundly embedded that it is often pedantically applied without any consideration to individual circumstances. This culture is often to the detriment of the patient's interest. The ability to treat each case on merit should not be beyond the bounds of professional judgement. There is some recognition of this problem within the Measure in relation to the care and treatment plan.* (Carers written response)

*So that's why I'm saying, that confidentiality should be opened up more in this Review and carers should have more of a say.* (Carer)

2.115 Carers also complained that their own confidentiality should be respected by care coordinators; that private information concerning the service user which had been shared should be respected to avoid harming the carer/service user relationship:

*If you actually tell someone with schizophrenia that your mother said this, or this you're putting that person in danger.* (Carer)

*So that CPN went to my son's house and said, 'your mother's said this'. Now I felt that was a terrible betrayal and my son did not have insight at the time and it made for very difficult relationships.* (Carer)

2.116 Another carer pointed to what he considered to be a significant contradiction in the Code of Practice[4] concerning the involvement of carers in care and treatment planning. Under point 3.4, 'the responsibilities of the care coordinator', the fifth point reads:

- *keeping in touch with the relevant patient. The care coordinator <u>may</u> also choose to keep in touch with family and carers <u>where appropriate or necessary</u>.*

2.117 This allows practitioners discretion about whether to involve carers or relatives. Yet under paragraph 3.36, this element of discretion is not mentioned and the code instructs care coordinators of the <u>need</u> to work with carers and relatives as partners:

*In undertaking their functions and meeting their duties, care coordinators in partnership with relevant patients <u>will need</u> to:*

f)  *develop and maintain relationships with carers and family which are supportive of their role and which values their contribution, treating them as <u>equal partners in the care relationship</u>;*

g)  *ensure the appropriate sharing of information.*

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[4] Welsh Government, 2012: Code of Practice to Parts 2 and 3 of the Mental Health (Wales) Measure 2012

2.118   One carer observed:

*The way it's written now, if you have practitioners who do not want carers involved in the process, they will find something to satisfy their needs and those that want to involve carers will find something to satisfy their needs too …* (Carer)

2.119   Carers pointed out that excluding carers – even at the request of the service user - could be detrimental to care and against the ethos of recovery:

*They (carers) should be involved in the meeting. They do more work than the CPNs do.* (Carer)

*I'd like the government to recognise how much work carers do regarding the care and treatment plans. It is a full time job managing another person with complex and severe disabilities …My mind is constantly on overdrive doing this job. Yes, I am responsible as the parent-carer, but I don't think I should be doing all this donkey work that other people are paid for.* (Carer)

*Without the carers' effective engagement the CTP is prejudiced.* (Carer)

*My son's care co-ordinator tried to persuade him to ban us from his care and treatment plan on the grounds that we were over-influencing what the plan was. I presume that's what the reason was. But he said, 'no', so we went.* (Carer)

2.120   Some participants said that many carers were unaware of the CTP process or if they were, they had little evidence that their opinions counted:

*The carer doesn't know about the care and treatment plan or they might have heard this phrase 'care and treatment plan' but they don't feel as though they're involved … Sometimes when they get involved in the system, initially they actually believe that their involvement will be part of the care and treatment plan; part of getting their cared for back into some semblance of order in their*

*life and once they realise that it's not, then they give up.*
(Practitioner)

### *Care Coordinator Training*

2.121    The need for more care coordinators to undertake training, and ideally the full training course, in order to change culture and working practice, was highlighted by many participants. A few suggested that training should be mandatory for all care coordinators:

*I don't think it is about having bad CPNs; bad social workers. It is very much about culture.* (Practitioner)

*There has been some movement, and I think it's where people have had good training … the full training. So in other words, where there has been a willingness to embrace care and treatment plans and we have got good people around, then it has worked very, very well.* (Practitioner)

*Staff really do want more training on how to write more outcome focused care plans; how to engage someone – to write a care plan that's meaningful. We now have to say what we're doing and why and how we're measuring it and writing it in a jargon-free way.* (Practitioner)

*So either there hasn't been training delivered to all care coordinators or where there has been training it hasn't been for three days or whatever it is, it has been like half a day … but when you think all of that work and all of that effort went into developing the materials … and they were very, very good materials, very good. The fact that few people aren't using them is very frustrating.* (Practitioner)

*There has been limited training in the recovery model and developing resilience from the initiation of the Measure.* (Practitioner, written response)

*I think we should have more training on how to actually complete them - issues to do with being more outcome focused. I think if we*

*had that training it would have probably been easier, whereas I feel, as a mental health nurse, we're learning by default. We're learning on the job.* (Practitioner)

*They have tried to deliver to front line but getting people to attend is another thing …* (Practitioner)

*Training should be obligatory … if this is going to be the basis upon which people's lives are managed, they should have training for this.* (Practitioner)

2.122 A practitioner described the approach to training staff in their area:

*Staff have had training on the instrument and there will be a repeat – CTPs that were designated as excellent will now be shared across the network – so there is going to be a reflective learning process … There are positive examples of how people have adapted to using the instrument and they are sharing with others their practice and saying that it's not as onerous as it appears.* (Practitioner)

2.123 In another area practitioners highlighted the benefits that arose from training, especially where service users and carers had been involved in developing and delivering the training and adapting the bespoke training materials developed for the Measure by Lincoln University to their own needs. They also used case studies as training aids and collected feedback from service users on the quality of CTPs:

*We've trained – 80-90% of our staff and are now doing mop up sessions for new staff and those who haven't attended … it can be quite a challenge but the benefits are coming back because we are looking at developing more recovery-focused and outcome-focused care plans and rewording those principles to make it live – making it a real document. If there is a service user or carer there they can see it from their perspective.* (Practitioner)

2.124 A shortcoming of the standard training materials was identified as the focus upon adult mental health and that there was a need to

adapt the materials for staff working with young people or people with cognitive impairments:

*I think just from my point of view as a local authority employee I do think it's terribly one sided in terms of what health expect from the CTP. I don't think there's any consideration of needs in terms of cognitive complexity for people in the community, service delivery or any other related agencies' involvement and I don't think there's enough separation from adult and older adult mental health.* (Practitioner)

*… and the training tends to be very much focused on the recovery model which is great but, it obviously doesn't have all the people in mind.* (Practitioner)

*Obviously the training coming in was not learning disability friendly at all … so we identified key people to go and have the initial training … then we had to take that away and adapt it to suit people with a learning disability … and then we delivered the training across all our learning disability service areas jointly with our local authority partners, so every training session was one health and one local authority trainer. So, again, joint working between us and the local authority was absolutely fantastic and they really took on board their responsibility to be totally responsible for implementing the measure within LD as equally as health which was great … We were making up scenarios to give people real live examples of how this would work in practise.* (Practitioner)

2.125 An OPMH practitioner in one area identified IT skills as another training need:

*Some team members have insufficient IT skills to complete CTPs electronically. There doesn't appear to have been adequate training to address this issue.* (Practitioner, written response)

### The Review Process

2.126 Some participants provided examples of good practice where reviews had involved all relevant parties; where good preparation

was evident and where relevant people were kept fully informed:

*We have these reviews every six months and we'd had those … for several years and I think they make a huge difference, a huge difference. Everyone is in the loop.* (Carer)

*Some (reviews) are good, yeah, where it is arranged around the individual service user and family member - that they're all invited and sometimes there's a meeting one-to-one first before the big meeting … because it's not just about one big meeting where everybody's sat around a table, there's preparation in advance of that coming together around the care and treatment plan and people are given information so they know what it's going to be about who's going to be there....* (Practitioner)

2.127 However, some participants were confused about whether the meetings they had were to review the CTP and thought that this should always be made clear. A carer, for example would have raised a number of matters on the CTP had they been aware that they were having a review meeting:

*It was only when I chased up the CTP was I told that that was a review meeting. We didn't discuss V's care and treatment plan in that meeting and neither of us has had a copy of it.* (Carer)

2.128 Whilst many participants felt that the duty to review at least yearly was a positive condition others thought that the CTP should be reviewed more regularly as appropriate to the needs and circumstances of the individual and particularly with significant changes in a person's life:

*My son's condition is very changeable: he goes from practically normal and manageable, to severely ill and delusional and paranoid. You've got a yearly care plan, and my son's illness can change within a week! How on earth is a year enough?* (Carer)

*It's something to work off, but it needs to be reviewed far more than once a year and it needs improvements.* (Service user)

*I don't think a set time period would work but any time that a significant change happened in your life, then it should be reviewed. (Service user)*

*It's not as useful to give direction because of the rapidity of change in young people.* (Practitioner)

*If we're looking to update or change a care plan we've got no mechanism to do that because the guidance and advice we're given is you only do that annually and that's that[5]. But actually with dementia care people's needs change frequently, constantly, all the time.* (Practitioner)

2.129   Several said that reviews should be in line with the goals set for the individual in the CTP although some thought that pressures of work meant that this would be unlikely to happen:

*How it should work is that you have a short-term goal and you review it. The short-term goal could be in two weeks, three weeks, four weeks' time and you have an unofficial review.* (Carer)

*And what they're (care coordinators) keen to do and what they continue to do, so they don't have to be continually reviewing, is put down basically short, medium and long-term goals but they're only going to review the long-term ones so it becomes an annual care and treatment plan review which means that the whole thing's useless.* (Service user)

2.130   When asked if they were aware that they could request a review of their CTP most service users and carers said they were unaware. However, a carer said that when he and his father asked for a review they were refused and another participant was also made aware that the decision to review was at the discretion of practitioners:

*We've asked for a review a few times and it's been refused. I or my*

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[5] This quotation reveals a misunderstanding as the Measure actually specifies a **minimum** requirement for yearly reviews.

*dad have said we don't remember these things being discussed in a formal meeting … so we say can we have a review then and they say, 'no, it was only done a couple of months ago'.* (Carer)

*You can ask for a review but you have no right to have one. It messes the whole thing up – it means that the Measure is meaningless for a lot of people.* (Service user)

*And, do you know, I had to ask for it to be revised because it's two years out of date and it's supposed to be reviewed every year. It's only when I ask for it to be reviewed can it be reviewed.* (Service user)

*How does that carer know that he might request that if he doesn't see (the care plan)?* (Carer)

*I've got a property. I've been in there 12 months. I had a phone call the other day asking me if I want to go into sheltered accommodation because on my care and treatment plan was that I was homeless. My care and treatment plan is out of date and my psychiatrist will not update it and I'm targeted because of that.* (Service user)

2.131   Some services were, however, reviewing plans more frequently than yearly as a matter of course:

*Well my understanding is there would be a minimum requirement for an annual review and then you review as often as you deem fit as a care coordinator anyway which is what we do already.* (Practitioner)

*In our service we review them every three months anyway.* (Practitioner)

2.132   Some practitioners complained of the difficulties in arranging CTP review meetings and the additional administration involved, meaning that they were conducting reviews only in line with the statutory annual requirement:

*It has had the unfortunate effect of overburdening clinicians such*

*that there is a tendency to undertake a minimum number of reviews.* (Practitioner written response)

*Clinicians commented on how onerous it was trying to get everyone together in one place for a review, with key team members especially GPs being too busy to attend.* (Practitioner written response)

*The expectation of reviews now is much more work than it was before – you know for the better but again it's very time consuming.* (Practitioner)

2.133 Inviting family members, carers, support workers or other significant people was considered to be good practice but sometimes efforts were not made to ensure that this was possible:

*She said next week we're going to fill in the CTP. She said you can bring people with you, we'll set aside an hour. So I said how am I supposed to get the people there in a week? There's not enough time and then the people who could come didn't know why they were coming because nobody told them formally. My support worker from (charity) would have been there if she had known.* (Service user)

*70% of the people involved don't turn up – the GPs never go to any meetings because they don't have the time to spare. It's a skeleton crew because other people don't see the point in going. It'll be the CPN, the individual and the social worker. I've never been invited.* (Carer)

*It didn't involve any other professionals that might well have impacted on my well-being. I personally would have been happier to have them there.* (Service user)

*In my work I've seen multidisciplinary teams fill this in and it's been wonderful. The downside is now that most people only see one person.* (Practitioner)

*We went for a care and treatment plan review. The wife was called*

*in and the husband was asked to wait outside for ten minutes while they had their initial chat and then he'd be invited in. After 45 minutes she walked out and the care and treatment plan had been done. So it still happens and I thought the Measure would have gone some way to addressing that but it hasn't.* (Practitioner)

*There is a tendency not to invite family and carers to care plan review and if not invited, they often don't feel able to come. But the real problem with the way those meetings are conducted is they don't involve the service user most of the time. The professionals meet together in a room before they meet you for the review, they make all the clinical decisions and then they present it to you. They say, what do you think? And you say what you think and they say, well that's tough – this is what we're going to do.* (Service user)

2.134　Some service users said that they would prefer small review meetings. Two young people made comments about how daunting large meetings could be and suggested more person-centred approaches for review:

*It's obviously very practical to get everyone together, but it can also be quite intimidating – it depends if you are well or not. When I went in there and I wasn't well I felt quite overwhelmed.* (Service user)

*It was like this big deal and I would get nervous and intimidated about this big meeting where everyone's talking about me. Like, if it was more personal with you and the psychiatrist and the nurse – you and your team or your support workers - I think it would be a lot better. I didn't feel comfortable saying what would help me. I held back so the CTP didn't really help me – I just let them put something down just for the sake of it.* (Service user)

# 3 Issues for Consideration

3.1    This section summarises suggestions for Part 2 raised by service users, carers and practitioners throughout this study. These suggestions are for consideration by Welsh Government along with the various additional sources of monitoring information being collected for the Review.

3.2    It should be noted that many of the suggestions are already included within the Code of Practice for Part 2 of the Measure.

| **The Care and Treatment Plan – Format** |
| --- |
| • Introduce guidance in identifying short and longer term goals; short-term, achievable, step by step goals to give service users a sense of progress. |
| • Tailor the template for CAMHS, older people, people with learning disabilities. |
| • Ensure that the language of the form is accessible to service users. |
| • Include a section for unmet needs. |
| • Include a place for carer's signature and comment on the form. |
| • Include a space for Care Coordinator comments on the CTP. |
| **The Care and Treatment Plan – General** |
| • Increase awareness of the CTP to service users, carers and practitioners including GP practices; its purpose and its legality. |
| • Use the CTP form as a guide for person-centred communication. Avoid a tick-box / prescriptive approach to completion. |
| • Ensure that all life categories relevant to the individual are covered by the plan and update the CTP regularly according to service user circumstances. Monitor change or progress towards goals regularly – not just at (yearly) reviews. |
| • Involve carers - take on board their lived experiences with service users. Change the Code of Practice so that the advice regarding involvement of carers is clear and non-contradictory. |
| • Implement actions included on plans. Ensure that support services are provided and sustained to contribute to care and treatment planning. |
| • Make sure that service users are asked to sign the form to indicate their agreement. The only exceptions to be where service users lack capacity. |
| • Provide service users with useful and comprehensive contact details including crisis services; out of hours services and third sector support organisations. |

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| • Provide more therapeutic interventions: psychotherapy; talking therapies; CBT. At signs of relapse, provide short interventions to prevent deterioration into crisis. |
| **Care Coordination** |
| • Develop and maintain effective working between professionals. |
| • Provide cover for care coordinators during times of prolonged absence. |
| • Involve all care providers in discharge decisions. Care coordinators not to make unilateral decisions to discharge. Avoid discharging patients owing to DNA. |
| • Respect patient and carer confidentiality and treat these relationships with sensitivity. |
| • Establish clarity concerning which practitioners are responsible for care coordination for hospital inpatients and prisoners. |
| • Increase eligibility for care coordination to other professions. |
| **Communicating with Service users and Carers** |
| • Aim for more person-focused skills including being responsive, listening, allowing sufficient time, having empathy, being interested and understanding, being sensitive and building relationships of trust. |
| • Provide more staff resources to ensure more time with service users. |
| • Treat complaints from service users with respect and act upon them speedily. Avoid negative repercussions for the service user. |
| • Recruit Welsh speaking practitioners and provide sufficient funding for translation services. |
| **Reviews** |
| • Ensure that service users and carers are clear when CTP Reviews are held to avoid ambiguity. |
| • Ensure that service users are fully engaged in the decision making process. |
| • Arrange meetings so that family members, advocates and others can attend at the request of the service user. Ensure that meetings are person-centred. |
| **Staff Training** |
| • Continue to roll out care coordinator training and consider making this mandatory. |
| • Train care coordinators and other mental health staff in order to standardise good practice in person-centeredness. |

## Appendix 1 – Case Studies – care and treatment planning

The case studies here concern people with direct personal experience of care and treatment planning. The real names of the participants have not been used. The case studies are derived from interviews with service users and carers only and do not, therefore, encompass the reasoning and opinions of the practitioners involved in their cases.

Findings from these case studies have been included within the main body of the report and are intended to highlight the experiences of individuals in regard to care coordination and care and treatment planning.

**Case Study 1: Arthur (carer) and William (service user)**

- Three interviews with Arthur (August, October 2014 and March 2015). William was not involved in the interviews

- Carer of adult son who has received treatment for schizophrenia since 2010

- Support from a CPN (care coordinator) and a psychiatrist including fortnightly injections

- Two Care and Treatment Plans (June 2012 and December 2013)

*Role of the Care Coordinator*

Building a positive relationship with the care coordinator based around accessibility, trust and familiarity was considered to be vital for the patient and carer:

> *He has had two - three nurses since he started and he wouldn't speak to them at first but he has got to know his nurse quite well now … If William has got a problem that has upset him I can phone him (CPN) and explain things to him and he is very sympathetic and he actually talks to him when he goes down there and he talks things over. He is very approachable…*

> *As a carer I can phone him anytime I want.*

By the third interview, Arthur explained that William had been unable to see the same CPN and assumed this was down to managing workloads. He felt that this could have a negative impact on William's care as continuity was highly important to him.

> *They are so short-handed there that he is supposed to see him every two weeks but for the last few weeks he has had to see someone else, which is a bit of a shame because it is good to have that continuity.*

*Care and Treatment Plan*

Arthur explained that they had to push for a CTP and feared if left to William, this might not have happened at all:

> *They were all talking about care and treatment plans and there was nothing coming out of it. We didn't realise how important it could be*

*or should be. It was just pushed to one side and I went through all the literature that I had from mental health services and I realised that these things should be done; they should be pushed! It took us months and months to get a care and treatment plan without getting any response. We were asking his nurse and we were sending letters to the care unit.*

The CTP was produced after several months but Arthur felt that it *could have been anybody* as the information was not specific to his son. At Arthur's request a meeting was held with the psychiatrist, the social worker, the employment advisor and the CPN at which Arthur presented his version of a CTP:

*I was prepared before going down there. William had all these problems yet there was nothing on the Care and Treatment Plan to say that and how he would overcome the problems and how well he was doing now. So I wrote it down: what I thought should have gone in, what he had achieved and what he had been through and what I thought was expected of the plan. One thing was checking his general health, it was all about his mental health, and it is an important thing to make sure that his general health is seen to so I listed all these things down. I gave them out at the meeting and when the care and treatment plan came out, what I had written down had been put in it almost word for word*

### Additional Support: Employment

One goal within the CTP was to *remain in employment* and it was particularly useful to have an employment advisor as part of the CTP process:

*His boss had asked him for a review when he found out that he was schizophrenic and he had only just started there, so I phoned up his employment advisor and she said she would go along to the interview with him and she got it sorted out for him. We have got sort of a coordinating group which I can phone up anytime. So things don't fester; if William has a problem it can be sorted out straight away.*

### Good Practice

- Fully involving the carer in CTP preparation and ongoing decisions about patient care.

- Taking on board carer's amendments to the original CTP in full.

- Value of involving all concerned with care in review meetings.

- Ease of access to care coordinator when needed.

- Sympathetic and helpful care coordinator.

### Areas for Improvement

- Full involvement of service user and carer in preparation of plans to ensure quality and relevance.

- Ensure that the plans are holistic – paying due attention to general health needs as well as mental health.

- Ensure that the patient receives a copy of their CTP and is invited to sign it.

- Aim to ensure continuity of care from trusted care coordinator.

**Case Study 2: Kelly**

- One interview (May 2014)

- A 26 year old woman living alone in supported housing; history of anxiety disorder and depression since teenage years

- Symptoms included: self-harming; attempted suicide and hearing voices

- Receiving care from CPN and Hafal

- Admitted to hospital under section shortly after interview

***Some Background - accessing services***

Kelly had received support from secondary services from the age of fifteen. She then moved to England for a short period. On her return to Wales it took nearly six months to access mental health services:

> *When I went there (CMHT) they said that I wasn't under their services and they told me that they couldn't see me because I was still registered in England.*

This was at a very difficult time for Kelly, but fortunately her parents were able to access support from Hafal, who she found to be very helpful and innovative; using a person-focused approach:

> *I started going to Hafal and the support there was instant; they were brilliant. At this point I wasn't communicating at all. The staff at Hafal very quickly found ways for me to communicate with them: like writing letters to them about what was going on in my head. I was given time, every day initially, to speak to them or sit there and not speak, it was up to me. Other people helped me out; other service users tried to help me and things started getting better. But still there was little support from the mental health team.*

Kelly's mental health continued to deteriorate and in 2011 she was admitted to hospital. While there she was informed she had a care plan, but only when a nurse referred to it:

> *In 2011 I started deteriorating again. I started hearing voices. Then a major situation happened where other people's lives were at risk. I was telling everybody this and I was admitted to hospital. That*

*was when I first saw a care plan. When I was admitted, the nurse said 'Your care plan says this…' I didn't know anything about it!*

### Care and Treatment Plan

Kelly saw her new CTP in 2013. Although she supported the principle of it, she was dissatisfied with the production of the document including inaccuracies and out of date information:

*According to this, my care and treatment plan was completed on this date. However, going through what it says, it is not consistent with the date … In the next bit about what to do in a crisis it is literally two sentences that they have copied and pasted with so much jargon in it, well! It says if Kelly starts to feel unwell Kelly should spend time with her partner and friends, and I didn't have a partner by the time I had the plan, so that was already out of date.*

This meant that health professionals had the 'wrong information', which was frustrating particularly during an episode of 'crisis':

*Once they have written on the care and treatment plan, it is supposed to happen the way it is written down and there is no scope for change. The crisis team is still referring to a document that was written nearly a year ago… Some service users think it is only a piece of paper but when I contacted the crisis team over the weekend, it showed that it does have a big impact on the treatment that I am getting; because that information is incorrect then my treatment isn't correct.*

Kelly felt that the CTP had been written in a rush and felt let down by the presentation of the document and lack of care to her personal circumstances:

*Looking at the presentation, there is not much care taken, which contradicts what is in the title.*

*I know it had to be done quickly. It was done in an hour, it was rushed. In the actual meeting I think we just got to medical needs.*

*I know it is supposed to be generic but where it says him/her, they haven't deleted it, or the he/she bit. First page, the date, I don't*

*think that is the right date. Next page, it is upside down. It has not been printed correctly. In another copy that I had the pages were not in the right order.*

*Looking at the relapse signals, I don't think these are right, because they say self-harming and suicidal thoughts. Those behaviours mean that I have already relapsed. What I think of as relapse is if I start withdrawing. If I have suicidal thoughts or I am self-harming, that means I have relapsed.*

### Recovery focus

Kelly felt that the CTP had not had a recovery focus and compared it with her more helpful Hafal recovery plan:

*The first page says 'my recovery plan' I fill it in and I write it. This whole plan is done so that I can fill it in. I am allowed to do with it what I want. I can share it if I want; it is totally my choice. I have updated it twice.*

*It is the same areas as the care and treatment plan bar one. Hafal have got medical forms of treatment plus other forms of treatment. The care and treatment plan just has medical.*

*What I find with this one (Hafal) is that there is long-term goals and short-term. For example, accommodation: the long term goal on my CTP is to keep my flat and live independently. I had just split up from my partner, he left and it was only half decorated. It wasn't just about being happy; I was overwhelmed at the time. My recovery plan broke it down and my first goal was unpack the rest of the boxes and get help to decorate. I still have to do my kitchen and tidy the garden, so that is my next goal. There is the bigger picture and the short-term goals and they don't come into the (CMHT) care and treatment plan.*

*Also, in the recovery plan there is an outcomes box, so it is recovery focused and I can update my plan – this is really important.*

Ownership of the document was particurlay important for Kelly, and after taking part in the focus group she contacted her CPN to inform her that she was not happy with the CTP and was going to write a new one:

> *I have started writing out my new plan and my CPN says it is brilliant … I have written it in the first person. If it is mine it should be like that.*

At the time of the interview it was clear that Kelly was struggling and her condition was deteriorating; she felt the CTP had done little to help her and also complained about the use of jargon on her plan:

> *It says that if my condition deteriorates then my must increase the visits and arrange an OPA. I have no idea what that is or what it stands for. It says Kelly is aware that she can contact the CMHT between the hours of 9 to 5pm and they give the number. If Kelly requires help outside these hours I can contact CRRHT, which I can only assume is an abbreviation of the crisis team. Trying to get hold of someone on the weekend I rang about nine numbers. I didn't even look at this (CTP) to find the number. That shows how much I rate this document; I didn't even look at it. It should be something that I look at in a crisis.*

Unfortunately, Kelly was admitted to hospital shortly after the interview and was not able to participate in any further interviews.

***Good Practice***

- Hafal good practice was identified by Kelly as person-centred; involvement in and ownership of her Hafal recovery plan and a step-by-step process of recovery based on short term goals leading to longer term goals. She did not identify any good practice in regard to the CTP.

***Areas for Improvement***

- Avoid use of jargon and abbreviations in the plan which are known only to practitioners.
- Ensure full involvement and engagement with service users and encourage their ownership of the CTP. Allow them to write their own plan if they want to.

- Ensure that the plan is holistic and personal to the individual.

- Include realistic short term goals as part of the recovery process

- Include helpful advice for the individual in the plan – out of hours support and crisis contacts, for example

- Use the CTP as an evolving document. Update when circumstances change so it is always relevant and accurate.

- Ensure that the relapse signals are not in fact descriptions of total relapse.

- Take care and attention when preparing the CTP; ensure accuracy.

**Case Study 3: Emma**

- Three interviews (June 2014, October 2014 and March 2015.)

- A female in her early thirties living alone; history of depression and anxiety diagnosed in 2009

- Receiving support from CPN and psychiatrist

- Refused medication - paid for private psychotherapist and self manages (meditation, yoga and spiritual therapies)

- Attended ten counselling sessions with CMHT

- Discharged in 2015 as a result of moving home

- CTP dated March 2014 – made aware of it in March 2015

*Accessing Secondary Care*

Due to what she describes as *quite of lot of bad experiences with the NHS*, Emma favoured self-management and had found different techniques to control her depression and anxiety including meditation, yoga and spiritual therapies:

> *I have always self-managed. Whenever I have had medication it has made it worse. I have gone a completely different health route. … I am learning how to cope with all my issues. I am recovering; I am healing and I am doing that on my own. To be honest I find the NHS is more likely to make me unstable than to help me. Every time I have tried to get help from the NHS it has made it far worse.*

In 2012 Emma felt she would benefit from talking therapy; was informed by her GP that this was not available on the NHS, paid privately and later found that she could have been referred to an NHS therapist:

> *I said to the GP that what had really helped me was talking therapy and he said that all he could offer me on the NHS was CBT and I said that I didn't fancy that and I wanted something more in depth. He said, 'okay, well I can recommend a few private psychotherapists' …. He should have referred me at that point but he didn't and I think that is wrong because it was available on the NHS. I don't think he even knew. As a result, I was unemployed and I spent thousands of pounds on private psychotherapy.*

By the second interview Emma was on the waiting list for counselling:

> *What has happened since is that I am now on that waiting list and it is an 18 month waiting list and if that referral had been made in 2011 or 2012 then I would have been seeing them by now.*

Emma explained that she had been on the waiting lists for both the primary care counselling service and psychiatry in December 2012 and felt there had been an unnecessary wait to see a psychiatrist. She was at the top of the list for psychiatry in June 2013 but was discharged before being seen because she had reached the top of the waiting list for primary care counselling:

> *Psychiatry thought it was more important that I get seen by the primary care counsellor and discharged me without seeing me. So having waited six months for the psychiatrist referral I got discharged.*

Nevertheless, the ten sessions with an NHS counsellor were *really good and helpful*.

### Care and Treatment Plan

At some point – probably once the counselling was complete - Emma entered secondary care and was under the care of a psychiatrist. However, she seemed throughout to be unsure of the system and confused of her rights and the care she could or should be receiving. This seems to be compounded by her wish to self-manage her care. At the first interview with our researcher, she said that in spite of being in the service she had not been offered a CTP until she enquired about it:

### Interview one

> *At no point have I been offered a CTP. I hadn't heard of one until I did the focus group with your colleague. I had another appointment to see a psychiatrist at the end of May and I told him I had been to the focus group and I told him about the CTP and he said, 'yes, I am your care coordinator and you should probably have one of those'. So he said he will do me one of those.*

Six months later she was unsure of whether she had a CTP:

> *I am supposed to have one and if it is going to help with my treatment then that would be good. I did see the CMHT last week because I have been struggling with anxiety. I always feel awkward doing that. Maybe if it is in my CTP then I would feel happier doing that. I just had a chat with the duty person.*

### Interview three

Emma had been unaware that she had a CTP until the third interview – nine months after her first interview. When Emma visited her new GP she was informed that there was a CTP on the system and printed a copy for her. When asked if it was helpful, Emma said:

> *It is very brief. There is not a lot in it. The thing that has jumped out is that in the last box it says that I agree with the CTP, but how could I have agreed when I hadn't even seen it and I haven't discussed it with anyone? This may be based on discussions that I have had and I may have agreed with it but I didn't ever actually agree with it – but my name is actually in the not agreed with box. It says on the front that this CTP was made in March 2014 and is due to be reviewed in 2015 and I have looked at the very end and the psychiatrist has signed it and it says 6th March 2015. He has just done it hasn't he? It makes sense that it is a retrospective CTP. I don't feel any animosity towards the psychiatrist about it. Basically I had reminded him that I needed one and I said that I can do it because I self-manage and he said, 'no I need to do it' so I said that it would be interesting to see what his perspective is on it and then it was never mentioned again so I was a bit upset that we had agreed to do it together and we didn't end up doing it together. It's not detailed enough to do the job. There is not enough in there to explain who I am..*

By the third interview, Emma had moved house and area and had requested that she be discharged from the services (rather than referred). She felt that she wanted a 'break from the services' to see how she felt. However, within a

short space of time she had reached a point where she felt she needed to be seen in secondary care again and at the time of interview was awaiting an assessment under Part 3 of the Measure.

***Good Practice***

- Helpful therapeutic intervention

***Areas for Improvement***

- Ensure the patient is made aware of all treatments available via the NHS
- Involve the patient in the preparation of the CTP to ensure quality and relevance
- Ensure that the patient receives a copy of their CTP and is invited to sign it
- Increase patient understanding of their rights under the Measure and about who it is that is delivering their care.

**Case Study 4: Sharon**

- Three interviews (July 2014, October 2014 and March 2015. A further short interview followed in October 2015 to check on her wellbeing.)

- A woman in her early fifties living with husband and children; history of anxiety and depression over twenty years

- Symptoms include: hearing voices and hallucinations

- Admitted to mental health ward on several occasions: longest stay was around six months

- Receives support from a CPN and psychiatrist (appointments every one to two months) and a voluntary mental health organisation.

*Care Planning*

Sharon had been receiving support for many years and was, therefore, able to compare the CTP approach with the Care Planning Approach (CPA). One of the main issues Sharon had with the CPA was her lack of involvement in its production:

> *It was quite odd really because I had a letter in the post and it was a care plan and I thought what was this? That was about three years ago and I phoned up the contact on it and I said, 'What's this?' and she replied, 'It's a care plan!' and I said, 'I can see that but what does it do, because I have no idea' and she said, 'Well you should have one when you are referred?' I then understood that it was my plan, or it should have been, but I had no input into … it. I had sort of agreed that I would go in as a voluntary patient for 72 hours, so if a member of my family or the voluntary group saw me going downhill or found I was stopping taking my medication, then I would need to go in for 72 hours. I thought, well I had discussed it but I hadn't agreed to it. I said to him, there were parts I agreed with and, 'you do know me quite well but you know that I would never agree to that'.*

When developing the CTP; Sharon certainly felt she had been involved in its production and was particularly grateful to the CPN who allowed her time to fill it in and add to it:

*I was part of the process… My CPN came out and she said that she was bringing the CTP and we sat talking about it and she said it is not a rush to do it, we don't have to do it all in one appointment … that was left up to me and we worked through it together. I thought the way she did it was brilliant. Obviously we couldn't have done it for months but she did give me time to do it. She said if you remember something, you can make a note of it or you can ring me or tell me at the next appointment and we can put it in. It wasn't set in stone.*

Although Sharon felt she had been informed and involved, she nonetheless described a 'tick box' approach and felt that the document was less personal than the previous care plan:

*I don't like it. I think the personal bit of it has been lost. I know from a form point of view, it has to be general; I can understand that. My personal view is it isn't personal… There are a few things in there that aren't relevant. Like housing, but you feel that you need to fill them in…there are lots of other things that I would like to put on there but I just can't seem to find the right box, because of the questions. There is almost nowhere to put it. I think the other one was better because it was more basic; you could fit more in. There were no headings as such. This one is almost like you can't put things in because it doesn't fit under the headings. On this one you spend more time reading the questions, than actually thinking; well I want this to go in there. I think one of the issues that I couldn't seem to fit in was that I am not violent.*

***Sharing information with other services/organisations***

Sharon particularly supported the principle of sharing the CTP with other organisations and she would have liked to share it with the police in particular. She had been held in custody on several occasions owing to her mental state and she felt those experiences would have been less traumatic and she would have received more sympathetic treatment had the police been able to refer to her CTP. It would have also meant that police were able to inform her husband much sooner:

> *It would be helpful, if I am picked up, because I do tend to wander and I don't quite know who I am or where I am. It would help my husband and the family in the sense that, it is there so they know the contact details. People used to say to me, 'why don't you carry a card with details on?' That is all very well, and I would do when I am well, but that is the first thing that will go when I am unwell. I would rip that one up and fill another one in so it doesn't make sense at all. Even things like my mobile phone. The first thing I will change is my husband's mobile phone number. Even then, if you are picked up by the police, because of data protection they wouldn't contact him. Which is understandable in other people's cases, but not in mine. So it would be helpful if the care plan could help with that. It would help with the voluntary organisation as well, although my husband works there and they know I would want them to contact my husband, they still can't because of data protection. I know my husband would appreciate it.*

By the third interview sharing the CTP with the local police had not happened and Sharon considered it unlikely under the current system.

### *Access to Care Coordinator/CPN*

At the first interview Sharon said she was really pleased with the care she was receiving from the CPN who was her care coordinator and found it easy to get appointments at times outside of her regular meetings:

> *She is good but the downside is she is part time and I know they are overloaded. She never makes me feel that she is thinking 'oh hurry up, I've got another appointment'. She is more or less available all the time. She will ring me back in a day or two and then she will make an appointment. There isn't really an issue about getting an appointment which is really good and it is up to me when I see her ... although we make regular appointments, the CPN will say if I need to talk or see her, just ring her.*

Unfortunately, by the third interview Sharon was having difficulty accessing both the CPN and the psychiatrist:

*I don't know what is going on with my local CMHT team at the moment. I was supposed to have a meeting with my CPN three weeks ago and they said that 'oh well, she is on annual leave'. Then she phoned me a couple of weeks after and she said she had turned an extra week in her diary and I said, 'well where were you last week then?' She didn't have an answer for that! I get worked up for these meetings and I think right I want to discuss this or I want to discuss that and then most of the time she doesn't turn up … The longest time I waited for the CPN to ring me back was five weeks and I think that is totally unacceptable. It could well be because of the staff but I have got to the point that that isn't a good enough reason to leave someone in limbo.*

*I had an appointment with the psychiatrist and they said that one wasn't there and to see a new one. So I saw another one … After I saw him I was waiting for another appointment with him and I didn't receive one and then I rang up and they said, 'oh well, he has left'.*

As a result of this, by the third interview Sharon was considering withdrawing from the service:

*I am on the verge of thinking 'do I really need the CMHT?' I feel let down. As each day goes by it is more of a struggle. I think the last week or so I have given up expecting anything off them in a way. I am lucky that I have support from the* [voluntary organisation] *staff and my family. I will talk to my husband but I don't like to lay too much on him because he will start to panic.*

This was concerning because during the third interview Sharon revealed that she was *up and down a bit and the voices are worse now than they've ever been*. Sharon at this time was still supported by the voluntary organisation and her family and had been in regular contact with the CMHT by phone.

### Before and after the Measure

Although Sharon supported the Measure in principle, she felt it had not met expectations and even suggested that she was worse off than previously:

*I would say that it is almost worse. Like the care plan; it is almost as if I have had more false hope in that way with missed appointments. I have talked to her several times about the care plan and she says 'oh yes, I will bring it next appointment' and then I don't see her. I think I have seen her twice in the last three months when I am supposed to see her every two weeks … It is almost as if there is more talk about what they are going to do or what they should do but again it doesn't materialise.*

ORS contacted Sharon in October 2015 to find out if she was any better. Unfortunately in September a serious situation led the voluntary organisation to contact her CMHT. This resulted in three weeks of regular visits from her CPN. At the time of the interview, however, she felt that this support was once again being withdrawn and she was highly concerned over this.

### Good Practice

- Full involvement in preparation of original care plan; allowed time to complete
- Initially ease of access to care coordinator outside of regular appointments; care coordinator responsive to requests for contact and extra meetings; allowed enough time for Sharon in the meetings.

### Areas for Improvement

- Sharing the CTP with the police would have helped in this case.
- The CTP encourages a tick box approach rather than a more personal approach to care planning. Sometimes difficult to find the place to put important information about the individual
- As time went on the care coordinator and psychiatrist became less available; not responding to telephone calls and missing appointments. Appointments became far less frequent than recommended in the CTP.
- The CTP ineffective as a plan for action – not referred to in meetings
- Changes in psychiatric staff resulting in infrequent meetings; no information offered to explain missed appointments and staff changes leading to a fragmented, inconsistent relationship with the service user.

**Case Study 5: Josh**

- Three interviews (July 2014, October 2014 and March 2015)
- A man in his twenties living with mother and brother; history of anxiety, panic attacks and a breakdown
- Since 15 years of age had received support from a variety of different organisations including a school counsellor, CAMHS, a private therapist
- Prescribed medication in the past but did not feel that it helped control symptoms
- At the time of the first interview was under the care of the CMHT and met with them every four to six months for a 20 minute appointment
- By the third interview he was so unhappy he had discharged himself from secondary care.
- Josh was accessing different services pre and post the introduction of the Measure and was, therefore, unable to make any comparisons.

*Accessing Services*

During the first interview Josh was experiencing difficulties in accessing services, particularly the CMHT. However, he spoke positively about the support received from the child crisis team:

> *I think a huge amount of credit should go to them because I don't think I would be here without them. It was good because I had continuity: I could see the same people and I could see them as little or as often as I would like … I met someone else who had also received support from the same people and they were thankful like I was. It was strange but I felt like I just clicked. I started to appreciate them more towards the end of the care.*

When Josh turned 18 he was referred to the CMHT and he thought the support he received was *terrible … I have an appointment which lasts all of 20 minutes every three, four or six months.* He felt that they had not been proactive in supporting him:

> *I asked them to enquire about education opportunities and they said they would. That came and went and I rang them up. At the*

*same time they had not emailed the GP to tell them about the change in medication and so I was without medication for some time.*

Josh thought his psychiatrist was his care coordinator and complained about the support; being patronised and:

*She just mirrored everything I said and that wasn't what I wanted. I could just have my brother do that. He could listen and just repeat what I have said back to me. Not just wait for four to six months to have them repeat things back to me.*

At the first interview in July 2014, Josh expressed his frustration with statutory services and said that he had not heard from his care coordinator since April 2014. By the third interview he had decided that he was going to discharge himself; not because he was feeling better but as a result of his past experiences - this was a concern since Josh was still feeling unwell:

*I am still anxious. I get anxious more or less every day. I get my down days when I just don't want to see anyone or talk to anyone.*

### Accessing CTP

Josh thought he had a CTP but explained that he had not seen it, even though he had requested to see it:

*There is one, but only they [CMHT] can see it and I have requested it. They haven't given me an explanation why they haven't given it to me. It's that bad. Initially I tried to access the crisis team, but they said I wasn't bad enough to need it. So basically they waited until I was bad enough to need it; I am not asking again. It will make me too irate. I have one (plan) with Barnardo's; one with Hafal.*

### Support from the Voluntary Sector

Josh was positive about the support that he received from the voluntary sector including Barnardo's and Hafal. At the first interview he said:

*I have rarely had a bad day with either of them. With Barnardo's. I was referred to a care worker. Once a week I can do whatever I*

*want - if I want to go for a coffee or go and watch a film. At the moment they are offering group sessions and therapy and I have been going to that for a few months. We have gone bowling, to the cinema, gone for a coffee, rock climbing, pottery and more. It has helped just doing different activities. Yes, the company is better, but … I find more of that socialisation with Hafal because I am constantly working with them; I am gardening with them at the moment.*

### Good Practice

- Support from the voluntary sector in terms of care planning, socialising and activities
- Good support from the crisis team

### Areas for Improvement

- Has not seen his CTP
- Limited, unsatisfactory support from CMHT and psychiatrist
- Promises of action by the CMHT not followed through

**Case Study 6: Samantha**

- Three interviews (July 2014, October 2014 and March 2015)
- A woman in her 50s receiving treatment for anorexia nervosa and depression since May 2012 (untreated for 40 years prior to diagnosis)
- Support from CPN (care coordinator), a psychiatrist and clinical psychologist
- Completed a Dialectical Behaviour Therapy (DBT) programme
- Two CTPs (June 2012 and January 2014)

*Role of the Care Coordinator*

Samantha complained that the care coordinator had not discussed her case with the GP (not fulfilling her role under the Measure):

> *The care coordinator was supposed to talk to my GP before I went, about weekly weigh-ins, blood tests and prescriptions, but they hadn't done that and this made me feel awkward. I felt awkward talking about the eating disorder as it was.*

*The Care and Treatment Plan*

Samantha felt that it was beneficial that everyone involved in providing care had also been involved in preparing the CTP:

> *It was really important to me that, as well as my care coordinator and my psychiatrist, my clinical psychologist was in there too. I felt that my recovery was very much dependent on psychology. I think my last one* [CTP] *was coming from a psychiatry point of view. If I was going to have an updated plan then it was important that it reflected what was happening on the ground.*

Samantha had been frustrated when it took a year and a half for the initial CTP to be reviewed and she had to take on the responsibility for writing the new plan:

> *My second* [CTP] *was due in July 2013 and I kept asking could there be a multi-disciplinary team meeting because I had my first in June 2012, and I was obviously feeling in a better place so I was hoping that the plan would reflect this. Eventually a meeting was*

*arranged for January which I thought was totally unacceptable. They asked me if I was happy to prepare and write it and basically to do the work myself. I could see the merit in it, to ask the patient what their priorities are and what services they want, but I felt that she was putting the work onto me. I wrote the plan and I emailed it to her so I have been dissatisfied with that side of the service.*

### *Usefulness of the Care and Treatment Plan*

Samantha was grateful that the plan provided written documentation about her condition as she was able to use this as evidence to support her entitlement to benefits:

> *It was very helpful in terms of accessing benefits. Because my diagnosis was documented, it helped when I liaised with the Department for Work and Pensions (DWP).*

However she felt this and the DBT (see below) was the only benefit of the CTP, which she thought was an additional burden on time pressured health professionals:

> *I think that if the care and treatment plan was done thoroughly it would take absolutely ages and who would have time to do that? I certainly don't think that anything happens as a result of it, nothing at all!*

By the third interview, Samantha did not have high expectations of the forthcoming CTP review in June 2015 and thought her care coordinator shared her feelings about the CTP:

> *Nothing more has happened and it is up for review in June but I am not anticipating my care coordinator being proactive about that at all. For me, I think it is done and then put in a file and forgotten about. It has been useful in terms of the DWP but in terms of my own recovery and treatment I don't feel that it has been any use at all. It definitely feels like it is not one of her priorities.*

### *Dialectical Behavioural Therapy*

Samantha explained that one of the positive aspects of her treatment had

been undertaking the DBT programme. By the second interview, there was a marked improvement in her mood; her outlook was more positive and she had gained the confidence to return to work:

> *I've come to the end of DBT - I am free flying now. I hit a blip about six weeks ago and I was having dark thoughts again. It got to the point where I thought I've got to contact the Community Mental Health Team and I got to the phone and thought I've got the skills in my own hands now to manage these extreme feelings, so I put down the phone again and re-engaged very strongly with the DBT. I think if I hadn't received that therapy then I would have probably spiralled downwards and intervention would have been necessary. I thought that's really an empowering experience, to think that things had gotten quite bad but I could turn it around for myself. I think that was confidence building as well when you can cope with those extreme black thoughts. I think I've made a difference to myself. It's DBT that has been so empowering. I don't feel fixed – in adverted commas – but I've got something to turn to when the going gets tough, so I'm not swept away by the intensity of emotions … I've just gone back to work this morning for the first time in two years. That feels like a huge milestone.*

The benefits of the DBT were still helping her manage her symptoms by interview three:

> *I have been in some dark places but I don't think I have been sucked in like I would have been without DBT. It hasn't been easy but I have managed it.*

### Discharge

By interview three Samantha had seen her psychologist for the last time; she felt this was too soon and that it could have a negative impact on her recovery:

> *My BMI is 18.5 so technically I am just about recovered but I am a long way off being 20-25 and the thought of reaching 20 - well I am not sure that I can ever get there because of that stupid mental*

*block and the psychologist did challenge me and I am processing that. I feel that I am anything but recovered from an eating disorder. It is frustrating. With the DBT I can definitely say that I am equipped to deal with and handle the depression and that feels okay but with the eating disorder I don't feel confident.*

Samantha was concerned that it would be difficult to refer back to the psychologist:

*I guess I would go to my care coordinator ... I feel like there were a lot of things unsaid … I have made headway in terms of managing my depression but I have got a long way to go to knocking the eating disorder on its head and no longer feeling that it controls my life. I would have liked to have been less signed off about the eating disorder. It is almost like time is up and it is a shame you didn't get as far as you would have liked to have come. If I had just had an eating disorder for a couple of years then I would have been in a better place than I am now.*

### Good Practice
- Involving all concerned in the preparation of the CTP.
- Having a written record as evidence – in this case of eligibility to benefits.
- Value of therapeutic intervention (DBT) for self-management of mental health and thereby avoiding professional support.
- Service user being able to write the CTP (although see below)

### Areas for Improvement
- Care coordinator not following actions as promised
- Delay in reviewing the CTP – this resulted in the patient being asked to write it herself and feeling 'fobbed off' by the service
- CTP preparation burdensome for practitioners
- Limited support from care coordinator – little arising from CTP; CTP not an active document
- Discharge from clinical psychologist too early for complete recovery.

**Case Study 7: Anna (mother and carer) and Katie (patient)**

- Three interviews (June 2014, October 2014 and February 2015)
- Carer of daughter with mental health problems and anorexia nervosa diagnosed in 2010
- Admitted to an adolescent unit in SE England in 2010 for six months. Under the care of Welsh CAMHS; admitted to Bridgend Hospital in January 2012 for five months. Outpatient of Bridgend hospital. Care of local services – transition to adult services March 2015

*Accessing Services*

Katie was diagnosed with anorexia nervosa in 2010 and was admitted to hospital shortly after. Owing to the lack of available beds in Wales, she was admitted to a child and adolescent unit in SE England where she stayed for six months. This was extremely stressful and distressing for Anna:

> *It was horrendous, horrific because it was a two and a quarter hour journey so it was four and a half hours to get there and back … I used to try and go up three days a week which was really hard particularly as it was her first admission and she was so far away from home and she was at her most mentally disabled at that time. She was 13 at that point.*

*Role of the Care Coordinator*

Anna stressed that developing rapport and trust with practitioners was crucial to Katie's care but that continuity of care coordinator had not been maintained. During the first interview Anna complained that there was no 'one point of contact' which she assumed was mainly due to staff shortages:

> *I think that every two to three months she has had a new coordinator. I don't think we have an alliance of any kind to the care coordinator because we have had our primary contacts and we work with them and the care coordinator is just someone who fills in the forms particularly when she is in hospital.*

During the second interview Anna felt that staff shortages had continued to have a negative impact on the care Katie was receiving:

*Katie's consultant psychiatrist is retiring unexpectedly. One of the members of her team, who was her care coordinator, has been on long term sick. That was after the interview we did three months ago. My parent liaison contact has also not been seen or heard of until recently.*

### Care and Treatment Plan

During the three interviews, Anna discussed the value or otherwise of the CTP. Reflecting on care planning prior to the Measure, Anna felt that the CTP was an improvement. Having a document for sharing that set out Katie's care was considered to be beneficial:

*My experience of the previous system was there was hardly anything written down and it wasn't visible to me whereas this is visible to me.*

Nevertheless, Anna's view of the CTP was mostly negative and she raised a number of issues about the production and usefulness of the document. She did not agree that the CTP was recovery-based and that it was more a communication tool. The usefulness of the CTP was considered to be dependent on the ability of the care coordinator:

*I think the value and the significance of the plan is down to the person writing it. So, if you've got a good care coordinator and someone who is looking at things and opportunities, which currently they are doing, then it would be a much better plan.*

During the first interview Anna reflected on Katie's involvement in the CTP review meetings and felt that, given her age at the time of her initial admittance to services, her involvment had been limited:

*They get Katie to sign her care plan and they expect her to read it and understand it. She was 13 at the beginning and she obviously didn't.*

The failure of the CTP as an evolving document was highlighted: an answer given by Katie in one of the first of her meetings stayed in later plans word for

word, indicating that they had not sought her views on this question in subsequent plans:

> *Things like what are the views of the patient on this care and treatment plan. They asked Katie and she said 'I want this plan to support me and my family in fighting it and getting over the tough times of anorexia'. Now that comment has been repeated numerous times so it is blatantly obvious that they didn't ask her what her views are, but they expect her to sign it.*

In addition, the environment in which the review meetings took place was particulalry daunting for Katie: she felt uncomfortable when a room of up to ten professionals were all staring at her and talking about her; that she invariably had to repeat her painful history at every meeting and that there were rarely any familiar, trusted individuals owing to regular staff changes.

> *She hates it; she hates people talking about her. Back when she was in hospital she used to refuse to attend because she found it so distressing. Sometimes she would come into part of the meeting. I think the older she has got the more she has got used to it and she comes in. Sometimes she will participate and sometimes she gets really angry and she shouts and other times she is silent because she doesn't know what to say.*

Anna said that the professionals had pre-review meetings and their decisions were reported to her and Katie with no right to reply. She felt that a better approach would have been for one person to present the decision in a sensitive, person-focused way.

Anna made the point that the structure and format of the CTP were inappropriate for young people, resulting in some of the headings being left blank; for instance they *have never filled in accommodation.* She felt that the form should be targeted to the needs of young people and that they were filled in for the sake of having one on the table rather than being beneficial to Katie.

She was sceptical over whether the CTP had made a difference to Katie's overall care:

> *It is very repetitive, cumbersome, not really helpful. Whether they*

*ever really look down their list and say 'I have to do this for Katie', I*
*doubt it ... I always feel that these care and treatment plans are*
*about filling in the paperwork and they can be a bit of a pain for*
*everybody rather than documents which are referred to. They are*
*something that is on the record so they could say 'but we had a*
*care and treatment plan' and we agreed this. I don't think on a day*
*to day basis they bother to look at this.*

At the second interview Anna said that the CTP had not been updated owing
to a lack of resources and administrative support:

*The last time we met with the psychiatrist she said that we need*
*the next stage of the care and treatment plan but we haven't seen it*
*because she hasn't got any administrative support so she can't get*
*anything typed. Totally under resourced and demoralised. It has to*
*be an emergency before they can get anything done.*

At the third interview the CTP had been produced but unsurprisingly given the
delay in writing up the plan, Anna described it as *'woefully out of date'*. Katie
was asked to sign the CTP whether or not she had capacity at the time and
according to Anna she invariably did not have capacity. The carer then was
presented with a fait accompli with no option to sign it herself. As time went
on, Anna's disillusionment with the CTP increased. She described care and
treatment planning as '*futile – it all felt a bit pointless*':

*I have always said that the care and treatment plan is always out of*
*date, whether that is because Katie is very reactive and it is*
*changing so quickly or whether that is the same for everybody.*
*Ideally Katie should have been involved in putting the care and*
*treatment plan together, but she wasn't because she was in school.*
*The CAMHS nurse wrote it and I reviewed it. Katie was able to*
*read it and make changes, which she rarely does so, in a way, all*
*the plan does, is give them future access to her reviews. It is a very*
*longwinded way of saying that this person has been going through*
*treatment and these are the things they have had and by the way*
*they will have a future review – there must be a better way! It took*

*hours for me and the nurse and I to go through them.*

Asked whether there were any benefits of the CTP Anna said:

> *The only value of it for me is that if you didn't have contacts that,*
> *you know, then you would have someone in the care plan. And*
> *also that it is written down somewhere that these are the things that*
> *they have said that they will do. So you could follow up and say*
> *'hang on – you never did do this and it is 12 months on'…*

Anna was aware that the CTP was a document that should be shared
amongst professionals, ideally reducing the need for both Anna and Katie to
'repeat' information. However, Anna has had to repeat her daughter's 'story'
many times, sometimes in one admission, and has found this particularly
frustrating:

> *One of the problems with the whole process is that you will repeat*
> *things many, many times in the scope of one admission. You tell it*
> *to the doctor; you tell it to the psychotherapist; you tell it to the local*
> *nurse; you tell it to the coordinator. If somebody had some sense to*
> *record it once and communicate it to all the others it would be*
> *really, really helpful: (a) because it is really distressing to the*
> *patient and the family; and (b) because it is such a waste of time.*
> *They ask, 'How old are you? Why have you done this? How long*
> *have you been feeling like this?' Something that is quite necessary*
> *and probing once but not four times in terms of an admission. I*
> *think they are totally inefficient.*

### Support for carers

Anna has felt unsupported since her daughter was diagnosed and complained
about the limited information or support for parents particularly in a crisis:

> *As a carer I feel like the information is limited. I could have a one to*
> *one appointment with a social worker, but my view is they are there*
> *on a wet Wednesday, you turn up at 2pm and you have a chat and*
> *that's fine, you share with them a few issues but when you are in*
> *the middle of it with your child waving a knife around and*
> *screaming and shouting … it is hard to get support. The trouble*

> *with CAMHS is that they are only available 9-5pm. If something*
> *happens over the weekend, if she collapses or something serious:*
> *'call in the police' or 'take her to Accident and Emergency'.*

Anna said that she has not been able to source any support from the voluntary sector in her area:

> *There is Beat, but it hasn't got a local group because they haven't*
> *got the funding and when I phoned the helpline I just found it*
> *useless. Once you think that – then you don't use it again. In the*
> *moment you need the support but once you're through it then its*
> *forgotten and you kind of just lurch to the next thing.*

### Transition to the adult service

At the second ORS interview, Anna complained of the lack of support for transition to adult services for Katie; the lack of family support and the unresponsiveness of the services:

> *She should have had much more transition support, even now this*
> *thing of her putting on weight in the last five weeks - that has been*
> *hell because if it hadn't been for the support from the school and*
> *her boyfriend, she would have been in a much worse place. My*
> *husband and I are just living from day to day – there is nowhere we*
> *can get help from anywhere. We know the resource isn't there –*
> *there is no point in sending emails or phoning because there is*
> *nobody there to answer.*

At the third interview Katie was somewhat reassured that the CAMHS service was helping with transition, albeit for a short time:

> *One thing that is positive is that Katie' s CAMHS nurse has said*
> *that she will still work with Katie for, I suppose it will have to be a*
> *limited time, to try to support her into adult services. That is only*
> *because she has known her for so long.*

However, she remained concerned about the future and particularly as she would be one step removed from her daughter's care in adult services. This was particularly worrying because Katie has dyslexia and is inclined to not read paperwork and would miss appointments without her mother's support:

*Once she gets to 18 we won't have the right to attend meetings. So if Katie does what Katie has been doing and saying that she is grown up and will be doing it on her own – then she will be doing this on her own! Although I will be there to sweep her up if something goes wrong, as a carer you have limited opportunities to get things done. If I phoned up and said that Katie has done something – then they would just say, 'she is 18; she needs to come to us for herself'.*

Once again, she highlighted the lack of facilities and administrative support which was continuing to hamper communications:

*I have no links to adult services and neither has she – so we will be going in there blind. They are woefully under resourced and they are not even in a permanent building: they are spread out in rooms across the hospital and the child care centre. So stupid things like files being in the same building – they are not. One of the rooms is a hearing or sight testing room and it is blanked out and has one chair and a collapsible bed and we all sit along that like a row of birds on a tree. It is dreadful. She apologised that she didn't get a letter to us since our last appointment which had been four weeks ago, because it hadn't been typed in time to be sent out.*

*I think the whole process could be more streamlined and efficient. If it is using the admission notes all the way through to the letters that come out, through to how the care plans are completed. We have the actual minutes - a ten page minutes of the review meeting, so why do we need that? The care and treatment plan could be an action plan. It could be one liners rather than a rewrite.*

### Good Practice
- CTP is a record for sharing with all concerned with care and support. It identifies actions and increases accountability of practitioners.

### Areas for Improvement
- Ensure CTPs are recovery focused, not just a communication tool.
- Work towards good quality standards across all care coordinators.

- Ensure that the CTP is used as a working document and remains relevant.
- Aim to increase resources  - particularly for administrative support for clinical practitioners.
- Fully involve service users and carers in the preparation of CTPs.
- Ensure that practitioners read case notes to avoid constant repetitions by service users and carers.
- Provide information and advice to carers – especially on what to do during critical episodes that occur out of hours.
- Aim for a more responsive service – respond to carer requests.
- Consider including space for carer comment on CTPs and for carers to sign in cases where the patient has limited capacity.
- Tailor the CTP to the needs of young people.
- Adopt person-centred communications appropriate to young people – find ways of making review meetings less daunting.

**Case Study 8: Brian (carer) and Sophie**

- Three interviews (September 2014, December 2014 and June 2015).

- A man in his early fifties living with Sophie who has had a recent breakdown and now suffers with psychotic episodes, OCD and destructive behaviour although she has had no formal diagnosis.

- Brian is not a family member and is not Sophie's partner – he shared a house with her prior to her breakdown and has been her primary carer for three years.

- Brian has a long history of depression and has been taking medication for a number of years.

*Accessing Services*

Brian described the difficulties they experienced in accessing services for the first time. This was a particularly stressful time for Brian:

> *When Sophie fell ill, first of all it was several months before we could get her to a doctor. She wouldn't go and the behaviour was getting more and more bizarre.*

> *There were no social workers, no CPNs … literally, it was from one month to the next we weren't seeing anybody. I had lots of different fears; fears that she'd do something to herself; fears that I would overlook something. I mean there was a time when I had to lock the cabinet to keep sharp knives away.*

Eventually Brian encouraged Sophie to see a doctor. However, he felt that things progressed too slowly and it was only when a new GP took over that things started moving:

> *We were seeing them (Social Worker and CPN) once every three to six months and there was no investigation it was just a little chat every now and again and I thought, 'well hang on something's not quite right'.*

Part of Sophie's behaviour involved destroying household items including food, clothing and furniture. She also ran up debts in Brian's name and was

stealing from his wallet and later hacking his bank account. The financial issues were particularly stressful for Brian:

> *She's quiet, demure; she's a very gentle person but she cut up all her clothes literally, when I say all I mean everything. She sold a good chunk of the household possessions; most of her personal possessions; a good chunk of my own; a CD collection; clothes; DVD collection … She's taken out thousands of pounds worth of debt through unrestrained spending, she doesn't see - personal loans, catalogues, broadband providers, mobile phones and she's been selling them cheaply … she's been destroying them; various things ...*

This issue was included in her CTP and during the first two interviews Brian said he was relieved that he could refer creditors onto social services and that they were arranging receivership to prevent Sophie running up further debt.

However, by the third interview Brian had been informed that social services would no longer take responsibility for debt and he had been advised to seek advice from a solicitor. This was a major blow to Brian and during the interview he was visibly distressed. He felt that if he had been told this from the start he could have made other arrangements:

> *The social worker's main role was helping with the debt management but they are not going to do that anymore and according to them they weren't supposed to be doing that in the beginning – we are not trained professionals…if we had known about the receivership 18 months ago we could have done something ourselves …we could have gone to a solicitors…it has been thousands of pounds since then.*

Brian also said that since the first interview Sophie's care had been steadily declining. At the time of the first interview Sophie had fortnightly appointments with her social worker and CPN; by the third interview these appontments were fewer and Brian feared that because the practitioners felt that Sophie had made some improvements they regarded her as better, whilst, in fact, little progress had been made:

> *The other day the social worker said that everything was fine because Sophie had done some gardening; she is not fine, she stole money from me and stole electrical equipment. Do you call that alright? … They only see her once a month – there are 31 days in a month!*

### Carers support

Brian grew increasingly anxious at each interview and was receiving no support other than anti-depressants. At the third interview it was clear that he was not coping with the worsening situation and had taken a week off work because of the stress. He feared for his own future:

> *I was off sick last week – I got up on Tuesday morning and thought, 'I can't do this' so I rang in sick and … I didn't go in for the rest of the week. The problem is you feel like you are taking advantage – you leave them short staffed. In fairness they didn't challenge it because the girls made me go to the doctors last week, they were saying 'you are losing weight, you are not looking well' …I haven't slept for months; in fact I have lost the ability to sleep. I get to bed. I am tired; I am worn out but as soon as my head hits the pillow, the lights are on and the machine is turning. I am still on anti-depressants and I have been for my check-up but I didn't tell them about this because I know the routine now – the doctor says I handle it well. Thing is I have had stomach cramps. It is all related but I have had two days off for that as well. I am aware of the dangers of playing on it, if you play on it all the time they are going to say 'look, are you able to do this job?'*

Brian explained that it wasn't so much emotional support or advice that he required but practical help. *When asked about the future Brian replied* I would love to walk away…it isn't going to happen!

### Care and Treatment Plan

Brian did not feel the CTP had been useful and that it had little impact on Sophie's care:

> *It's somebody's baby. I don't know who wrote it; how specialised*

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*they are; whether it's just somebody who's come up with a few ideas or somebody who's medically trained … I have come to the conclusion that they hear what they want to hear.*

### Good Practice

- Regular practitioner visits shortly after diagnosis.

### Areas for Improvement

- Speedier access needed to secondary mental health services.

- Limited real intervention or support to service user.

- Listen to the lived experiences of carers before withdrawing services.

- Care for the carers. In this instance caring has severely harmed the mental health and well-being of the carer and yet he had received nothing in the way of support either for himself or the service user.

- Involvement of carer in preparation of the CTP.

**Case Study 9: Phillip**

- Three interviews (September 2014, December 2014 and June 2015).

- A man in his thirties, currently unemployed and living with his wife and three children

- Phillip was diagnosed as bipolar in the 1990s and was admitted to hospital for two months. He has since self managed his condition although recently has sought medical intervention as the symptoms have worsened.

- Up until the recent illness, he held managerial posts in nursing.

-  Phillip is being supported by his GP and CMHT.

*Accessing Services*

Phillip had been self-managing his symptoms for a number of years and had been prescibed Citalopram by his GP for three years. However, symptoms worsened and Phillip left his job because he was growing increasingly agitated and his GP was unable to prescribe the medication that he required, so he was referred to secondary care in 2013. Within a week he had an appointment for assessment. He was under the team for around a year before he was referred to the psychiatrist:

> *I didn't really want to change my CPN but I had to go up the services. It is part of the longer term problem, if I want to get back into work.*

Overall, Phillip felt positively about the access to services and professionals:

> *I think I have had pretty good access to the services. I was seen pretty soon after the initial referral. I have managed to get on with the CPNs. I think the psychiatrist recognised that it was a long term condition.*

*The Assessment*

The primary care team completed the initial assessment and Phillip was glad that his wife had been involved:

> *My wife came with me and I think it is much easier when my wife is with me. She can give a more outside perspective. You can think you're alright, particularly when you are on a high, you don't*

*particularly want them to change.*

### Care and Treatment Plan

During the second interview Brian said that he had requested an accurate version of the first draft of the CTP because his wife had been very concerned at the misrepresentation of their living conditions and Brian's ability to cope in the CPN's version:

> *The one the first CPN gave me wasn't really accurate and it said things like the house is well looked after and that I cleaned all day. It gave the impression that I was coping very well and that wasn't true and my wife didn't really want those things said on record for the whole world to see.*

The task of writing the CTP was then left to Phillip who admitted that it was difficult due to his symptoms:

> *So I wrote a care plan around what I want from the CPN. The problem is I can't function ideas together so what she got was a mismatch of some things typed and some bits written on all bits of paper and dumped together. So she would have had to have gone through this to put it together and make sense of it. I haven't received a copy of it yet.*

### Progress

During the three interviews Phillip was mainly concerned about his prospects for employment and his 'functioning' and ability to perform day-to-day tasks. During the second interview Phillip had recognised that he needed to concentrate on 'getting better' before thinking about employment, although he was in the process of arranging voluntary work:

> *It is looking less likely that I will be able to get back into my former employment. I think now I realise that I need to get myself better first. I am a bit at a loss because the work had been everything. Everything is okay when you wrap yourself up in work because you don't have to think about things. Now I have to think about getting better. I am beginning to be more realistic …*

Performing domestic tasks was a problem for Phillip and a particular issue since he looked after his three young children. Unfortunately, he felt that his abilities were becoming worse and in the second interview he said:

*My functioning has probably gone down. I can't multi task. I am losing skills and I don't know how I will get all of those back. In the CTP it does say about getting me an independent living support worker so that may help.*

By the third interview, Phillip was resigned to the fact that his symptoms were unlikely to improve in the short term and explained that the CPN and GP had made the decision to prescribe diazepam medicate his bouts of extreme agitation:

*I am on a slow burner and I am probably going to be as well as I am going to be for a while. I am beginning to realise this is how good I am going to be – I need to deal with short term problems. The last time I spoke to you I was very agitated. I am feeling a bit more mellow now. The CPN advised me to take diazepam if I am getting agitated, rather than changing my medication … at the moment I am okay. I just get a bit overwhelmed when there are a lot of problems – I can't seem to cope.*

By the third interview, he had not yet secured a voluntary post and had not been provided with the help of an independent living support worker.

***Good Practice***
- Speedy access to secondary care following GP referral.
- Involvement of family member (wife) in original assessment.

***Areas for Improvement***
- Limited intervention or support apart from medication.
- Focus on the positive by practitioners when writing CTP, rather than the real experience.
- Failing to work with the patient and his wife to prepare the CTP; in the first instance writing an inaccurate one and then handing it all to the service user to write in spite of his chaotic state.

- Not providing a service identified in the CTP (independent living support worker).

# Appendix 2: Part 2 Profiling information: Service users and carers/relatives

| | Part 2 Participants | |
|---|---|---|
| | Total: 99<br>Service users: 60<br>Carers: 39 | |
| **Age** | SUs | Carers |
| 16-24 | 7 | - |
| 25-34 | 6 | 1 |
| 35-44 | 5 | 4 |
| 45-54 | 21 | 3 |
| 55-64 | 15 | 13 |
| 65-74 | 6 | 15 |
| 75+ | - | 3 |
| **Gender** | | |
| Female | 33 | 25 |
| Male | 27 | 14 |
| **Working status** | | |
| Working | 10 | 16 |
| Volunteering | 14 | 10 |
| **Ethnicity** | | |
| White British | 55 | 32 |
| BME | 5 | 7 |
| **First language** | | |
| English | 49 | 31 |
| Welsh | 8 | 3 |
| Other | 3 | 5 |
| **Physical Illness/disability** | | |
| Limits a little | 5 | 12 |
| Limits a lot | 3 | 6 |
| Living with learning disability | 5 | - |

## Appendix 3: Mental Health Practitioners involved in the study

Mental Health Practitioners working in each of the seven Health Boards in Wales participated in interviews or focus groups throughout the study in relation to the four parts of the Measure. Their job roles are presented below.

**Primary Care Practitioners**

Three focus groups – one in each of three Health Boards involving 29 practitioners:

Strategic Leads and/or Programme Managers and County Managers for Part 1 of the Measure; Nurse assessors and practitioners; Senior Nurse OPMH; Community Development Workers; Operations Manager; Psychologist; Psychiatrist; Team Leaders; Mental Health Development Manager; Managers of CAMHS Primary Mental Health Support.

**Secondary Care Practitioners**

Four focus groups – one in each of four Health Boards; qualitative interviews and written responses involving a total of 41 practitioners:

Heads of Adult Services, Children's and Family Services and Children's Services;

Team Manager, Assistant Managers, Heads, Clinical Psychologist and Occupational Therapist for older adults services; Team Leaders/Managers, Assistant Head; Community Services Manager; Occupational Therapist and Student Nurse in specialist learning disabilities services;

CTP Trainer; CTP and Audit Officer;

Team Leader, CPNs, Occupational Therapist, Social Worker, Integrated Manager in CMHTs;

CPN Lead for Forensic Team;

Prison in-reach Nurses;

Service Improvement Partnership Lead and Part 4 Lead;

Manager, Assistant Head of CAMHS;

Service Improvement and Partnership Lead;

Psychiatrists;

Member of Home Treatment Team;

Adult Social Services Manager;

Day Centre Nurse Manager;

Social Work student.

**Voluntary Sector Practitioners**

Representatives from the following organisations were involved in practitioner focus groups and interviews (20 participants). It should also be noted that voluntary sector staff participated in many of the service user/carer sessions and were invited to share their opinions. A further 19 were involved in this way. In the end, 39 staff from the following voluntary organisations were involved in the study:

Advocacy Support, Cymru; Barnardo's; Cais (Parabl); Cardiff and Vale Action for Mental Health (CAVAMH); Conwy and Denbighshire Advocacy Service; Flintshire Advocacy Service; Gofal; Gwynedd and Ynys Mon Advocacy Scheme; Hafod Care; Mind; Hafal; Gwent Association of Voluntary Organisations (GAVO); Interlink; Eiriol; Mental Health Matters Wales; Patients' Council; Powys Association of Voluntary Organisations (PAVO); Tros Gynnal Plant; Unllais; Vale Council for Voluntary Services; West Wales Action for Mental Health; YMCA.

The table below presents a distribution of practitioner type by Health Board area.

|  | ABMU | ABU | BCU | C&VU | CTU | HDU | PT |
|---|---|---|---|---|---|---|---|
| LPMHSS | ✓ |  | ✓ |  | ✓ |  |  |
| Primary CAMHS | ✓ |  |  | ✓ | ✓ | ✓ |  |
| Memory clinics |  | ✓ |  | ✓ |  | ✓ | ✓ |
|  |  |  |  |  |  |  |  |
| CAMHS | ✓ |  |  | ✓ | ✓ | ✓ |  |
| CMHT |  |  |  | ✓ |  |  | ✓ |
| Crisis |  |  |  |  |  |  | ✓ |
| Learning Disabilities |  | ✓ |  |  |  | ✓ |  |
| Forensics |  |  |  | ✓ |  |  |  |
| Older People's Mental Health |  | ✓ |  | ✓ |  | ✓ | ✓ |
| In-patient |  |  |  |  |  |  | ✓ |
| Prison in-reach |  |  |  | ✓ |  |  |  |
| Third Sector | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Advocacy organisations | ✓ | ✓ | ✓ | ✓ | ✓ |  | ✓ |