Shared Decision-Making 2012-2015

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1 Acknowledgements

With thanks to all the clinicians and young people who contributed to this project

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2 Executive Summary

2.1 Aim

This three year DH funded project set out to develop and disseminate a range of free resources and training to child mental health professionals to help them adopt 'Shared Decision Making' (SDM).

See appendix 1 for a project summary.

2.2 Activity

2.1.1 Materials were developed

2.1.2 Training courses were developed and held, such as Promoting Active Choices Together – PACT.

2.1.3 Evaluation was undertaken

2.3 Outputs

See attachments (PowerUp toolkit and SDM practitioner training manual)

2.3.1 Materials and tools to support implementation of SDM in CAMHS (PowerUp toolkit)

2.3.2 Training in SDM in CAMHS (PACT)

2.4 Evaluation

To evaluate the direct impact of these resources and training events by interviewing young people and professionals from services that have accessed these resources to their feedback on these and how they are affecting their practice. It was noted that whilst most attending the training reported that they were already positively disposed towards SDM they valued the impact of the training "*SDM feels natural, but the training has made me more mindful of it, not to let it slip and keep the young person at centre"*

A mixed qualitative (5 case studies) and quantitative evaluation (pre and post training questionnaires) was undertaken to explore and assess the impact of the materials and training on implementation of SDM. Materials were well received and use and training found to have impact on professionals attitudes and willingness to embrace decision-making although not necessarily on reported behaviours or information giving. Barriers to implementation identified included appropriate I support and sufficient time to trial approaches.

3 Background

Shared Decision Making (SDM) aims to empower children and young people and their families to play an active part in decisions about their care in order to lead to increased choice, personalisation and empowerment (Abrines-Jaume et al., 2014; Coulter, Edwards, Elwyn, & Thomson, 2011).

As we have noted elsewhere; “There is an increasing demand from policy makers and others to include more shared decision making (SDM) in healthcare (Department of Health, 2012; The Health Foundation, 2012). In particular, the Chief Medical Office recently called for more SDM in provision for children and young people (Chief Medical Officer, 2013). There is increasing evidence that ensuring collaborative practice and SDM in interventions with those with long term physical or mental health conditions may contribute to improved self-management and patient activation (Hibbard, Mahoney, Stock, & Tusler, 2007; Storm & Edwards, 2013) along with better treatment outcomes (Storm & Edwards, 2013). Whilst the mechanism of impact of SDM is not fully clear, evidence from across a range of healthcare settings suggests that implementing SDM tools may improve increase autonomy and self-confidence, which is in turn associated with better treatment adherence and improved clinical outcomes (Burton, Blundell, Jones, Fraser, & Elwyn, 2010; Center for Substance Abuse Treatment, 2009; Desroches, Lapointe, Deschenes, Gagnon, & Legare, 2011; Edwards & Elwyn, 2006; Joosten, De Jong, de Weert-van Oene, Sensky, & van der Staak, 2011; Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007; Wilson et al., 2010).

3.1 SDM in CAMHS

The implementation of SDM in CAMHS is a relatively new phenomenon but with some early indications of positive uptake (Abrines-Jaume, et al., 2014) and involves complexities and challenges due to ongoing complex relationships over time and the need to balance multiple stakeholder views (e.g. parent, child, clinician).

SDM in CAMHS is taken to involve the following five steps (Wolpert et al 2014):

1. Young people, and their families, and those working with them agree key problems and goals together
2. Those working with young people, and their families, support them to understand the options available to them
3. Young people, and their families, and those working with them agree which options for help they will try
4. Young people, and their families, and those working with them review progress
5. Young people, and their families, and those working with them discuss options and make any changes if necessary

Drawing on earlier work and trialling, this project set out to refine and develop materials to support spread of implementation of SDM by:

a) Developing materials and tools to support implementation of SDM in CAMHS.

b) Providing training in SDM in CAMHS (Promoting Active Choices Together- PACT).

4 Materials and training

4.1 Content

Over the course of three years, the project developed and disseminated a range of free resources and training to child mental health professionals to help them adopt ‘Shared Decision Making’ (SDM). These resources were developed, tested and refined with central input from service users. The outputs developed from this were: Promoting Active Choices Together or PACT helped to improve professionals’ attitude toward, confidence in, and frequency of supporting children, young people, and families engage in SDM, and Power Up, a tool kit for young people designed to help them have a voice in how they want support services to work with them.

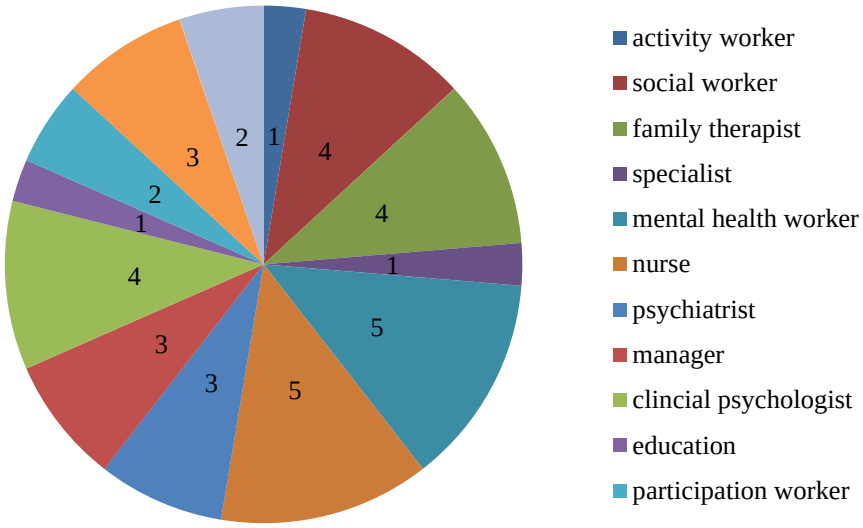
5 Evaluation

5.1 Quantitative

To evaluate the effectiveness of PACT in improving professionals’ attitude toward, confidence in, and frequency of supporting children, young people, and families engage in SDM, a pre-post service evaluation design was used. Professionals attending PACT complete a survey up to four week before attending training and again up to four week after attending training.

Overall, 109 professionals attended PACT training. Of those who attended training, 38 professionals completed both the before and after survey. Figure 1 shows the reach of the training and a range of professionals attending PACT, with mental health workers, social workers, clinical psychologists, family therapists, and social workers being the most frequently attending professionals.

Figure 1. *Types of professionals attending PACT.*



Professionals attending PACT came from mostly Tier 2 and 3 services, comprised of outpatient and specialist services, in line with the most prevalent types of child and adolescent mental health services (see Figure 2-3).

Figure 2. *Types of services reported by attendees.*

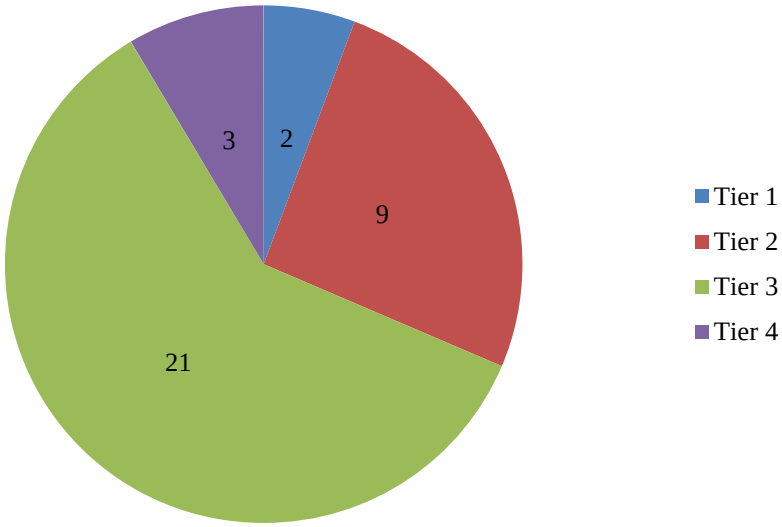
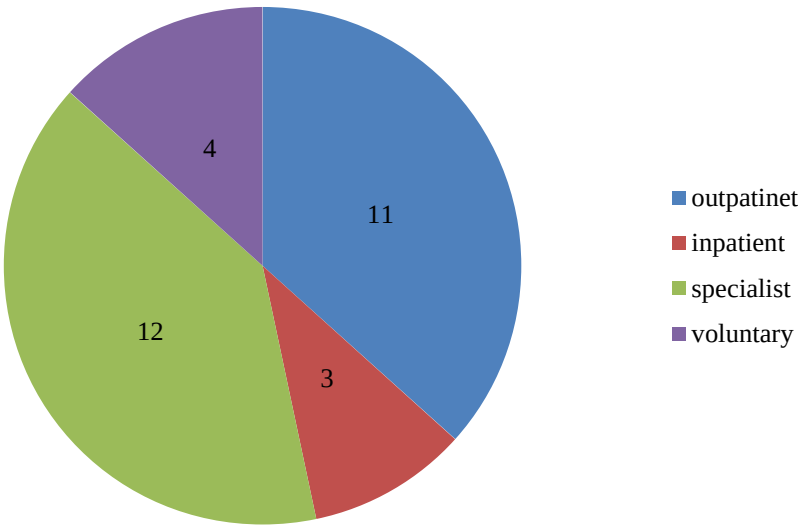


Figure 3. *Types of services reported by attendees.*



Most professionals worked full time (22 or 58%). Overall, three professionals (8%) had no hours of patient contact a week, 4 (11%) had 1-5 hours, 10 (26%) had 6-10 hours, 9 (24%) had 11-15 hours, 8 (21%) had 16-20 hours, and 4 (11%) had 21 hours or more, which suggests that professionals had substantial active caseload.

In line with the aims of the survey, robust existing measures were used to professionals' attitude toward, confidence in, and frequency of supporting children, young people, and families engage in SDM.

To measure attitude toward SDM, the Clinical Decision Making Style (CDMS) was used[1]. The CDMS measures professionals' attitudes towards SDM (15 items; e.g., "Important treatment decisions should be made solely by the treating clinician" which were rated from 0 [strongly disagree] to 4 [strongly agree], "Who should make the following decisions? If the

[1] Puschner, B. et al, (2013). Development and psychometric properties of a five-language multiperspective instrument to asses clinical decision making style in the treatment of people with severe mental illness (CDMS). *BMC Psychiatry, 13:48.* Permission was received from the first author to use the CDMS and modify items to make them applicable to professionals working in child mental health settings.

service user can return to school" which were rated from 0 [me] to 4 [service user]) and professionals' desire to share information with service users (5 items; e.g., "The worse the illness becomes, the more he/she should be informed about the facts" which were rated from 0 [strongly disagree] to 4 [strongly agree]).

To measure confidence in supporting SDM, the 8-item SDM Self-Efficacy (SES)[2] was used. Professionals were asked the initial question stem: "How well do you feel able to perform the following activities?" Next, a list of activities was presented related to confidence in SDM, (8 items; e.g., "Communicate with a young person that a decision needs to be made about treatment"). These activities were taken from the aims of the PACT module. Professionals responded to the activities on a six-point scale from not at all well (1) to extremely well (6).

To measure frequency of supporting children, young people, and families engaged in SDM, the Frequency of SDM FSDM was used[3]. The FSDM measure asks how often professionals performed SDM behaviours over the past two weeks (4 items; e.g., "How often did you encourage service users to ask questions or raise concerns?" which are rated from never [0] to always [3]).

Professionals' attitude toward SDM significantly increased after training, as shown in Figure 4; $t(27)=2.19, p<.05$. Changes in attitudes toward giving young people information did not significantly change, but may be because it may not be perceived as appropriate to give young people more information that could potentially be distressing.

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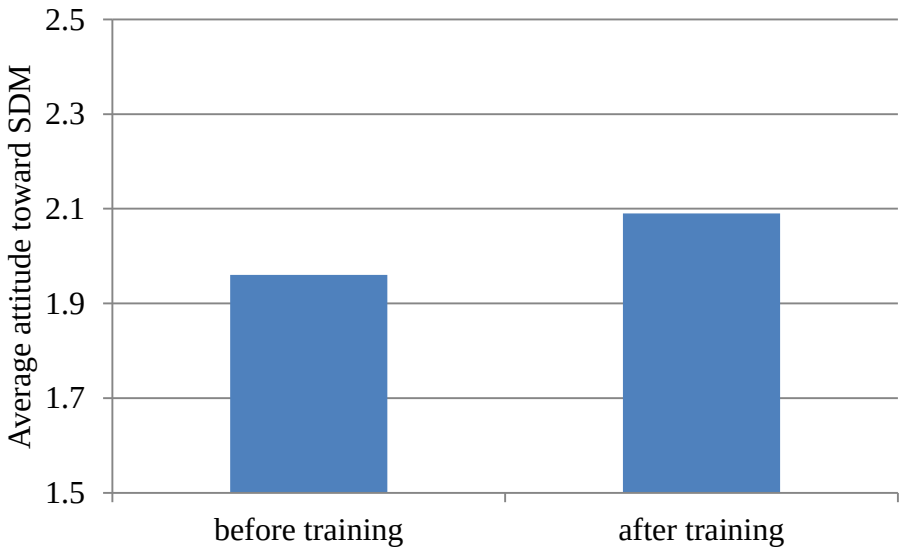
[2] The structure of the SES was based on previous confidence measures: Edbrooke-Childs, J., Wolpert, M., & Deighton, J. (2014). Using Patient Reported Outcome Measures to Improve Service Effectiveness (UPROMISE): Training clinicians to use outcomes measures in child mental health. Administration and Policy in Mental Health and Mental Health Services Research. doi: 10.1007/s10488-014-0600-2
Michelson, D., Rock, S., Holliday, S., Murphy, E., Myers, G., Tilki, S., & Day, C. (2011). Improving psychiatric diagnosis in multidisciplinary child and adolescent mental health services. The Psychiatrist, 35(12), 454-459. doi: 10.1192/pb.bp.111.034066

[3] Butler, A. M. (2014). Shared Decision-Making, Stigma, and Child Mental Health Functioning Among Families Referred for Primary Care–Located Mental Health Services. Families, Systems, & Health. Advance online publication. doi: 10.1037/fsh0000004. As the FSDM is completed by parents, it was modified to be applicable to professionals.

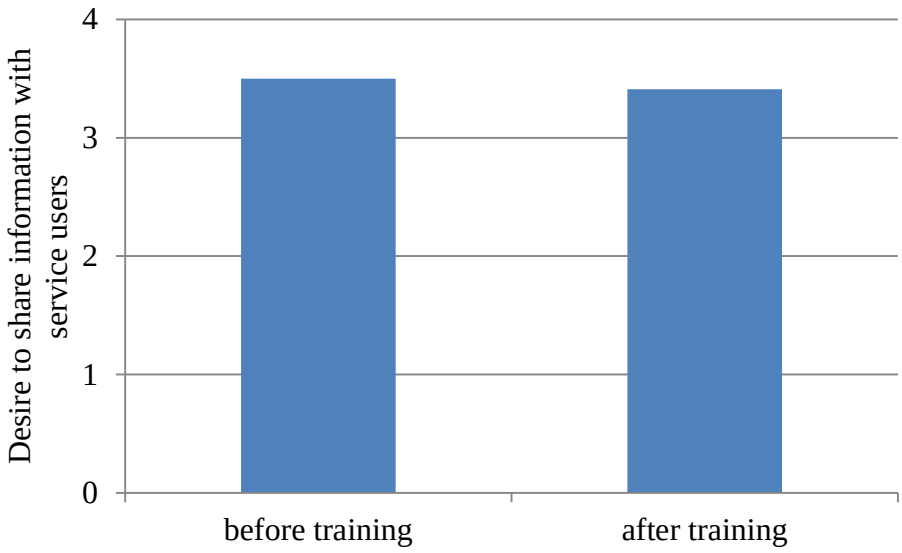
Figure 4. *Professionals' attitude toward SDM before and after training.*



N=28.

Professionals' desire to share information with service users did not significantly change after training, as shown in Figure 5. Despite having more positive attitudes toward SDM after training, professionals may have concerns with sharing information with children and young people, especially during episodes of distress. Therefore, professionals may not necessarily have perceived sharing information as necessary to support SDM, whereas giving children, young people, and families the opportunity to raise questions and concerns may be more appropriate.

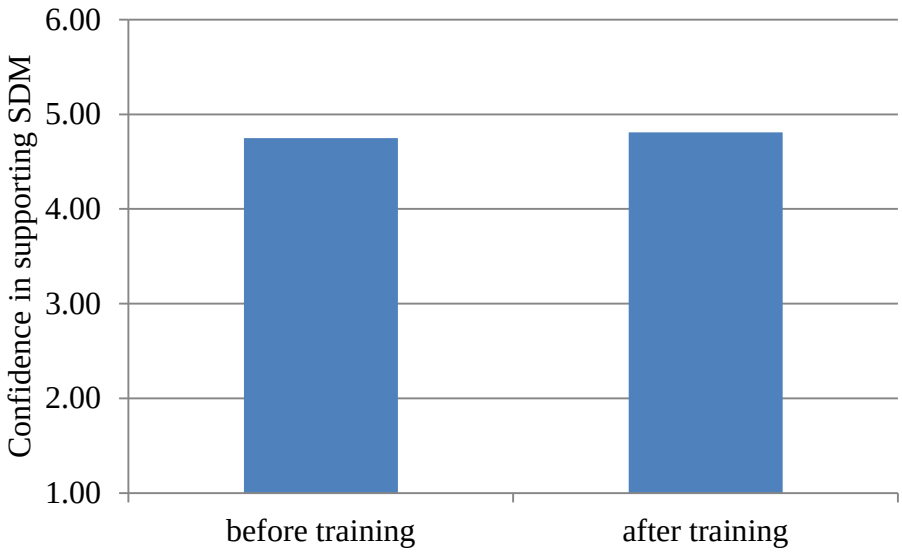
Figure 5. *Professionals' desire to share information with service users before and after training.*



N=37.

Professionals' confidence to support SDM did not significantly change after training, as shown in Figure 6. Approximately 70% of respondents reported feeling very confident to support SDM before and after training. Higher ratings of feeling extremely confident to support SDM may be unlikely to observe with a short follow up and a longer follow up may enable further changes to be observed as professionals embed and utilise learning, thereby increasing in confidence through experience.

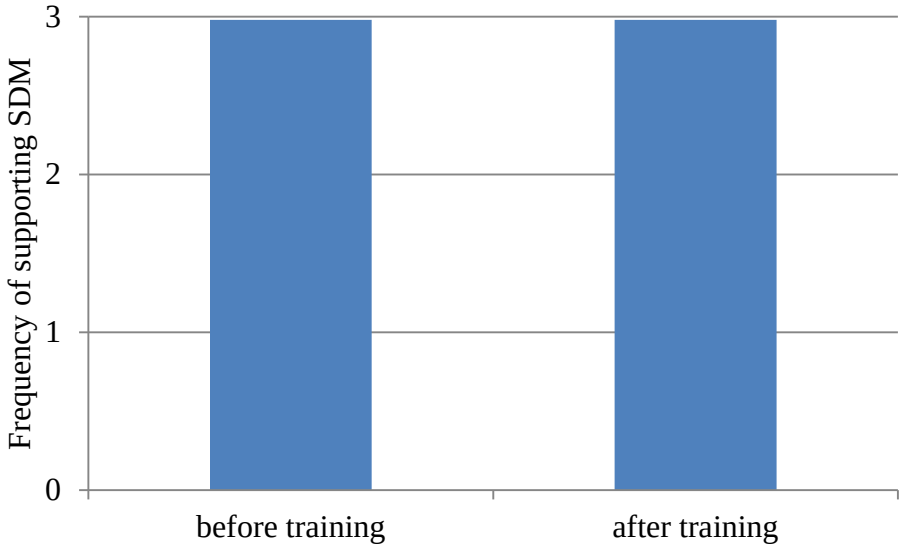
Figure 6. *Professionals' confidence to support SDM.*



N=35.

The frequency professionals support SDM did not change after training. Professionals' reported nearly always supporting SDM both before and after training, suggesting a ceiling effect. This finding may also reflect a selection bias, in that professionals who already endorse and agree with SDM may have been more likely to self-select to attend training. Future projects and evaluations should explore the best ways of promoting PACT training with professionals less engaged with SDM at baseline.

Figure 7. *Professionals' frequency of supporting SDM.*



N=32.

5.2 Qualitative case studies

Five in-depth qualitative case studies were collected via interviews following attendance at PACT training. These took place roughly two months after the participants attended training to give them time to use the principles of shared decision making in their practice. The case study questions probed how the respondents used shared decision making as part of their clinical practice.

All those who took part in the case studies reported already having a positive attitude towards shared decision making, (this may be an effect of selection bias – as those who agreed to be interviewed may have been the most positively positioned in relation to SDM). However, they all pointed out that both the training and the materials had helped prompt them to put their principles and values into practice and keep the young people at the centre. Both training and the materials seem to help act as prompts and prevent slipping back into old habits or ways of doing things

Case study 1: *previously [before attending the training] there wasn't an explanation about why we agree a plan together. I wasn't explicit, but it's good to explain they should be active participants in their plan. It's easy to go back to old habits, I'm trying to think in supervision 'have I done it?', and 'can I go back and do it?'*

Case study 2: *SDM feels natural, but the training has made me more mindful of it, not to let it slip and keep the young person at centre.*

Many of the interviewees stressed their commitment to continue using the tools:

Case study 3: *I will continue with what I'm presently doing – i.e. using assessment and goals and priority areas. I will continue to use the bullseye as a means of thinking about future sessions. I used the CAMHSWeb applications with young people doing with OT specific work. I will think about using with young people who don't have OT specific work. Using the bullseye will definitely continue.*

5.2.1: Step 1: agreeing goals

The interviewees noted that setting goals with young people from the start was the basis for changing the power relationship throughout therapy:

Case study 3: [*via the] assessment tool you get the areas young person wants to work on and then generate SMART goals for the 4 areas. I used CAMHSweb here again – the doodle goals. He chose his priority out of the treatment options e.g. community based work, role play, session based. Doodle goals gives a visual representation of options generated from him and from his priorities. It also gives the young person an opportunity to raise things themselves and review. It's a very inclusive way of working; it feels like a more equal relationship rather than a prescriptive one. It shifts the balance to being equally active in the process, and empowers young people to feel they have control and have a voice. It's not a prescriptive medical model and this helps balance things out.*

Another interviewee noted that they were more likely to explicitly encourage active involvement in goal setting [case study 1]:

I feel a change (since training) because before I was setting goals but not explicitly saying we all have a role to play and saying they have to actively participate.

The interviewees noted that the materials and training encouraged them to make the SDM approach central to their relationship with service users from the start [case study 1]:

Being explicit – I've found that helps me a lot. A lot of people come with view you will sort them out, but by agreeing joint working it helps [support SDM].

They noted this had implications for working in a range of ways and gave examples of how a focus on agreed key problems and goals would infuse the therapy and inform all stages:

Case study 4: *I understand it's about a flattening of power and setting a culture in way session goes that everyone opinion is valuable, its complex.*

....I had a really challenging girl, 14 who was not at school. She was desperately unhappy and isolated, she was very difficult to engage, she didn't want to come to session, and she had already done lots of research about treatment and come to the conclusion it wouldn't help her. We came to a compromise to meet for three sessions and then talk about whether it had helped. At end of the second session she decided it wasn't working, so we looked at more pragmatic ways she could be treated. For example via a reintegration project - a home education service, which also take the young people on group activities e.g. outward bounds with other young people to get used to that reintegration. She wanted it and the family agreed, I offered the family some ongoing support, and the offer to her is that she can come

back anytime, so she is still on file. Things are going quite well, I'm just contact with parents at moment, and I also support the service through a consultation model.

Case study 2: *We sit down and really speak to them; drug and alcohol services are often difficult concepts to grasp.*

Before, I did a lot of talking, but when I had the tablet, it was more helpful. Showing was more effective than telling. Using other tools and actually visiting clinics was great way to talk about treatment, and over time she grew more confident about what she wanted. She didn't want to be in a big clinic, but somewhere more homely that would be nurturing.

5.2.2 Step 2: looking at options

The materials and training encouraged explicit discussion of service users as having a right to information and choices available.

Case study 1: *Now I'm more about explicit about purpose about why they should be involved…if we work together it will be more effective than if I just tell you want to do. Being explicit about saying yes we need to share things and participate equally – because in the long term you will face similar issues and being active gives you the knowledge for the future.*

It's about explaining options available, and then weighing up what they can commit to, for example I was using CW and we went through that with them, saying to them we need to make a decision jointly, but highlighting issues of risk that we are working on this together but if I've identified a risk I need to take somewhere else – and understanding what I'm saying or what I mean, so I'm much more explicit about saying these are the options, exploring together what works for them and explaining something similar to their parents.

The case studies revealed examples of when SDM helped identify different choices for young people in relation to family involvement and this might be an ongoing process.

Case study 5: *I see her on her own and I see her with mum; she's open with me and tells me things and I can ask her what she feels about this being shared with mum. There was one thing she didn't want mum to know, and I said to be honest it think it will be helpful to tell mum. In the end it was the best case and we told mum on the third session…it is a process, but could also be something simple and easy.*

They also revealed practitioners trying new ways of exploring options [case study 2]:

The difference between statutory and non-statutory and what that means for access etc.; I try to explain as much as I can, but it really helps if you can show different options rather than saying 'why don't you try centre x, and z' .

For example, I was meant to be accompanying my client to an appointment with the police, the appointment got cancelled so we went to a coffee shop instead. We were able to use that hour looking a different clinic websites, and google mapping how to get there, understanding what was in the local area. By showing rather than telling it helped my client

get a sense of the organisations and decide which one was right to seek recovery in. I was surprise to find she wanted to be out of London, and whilst it look a while for this information to be offered it was really useful to spend that time together.

5.2.3 Step 3: making choices

The interviewees noted that allowing young people to make choices had to be in a context of limited options but to retain a young person-centric view as central [case study 2]:

SDM makes you more mindful to be inclusive of people around you and the young person themselves. For example I have a case where a young person is due to give birth in June and needs to make a decision about where they are going to live, its helping me keep their view at the forefront when we're working with other services.

Shared making of decision could mean that options emerged that were uniquely tailored to a young person's needs (personalised care) as in case study 2:

We talk via the application [CAMHSweb] about decisions: e.g. going back to school and the best way to approach this. I've used the tools to tease out pros and cons, e.g. do I go back to school for an hour (staged return), half a day, or full day? We used the tool to break down what would be positive and what else we needed to consider. It was helpful to weigh up pros and cons and the young person was able to make an informed and measured decision. We broke it down into more detail and unpicked elements...They went back for one lesson to start with, and then a half day, and then full day. The graded approach helped the young person feel confident. We also looked at what support was needed: e.g. dropped off and picked up on first day.

They gave examples of how can mean less resource use as the young person made an informed decision not to take up services as well as to take them up.

Case study 4: *Well I work with tier two CAMHS and had a young girl who had low mood and was self-harming, but she did not totally meet the criteria for depression. I talked to her alone about what she thought might be helpful and she thought she did want to talk about it a bit more, I explained CBT and other coping strategy, and resources I knew were available in her school. We then talked with mum and they made decision to have counselling in school. She was 13.*

Training and materials help keep focus on patient and their unique decisions [case study 2]:

It gets you thinking and brings you back to being young person-centred. It helps you keep including and encouraging young people to be active in their treatment and decisions. It keeps dialogue alive. It's easy to formulate SMART goals and follow these without thinking about whether are we going in right direct, things can come up and you think 'ahh I should spend some time on that'. It also gives the young person an opportunity to raise things themselves and review.

5.2.4 Step 4: reviewing options

The materials helped practitioners to ensure that young people and their families knew they had a part to play in decision making and in challenging decisions as relevant [case study 5]:

We tried to introduce shared decision making with ROMs, and all of a sudden clinicians were passionate about it as their clients saw self-improvements and self-esteem rose as they saw their progress being recorded and achieved. It was a switch as we saw changes better and quicker. However when (SDM) is not used fully there is a mismatch, it needs to be used appropriately for clients to see their achievements and see the steps needed to keep moving.

The SDM materials helped even with very difficult decisions:

Case study 2: *We have a number of clients who are suicidal and it's really useful to use SDM in putting together their safety and support plans as well as being mindful to review these and make sure clients who need it have it. Yes I think it's made me more mindful to review these plans and make sure they cover everything.*

My client is currently detoxing prior to going into rehab. We have had to change rehab clinic because of bed availability. She wanted to be in the country but the clinic switched us to another branch in London. This decision is out of her hand, and mine but I still tried to be inclusive and be honest with her about options. I try to give all the information, as much as possible about what is available and be mindful to communicate as much as possible.

I think a person's free will has a bigger influence on their actions, but SDM gives framework for conversations.

Case study 5: *Well it's automatic really. It's about checking understanding, seeing they are happy, not uncomfortable, or does it need speaking about in different way to give more clarity. I need them to be inputting, so it's come back at me whilst I'm talking, they are coming back at me with options and decisions.*

SDM creates opportunities to be open to learning for young people, and their families, and those working with them and for reviewing progress [case study 3]:

As a service we are trying to use ROM regularly, and encourage using that. Traditionally we used ROM as mandated by trust just giving forms and I actually said to someone yesterday it's about dialogue and can be used to review treatment. This is not perfect but we are aiming towards it.

Tools can prevent clinicians falling back into bad habits:

Case study 4: *It's the start of journey. I have to be open myself and make sure young people have a voice…it's not my assumption about what is the most helpful thing it's what the young person needs (at that time). It's a process over time and they are the experts on what they are ready to do and what they are not, we think we know and we don't.*

Case study 1: *Well, like the girl who had anxiety and we had get a second opinion. What we did with family didn't seem to be moving forward, I think having option for second opinion or*

being able to change the opinion and being able to say this is recommend but it's not right for everyone, if not working we can consider other options is important.

Case study 3: *I'm using feedback bullseye to have dialogue session by session. I'm then using feedback to inform next session. It brings out each session and gives me the opportunity to review what I'm offering to young person session by session. It helps us [me and young person] to hone in as they think about it rather than six weeks later. It's more immediate and therefore I can build in things at the time. Sometimes we will change next week session because of something that comes up. The young person feels more in control because they are driving it and there is a big impact in that respect: i.e. they know what's coming next session because they planned it rather than waiting and wondering what they are going to do.*

5.2.5 Step 5: make changes if necessary

Case study 1: *They've got a right to say if it's not what you expect, sometimes they get mixed info from different professionals. SDM helped me let the parents know they can challenge and this keeps me on my toes. It also helps evaluate where you are at with the young person and people feel like they are able to do something, it's not a dependency but builds resilience for future of young people and family. They come and think what will you do for them, but with SDM at the end they have done the whole thing themselves and they are in a better place to improve life and they can challenge - you give them right to challenge - (and if they don't have right to challenge it can create a negative cycle). We need to question along way – I say we already agreed we can ask each other questions.*

5.3 Overall views

- The SDM process/framework enables positive conversations to occur in a natural way.
- It keeps the young person at the centre of processes e.g. ROM collection or liaison with other services.
- It enables young people to overcome challenges or setbacks and feel in control of process.
- Two way communication and dialogue are consistently highlighted.

5.4 Challenges notes

- Decisions around resources where options on offer are limited can be challenging.
- Need to invest time in the process

5.5 Conclusion

This evaluation has highlighted a number of key learnings from this project of the impact of SDM training on services. There are high levels of support for SDM existing out in the field. Training and resource materials helps prompt clinicians to put their principles and values into practice and keep the young people at the centre. SDM enables clinicians to allow young people to make choices in a context of limited options and retain a young person-centric view as central; it enables young people to overcome challenges or setbacks and feel in

control of process and can prompt discussions which previously may have not been perceived as relevant.

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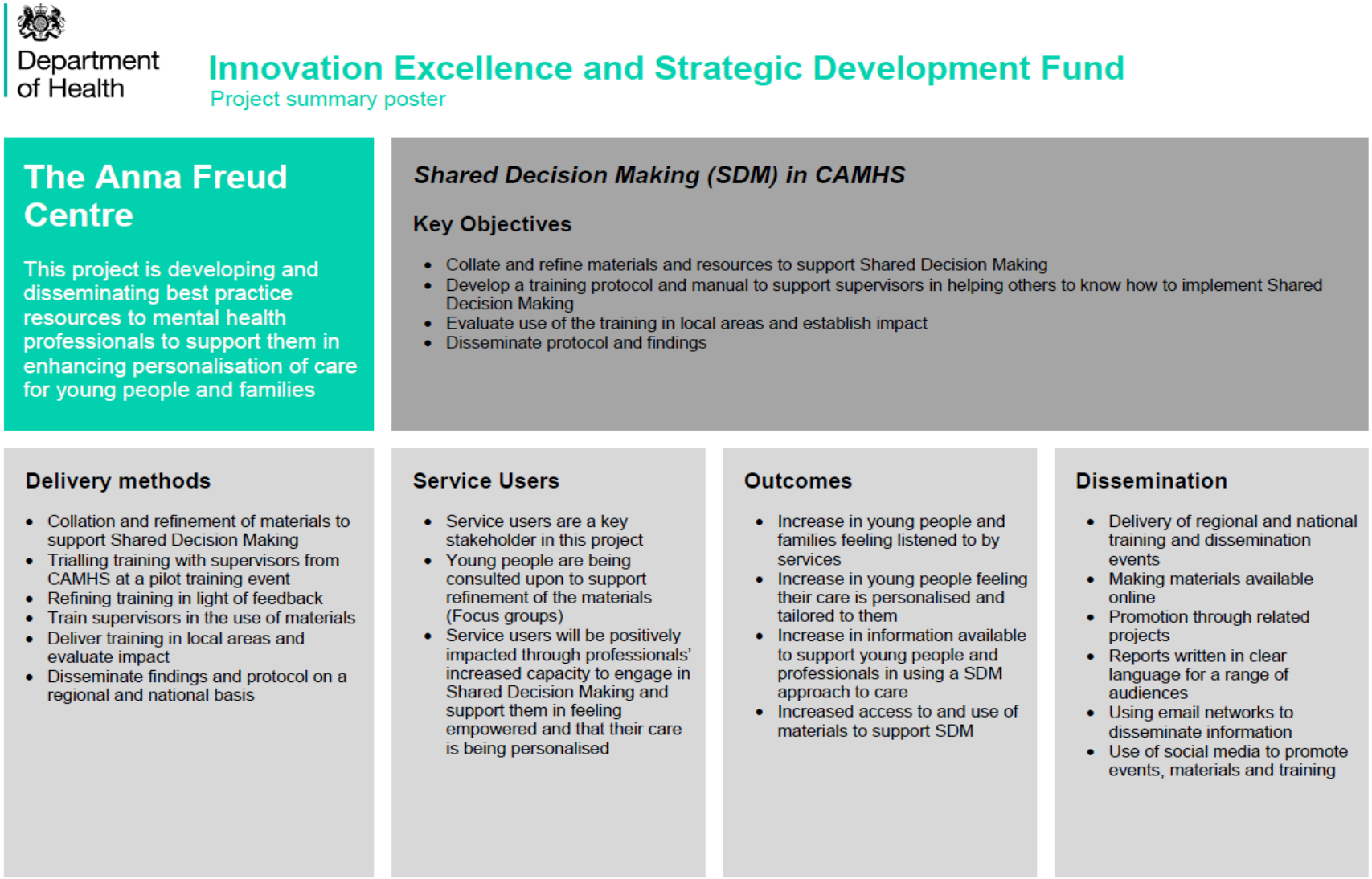
7. Appendix



Department of Health

Innovation Excellence and Strategic Development Fund

Project summary poster

The Anna Freud Centre

This project is developing and disseminating best practice resources to mental health professionals to support them in enhancing personalisation of care for young people and families

Shared Decision Making (SDM) in CAMHS

Key Objectives

- Collate and refine materials and resources to support Shared Decision Making
- Develop a training protocol and manual to support supervisors in helping others to know how to implement Shared Decision Making
- Evaluate use of the training in local areas and establish impact
- Disseminate protocol and findings

Delivery methods

- Collation and refinement of materials to support Shared Decision Making
- Trialling training with supervisors from CAMHS at a pilot training event
- Refining training in light of feedback
- Train supervisors in the use of materials
- Deliver training in local areas and evaluate impact
- Disseminate findings and protocol on a regional and national basis

Service Users

- Service users are a key stakeholder in this project
- Young people are being consulted upon to support refinement of the materials (Focus groups)
- Service users will be positively impacted through professionals' increased capacity to engage in Shared Decision Making and support them in feeling empowered and that their care is being personalised

Outcomes

- Increase in young people and families feeling listened to by services
- Increase in young people feeling their care is personalised and tailored to them
- Increase in information available to support young people and professionals in using a SDM approach to care
- Increased access to and use of materials to support SDM

Dissemination

- Delivery of regional and national training and dissemination events
- Making materials available online
- Promotion through related projects
- Reports written in clear language for a range of audiences
- Using email networks to disseminate information
- Use of social media to promote events, materials and training