Closing the Gap through Changing Relationships

Final Report for Closing the Gap through Changing Relationships (award holders)

Project Title:	Closing the Gap: Shared Decision Making in CAMHS
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Partner Organisations:	CORC, YoungMinds
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With thanks to staff of the four centres of excellence whose work was integral to this project:

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- Bluebird House, Southern Health NHS Foundation Trust

- Bradford District Care Trust CAMHS and Barnardos'

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ABSTRACT

Young people attending specialist Child and Adolescent Mental Health Services (CAMHS), for a range of problems including self-harm, depression, anxiety, family relationship difficulties and assessment for neurological disorders, are often bewildered and disempowered.

This project attempted to close the gap between current practice and the rhetoric of "collaborative working" and "user participation" in order to ensure young people become active participants in their care by developing and promoting models of shared decision making (herein referred to as "SDM"). "Closing the Gap: Shared Decision Making in CAMHS" involved a collaboration of service users and professionals who set out to develop innovative practice in relation to SDM across four UK CAMHS (one outreach centre, two outpatient services and one inpatient unit).

Attempting to implement SDM in CAMHS raises particular challenges in terms of complex conversations with vulnerable and often highly stressed or disturbed young children, involving on-going and complex relationships over time (rather than in a single decision point) and balancing multiple perspectives (e.g. child and parent).

SDM in CAMHS was conceived of as involving five key steps: (1) Agreeing key problems and goals (2) Understanding options available (3) Agreeing which option will be tried (4) Reviewing progress (5) Making changes as necessary. The project explored and developed a range of tools to support SDM including materials to help young people express their goals and feelings and to be able to give honest feedback to those they were working with.

SECTION 1- INTRODUCTION

1.1) Background Knowledge

There are 129 Child and Adolescent Mental Health Services (CAMHS) across England. They see an estimated 250,000 newly referred children per year, the most common age group being children between 11–16 years old, and the most common referrals are for a range of emotional or behavioural problems.
Although it is without doubt that clinicians in CAMHS are committed to helping young people and are dedicated to their care, it is not known how consistent best practice is or what best practice might look like in relation to areas such as collaborative practice. Progress does exist however, including through initiatives such as the Choice and Partnership Approach (CAPA), Goal Based Outcome Measurement (GBO)), and new initiatives started during the course of this project such asCYP IAPT.

We understand that some current practice might be unstructured and open ended, leaving clients sometimes confused as to the purpose of meetings and lacking clarity as to whether appropriate progress is being made. Practice does not consistently embrace active involvement of clients in decision making or in tracking of progress. This is thought to link to high drop-out rates from treatment (30-40% in 2010), mixed user satisfaction (with up to 40% of children and parents indicating some degree of concern about how much information they are given by services and how far children feel listened too) and potentially poor outcomes (www.corc.uk.net). These challenges were identified at a national level, as part of expert consultation between service users and service providers, and a proposal was then put to the Health Foundation to support a new service improvement initiative supporting shared decision making in CAMHS.

The "Closing the Gap: Shared Decision Making in CAMHS" project set out to develop an articulated model of shared decision making, in order to promote best outcomes in CAMHS. Shared Decision Making (SDM) is an innovative approach that aims to transform the CAMHS experience from one of service user passivity to a situation in which interventions are genuinely agreed in collaboration between service users and their practitioners, informed by their shared knowledge of the evidence and their on-going review of progress in relation to the specific episode of care.

The use of SDM in adult mental health services to date has been related to several benefits such as higher rates of user satisfaction, better adherence to treatment and better outcomes (see e.g. Drake, 2009). Moreover, studies of youth involvement in non-mental health treatment decisions suggest that youth want to be involved in decisions about treatment (Coyne 2006; Kelsey et al 2007) and have the capacity for involvement in these decisions (Alderson et al 2006), which can have positive benefits for youth self-esteem, support successful transitions to adulthood, and have therapeutic benefits for youth (Costello 2003; Huffine 2005).

It is suggested that the implementation ofSDM in CAMHS will impact positively on a variety of outcomes for children and young people - including a shorter length of care episode, lower drop-out rates, and better levels of satisfaction among those using the services.

The CAMHS Evidence Based Practice Unit (EBPU), in collaboration with the CAMHS Outcomes Research Consortium (CORC), and YoungMinds led this programme of work.

- CAMHS Evidence Based Practice Unit (EBPU) - an academic and service development body dedicated to improving practice, through promoting the evidence base

- The CAMHS Outcomes Research Consortium (CORC) - a learning collaboration involving over 70 health service trusts and voluntary sector providers across the UK, with interest in routine outcome monitoring

- YoungMinds - the UK's leading charity committed to improving emotional well-being and mental health of children and young people and empowering their parents and carers

A small central team, based at CAMHS EBPU, was made up of a part-time project manager with a public health project management background, a part-time senior service developer with a clinical background and a full-time clinically experienced support worker, with support from a change management/ leadership consultant.

The central team work was supported and guided by a steering group of six additional stakeholders across the collaborating organisations: two past CAMHS service users ("experts by experience"), a service user advocate, a user participation lead, the director of a charity leading service user rights and input, and a senior clinician representing an international collaboration of CAMHS committed to reviewing outcomes to improve services. The steering group met once a month and were in email contact with the central team in-between meetings.

1.2) Local Problem and Context(s)

This project trialled SDM initially in four sites in England, following the Institute for Healthcare Improvement Collaborative's model for Quality Improvement. Overall CAMHS nationally see around 250,000 new referrals a year. The four CAMHS that were selected to be sites were chosen from an open competition and selected by the central group (see above) on the basis of their interest in developing their already innovative practices in SDM further and between them are estimated to take on over 7,000 new referrals a year .

The sites involved were based in the North East, South West, West and South East of England. Each CAMHS site identified a project group of six to nine people who work directly with the central team. The CAMHS site project group members were all part of wider clinical teams and were involved in passing on learning and sharing ideas with their wider teams as well.

The sites included both outpatient and inpatient provision, and are described in further detail in table 1(a-d).

Table 1: Description of sites that took part in the Closing the Gap: SDM in CAMHS project

A. Outreach service	
Types of service:	This service provides help for children, young people and their families who are experiencing more severe, complex and persistent difficulties than seen within general CAMHS and often coming after attempts to provide support in general CAMHS have not proved possible. Most of the work of the service is outreach with young people being seen in the community in cafes and other locations of their choice. (This service was involved in a large scale service configuration during the period of the project).
Professional groups directly involved in the SDM project:	Senior Management, Mental Health Practitioners, Occupational Therapy, Participation workers and Administrators.
Types of problems:	The service works with young people aged between 0 and 18 in the local community who are having serious problems related to their emotional or mental health and are struggling to stay in their home or placement, and may also find it difficult to stay in touch with health services, social care and education.

B. Inpatient Forensic Unit	
Types of service:	This service is a specialist, secure mental health inpatient unit, providing assessment, treatment and care for young people who have both mental health and forensic needs. They help young people, both male and female, aged 12 to18 years. The project worked with one ward in particular from the Trust but had links to other wards.
Professional groups directly involved in theSDM project:	Nursing, Family Therapy, Psychiatry, Ward Management and Administration.
Types of problems:	Young people using this service have complex mental health problems, including attachment problems, eating disorders, psychotic symptoms, etc. They are admitted to the unit because they pose a risk to themselves or others. They are detained under the Mental Health Act and may be subject to Ministry of Justice restrictions.

C. Outpatient clinics	
Types of service:	This service provides tiers 2 and 3 CAMHS (i.e. specialist mental health work ranging from unidisciplinary input being required to multidisciplinary team work), however they also have links with primary care and tier 4 (i.e. work in the community emerging problems and with those requiring highly specialist care and inpatient work). There are three principal sites that CAMHS operates from. Two of the three sites were directly involved in the project.
Professional groups directly involved in the SDM project:	Clinical Psychology, Child and Adolescent Psychiatry, Occupational Therapy, Play Therapy, Participation Worker, and Service User Representation.
Types of problems:	This service works with problems ranging from sleep and behaviour problems through to deliberate self-harm, specialist assessment for autism and eating disorders. This service is in a highly ethnically diverse community and has specifically developed SDM tools for reaching out to the most disadvantaged children and young people in their catchment area.

D. CAMHS teams including Learning Disability	
Types of service:	The service covers a large geographical area and provides community mental health services including learning disability, looked after children (children in care), substance misuse and youth offending services. The service is committed to using the Choice and Partnership Approach (CAPA) to managing clinical load and promoting choice for young people and families. Discrete teams work on specific issues and in discrete geographical locations across the area. Individual workers from different teams came together for the first time for this project.
Professional groups directly involved in theSDM project:	Primary Mental Health, Clinical Psychology, Speech and Language Therapy, Play Therapy, Participation Worker, General Manager and Administration.
Types of problems:	A wide range of problems are seen by this service including mental health support for young people and their families with learning disability, anxiety, depression, obsessive compulsive disorder, deliberate self-harm and complex trauma.

1.3) Intended Improvement

The aims of this Closing the Gap initiative were:

1. To transform the dynamic between service users and their practitioners in CAMHS by April 2013, drawing upon "Shared Decision Making" as a conceptual framework for empowering children and young people to play an active part in decisions about their care.

   SDM focuses on the detail of interactions between individual practitioners and the children and young people they work with. It includes five key stages:

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

2. To improve the quality of care for children and young people in CAMHS by April 2013, in three domains of quality: effectiveness, efficiency and person-centeredness

We set out to deliver these aims by working with four SDM project teams to test out and refine elements of the SDM model in a CAMHS context.

Our intention was to test out different tools and approaches to see if they could support SDM and investigate what were the barriers and facilitators to the integration of SDM into routine practice.

The project team made an active decision to work with sites already committed in principle to the SDM approach, where there was senior management buy in and where staff had the capacity to try out new approaches. Provision of support, training, guidance and constructive critical challenge by a central team along with additional dedicated funds for sites to use themselves were thought to be facilitators to development and implementation.

Factors we thought might hinder the process included lack of time, changes in the NHS, staff turnover and anything that meant the initiative or new ways of working might be experienced as a burden by already busy and over committed staff.

Figure 1 below outlines our logic model, showing how our desired project outcomes described in this section link to the resources and planned activities.

Figure 1: Logic model for the Closing the Gap: SDM in CAMHS project
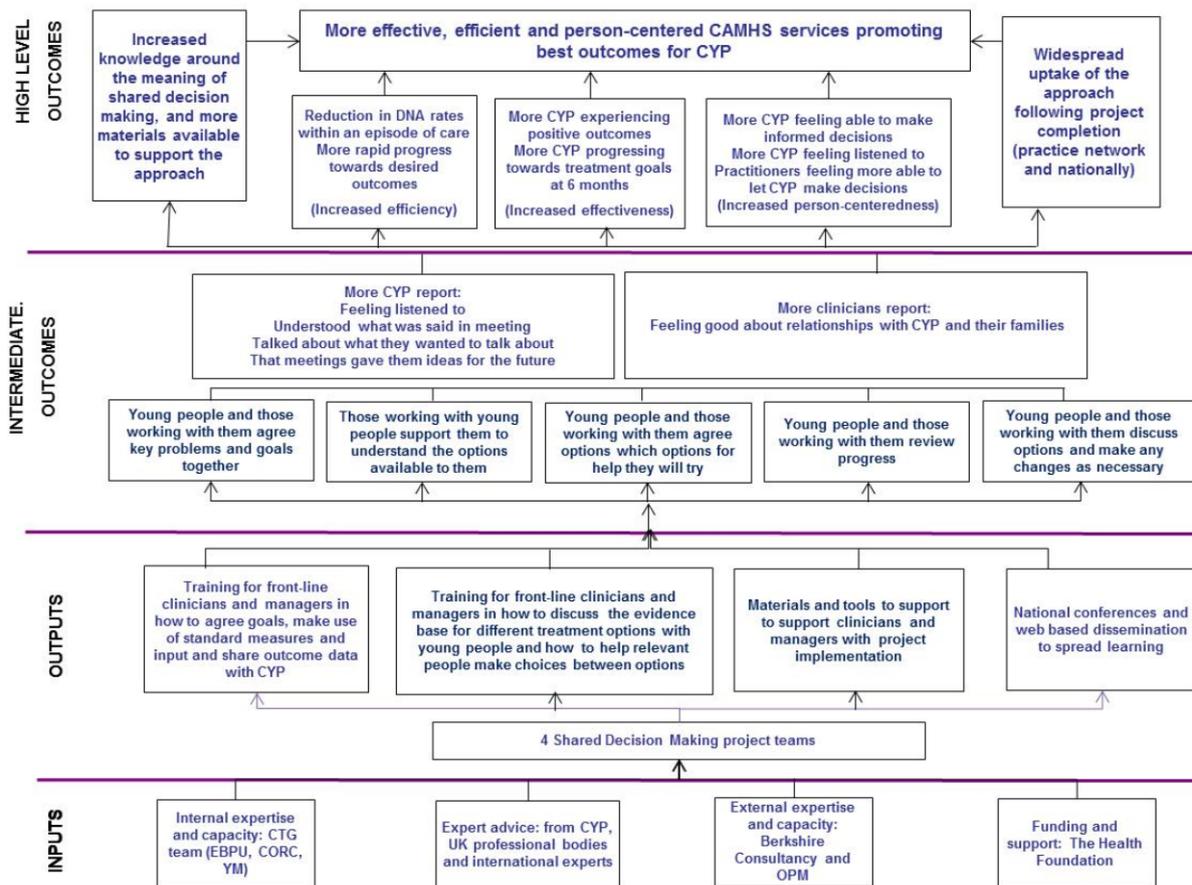
1.4) Changes Along the Way

This has been a journey of discovery for both the central team and the sites. The following two key change areas are particular learning points along the way:

1. **Change to intervention: SDM vs. clear direction**

When we first set off with our project, we were really keen to use the principles of SDM to guide the interactions between our central team and the four sites, in addition to the collaborative effort to make this a reality within clinical interactions.

We came to appreciate that adopting a SDM approach across all interactions between the central team and sites was not always helpful to individual project group members; and sometimes feedback indicated that they required more steer and direction, particularly for establishing working frameworks and getting started with testing out different approaches that support SDM. Therefore, for the first six months of working with sites, we focused quite heavily on training them in concepts, tools and approaches that support SDM, generated by the central team and steering group.

When it started becoming clear to us that sites had increased in confidence as to the scope and approach for this project, we shifted our approach to working with them again, away from emphasising training, and back to giving them space and time to take forward their own creative ideas and facilitating increased opportunities for learning and collaborating together. We think this really helped to create a sense of ownership of the project.

Additionally, the need to manage the competing priorities of different work streams and service developments, alongside pressures in the face of NHS organisational change meant that this project was not always able to be prioritised by teams at centres of excellence as much as the project team might have desired. When this happened, we found reverting back to a more directive approach helped, in order to move individuals forward through the different stages of change.

What we have learnt is that achieving an appropriate balance between push (shaping) and pull (openness to being shaped) is what is important. Flexibility in approach is essential to making SDM a reality within the diversity of contexts that we are working within.

2. **Changes to methodology of evaluation: became less ambitious about data collection- more fine grained and focused more on PDSA analysis**

We began this project with an ambitious plan for data collection, which was formulated before the four project sites were selected and in place. Our intention was to draw on support from CORC membership to facilitate the process of data collection and analysis. Originally we were aiming for a set of consistent measures across sites to aid comparative evaluation.

By December 2011, it became clear to us that generating a suite of feasible outcome measures was going to be more difficult than originally anticipated, because the existing IT systems across services were not sophisticated enough to support reliable data entry and/or collation at a meaningful level. Agreeing a common set of service-level measures across sites presented further challenge as sites varied so much in the context of the work they were doing.

After some time of grappling with these issues, we realised that the PDSA logbooks that we launched with sites in January 2012 (to complete each time they tried out an aspect of SDM) in fact captured a lot of rich information on the lived experience of doing SDM, which warranted more detailed analysis. It became clear to us that while we were still working towards defining an articulated model of what SDM in CAMHS actually is, this type of information would be most useful. By July 2012, we migrated all our PDSA data onto a qualitative evaluation platform - Atlas Ti. The system helped us to draw out key themes and learning to a much finer granularity than originally intended, and this reporting forms the basis of learning derived from this project. We also started to explore other data sources, specific to individual sites which are further detailed later in this report (results section)

SECTION 2- METHODS

2.1) The Intervention

We conceive of the "intervention" on two levels:

1) The intervention(s) directly employed to change relationships between service providers and users to develop and support SDM
2) The intervention used by the central team to support this change

These are described below. In addition we explore:

3) How the support and "intervention" provided by the central team relates to the site's trialling of SDM "intervention"

This is also described below.

1) The intervention(s) directly employed to change relationships between service providers and users to develop and support SDM

a) Tools to support agreeing key problems and goals (step 1 above)
Here we drew on existing work nationally led by members of a central team such as being developed by Duncan Law and CORC (http://www.corc.uk.net/) and CYP IAPT (http://www.iapt.nhs.uk/cyp-iapt/) which focused on goal- based outcomes and initial assessment and formulation (such as using SDQ or RCADS) along with drawing on work developed in the sites such as care planning approaches, personal portfolios and a "getting to know you" booklet.

Examples of centrally developed work include GBO www.corc.uk.net/wp-content/uploads/2012/03/Goals-and-Goal-Based-Outcomes_Sep2011.pdf and use of SDQ (http://www.sdqinfo.com/) and RCADS (http://www.childfirst.ucla.edu/RCADSGuide20110202.pdf). Training was provided to sites in these approaches (see below for more details).

Examples of local site-developed work include a "getting to know you" booklet (authored by Rivkah Cummerson and Olivia Trimbee, from the Sussex Partnership Trust) personal portfolio and improved care planning materials. Sites shared with each other these materials at joint learning events.

b) Tools to support those working with young people support them to understand the options available to them and agree which options to try (steps 2 and 3)
Again we drew on a mixture of centrally developed materials and locally developed innovation in the sites- focusing on materials that could support informed choice and information sharing.

Examples of centrally developed materials include introduction to the "3 Questions" approach from MAGIC and use of the Choosing booklet and website developed by EBPU (http://www.choosing.org.uk/English_Home.aspx). Training was provided to all sites in best practice and theory of how to support decision making and possible tools.

Examples of local site-developed materials include choice cards, talking mat, options spreadsheet to support professional knowledge, confidentiality postcards, collaborative risk planning as part of portfolio development, and options agreement in ward rounds. Sites shared these materials with each other and further developed them at joint learning events.

c) Tools to support young people and those working with them to review progress and make any changes as necessary (steps 4 and 5)
Here we drew on a mixture of centrally developed materials and locally developed innovation in the sites- focusing on materials that could support tracking progress (in terms of experience and outcomes) and using this information to identify when and what changes might help to try.

Examples of centrally developed materials include training in use of feedback tools as developed by CORC and CYP IAPT (http://www.corc.uk.net/wp-content/uploads/2012/03/a-practical-guide-to-using-service-user-feedback-outcome-tools-.pdf) and customisation of feedback tools including drawing on

the bulls-eye approach (developed by Bill Badham and others). Training was provided to all sites in best practice in feedback use and examples of innovative practice nationally (e.g. OO CAMHS, http://www.oocamhs.com/).

Examples of local site-developed materials include reviewing young people's experience of ward round involvement, ensuring feedback was requested, using the bulls-eye online approach, with stickers etc., reviewing goals using different materials and approaches and of video interactive guidance (VIG) to support professional development on SDM more generally. Sites shared these materials with each other and further developed them at joint learning events.

A summary diagram of these approaches used across the different sites is presented in figure 2. Table 2 presents learning from PDSAs in terms of what was tried with whom:

Figure 2: Initiatives trialled by sites to increase SDM in CAMHS
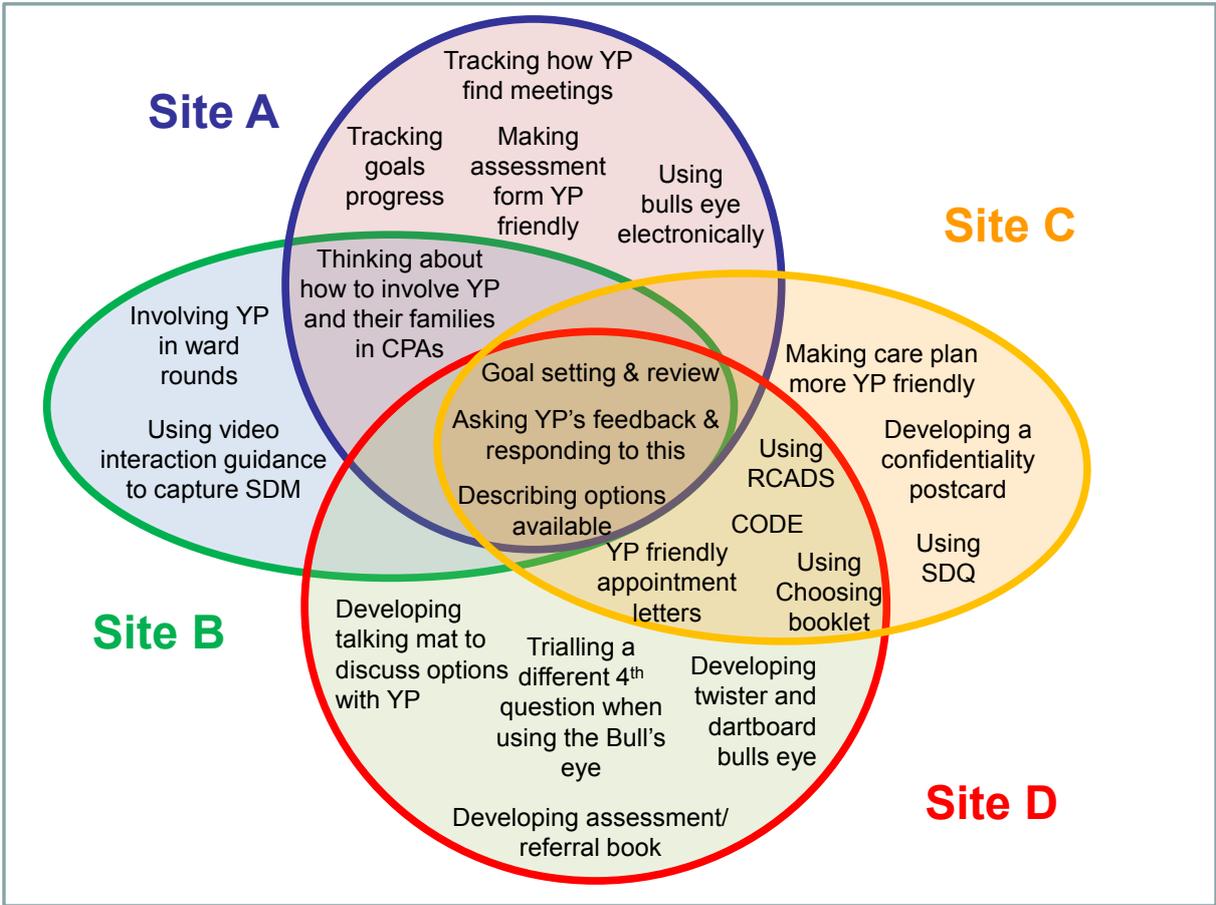

Figure 2 Key:
YP- Young Person
SDQ- Strengths and Difficulties Questionnaire
RCADS- Revised Child Anxiety and Depression Scale

Table 2: Learning from PDSAs; what was tried and by whom

	Number of times SDM tried as reflected in PDSA reports	Most frequent types of problem where evidence of use in PDSA reports	Age range of CYP worked with as reflected in PDSA reports
Outpatient service	At least 70	Anxiety, autistic spectrum, eating disorders and deliberate self-harm	6 to 18 years (most frequent age range was from 13 to 16 years).
CAMHS including LD	At least 80	Anxiety, OCD, deliberate self-harm and learning disabilities	7 to 17 years (most frequent age range was from 14 to 17 years)
Outreach team	At least 120	Anxiety, low mood, anger and deliberate self-harm.	7 to 18 years (most frequent age range was from 14 to 17 years)
Inpatient unit	All the children and young people who have been in one of the wards (about 15)	Young people using this service have complex mental health problems, including attachment problems, eating disorders, psychotic symptoms, etc. They are admitted to the unit because they pose a risk to themselves or others. They are detained under the Mental Health Act and may be subject to Ministry of Justice restrictions.	12 to 18 years (most frequent age range was from 14 to 17 years)

2) Intervention used by central team to support SDM in the sites

We selected four CAMHS to be part of learning collaborative for this project, on the basis of their interest in developing their already innovative practices in SDM further. We recruited them through a competitive bidding process, from a wider pool of 23 applicants. Our work together involved three phases:

a) Launch phase (September 2011 to January 2012)
- The project was launched with sites in September 2011. Launch event held in London, at which sites were introduced to key concepts relating to SDM, user participation and quality improvement (September 2011).
- Quality Improvement training provided to sites via regional EBPU "Masterclasses" in Quality Improvement (September to November 2011).
- 1-2-1 planning meetings held with each site in their localities, to understand their existing ways of working, identify key strengths and areas for development, agree ways of working going forward and to develop action plans in line with this (October to November 2011).
- Participation meetings held with each site in their localities, to establish approach for involving young people in project development at a local level (December 2011 to January 2012).

b) Testing phase (January 2012 to September 2012)
- We provided training and support to individual practitioners across the four sites to encourage more focused SDM in sessions with clients, based on the five steps outlined in section 1.3

Direct training included:
- Assessment, goal setting and progress review training at all sites (steps 1 and 4). With central project team- half or full day training (depending on which they preferred) at their sites. In three of the services this was for the core project team only and in one service it was for the wider clinical group. These took place between January and February 2012.
- Exploring, agreeing and changing options training at all sites (steps 2, 3 and 5). With central project team- half day training at their sites. These took place between March and May 2012.

Support provided included:
- Launch of PDSA reflective logbooks (January 2012).
- Cross-site learning events for all sites. These were all-day events, held in London, organised to include a combination of the following as agreed in collaboration with the sites: 1) Central team

and individual site project updates 2) Action Learning Set sessions 3) Creative workshop time to work together on the development of new ideas (held in March, June and September 2012).

- On-going responsive support including: site visits, email guidance, and follow-up telephone calls.

c) Implementation, sustainability and spread phase (October 2012 to March 2013)
We provided training and support to sites to encourage thinking around sustaining change and developing plans for spread.

Direct training included:
- Implementing change (October 2012).
- Sustaining and spreading change (February 2012).

Support provided included:
- Launch of Implementation booklets (October 2012).
- Cross site learning event for all sites (held in October and December 2012, and January, February and March 2013).
- On-going responsive support including: site visits, email guidance, and follow-up telephone calls.
- Providing support and challenge for site local sustainability and spread plans (March 2013)

Consolidating key learning included:
- Qualitative analysis of 307 PDSA forms received back from sites.
- Developing best practice briefing notes based on PDSA analysis.
- Focus group discussion with sites to learn more about their lived experience in project

3) How the support and "intervention" provided by the central team relates to the site's trialling of SDM "intervention"

Profile boxes 1 to 4 show how local implementation of SDM was supported and influenced by central team activity. We drew on Prochaska and DiClemente's Stages of Change model to guide our approach to working with sites.

Profile boxes 1 to 4 capture the number of PDSAs completed by each site up until October 2012 during the phase of testing and trialling of new approaches. One observation that warrants some further reflection is that that the number of PDSAs being received, across all sites, declined over the last quarter period. On one hand, this trend is to be expected, as sites have been getting increasingly ready to move towards implementation, which means that PDSA testing is less relevant for select key changes. On the other hand, we do suspect that declining numbers of PDSAs being returned is indicative of problems being faced by sites more generally as a result of funding cuts and key jobs being put at risk, thus resulting in less than would be ideal amounts of time for clinicians to focus on this project

We used this conceptual model to try to determine best ways to support sites in different phases of change

When in a contemplation phase – which according to Prochaska's model (2009) means that individuals are evaluating the pros and cons of change, but haven't yet decided to change – approaches we tried included:
- Decisional Balance technique: Talking with team about the pros and cons of changing.
- Developing Discrepancy: Pointing out the discrepancy between how they would like to be and how they are e.g. the team has wanted to change their CPA meetings since the beginning of the project but still haven't done it.
- Instilling hope

When in a relapse phase – which according to Prochaska's model (2009) means individuals may be returning to older behaviors - approaches we tried included:
- Identifying what barriers exist that might prevent them from getting back on track
- Considering the relapse as an opportunity to learn limitations of the approach

When in an action phase - which according to Prochaska's model (2009) means individuals are feeling comfortable with making changes, the aim is to continue supporting their self-efficacy. This was attempted using a combination of the following approaches:

- Providing verbal reinforcement and supporting the belief that change is sustainable.
- Identifying specific practices/ behaviours that have successfully changed and linking this to positive change being observed in their service.

What emerged from this analysis was our sense that regular site visits to support clinicians trying out new things may be essential for moving them through the cycle of positive change. This was also borne out by comments from clinicians about their positive experience of central support.

"When you first came and talked about trying out some of these ideas, I was sceptical. I thought 'that won't work!' and I thought of all the reasons why it wouldn't work. One thing this project has taught me, is to at least try it once, before I decide if I want to pursue it further or not."[1]

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[1] *Note- text in Italics are taken from notes from conversations with clinicians and not from verbatim recordings*

Profile box 1: Site A (Total returned = 122, average 13.5 = per person)

Left chart — Number of PDSA's received:
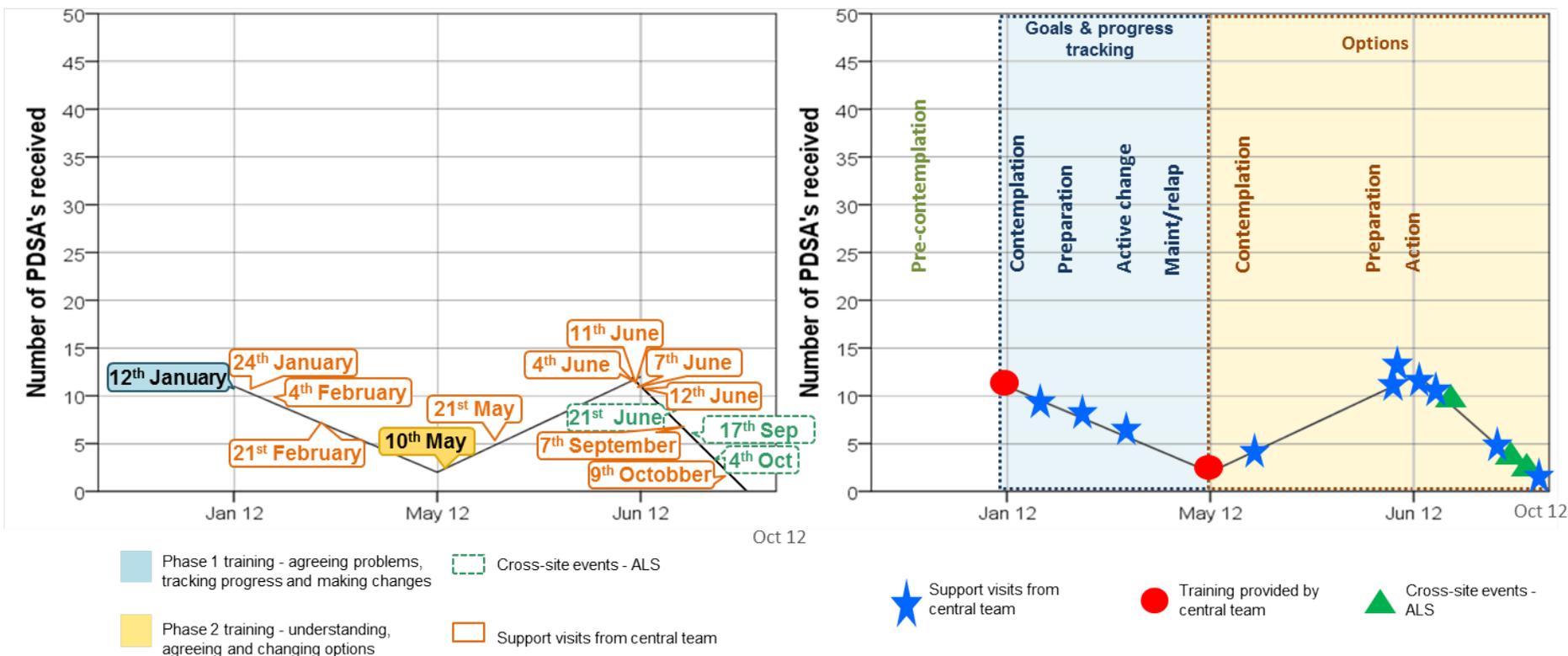- 26th January
- 15th February
- 28th February
- 14th March
- 15th March
- 4th April
- 26th April
- 21st June
- 1st Aug
- 29th Aug
- 17th Sep
- 4th Oct

Legend (left):
- Phase 1 training - agreeing problems, tracking progress and making changes
- Phase 2 training - understanding, agreeing and changing options
- Cross-site events - ALS
- Support visits from central team

Right chart — Number of PDSA's received:
- Goals & progress tracking
- Options
- Pre-contemplation
- Contemplation
- Preparation
- Active change
- Maint/relap
- Contemplation

Legend (right):
- Support visits from central team
- Training provided by central team
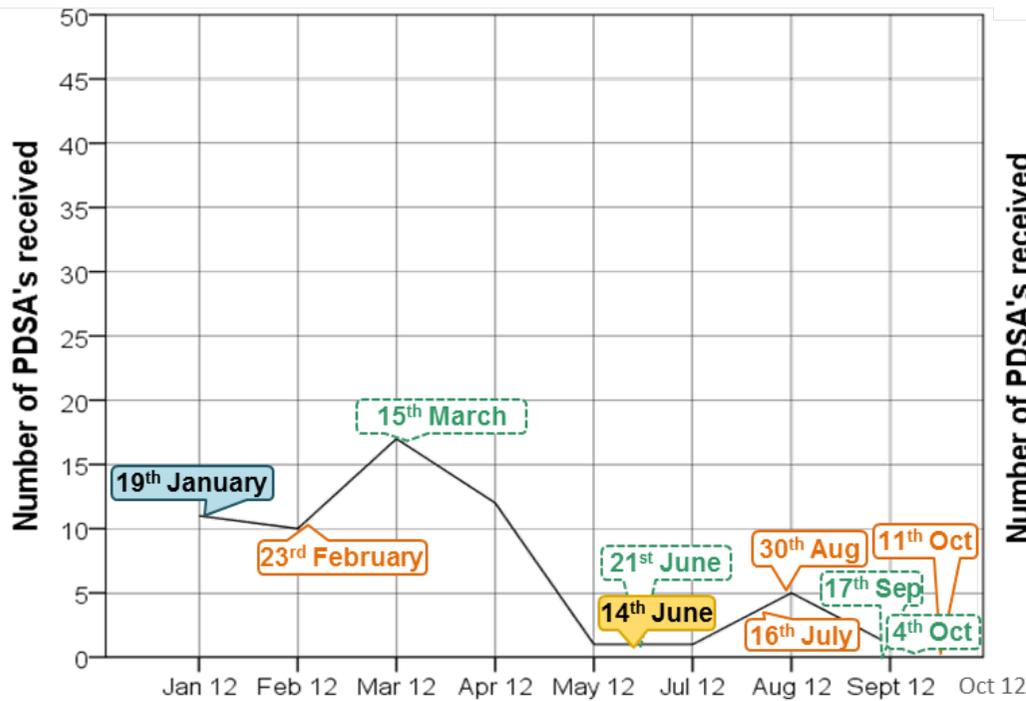- Cross-site events - ALS

Pre-training	
Pre-contemplation	We assume that most members of the team were already in the contemplation phase when they joined the project as they volunteered to participate.
Training 1 : Agreeing key problems, setting goals and tracking progress	
Contemplation	Received fortnightly visits from a member of central team Pros and cons of changing were considered and discussed with team
Preparation	Over a series of meetings, a plan to implement the changes in the service was generated Team developed a method to regularly set and track goals, and to ask for session feedback
Action	The whole team started to try things out and to send in PDSA's We hypothesise that the support received helped them to reach this phase quite quickly
Maintenance/ relapse	Central team site visits were less frequent They kept sending PDSA's as the whole team was clear about changes they wanted to implement Team committed to maintain those changes
Training 2: Understanding, agreeing and changing options	
Contemplation	Team has been experiencing a very busy clinical period and have not been available to receive many visits from central team Despite site visits by the central team, the team do not seem to be actively testing out new changes The number of PDSAs being sent in to the Central team has declined As far as we know, no changes relating to this next phase of SDM have been taken forward We assume the team is still in the contemplation phase
Action	*No further updates*
Maintenance/ relapse	*No further updates*

Profile box 2: Site B (Total returned = 28, average 4.5 = per person)

Pre-training	
Pre-contemplation	We assume that most members of the team were already in the contemplation phase when they joined the project as they volunteered to participate.
Training 1 : Agreeing key problems, setting goals and tracking progress	
Contemplation	Received fortnightly visits from a member of central team
Preparation	Over a series of meetings, a plan to implement the changes in the service was generated
Action	Team start to complete PDSAs with support from Central team When they started to make changes, they realised that the "model of shared decision making" provided by central team did not fit with their context Team had a number of challenges to face, including a particularly busy clinical period and departure of their project team lead
Maintenance/ relapse	Team did not have the capacity to meet with the central team for an extended period of time. This included being unable to attend the first cross-site learning event. Therefore team no longer reporting PDSA learning. They later informed us that lack of PDSAs did not equate to low project activity. In fact, they had continued making changes but were not reporting these through PDSAs due to very stretched capacity
Training 2: Understanding, agreeing and changing options	
Contemplation	A new team lead was appointed Team felt motivated to get project back on track – and to find a less 'burdensome' approach to capturing learning
Preparation	Central team increased number of visits to team to support them with clarifying changes to make and reporting learning from their experiences.
Action	Team became more accustomed to reporting learning from the changes being made. PDSA's were filled in with help from central team
Maintenance/ relapse	The team has been experiencing another busy clinical period and team lead was not available for a couple of months Team was not available to receive visits from central team for a while. This seems to have given rise to a halt to PDSAs being received At the most recent set of site visits, new actions were agreed and plans put in place, however this has not resulted in more PDSAs being received

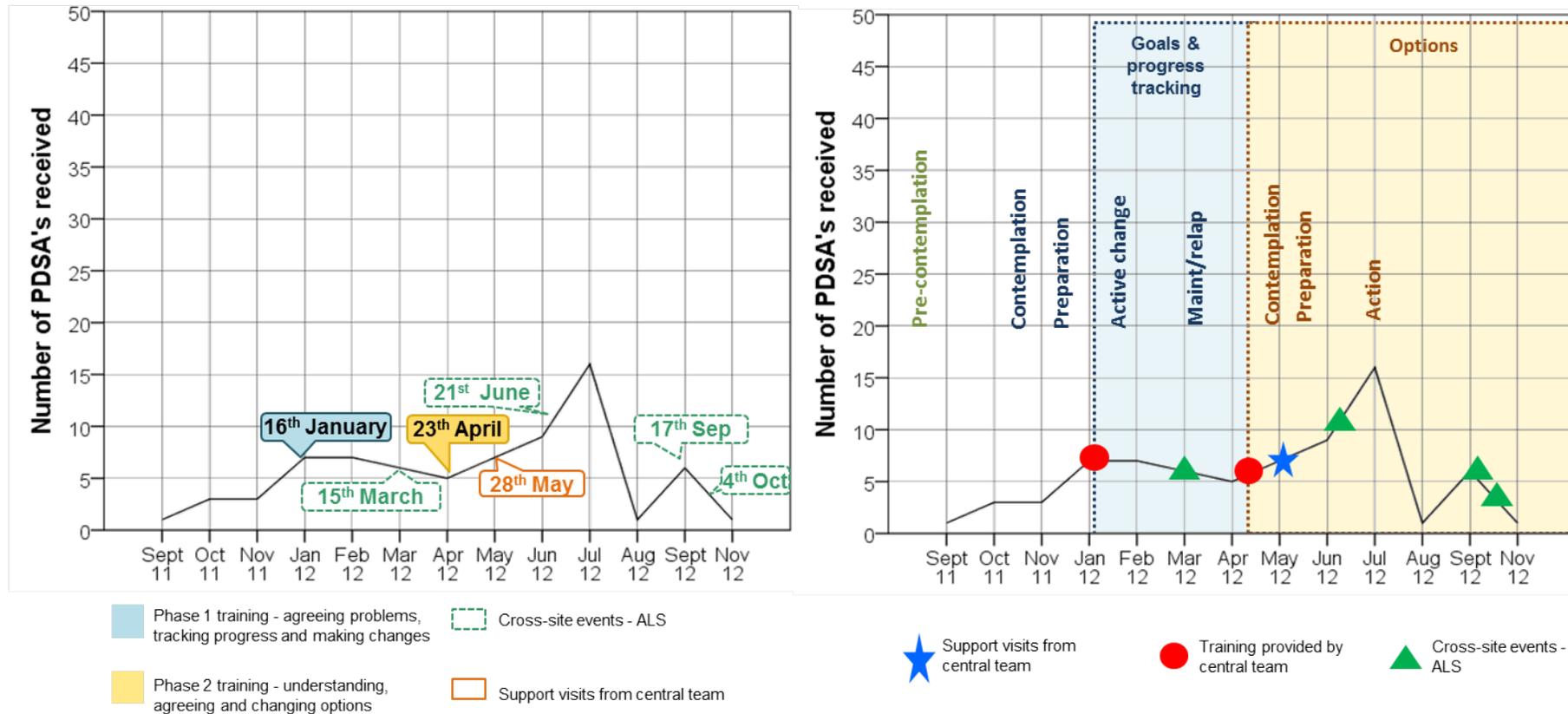# Profile box 3: Site C (Total returned = 74, average 18.5 = per person)

Legend (left chart):
- Phase 1 training - agreeing problems, tracking progress and making changes
- Phase 2 training - understanding, agreeing and changing options
- Cross-site events - ALS
- Support visits from central team

Legend (right chart):
- Support visits from central team
- Training provided by central team
- Cross-site events - ALS

Pre-training	
Pre-contemplation	We assume that most members of the team were already in the contemplation phase when they joined the project as they volunteered to participate.
Training 1 : Agreeing key problems, setting goals and tracking progress	
Contemplation	Team supported by Central team at a site visit think about what changes they wanted to make
Preparation	Team supported by Central team to plan way forward
Action	The team identified a number of specific changes try out, and were very active at sharing new learning with the central team via PDSAs
Maintenance/ relapse	As changes became routinely integrated into individual clinical practice for some team members (i.e.,. change maintained), the number of PDSAs being sent back to the central team declined
Training 2: Understanding, agreeing and changing options	
Contemplation	The team became aware that more frequent visits from the Central team would help them to move forward. Monthly visits were scheduled.
Preparation	The team have received a number of visits from the central team to support them with planning the changes they said they would like to make
Action	The team have started to send in PDSAs based on the new changes agreed
Maintenance/ relapse	*No further updates*

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Profile box 4: Site D (Total returned = 83, average 16.5 = per person)

Pre-training	
Pre-contemplation	We assume that most members of the team were already in the contemplation phase when they joined the project as they volunteered to participate.
Training 1 : Agreeing key problems, setting goals and tracking progress	
Contemplation	The members of this team are based in different locations which makes it difficult to meet in person as frequently as the other teams. Therefore the team preferred to receive contact via e-mail and/or telephone, which was provided more frequently than for other sites
Preparation	Team got ready to start changes, deciding what they wanted to try out
Action	Team sent PDSA's about their experience of change
Maintenance/ relapse	As changes became routinely integrated into individual clinical practice (i.e.,. change maintained), the number of PDSAs being sent back to the central team declined
Training 2: Understanding, agreeing and changing options	
Contemplation	The team felt overwhelmed learning about all the new ideas presented at the second site training event. The felt a follow up visit from the central would help them to clarify their ideas and plan new changes. The Central team were only too pleased to oblige.
Preparation	After the follow-up visit, the team has been creating tools to help them implement these changes
Action	Team members are sending back PDSA's about their experiences regarding explaining and agreeing options for help.
Maintenance/ relapse	*No further updates*

SECTION 3- RESULTS

The results outlined below have been extracted from the analysis of over 200 PDSAs completed by 26 clinicians, from interviews with 12 clinicians, 15 young people with experience of service use, 4 service managers and 4 participation leads. Where relevant, comments are linked to particular stages of SDM as outlined above.

3.0) Outcomes

Changes in relationships and linkages between changed relationships and improved quality of care are discussed below.

1.   Changes in relationships- clinicians and young people

We are able to draw on learning from PDSA analysis and focused discussion work carried out with sites to describe how relationships changed between clinicians involved in this project and young people they worked with. In general, clinicians report that relationships radically changed in terms of trying to be more open and fostering more collaborative ways of working.

The approach helped clinicians be more open with young people and more transparent about what everyone was agreeing to work on

> *"Discussed client's goals in context of how it would be useful to spend our time together and what client would like to achieve/ what she's motivated to do. It felt like a natural part of the conversation and a way of focussing what she wants to achieve as well as a way for me to find out what motivates her."* Clinician on using more collaborative and explicit goal setting at start of contact (SDM step 1)

Sometimes this meant being clear that the young people were choosing not to take up the offer of therapy rather than being offered it and just not turning up:

> *"I talked with YP about options for support and acknowledged with her that she could choose not to seek help - as she finds it very hard/relevant to meet. We talked about options for self-help. The session was very hard. But by being open with her about discomfort with the help and her reluctance to meet we were able to talk about her rights choices about CAMHS support."* Clinician on exploring and agreeing options (SDM steps 2 and 3)

> *"I have been encouraging her to feel confident to voice her opinions. Today she said that she did not want to continue seeing me. This was a positive step for her and we agreed to break from sessions whilst some work with xx service happened, and agreed to meet after this to review"* Clinician on exploring and agreeing options (SDM steps 2 and 3)

> *"Met with client to discuss current involvement (or lack of!) with CAMHS … Client requested discharge from CAMHS and felt able to say this within her meeting. Client stated she didn't feel able to request this beforehand- wasn't sure if she was allowed?! If faced with a similar situation I will try to encourage client to ask for discharge on their terms - ensure they know their rights re treatment."* Clinician on exploring and agreeing options (SDM steps 2 and 3)

Monitoring progress helped clinicians be open with young people about progress or lack of it:

> "*A key shift in my thinking has been that reviewing how things are going is all about making sure a young person's needs are being met. What is the young person's view? Is what we are doing in their best interests*?" Clinician on using routine monitoring of progress for first time (SDM 4)

Getting rapid feedback informed further decision making and treatment planning:
> *"Receiving honest feedback feels helpful because you can identify and make changes that feel important to the family."* Clinician on using feedback to inform clinical decisions (SDM steps 4 and 5)

"Discussion about '3' for 'understood what was said' made me realise that I need to be even clearer about why I am trying certain things out." Clinician on using feedback to inform clinical decisions (SDM steps 4 and 5)

SDM helped facilitate more explicit conversations and negotiations even in very stressed contexts such as forensic inpatient wards:

"*I think young people have started making informed risk decisions about their own risk level and they understand it more. They understand if I do this, if I punch this person in the head I'm going to get restrained. I can choose not to do this and ask for some time off the ward."* Clinician on exploring options and being explicit about consequences in context of forensic inpatient setting (SDM steps 2 and 3)

"It was helpful to provide a rationale so they understand it's not just a system for the sake of a system. And sharing personal experience of frustration and acknowledge that we actually need their help to resolve. And responding to what they were unhappy about in the system." Clinician in inpatient setting (SDM step 3)

There was some evidence from discussions with young people about their experience of the approaches being piloted here that these had a positive impact on their experience (though it should be noted that some of these young people were part of a national group not necessarily accessing services).

"When I left the young person's unit I was in, they then asked me where I wanted to go, what would help – I think having that conversation made me more committed to being in a therapeutic community – if someone had said 'you are gonna be here for another year' I probably would have been like 'no I'm not!'. I wouldn't have engaged. The fact that it was partly my decision meant I thought 'I chose to be here, I'm gonna commit to it, I'll give it everything I can." (SDM step 5)

"A lot of my change has come from the fact that I know I don't have to get to crisis point to get someone to listen to me now, and that actually gets other people to respond better. It was having people start asking and start checking in with me pretty much on a weekly basis and saying what can we do? What's working? What's not working? So I began to trust that they actually did care. And if I said 'no this isn't working' they'd say 'ok what can we do?'" (SDM step 3)

"I have session by session monitoring- I have to do a daily diary card and part of that is every week I have to record any problems that have occurred in therapy. My therapist frequently asks me if I am happy, what she is doing right, what she is doing wrong, if there are any changes I want to make. And when I started I had to do goals of treatment – what my priorities were etc. I found it really difficult at first because I found someone asking me 'what do you think, am I doing a good job'...I couldn't say no! And I'd sit there and I'd say yeh yeh I'm happy, I'm fine, whereas now she says if I leave upset or something 'I want to know what pissed you off and then we can work through it'. And that's part of dealing with my behaviour but also like you know, what works for me. It's been quite good...I trust her a lot more" (SDM steps 3 and 4)

2. <u>Changes in relationships- clinicians parents</u>

Clinicians involved in the project reported changed relationships with the parents they worked with in terms of them trying more open and collaborative ways of working, for example:

"I wanted to use care plan at end of 1st session. Child not interested - so worked with Mum. Mother felt reassured that she had been heard and clear plan to cover physical health as well." Clinician on using clear goal setting (SDM step 1)

"Family reported using the website to look at ADHD care pathway treatment options. Enabled them to participate in an informed manner. Benefit of families being informed of options for identified issue prior to appointment. More meaningful discussion. When offering more than

one choice appointment direct people to website (alongside other websites) to consider treatment option.” Clinician on helping family members explore options (SDM step 2)

“Re-assessing goals. Joint meeting with client, mother, father and step-mother to discuss how best to work together to support client in reducing OCD behaviours. The care plan acted as a joint contract for the client and adults to be clear what behaviours are OCD and when client is pushing boundaries with his mother and being aggressive and how to respond accordingly. Felt it went well as client and family acknowledged that lack of progress has been due to mum not being firm with her son when he is physically and verbally aggressive. She and client now have support from father and step-mother with whom client spends time with.” Clinician on using goals to review progress and make changes (SDM steps 4 and 5)

“Mum of young person with learning difficulties, needs support with coping - requires support from interpreter. I tried the ‘How was this meeting feedback’. I had tried this with before on the previous visit. I did this with mum that previously had given me a score of 3 (out of 4) for ‘talking about things that were important to them’. Started the meeting with agreeing what the focus of the meeting was going to be and said that we would be getting feedback, like before, after session finished – also checked in at different times during the meeting to remind her that the feedback activity was on its way. The session was a home visit being mediated by an interpreter. Interpreter did form with mum. Then we made time at end of session to score together and talk about scores. Mum gave a higher score for ‘talking about things important to them’ compared to last time [4/4]. When we explored why this was we realised it was because mum does not normally have access to an interpreter and so often is unable to do the things she wants to do in meetings with me, and also with other services like education, social care etc. Discussion about ‘3¹⁄4 for ‘understood what was said’ made me realise that I need to be even clearer about why I am trying certain things out. This conversation enabled us to realise that mum’s needs had not been met at the last meeting and therefore we need to spend some time thinking together about helpful plans and goals for future meetings.” Clinician on using feedback from meeting (SDM steps 4 and 5)

3. Changes in relationships- clinicians and colleagues in the MDT

We asked our sites for their reflections on how their relationships with colleagues may have changed as a result of being involved in this project. Clinicians involved in the project report it changed their relationship with the colleagues they worked with in terms of forming tighter ties with those trying out similar ways of working. Not all changes were positive- perceived jealousy etc. from those outside SDM group.

Relationships within the project teams:
Site A (outreach setting): *I have found working with colleagues on this project to be really rewarding, and it’s been helpful to have people around that you can talk to when developing new ideas, it’s given me the courage to try out things and discover the clinical relevance of things that previously I didn’t appreciate as being very helpful. I really feel our team have experienced a culture shift towards collaborative working. Now I always have in mind that sharing decisions will improve a young person’s experience, so I am always much more explicit about all the options and being able to make changes when working with them. It’s all about the spirit really isn’t it?*

Site B (inpatient setting): *Well our project team has changed membership a lot throughout the project, and there is only one original member working in our service still! But we are glad that we have been able to join the team, as focusing on doing shared decision making feel very naturally aligned to how we would want to work anyway. It just doesn’t make sense to be doing anything different!*

Site C (Community CAMHS across 2 services): *It has felt really helpful to have a group of professionals together thinking about shared decision making, and working together on this has helped to keep the message alive.*

Site D (Community CAMHS- multi-service team): *Prior to being involved in this project, we hadn’t ever worked together, so that’s been really nice getting to know each other and coming together on a topic that we all feel really passionate about. Having a service manager as one of our team members has really helped us to carry things forward, which is great!*

Relationships between project team members and others in clinical networks:
Site A (outreach setting): *Well the great thing about our service is that we are a closed team. So everyone has been joining in with the things that we have been trying out for SDM, which in turn has supported us with keeping momentum going with the project. Also since we've become an IAPT site, things like goal setting and asking for feedback are an essential requirement for everyone anyway, so colleagues outside our immediate CTG project team have derived huge benefit from the CTG project because it's helped us to do the things we have to do in the 'right' way... Everyone likes the bull's eye, but* <u>why</u> *are you doing it? And* <u>how</u> *is it helpful? … That's the different mind-set we've all acquired through CTG.*

Site B (inpatient setting): *'The SDM project' is something that everyone in the wider service has known about, and it's been viewed with mixed reactions. Some people are really excited to know about what's going on- but for those that don't really understand the underpinning values; they haven't been very supportive or confident to take small risks to try things out themselves. Some colleagues are even frightened! They say, 'if it's going to go wrong, it will go really wrong!' But it hasn't! In fact, the number of restraints within our wards has noticeably dropped, so surely that's a sign that it's going really right!*

Site C (Community CAMHS across 2 services): *Challenging the status quo, rather than maintaining it, has been a challenge that we've experienced outside the project team. But what we have come to realise is that negative opinions from some about different initiatives we have been trying out is really only coming from professionals- not children and young people -e.g., encouraging colleagues to add their photo into letters has evoked a real emotional response. Sometimes you just want to say: 'stop being so precious and listen to what young people want!'*

Site D (Community CAMHS- multi-service team): *I think it's fair to say those outside our project team have been quite 'curious' about what we've been doing – it's been seen as something 'special' because we have regular meetings set up and we have regular trips to London. We have all been sharing new developments with colleagues in our own teams as we've been going though, so it's not like the curiosity is a 'hostile' one. Mostly they are just interested to know what's going on, and are excited about possible opportunities, but we haven't got far enough with the development of ideas to share with them in full. What we really need to work on now is the senior-senior managers... they can be difficult to get real support from… but we are trying!*

4. Changes in relationships- user participation workers and colleagues in the MDT

Service user participation and advocacy leads involved in the project report changed their relationship with other MDT colleagues, not involved in the project, in terms of championing participation as key in terms of direct clinical work not just at service level. They commented on this as a change in their own views on this issue. Previously the main focus of participation work within mental health services (including within CYP mental health services more generally), has been of user participation in influencing service design and delivery. Thus, this predominantly focused on service user involvement in areas such as staff recruitment, participation groups, influencing policies and procedures. When participation is predominantly at a service level, this often results in participation being seen as the preserve of the participation worker - rather than something that sits within everyone's role - as it is often seen as disconnected and separate from clinical practice. Involvement in Closing the Gap has resulted in a wider, shared understanding of participation where participation is seen as a continuum - in that clinical work is also seen as a vital space for children and young people's participation and involvement in decision making. While clinicians often support the concept and principles of participation, there is often an accompanying lack of understanding of what this means within direct clinical work. Closing the Gap and the model of SDM has given a coherent framework, approach and tools to bring the values of participation into direct clinical work, and to show how this facilitates collaborative practice and improved therapeutic alliances.

5. Changes in relationships- members of the steering group

Members of the steering group commented on experience of working in a group with half service users/advocates and half professionals- changed relationships in terms of increased equitable balance of power over time.

These are the elements that we think made it work:

- Recognising different roles, experience and expertise, and valuing these equally. This meant an appreciation of both kinds of expertise- by training and profession, and by experience.
- Creating a safe, supportive environment and being honest about anxieties (not just the anxieties of young people) – we did a 'check out' at the end of every meeting where everyone shared how they thought the meeting went and how they were feeling.
- Being open to working in new ways – for example, we held a team away day where we 'turned the tables' and divided up the day so that the professionals planned and ran the ice breakers and games and the young people/participation workers facilitated the serious bits.
- Spending time building relationships and trust – this led us to a place where we disagreed, challenged and posed different perspectives on issues with ease. These debates were where most of our key learning took place and was an important part of the process of sharing decisions.
- Having the right people around the table to make things happen – both skills/knowledge and energy. Everyone involved in the steering group genuinely wanted to be there and this motivation enabled meetings to be productive.

Duncan Law, consultant clinical psychologist:
"I try and use a shared decision making approach in my clinical work with young people, and their families, but it is a very rare opportunity to be part of a project steering group which aims to use shared decision making ideas to run a project. It was anxiety provoking at first, particularly to have two young people with direct experience of mental health services on the steering group. Would what I thought to be my clinical skills in using a shared decision making approach be seen as lacking by the young people? Would, what I saw to be collaborative practice be seen as coming from a rather narrow professional view of mental health and not really collaborative at all? Well I'm pleased to say that I have found both to be true to some extent; but learnt that that is the point of collaborative practice – to learn from each other, to risk sharing thoughts and views and practice, and invite, and be open to, constructive feedback and comment, to have a richer experience as a consequence and to get better at what we do. This is as true on a well-functioning committee as it is in well-functioning therapy. My experience is that it worked because we all held the philosophy in mind and had the right mix of people in the group, with a range of views and complementary skills."

Lisa Baird, young person:
"This is not my first foray into collaboration – I've been drafted onto various boards and projects over the years, many of which have left me despairing over clinicians' comprehension of 'shared'. As a result I've learnt to distinguish between those paying lip service to a model of shared engagement and those who truly believe it's a good thing. These guys are clearly in the latter. I'm proud to work in such a dynamic team where everyone's opinion is a meaningful contribution. Coming from being sectioned – being legally viewed as incapable of making decisions about my own life even – makes this a really difficult thing for me to believe, and I struggle with accepting that I may have an opinion worth listening to, especially in a group of such amazingly skilled individuals. Every meeting feels like an emotional rollercoaster but it is a challenge that pays dividends as, little by little, my confidence grows and I begin to have faith in the good of some people working in the mental health system. I want other people to understand the value of shared decision making. I want meaningful ward rounds taking place, collaboration in care – things that I never had and that have royally screwed up my ability to have confidence in my own view. I want better outcomes for the kids who came along after me, so that they have a better chance at recovery than I did; for young people to leave services with some sense of who they are, not just who their illness makes them. By experiencing the collaborative process within our own team I believe that this is a key part to enabling that."

Kate Martin, participation manager:
"The best bit about being part of the Closing the Gap steering group, is that when you walk in the room, you can't tell who are the professionals and who is there representing young people's voices – everyone really is on an equal footing around the table. This is most apparent in not only how many ideas people contribute, but also, more importantly, the ease with which we disagree, challenge and pose different perspectives on issues and then come to a shared way forward. It's hard to quantify how this happens – but predominantly I feel it's about having developed trust, that collectively we have sought and welcomed each other's opinions, and are always reflecting on where we are and what we're doing. I also think that we've collectively acknowledged and understood that at times this can feel uncomfortable but that this is a true test of whether we really are working collaboratively. Being involved is invigorating – there are not many other steering group meetings I actually look forward to

going to. I always come away feeling challenged, that I've been able to contribute and that I've learnt or seen something from a different perspective."

3.1) Measuring the outcomes of your project on changing relationships and improved quality of care

Summary

Below (table 3), we present a summary of our approach as applied (we note below where we had anticipated a different approach but had to change it for one reason or another). Details of each aspect are then provided.

Table 3: Overview of measures for the CTG: SDM in CAMHS project

Measure	Scope	Measures used	Amount of data collected/ sample size	Analysis	Challenges issues	Very tentative findings/learning
Outcomes						
1. Patient reported experience of clinical contact	All sites	Answers to feedback questions as recorded in PDSAs	150	Analysed in aggregate and by age, gender, type of problem	Being used as clinical tool to encourage negative feedback so difficult to interpret as outcome tool	Some indication that harder to implement SDM with some groups of young people
2. Did not attend (DNA) rates	Outpatient outreach service	DNA rates as recorded in hospital records	18 months of data	Plotted over time for whole team and those involved in SDM	Data hard to interpret- overall rates lower than national average	Some evidence that very low DNA rates in those using SDM
3. Incident information	Inpatient services	Incident information as recorded in clinical notes	50 time points for 2 case studies	Plotted over time for two individual cases	Small amount of data from individuals- no norms to make comparisons	Indicates lower risk following implementation of SDM for individuals
4. Young People experience of SDM	National	interviews	15	Thematic	Not necessarily accessing services involved in this project	SDM valued by YP who had experienced it
5 Young people experience of implementation of SDM	Forensic inpatient unit	Interviews and questionnaires	4	Thematic	Small numbers	Importance of flexibility of approach Key impact may be on experience of YP rather than direct clinical outcomes as such
Processes						
1. Evidence of implementation	All sites	PDSA booklets	307	Qualitative Framework Analysis	PDSAs did not necessarily reflect all work done and returned differentially across sites	Potential framework for SDM implementation derived highlighting different stages or states (apprehension, feeling clumsy and integration) and role of attitudes, behaviours and tools
2. Experience of implementation	All sites	Interviews and focused discussion	8 clinicians over various time points	Data summary	Opportunistic sampling	Interviews and feedback suggest use but patchy if not supported
3. Extent of implementation of SDM	All sites	Implementation booklet	0	Not possible	Booklets not used at all- data collection burn out!	N/A
Balancing						
1. Clinician report on how happy they felt about their relationship with clients	All sites	Back of PDSA booklets	137	Plotted over time and linked to experience of implementation	Not many completed so not possible to safely interpret	Generally positive about relationships for those who completed
2. Clinician report on how overwhelmed with admin they felt	All sites	Back of PDSA booklets	137	Plotted over time and linked to experience of implementation	Not many completed so not possible to safely interpret	High levels of burden from admin for those who completed – some possible link to service reconfiguration and wider NHS landscape indicated
3. Clinician report on how exposed to risk they felt	All sites	Back of PDSA booklets	137	Plotted over time and linked to experience of implementation	Not many completed so not possible to safely interpret	Low levels of sense of feeling exposed to risk for those who completed

3.1.1) <u>Outcome measurement</u>

It was challenging to decide on the best outcome measures to use due to a range of factors including the fact that either the measures related to a whole service and might not reflect any changes in practice at the site level or numbers seen were small (due to the intensive nature of CAMHS work) to make meaningful measure collation possible. We therefore opted for a range of measures to help us explore impact in a number of ways and at a number of different levels, each of which had their own strengths and weaknesses. Table 3 presents an overview of the outcome measures we selected and the benefits and challenges or issues associated with each of them. A full description of each measure and outcomes achieved in relation to these then follows

1) Patient reported experience of clinical contact
We originally wanted to use ESQ (Experience of Service Questionnaire) scores at end of therapy- to show how positive or otherwise the outcome and compare with national averages. Lack of IT support meant we could not get these data. So we agreed to look at the experience of clinical meeting feedback from individual sessions, based on four questions (below). However we anticipated that this would be problematic as these questions were also being used as a tool to increase SDM by encouraging negative feedback from young people.

Many clinicians made use of the SDM bulls eye tool when asking YP for experience of session feedback. Feedback for each service user was logged into PDSA forms contained within the PDSA log book. Our very tentative interpretation around this follows, however the tension between function as a tool for SDM and function as a measure for best practice should be kept in mind at times when considering the findings.

Extremely tentative thoughts relating to experience of session feedback as linked to different presenting problems
- Children with autistic spectrum disorders (ASDs) seem to be more likely to give negative feedback, more able to be honest if they are asked to say what they think of the session. This might be because they are less aware of the social context of giving feedback.
- Young people with internalising symptoms are likely to be ready and willing to receive help, and appear to be more interested in ideas for what to do than others.
- People with externalising symptoms including attention deficit hyperactivity disorder and behaviour problems may have most issues in terms of understanding what was said to them in the session.

Extremely tentative thoughts relating to experience of session feedback as linked to different presenting ages
- Younger children may be more interested in having concrete suggestions for what to do than older children.
- Older children are more likely to say they understand what is said in a session. Adapting the language for younger children and using child-friendly tools might be required to make sure they understand what is said in the session.
- Also younger children seem to feel less listened to than older children. This might be because parents tend to talk more during the sessions.

SDM: Young people's view:

To enrich the tentative findings described above, young people's views about the impact of various aspects of SDM on them and on their experience of care were gathered through questionnaires and focus groups. The over-arching theme was that being listened to gave young people a sense of empowerment and control that enriched their experience of care, allowed them to take ownership of their treatment and to begin to understand the reasons behind the clinical work being done.

"I was sent to my adult services team by my psychiatrist so I wasn't that committed I don't think. After two or three months there I had the discussion with my CPN, about why are you coming ('well my psychiatrist told me') and we worked through 'well what are we trying to get out of this, why are we doing this, what is the problem we are trying to address, what are the goals'. And actually I hadn't been committed before and that made a real difference."

Young people pointed out that *"You are never too ill to be involved"* and *"Someone can talk to you whether you are really psychotic or really unwell; it doesn't take away the fact that they can talk". "Different levels of sharing decisions at different times is ok. Help us understand what the decisions actually are."*

As one young person commented: "*I've had that experience, of people trying to do Shared Decision Making with me… and I've made the decision that I'm going into hospital and at that point I want other people to make decisions for me.*" In this type of situation, it may make sense that decisions be made by the professional but drawing on their knowledge of the young person and their previous decisions to inform this as well as observation of what they might be transmitting using non-verbal methods of communication (e.g. closed body language). It was felt it might be important also to be explicit that you are making the decision on their behalf and to be sensitive to any signs they give you that may be their way of telling you that they are making a choice. Professionals may be able to find small choices to offer them that are not too overwhelming (e.g. what flavour drink they would like or where they want to sit).

Young people's views about SDM
East Sussex CAMHS held a YP participation event, where they gathered and collated YP views about SDM. Emerging themes from this event included the following:

Trust and communication:
- *"Trust is very important, communication is the key"*

Need to feel listened to:
- *"Not saying something because you feel you can't"*
- *"The clinician should ask the patient if they are chatting about the right thing"*
- *"After 30 mins, check – that way there's still time to change the subject"*

Lack of time or consideration for YP can hinder SDM:
- *"Want to talk but don't have time cos they are late"*

Young people's views on impact of SDM:
- YP felt it wasn't their behaviour or presentation that had changed as a result of SDM, rather it was the way they felt.
- They spoke about feeling more valued and more 'empowered'.
- A lot of the YP feel that their delivery of care is better because they are more involved in their own lives and have taken more responsibility and ownership of core documents and decisions made.

Key themes emerging from questionnaires:
- Feeling more involved in care
- Taking ownership of care
- Increased engagement
- Taking more responsibility for own actions
- Greater understanding of risk and of restrictions placed on them as a result of risk
- More likely to attempt to follow care plans if involved in writing process

Advice from YP to clinicians on obtaining feedback in particular to support SDM:

Flexibility
- Offer a range of ways for YP to give feedback
  - YP are often not comfortable giving feedback face-to-face and are reluctant to discuss at the next session (not wanting to review the last session)
- Do not pressure YP to give feedback if they really don't want to

Information and reassurance
- Inform YP at the beginning of the session that you will ask for feedback at the end

- Display posters informing YP that it's OK to give honest feedback
- Reassure YP that you will not be upset or offended and that you want their feedback so sessions can be made more effective
- Explain that they won't get into trouble for giving feedback
- Explain the feedback tool properly to the YP and ensure that they understand
- Explain that the conversation around the feedback is most important so a clinician knows what needs to change

Balance
- Don't allocate too much time to feedback – YP don't want it to take over the session

## 2) Did not attend (DNA) rates: Outreach service

We originally set out to collect monthly DNA information from each site, in relation to non-attendance of clinical sessions for community sites and non-attendance of educational events for the inpatient unit. However, data collection proved difficult for a number of reasons:
1) Difficulties collating relevant information, due to limited infrastructures being in place.
2) Difficulties generating relevant information at a meaningful level, for example in one service, data could only be made available at a service wide level, which could not reflect the impact of individual clinicians trying out new approaches.
3) Difficulties generating accurate information, for example in one service DNAs are measured on the basis of individual clinicians so if three clinicians are due to see one family, and the family DNAs, this would count as three DNAs in the records.

After some time of grappling with these issues, we resolved ourselves to collecting DNA information from one site only (outreach service) who did have an infrastructure in place to generate this information at the level of team who were all trying out approaches to SDM. Non-attendance at clinical sessions was collected from the outreach service on a monthly basis, from May 2011 until February 2013 (figure 4. Our hypothesis at the start of the project was that as SDM increases, we may see fewer DNAs.

In fact, the data we collected do not reflect any change linked to SDM. This may be because the nature of outreach work means that DNAs will be on the low side anyway, as CAMHS practitioners go out into the community to meet young people that they are working with, and/or may reflect good practice in the service already meaning very low dropout rates. Certainly the DNA figures for this service are lower than the national average (which is around 30%). Ideally we might look at dropout rates or DNAs for other services, however there are a number of limitations associated with collecting data of this kind (including how data are counted e.g., if a family of three do not attend this is recorded as three DNAs).

Figure 4: DNA figures for the outreach team, May 2011 toFebruary 2013
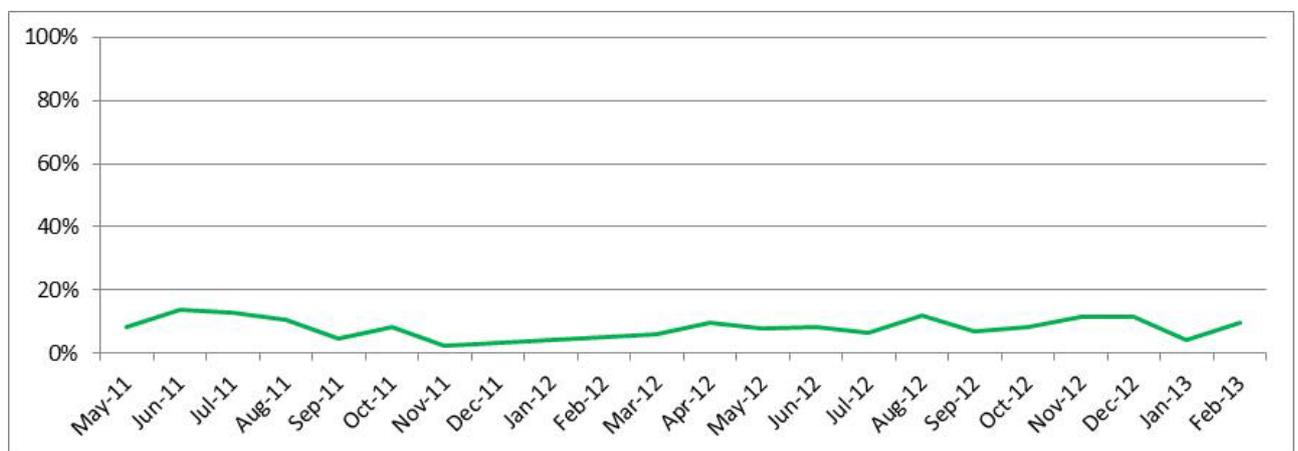
3) Risk Incident information- inpatient unit

The inpatient unit participating in this Closing the Gap project is a forensic secure unit, which means that acts of aggression (towards self, property or others), known as 'risk incidents', are not unusual. Anecdotal stories from nurses on the ward where SDM was being implemented, however, reported that risk incidents seemed to be reducing as young people were becoming more engaged with SDM approaches. On hearing this we carried out some audit work with the team, specifically looking retrospectively at weekly incident information relating to two young people staying on the ward, since their point of admission (figure 5a and 5b). Data strongly suggest that a SDM culture positively impacted on risk incident levels for both young people.

On speaking to young people staying on the ward where SDM is being trialled, some interesting insights as to why number of incidents may have decreased have arisen. They say that it is not their behaviour that has changed, but rather it is the way they feel. They spoke about feeling more valued and more "empowered". They say they are experiencing the delivery of their care more positively because they are now more involved in managing their own lives. Professionals who are trying SDM out in the ward report feeling like this way of working has really improved their skills set towards providing a better service to young people they work with.

The mechanism whereby risk is reduced may be to do with young people feeling more in control and respected. Young people spoke of feeling more empowered and taking ownership as a result of being involved in decisions about their care:

> *"When I left the young person's unit I was in, they then asked me where I wanted to go, what would help – I think having that conversation made me more committed to being in a therapeutic community – if someone had said 'you are gonna be here for another year' I probably would have been like 'no I'm not!'. I wouldn't have engaged. The fact that it was partly my decision meant I thought 'I chose to be here, I'm gonna commit to it, I'll give it everything I can."*


Summary of learning from outcome measures

We have considered a range of outcome measures and tried hard to look at impact in relation to a range of indicators including DNA rates, service experience and risk behaviours. All measures have limitations and these have been discussed above, along with tentative hypotheses for potential routes to impact. There is some evidence of impact for individual cases, in particular in relation to risk behaviours on inpatient wards, but it needs to be noted that data quality and capture issues make it hard to make definitive statements about impact at a wider level.

Figure 5a: Incident Information for inpatient unit, YP 'X'

Incident information for Inpatient Unit, YP 'x'
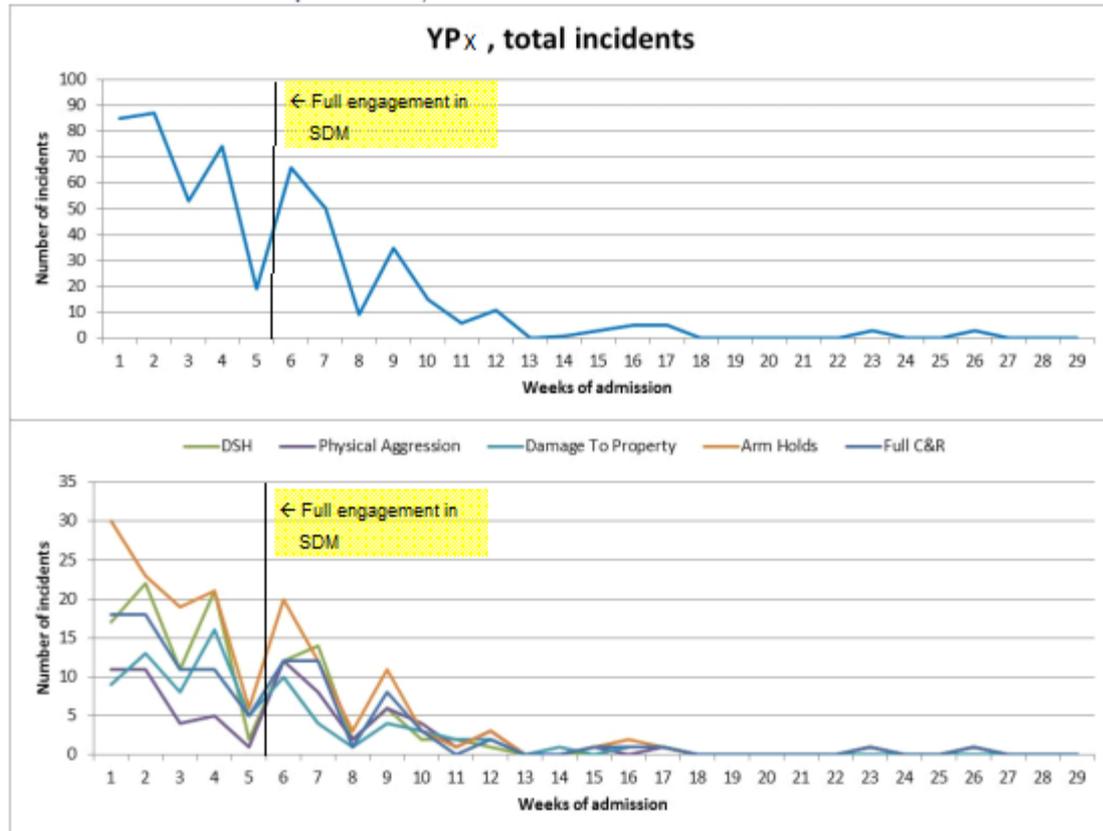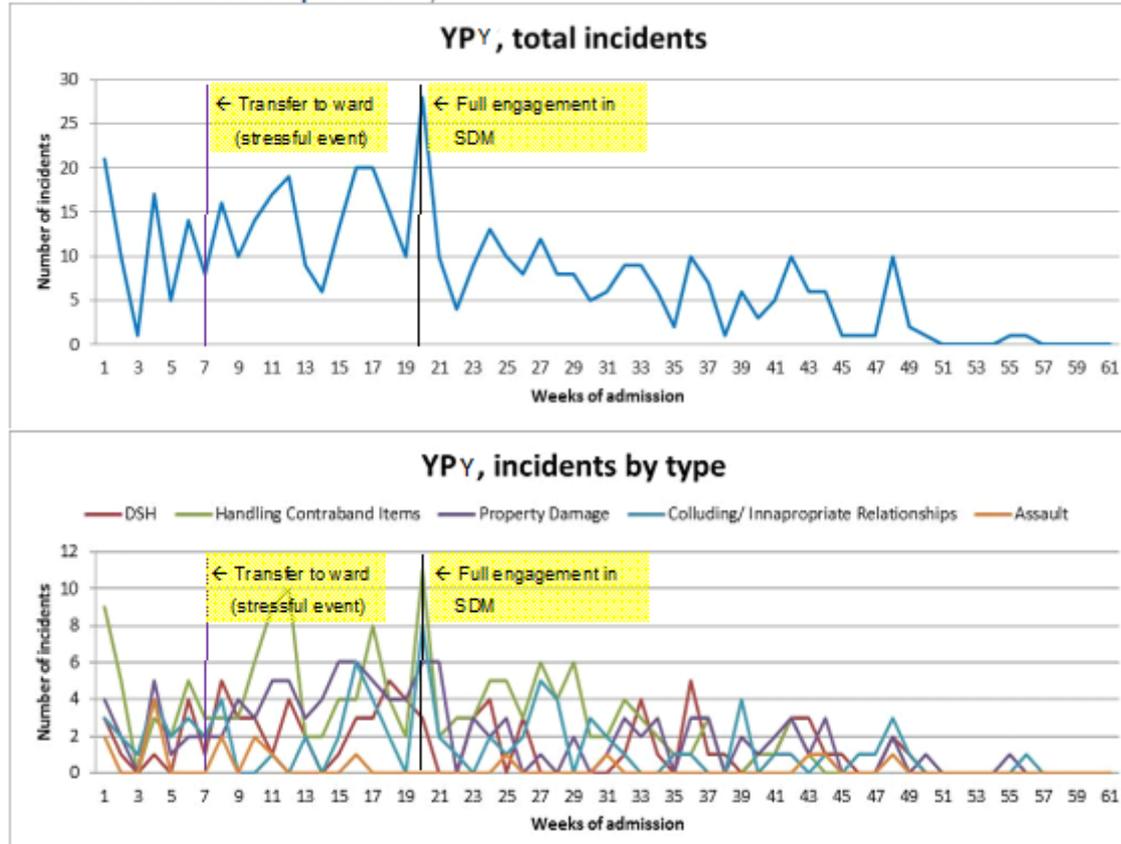
3.1.2) Process measurement:

We also considered measurement of implementation of SDM:

1) Evidence of implementation (insight from PDSAs)

We asked all those involved in site project groups (and in some cases wider group as well) to complete a PDSA form each time they try an aspect of SDM. From January until September 2012 (the 'testing phase' of our project), a monthly count of PDSAs sent back to the central team was taken as a proxy for SDM activity being trialled in each site. Over the course of the project, 307 PDSA forms were received back from sites. These data are presented in profile boxes 1-4.

We collated all PDSA forms completed by clinicians to capture learning about implementing SDM in CAMHS. The content of the forms was transcribed and introduced into qualitative analysis software, AtlasTI. We then analysed the content to explore the mechanisms of change and the impact of this in a more detailed way, using framework analysis methodology. Our analysis shows that:

  i.   There are three different states or stages (it was not possible to determine which) that clinicians can experience when attempting to implement SDM in CAMHS: apprehension, feeling clumsy and integrated in practice (figure 6).
  ii. Facilitators of SDM can be grouped into two main categories: those relating to clinician attitudes and behaviours, and appropriate use of tools (figure 7).

A full description of this framework now follows.

i) States towards implementation

Figure 6 describes the three states we have identified towards the implementation of SDM: apprehension, feeling 'clunky' (clumsy) and integrated in practice. These are not necessarily sequential states. Indeed, our data suggest that professionals can hover in between different states, depending on the context within which they are trying out SDM:

Apprehension
- Worried about the consequences of changing practice
- Aware of the possible risks, why it might not work
- Tendency to protect young people
- Difficult putting things into practice
- Firsts attempts to try it out

Feeling 'clunky'
- Actively trying to put SDM into practice but feeling deskilled
- It's more an internal feeling rather than real external "clumsiness"
- Tendency to protect service users
- Not knowing what the best way of introducing the approach is
- Forgetting specific actions or parts of the process
- Need some time to adjust
- Being up front that you are not used to this approach might be helpful.

Integrated in practice
- SDM is integrated into normal practice
- Professionals found the best way to incorporate SDM in the way they work
- It feels like a natural approach and part of their everyday practice
- Young people are also used to the approach and feel comfortable with it
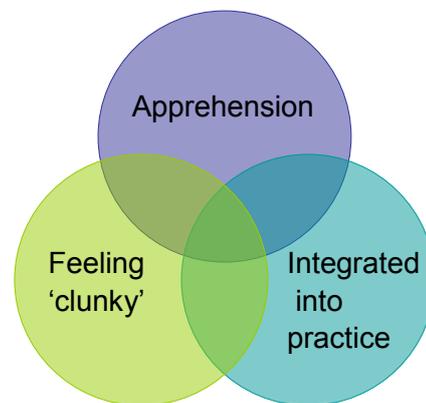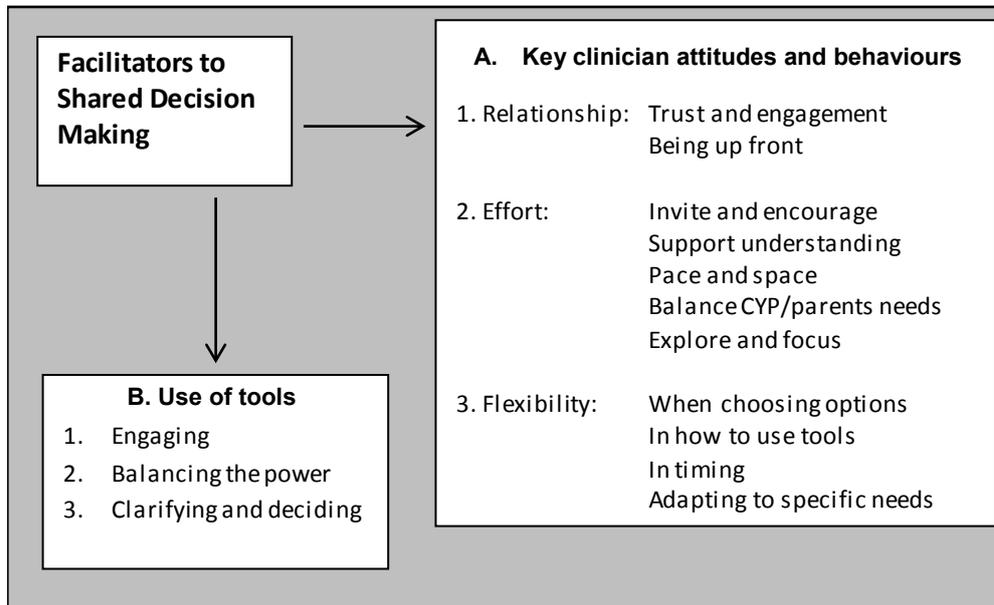

Figure 6: States of SDM (from PDSA analysis)

ii) Facilitators for implementation

Figure 7 provides an overview of facilitators for SDM, which can be grouped into two categories: Clinician attitudes and behaviours and appropriate use of tools. It seems to be important to have a combination of both in order to succeed with the implementation of SDM. A full description of these now follows.

Figure 7: Facilitators in SDM (from PDSA analysis)

A. Key clinician attitudes and behaviours

Facilitators to Shared Decision Making

→ **A. Key clinician attitudes and behaviours**

1. Relationship: Trust and engagement
                  Being up front

2. Effort: Invite and encourage
                  Support understanding
                  Pace and space
                  Balance CYP/parents needs
                  Explore and focus

3. Flexibility: When choosing options
                  In how to use tools
                  In timing
                  Adapting to specific needs

B. Use of tools
1. Engaging
2. Balancing the power
3. Clarifying and deciding

A. Key clinician attitudes and behaviours
(1) Relationship
Trust and engagement
- With good level of trust and/or engagement, users are more likely to participate in decisions about their treatment and less likely to be resistant to express their preferences or say what they would like to achieve from attending the sessions.
- Professionals might find it difficult to trust or believe what children and young people say.
- Bidirectional trust is required.

Being up front
- Being open and honest with young people even about things that were considered to be "negative", controversial or troublesome.
- Inviting young people to be honest and express their concerns or things they don't like about sessions.
- This seemed to result in positive outcomes and increased genuine participation of young people in those conversations and decisions.

(2) Making an effort
Invite and encourage
- Young people might not be used to give their opinion or express their preferences.
- Preparation might be required to enable young people to participate in decisions.
- Encouraging them to participate as much as possible in the decisions about their care, will improve their ability to be active in their treatment.
- Professionals have to genuinely believe that young people's contributions will be useful.

Support understanding
- Service users will need to have a good understanding of what happens in the sessions, the different options for treatment, what the process might be, the meaning of questionnaires/tools, etc.

- Clinicians might need to aid understanding.
- Some concepts might be difficult to understand.

Pace and space
- Professionals need to be prepared to:
  - Work at a young person's pace to reach genuine shared decisions.
  - Give time and space to service users to think, reflect and express their opinion.
  - Put their agenda to one side.
  - Services should create that time and space.

Balancing CYP/Carers needs
- Working with children and young people (CYP) also means working with their parents or carers.
- Some decisions around treatment for children and young people will not only be shared with them but also with their parents or carers.
- It might be a challenge in some occasions.

Explore and focus
- Encouraging service users to express what they think might result in them talking more and giving more information.
- This might reduce the time to do other parts of the process during one session.
- Therefore, clinicians found that sometimes they had to re-focus the session.

(3) <u>Being flexible</u>
Flexibility when choosing options
- It might be difficult to step back and be open to CYP's preferences (protecting them).
- Maintain a good level of flexibility, being open and supporting users with their decisions, even if their choice was not the best choice according to the professionals' opinion.
- However there will be risky situations where safe guarding will be a priority and no flexibility will be allowed.
- This could lead to better results in terms of treatment adherence and patient satisfaction.

Flexibility in how to use tools
- Be flexible when using the tools in clinical practice.
- They might not always be useful or they might have to be used in a different way in order to be meaningful.
- Tools are helpful but clinical judgement and service users' preferences are more important.
- Do not be ruled by the tool when making decisions.

Flexible timing
- Service users will not always be prepared or in the mood for being involved in making decisions about their care.
- Clinicians will have to use their clinical judgement and be flexible in order to find the best moment to introduce these discussions.
- However, this should not result in procrastinating and not doing it.
- Asking young people when is best for them is a good way to find out.

Flexibility adapting to specific needs
- Professionals will have to find creative ways of adapting tools and procedures to the specific needs of CYP and their families.
- Younger children or children with some developmental problem (e.g. learning difficulties, ASD) will need different explanations in order to understand the information and to be able to participate in decisions (e.g. pictures, drawings, diagrams).

B. Appropriate use of tools
Tools can help engagement
- The use of tools can sometimes make it easier to engage with CYP and families.
- It provides something tangible for children and young people to participate in the session.

- Tools might help YP to have more control.

Tools can help balance the power
- Visual support to a verbal discussion which will make it more clear and understandable for children, young people and their families.
- Good prompt for discussions, enabling some conversations that might otherwise be difficult to have.
- All voices heard.

Tools can help clarifying and deciding
- Provide additional information.
- Help clarifying different aspects of the treatment process for both professionals and service users.
- Help finding common ground.
- Help making decisions.

2) Experience of implementation (insight from focused discussion work)
During the final phase of project activity, we carried out in-depth discussions with 8 clinicians across the 4 sites via opportunistic sampling to supplement findings from PDSA analysis. In particular we explored with clinicians, their views around:

- What works well to facilitate SDM?
- What gets in the way?
- What are the main elements that have made a difference to working in this way?

Here is what we found out:

Facilitators
- A trusted relationship is a necessity. This is a two way process (trusting the answers and opinions of the young person as well as young person trusting in the adult) and requires genuine and explicit communication. Informal language, not manipulative, no hidden agenda.
- Having enough time to explore the problems with both CYP and their families, to set goals and to explain and discuss options.
- Being explicit, open and transparent about the options available and what the restraints are feels helpful.
- Giving "opt outs" to choices is important, young people need to be given space to change their mind. Options conversations framed in a way to encourage individual responsibility.
- In instances when CYP initially resistant, helped to use humour, not taking ourselves too seriously.
- Explaining that there would be review points, at which point changes could be made if things weren't working.
- Exploring options helped to further think about the problem. Inform each other- dynamic process.
- Having tools and information leaflets helped to explain the different options available and have meaningful discussions with CYP and their families.
- A key shift in thinking is that reviewing how things are going is all about making sure a YP's needs are being met. What is the young person's view? Is what we are doing in their best interests? Review with young person and draw in other professionals as relevant.
- Receiving honest feedback feels helpful because you can identify and make changes that feel important to the family.
- When reviewing- always keep in mind: is this in their best interest? Helps to provoke discussion when lots of people are involved.
- Preparatory work with YP prior to multidisciplinary review meetings feels helpful, and is now a normal part of the process, as when CYP have a more proactive role, the review meetings are more able to meet their needs. It helps to get reports from professionals in advance and to share these with CYP in advance so that they have space to reflect and react.
- At times when it is not possible to meet in advance with CYP, good to have debriefs.

Challenges
- Sometimes there are genuinely not very many options available.
- Doing SDM in risk situations. Sometimes there may be a disagreement that a non-negotiable needs to happen (e.g., CYP does not agree that risky behaviour is a problem), but you can still

reach an agreement on how to approach working together, even if this disagreement exists. It's all about being explicit about what is non-negotiable and what is negotiable.

- People in the initial teams leaving. Lack of consistency in the team and less people doing SDM in the service, so it's difficult to maintain and spread.
- Finding time for the project, to meet, think about it, etc.
- Young people not wanting to be involved. This is more likely when there are not many options so things are very likely to remain the same no matter what he/she decides. Some helpful approaches in these situations are: being honest and acknowledging the fact that there are not many options, professionals being flexible and creative in the way they try to involve young people and CYP being able to decide how much and how they want to be involved in decisions.
- Moving from engaging with young person to agreeing a plan, the narrowing down to make the actual choice to move forward. E.g. Young person engaged with clinician and happy to meet but not really wanting to agree any goals or try any options.
- Adjusting their approach, changing their practice. Fears about how it will be experienced by the young person. Doing things that at first felt quite 'clunky'. Possible solutions are receiving support and training to best understanding the philosophy behind it, provide a structure to incorporate the approach, and having managers and supervisors on board. These factors might encourage clinicians to take the risk to try SDM and check out what is the young person's experience.
- Offering choices in an unbiased way and managing risk at the same time.
- Changing the way clinicians work half way through the treatment and managing expectations of the family. Goal setting can be difficult when the family is used to not have a goal and to just use the service as they want, without really working towards a specific goal.
- It felt uncomfortable at the beginning as you are creating a different dynamic in the relationship.
- Working together (more than one professional working with one family in the same session) with colleagues who have not been involved in the project makes it difficult to make changes in the session, as some professionals might not agree or feel comfortable with it.
- Having to work and share decision with the whole family, not just around the individual.

Other factors
These are some possible factors that should be taken into account when trying to implement SDM:
- There is a possibility of professionals going to the other end, which would mean young people deciding on their own.
- Professionals might end up responding and acting according to YP's decision too quickly. The young person might not have considered all the options carefully and the fact that professionals act so quickly might take away the chance to change their mind.

Possible solutions:
- When there is some degree of confusion allow time to try things out and to see how they feel and what is best for them.
- Always allow the option to change your mind.

3) Extent of implementation of SDM

In October 2012, we also introduced 'change implementation' booklets to sites to audit the extent to which selected changes were being used. However, unfortunately, although enthusiasm for these booklets was high, in reality they did not get taken up. When asked about why this may be, consistent feedback was a sense of 'feeling full' (i.e., too many admin/competing external pressures to manage).

3.1.3) <u>Balancing measures:</u>

Clinicians were asked to report on 3 balancing measure questions once a week, using a 10-point scale. They were able to do this via an online survey on SurveyMonkey or in hard copy at the back of the PDSA logbook.

The balancing measure questions were chosen in collaboration with the sites as the key areas they wanted to report back on and/or were concerned might deteriorate as they experimented with SDM (Question 3 was of particular relevance to the forensic inpatient site):
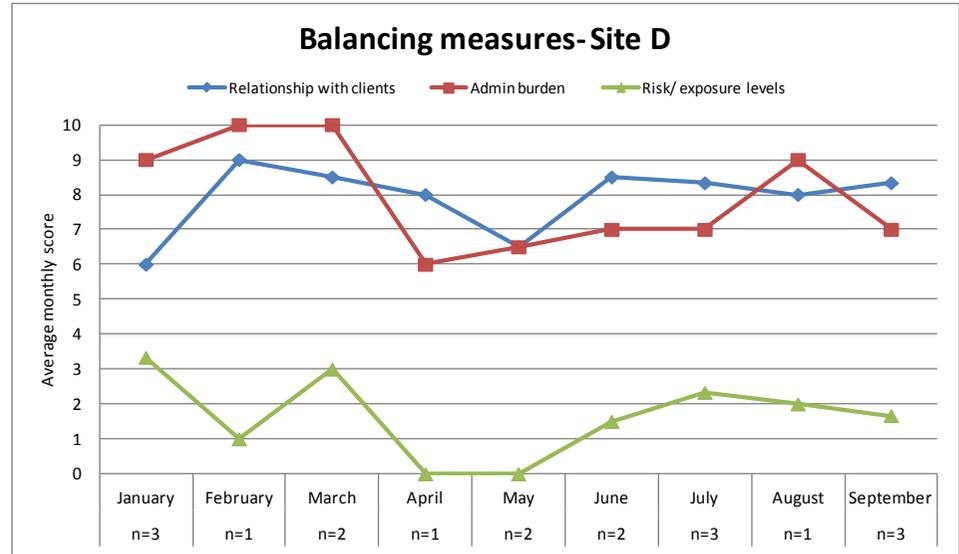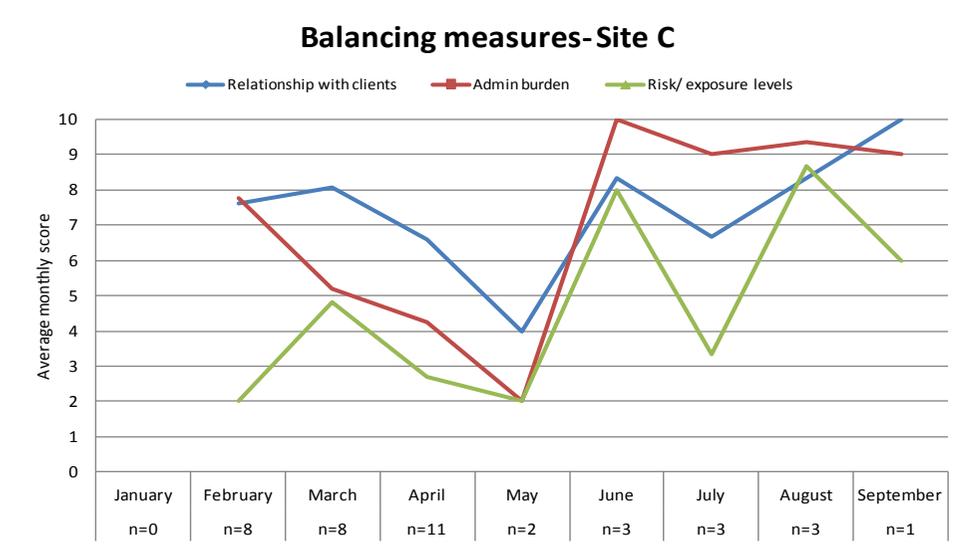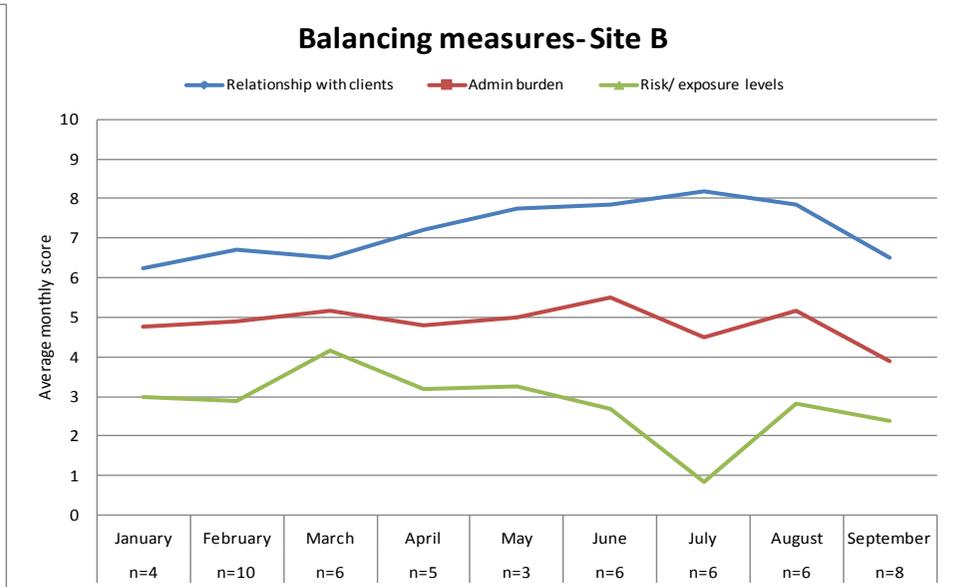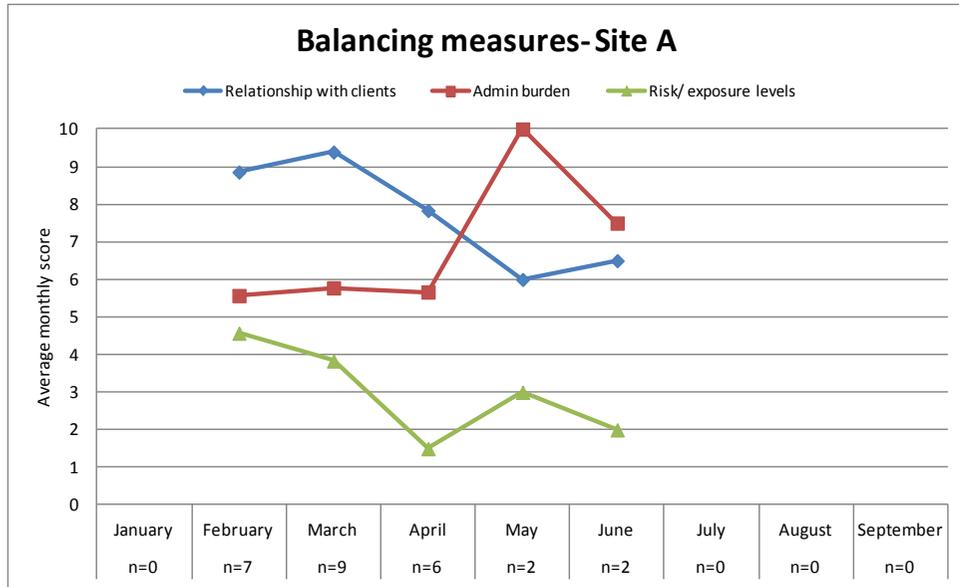
1. How happy have you felt about your relationship with your clients this week?
2. How overwhelmed have you felt by admin tasks this week?
3. How exposed or at risk have you felt in your work with clients this week?

Balancing measures were aggregated at a team level and viewed in a run chart to check the impact of SDM on issues of concern to clinicians in teams. Figure 8 (a-d) presents these data across all four sites up to the end of September 2012. The figures presented have been calculated based on clinician weekly self-report. Low returns rates make these problematic to interpret but some key themes can be tentatively suggested.

Summary of learning from balancing measures

Those trialling SDM were generally positive about their relationships with clients, they did not experience high levels of sense of risk but some sites did experience high administrative burden (though they pointed out that this was due to a range of factors not necessarily SDM itself).

Figure 8 (a-d): Balancing measures for each site

Balancing measures- Site A
Relationship with clients, Admin burden, Risk/ exposure levels

Balancing measures- Site B
Relationship with clients, Admin burden, Risk/ exposure levels

Balancing measures- Site C
Relationship with clients, Admin burden, Risk/ exposure levels

Balancing measures- Site D
Relationship with clients, Admin burden, Risk/ exposure levels

Relationships with clients (higher=better), **Admin burden** (higher=worse), **Risk/ Exposure levels** (higher=worse)

3.2 What has been the overall impact of your project?

Intended outcomes
- Clinicians involved reported that they had developed and refined their skills in SDM (see section 3 above)
- There is some evidence of impact for individual clients (see section 3 above)
- A range of tools and approaches were developed
- We developed links with a number of other projects, concepts and networks outside the CAMHS community, for example the MAGIC team, Co-Creating Health/ self-management support, colleagues in the USA, colleagues in Spain, colleagues at UCLP.

Unintended outcomes - positive or negative - arising from the project
- We have increased our awareness as to the difficulties of measuring the impact of making changes to practice (see section 3 above).
- We learnt about stages and states in implementation of SDM. Our learning around this is captured in section 3.1.2 (insight from PDSA analysis).
- We have influenced a number of allied projects and organisations through our learning on SDM. SDM is now the bedrock for other initiatives that are being developed, including CYP IAPT. For example, the advice being provided for clinicians in use of service user feedback and outcome measures in CYP IAPT now stresses the need to conceive of clinical use of outcome measures through the frame of SDM and is being actively conceived as the core of the accreditation framework being drawn up for CAMHS nationally. Our work through Closing the Gap has set a benchmark (in terms of context, intervention, barriers and facilitators), around which other initiatives we are also progressing now fit in (see section 7 on spread for further detail). Other initiatives that draw on concepts partly developed through this project include CAMHSweb (Department of Health-funded project to develop IT tools to support SDM in clinics) and U-PROMISE, a training developed to support clinicians to use feedback and outcome monitoring tools in meaningful ways to support and enhance service user experience.

Outcomes we anticipate being realised beyond the lifetime of the project (and evidence for this)
- Clinicians and others involved have stated their aim to continue to practice SDM and disseminate it to wider communities (events planned and in progress).
- Tools and approaches are available and being disseminated by new DH-funded project (SDM in CAMHS).
- Learning about facilitators and barriers to SDM are being written up and submitted for publication.
- Collaboration between service users and professionals continues into other projects (including DH funded Informed choice and SDM in CAMHS).

How the intervention has contributed to building skills in changing relationships
- We developed our understanding about driving forward change in the health sector. In particular:
  - We have identified three different 'states' towards implementation of SDM (section 3.1.2 (insight from PDSA analysis).
  - We have gained a sound appreciation for need of 'institutional courage' to support individuals changing practice (see section 7.3 for further detail).
  - The PDSA approach has now been incorporated more widely into our service development work at EBPU.

How the intervention has contributed to building skills in engaging patients and service users in improving services
- The way the intervention supporting SDM aided engagement of service users directly is detailed in section 3 above
- In addition the genuine partnership between professionals and service users in our steering group and in the sites teams has left a legacy of joint working (see section 3 above)

Extent to which positive outcomes would have happened anyway, in the absence of our project
- This is hard to determine. Anecdotal reports from the sites showed that they found the presence of the central team "essential", the chance to meet other sites "very helpful" and it was "crucial" to

enable them to have time to focus on these issues. However we do not know the counterfactual. Key points raised by the sites include:

- o There has been tremendous benefit from sites and collaborating organisations all learning together
- o Sites say that having the central team to drive the project has been essential- in a sense, we have functioned as a catalyst for change
- o Our feeling is that these positive outcomes would not have been realised without the infrastructure and support provided through the Closing the Gap project, but we cannot prove this!

3.3) Economic Impact

The overall cost of the project was £398,000. We were not in a position to do an economic analysis.

3.4) Assessment of the quality of the data

Section 3.1 outlines in detail our thoughts around the quality and robustness of the data we have used.

SECTION 4- DISCUSSION/ LEARNING

4.1) Summary
Tables 4 and 5 summarise our achievements, learning and key challenges.

Table 4: Learning about key achievements

Key achievements	What helped
Did change relationships	- Supportive central team - Clinicians engaged from outset - Systems in place to support process
Clinicians involved and enthusiastic	- Approach chimed with core values - Approach not forced; shared and created in collaboration with them
Service users involved and enthusiastic	- Genuinely involved - Were part of the project from the very beginning - Approach fitted with their values and what they would have liked for them
Being rolled out	Resources, tools, support
Genuinely collaborative	As SDM in CAMHS is a very new field, no one felt like an expert. Everyone was learning so we had to collaborate. The power was balanced
Good mix central and local input	Being flexible in our approach
Genuinely mix service user lead and professional lead	- Participation workers in all sites 50% of steering group
We got clarity on what SDM is	- Have been interested in understanding the underpinning concepts and processes rather than worried about implementing a "specific approach" - Open and flexible from the beginning - Listening to professionals and users and exploring what helps and what doesn't - No strong preconceived ideas
We have future funding to develop further	- SDM in CAMHS is a new area of work and very little has been done - Good results and experiences from both professionals and service users - There is a need to change how CAMHS work now, to best help CYP and their families - It is helpful and reassuring to know that the project will not finish here
It has influenced national projects	- SDM is part of a national agenda - It has enhanced other projects (e.g. IAPT, CAPA) as SDM provides a meaningful conceptual framework for collaborative work
All those involved feel passionately committed champions	People joined the project because they felt passionate about it
We all learnt a lot	There were no experts, we were all learning together
Other projects as a direct result- SDM in CAMHS IncludeME!, U-PROMISE, training in Spain	- We were passionate about it when talking to others - Successful stories to explain - Hot topic, national agenda

Table 5: Learning about key challenges

Key challenges	Why?
Over ambitious in data collection and analysis originally	• Sites describe a sense of feeling 'full' – we have not been able to convince them to fill out implementation booklets because they are already overburdened with lots of admin. So we are not able to demonstrate a link between changing relationships and improving outcomes as strongly as we would have liked • Site very diverse in terms of context of work they are doing, so common measures have not been possible to implement • We did not have a clear idea about our intervention at the start of the project- this has been part of the learning process for us. So at the beginning selecting an appropriate measure was a challenge. Now we would be clearer about a way forward
Stymied by IT limitations	• General difficulties in measuring SDM due to IT infrastructure lacking sophistication and also 'SDM' not being a tangible 'thing'- rather a philosophy underpinning a set of practices • Also, NHS IT systems are difficult to change or have access to (as we are outside the trusts)
Difficult NHS environment	• Big organisational structures which are difficult to deal with. • Conservative culture where taking risks is not encouraged. • A deeply ingrained belief that everyone "has" to agree on changes and all do the same thing- PDSA has helped to shift this mind-set but it still presents challenges (more so for those that have not been fully immersed in the project). • Tendency to protect the service/system (which can make innovation difficult to take forward)
Staff changes and losses	• Many changes taking place now, restructuring services, cuts, etc. NHS reconfiguration is causing much stress - jobs are at risk. And with staff turnover comes loss of knowledge, skills and motivation, depending on how embedding some new ways of doing things was already embraced
Envy from those outside	• There can exist an unhealthy culture from those outside our project groups to maintain the status quo • NHS should encourage innovation and develop a culture of sharing learning in order to improve services

4.2) Whether you were as successful as you wanted to be or not, what would you do differently next time?

If we were to start this project again, we might develop this project with just two sites coming together as a smaller learning collaboration. This would mean we could focus our energy in a more targeted way. On the other hand if one had dropped out this might have jeopardised the project in other ways and the sites all commented on how much they had learnt from each other.

Additionally, we would want to be more rigid with team structures to facilitate on-going project priority. A nominated lead person, with protected time, is what is needed for each site. Some profile descriptions we have thought about are: dedicated energiser, champion, stimulator, catalyst, practice improvement lead, support and challenge lead, culture carrier.

Certainly, this project has been a really enriching learning opportunity for us as a central team. Quality Improvement methodology has been hugely enabling. We have developing our approach as we go based on learning from Quality Improvement, the Health Foundation and learning from sites, and we are now really clear about what the SDM intervention best looks like. Would it have been better to start the project with a clearer process in mind? Perhaps so, but for us, the real benefit has been the process of learning, and although this project is now formally drawing to a close, our work in SDM is only just beginning.

4.3) Interpretation

Section 3.1.2 on PDSA analysis provides detailed consideration of contextual and other factors that influence impact and outcomes

4.4) Link between interventions, changed relationships and quality of care

Figure 9: Relationship between changed relationship and quality of care (RAND)
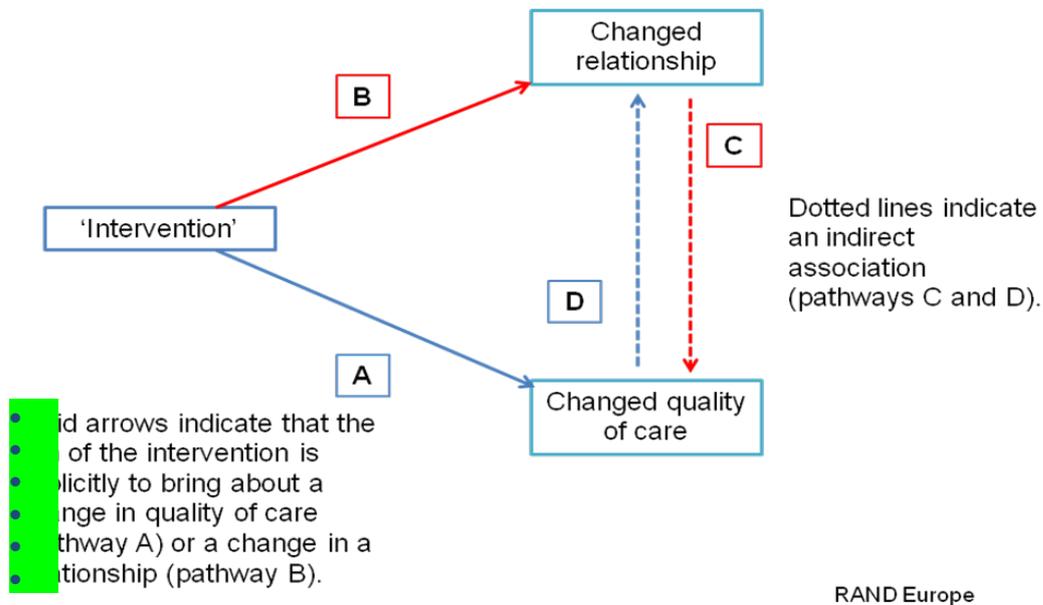
We find this diagram (figure 9) interesting. Our thoughts are as follows:

- Potential contextual factor: SDM can only happen with structure of services that support safe risk taking and a no blame culture
- Potential mechanism 1: SDM leads to CYP feeling more valued and involved, therefore care is experienced better and more informed by their wishes
- Potential mechanism 2: SDM leads to better therapeutic alliance, leading to better outcomes

SECTION 5- SUSTAINABILITY

We conceive of sustainability as relevant in three domains, each is explored below.

1) <u>Sustaining a shared conceptual framework</u>
- Linked SDM in CAMHS model to already existing evidence base.
- Linked SDM in CAMHS to other initiatives that are "hot topics" in government policy (i.e. CYP IAPT).
- Carried out qualitative analysis of PDSAs which has provided a clear roadmap for what facilitates implementation of SDM in CAMHS.
- We are working towards developing clinician briefing notes to capture learning about how to use all the different tools, models and approaches that we have been trying out as part of the CTG SDM project. These are based on PDSA learning and discussion with sites over the course of our project. We will use these briefing notes to support the dissemination of learning from our project.

2) <u>Sustaining work in sites</u>
- We selected teams that had senior management involvement already to support the promotion of a culture in which project learning would be shared and valued by the wider organisations that the sites were part of.
- Learning collaborative approach has helped sites to take ownership for SDM approach- genuine bottom-up approach resulting in increased commitment to changing practice.
- Sites seeing and experiencing benefit of SDM has generated motivation to embed a new approach into routine practice.
- We are working with sites to evidence impact of the SDM approach.
- Sharing learning with sites has been an on-going process, so they have helped shape interpretation along the way, resulting in key learning feeling genuinely representative of their lived experience and very real.
- We have trained sites in concepts and methods relating to implementation, sustainability and spread – and explored with them how to present local learning to senior managers and others.

3) <u>Sustaining SDM in our organisations (CAMHS EBPU, CORC and YoungMinds)</u>
Links to other projects - Because of our existing networks we set out to ensure the CTG project was complementary to, compatible with, and informed concurrent projects across the CAMHS landscape. For example, members of our team have been involved in national initiatives such as Child and Young People Improving Access to Psychological Therapies (IAPT) and Payment by Results (PbR) for CAMHS, CODE (Child Outcome Data Explained) database (a tool for tracking outcomes over time), the DH-funded 'Informed Choice' project (which is focusing on the development of relevant decision making aids) and UPROMISE - a training package to help make use of Patient Reported Outcome Measures (PROMs) in the context of SDM which has recently been developed (U-PROMISE: Using Patient Reported Outcome Measures to Improve Service Effectiveness.

Challenges associated with sustaining change
<u>Context of change in the NHS and emotional and admin burden associated with this</u>
Sites say that they have felt really supported and nurtured by the central team, so when we reduce our presence, will they be able to keep going? This is particular pertinent in the context of admin burden associated with current health and social care change which has already presented as a challenge to them throughout the course of the project- i.e., a sense of feeling "full up".

<u>Institutional courage to support real change at a clinician level</u>
A critical realisation that we have come to is that being able to "do" SDM within a child and adolescent mental health setting, and given current practice in the NHS, requires willingness to try new things that you may have doubts about at first.

Practitioners already have extensive knowledge and skills to have collaborative and caring conversations with young people and families. However, taking the next step towards trying out new tools to support specific instances of SDM requires both individual and institutional courage, and a belief that you will not be blamed for trying something that may not work (as long as you have taken sensible precautions to not do any harm).

In order to allow such individual and institutional courage, strong leadership and support or at least a network of peers to support each other, seems to be crucial. It may also require a change in mind-set for some and a management or collegiate nudge for others.

Being able to obtain quantitative data to support the story of change
- Difficulties collating relevant information, due to limited infrastructures being in place
- Difficulties generating relevant information at a meaningful level, for example in one service, data could only be made available at a service-wide level, which could not reflect the impact of individual clinicians trying out new approaches.
- Difficulties generating accurate information, for example in one service DNAs are measured on the basis of individual clinicians so if three clinicians are due to see one family, and the family DNAs, this would count as three DNAs in the records.

SECTION 6- SPREAD

We have taken (and continue to take) every opportunity to update members of the wider CAMHS community on learning from the project such as via other learning events at which we are present. As several members of the steering group and core team are part of a range of allied national initiatives ideas are constantly flowing across projects. In addition we have been proactively developing our spread strategy. The main activities include:

Dissemination already achieved
We undertook a series of "Masterclasses" in SDM to share learning from the sites with wider stakeholders. These were held in November and December 2012. Around 200 senior managers and front line practitioners across England attended these events.

Feedback received from attending delegates was very positive. Here are some comments received in relation to the question: "*What effect (if any) is today's training likely to have on the way you work?*"
- To raise awareness of clinicians core skills within teams and ask to offer more options to YP.
- Awareness of how to best use reflection on discuss options.
- I will continue with SDM I am doing and put into practice using tools provided today. Will discuss with colleagues.
- This was some of the best training I've been to, so a lot I hope! Hope that I will be more structured in my approach - so clearer to service users what I am doing and why.
- The way I do a choice appointment.
- I hope we use some of the client satisfaction questionnaires try to help clients with choices and discussions about their care.
- Less on a tread wheel!
- Think more carefully how I present options re treatment and measuring session outcomes.
- Encourage me to spend more time on explanation.
- Evaluate the process, and how's going the therapy - feedback with user service.
- Develop new materials to help service users to understand and explore their options.
- I hope it will have a great effect since it will help me grow professionally and adapt new concepts that will enhance my practice and clients treatment satisfaction.
- More structure when discussing treatments and choices.
- I feel equipped to try some new things out.
- Enthusiasm for SDM etc. has been increased and will use logbooks to reflect on new approaches
- Sharing with colleagues ideas about SDM.
- I will aim to implement on my professional practice.
- Will start to try implementing into and hope to implement this in service? Alongside IAPT monitor and sessions.
- It has been helpful to offer a space to think about working with adolescents which is hectic in the NHS. I feel refreshed and equipped to rise again to the challenge.
- Taking back to team.
- Incorporating best practice principles and disseminating to my team.
- Will try to use SDM thinking in future CPA meetings with clients.
- Specific idea re how to do SDM clinically (and reflect on this using PDSA cycle). Ideas to share with team.
- Tighten up clinical practices - use combined with goal based outcomes.
- I will think more about the way I work and discuss with the team.

We also disseminated learning to stakeholders via a CORC forum involving around 60 frontline practitioners, commissioners and managers. Finally, we have developed and disseminated a number of articles and blogs through the YoungMinds network.

Publications and conferences
We have already presented the learning from our project in one international conference
- Abrines, N; Hoffman, J; Wolpert, M. *Shared Decision Making in Child and Adolescent Mental Healthcare*. VI International Conference *Afin*. New glances at adoption in/as risk. Valladolid, Spain, November 2012.

Two abstracts have been accepted for the ISDM 2013 (International Shared Decision Making conference) (appendices37 and 38):
- Abrines, N; Hoffman, J; Wolpert, M. *Developing a Model for SDM in Child Mental Health.*
- Abrines, N; Hoffman, J; Wolpert, M; Martin, K; Wright, E; Feltham, A; Baird, L; Law, D; Constable, A. *Barriers and Facilitators to Implementing Shared Decision Making in Child and Adolescent Mental Health Services.*

We have written an article about the project and the qualitative data we have obtained. The article has been submitted for publication.
- Abrines, N; Hoffman, J; Wolpert, M; Martin, K; Wright, E; Feltham, A; Baird, L; Law, D; Constable, A. *Facilitators to Shared Decision Making in Child and Adolescent Mental Health Services in UK: Professional's Experience.*

DH Promoting SDM in CAMHS (dissemination project) and briefing notes
This project builds on the work we have been engaged in through the Closing the Gap project and seeks to further develop and disseminate a range of free tools and training resources to child mental health professionals to support increased use of SDM in clinical practice in CAMHS. We are drawing on our learning as part of the Closing the Gap project to facilitate the spread of best practice across a diversity of CAMHS contexts nationally. Development of clinician briefing notes, based on the PDSA analysis, is one resource that is being developed as part of this project. We are holding events in June 2013 as part of the dissemination strategy for the DH project.

IAPT
Learning from the CTG project has provided a set of values and philosophy to underpin activity required as part of the IAPT programme. In addition some of the processes we used as part of the CTG project have been taken up by the IAPT approach, for example the PDSA logbooks were shared with members of a working group for CTP IAPT and requests were made for their use and adaptation to that project.

U-PROMISE
The U-PROMISE training package is a vehicle through which important learning and best practice from this project can be spread. In part arising out of collaboration and learning developed as part of this project, we developed UPROMISE; a training package to help make use of PROMs in the context of SDM (UPROMISE: Using Patient Reported Outcome Measures In Service Effectiveness). This package in part draws on learning from the CTG project and incorporates perspectives of members of the Closing the Gap SDM in CAMHS Steering group- including service users, and is a collaboration between EBPU, CORC, YoungMinds, and Hertfordshire CAMHS.

Other training activity
We have been commissioned by different organisations to provide training, for professionals, about SDM in child and adolescent mental health services:
- Lecture for the Msc in Developmental Psychology and Clinical Practice. Anna Freud Centre - University College London.
- Training for a public service specialised in early childhood and development in Barcelona, Spain.

Resource Development
We have also been contacted by the programme facilitator of the Shared Decision Making programme that is part of AQuA (Advancing Quality Alliance) to seek permission to further develop and adapt the PDSA log book to support their work in a number of improvement projects across the NHS.

Network
We have been working towards developing a network for CAMHS to disseminate our learning and facilitate spread of our activities more widely. We held network consultation events as part of the SDM Masterclass series, with support from the Health Foundation, as part of their 'Supporting networks to

improve quality in healthcare' grant. We also have agreement to develop this network further through the DH promoting SDM in CAMHS project.

New grants
EBPU have been awarded two new grants: (1) from the DH to use interactive technology and support packages to facilitate SDM for children CYP accessing specialist CAMHS across England ("CAMHSweb project") and (2) from the Department for Education to undertake a randomised controlled trial across secondary schools and Myplace centres of web based support materials and web support for young people who have significant emotional or behavioural difficulties ("What's Up" project). Learning from CTG has informed the ideas upon which these bids were developed.

UCLP Integrated MH programme- Child SDM
Our project manager moved from this role to the position of 'Improvement Fellow' with UCLPartners - who are an accredited academic health science network working towards innovating frontline practice based on latest research. She will be working on their Integrated Mental Health Programme, which will in part involve spreading learning of SDM in CAMHS across their clinical network (and developing our ideas further).

Others
We are aware that other initiatives/organisations have shown their interest in our project or are already using our learning to influence their work:
- YoungMinds
- CAPA, The Choice and Partnership approach
- BPS, The British Psychological Society
- Headspace (National Youth Mental Health Foundation) Australia
- Hertfordshire CAMHS
- Associacio EDAI (Mental Health Service, Barcelona)
- 5 Boroughs Partnership NHS Foundation Trust
- ACAMH
- ADHD Foundation
- Adler Hey Children's NHS Foundation Trust
- ATTACH Children's service
- Barnardos' Cymru
- Barnsley CAMHS
- BEH NHS Mental Health Trust
- Blackpool Teaching Hospitals NHS Foundation Trust
- Bristol NBT NHS Trust
- Buckinghamshire
- Cambridge Women's Aid
- CAMHS Devon
- Child and Family Play Therapy Ltd
- Conatus Child Psychology
- Conwy and Denbighshire CAMHS
- Ealing CAMHS
- East London Mental Health Trust
- Greater Manchester West NHS Foundation Trust
- Greenwich CAMHS LAC Team
- Hackney CAMHS
- Hertfordshire Partnership NHS University Foundation Trust Specialist CAMHS
- Islington TYS-YOS
- Kingston CAMHS
- Lancashire Care Foundation Trust
- Lancashire Care NHS Trust
- Merseyside Youth Association Ltd
- Milton Keynes Community Health Services
- NELFT

- Newham CAMHS/CFCS
- NHS Grampian
- NHS South Essex PCT
- North East London NHS Foundation Trust
- Oxford Health NHS Foundation Trust
- OXLEAS NHS Foundation Trust
- SEPT CAMHS
- Shropshire Community Health NHS Trust
- South Essex Partnership NHS trust
- South Staffordshire & Shropshire NHS Foundation Trust
- South West London and St Georges
- South West Yorkshire NHS Trust
- Spinning World (PSS)
- Stafford CAMHS
- Stockport MBC
- Surrey & Borders Partnership
- Surrey and Borders Partnership NHSFT
- Tavistock CAMHS
- TEWV NHS Foundation Trust
- Torbay CAMHS
- Wirral CAMHS
- WLMHT
- Young Person's Advisory Service
- YPAS, Liverpool 3rd Sector CAMHS

6.1 How are you promoting your innovation and convincing others of its value?

We have already started several initiatives to promote SDM across the CAMHS community as described in section 7.1. Our aim is to spread our knowledge and learning for why it is important and specifically how to implement it.

6.2 What advice would you give to someone attempting to replicate your work in another organisation / setting including consideration of barriers?

1)   What levers should they employ to facilitate change?

Institutional courage
A critical realisation that we have come to is that being able to "do" SDM within a child and adolescent mental health setting, and given current practice in the NHS, requires willingness to try new things that you may have doubts about at first.

Practitioners already have extensive knowledge and skills to have collaborative and caring conversations with young people and families. However, taking the next step towards trying out new tools to support specific instances of SDM requires both individual and institutional courage, and a belief that you will not be blamed for trying something that may not work (as long as you have taken sensible precautions to not do any harm).

In order to allow such individual and institutional courage, strong leadership and support or at least a network of peers to support each other, seems to be crucial. It may also require a change in mind-set for some and management or collegiate nudge for others.

As one clinician commented: "*When you first came and talked about trying out some of these ideas, I was sceptical. I thought' that won't work!' and I thought of all the reasons why it wouldn't work. One thing this project has taught me, is to at least try it once, before I decide if I want to pursue it further or not.*"[1]

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[1] *Note- text in Italics are taken from notes from conversations with clinicians and not from verbatim recordings*

Set up the infrastructures to support <u>real</u> change
Even the best will in the world does not give rise to change. It is really important to provide clear direction from the outset by (1) being clear about everyone's roles within teams and (2) providing focused training on the particular intervention.

Clinicians require a lot of steer and guidance to get them started. However, this needs to be within the context of flexibility to make this a reality within the diversity of settings that they are working within. It is very important to strike the right balance between focusing on direct work with clinicians and drawing on the support of non-clinical team members as key drivers of the improvement work.

Nurture relationship with sites
- Approach your work together with an open and facilitative mindset - be curious and 'can do'
- Be really honest that you are all learning together- the central team are not coming from the perspective of already knowing everything
- Use a mixture of generic central team and personal email addresses to communicate with sites – the central team ('faceless') email address for group communications (i.e., update emails), and personal email addresses for 1-2-1 emailing, as this allows for 'banter', which helps to strengthen individual relationships
- Be willing to go along to site team meetings, even if they only last for an hour, as this sends across the message that we are genuinely here to be used as a resource by them
- Don't underestimate the difficulty of having presence at sites- you can never have too much!
- Last but not least – time! Building rapport is not something that can be forced; rather it comes about through an organic timely process because both parties are committed to making that happen and willing to putting the time in to ensure it does.

2) What barriers and challenges should they prepare for?

- *Tools vs. frame of mind*

Interestingly we have gone back and forth with respect to our thinking about what to focus on: encouraging use of tools or working towards shifting mindsets. What we have learnt is that achieving the right balance between both of these things is probably what matters the most. It can be very easy to get diverted by focusing on tools, and appealing to think "I just need to find the right tool, and then…" - but this doesn't mean that SDM is actually taking place. However, tools are still helpful as a vehicle towards doing it.

- *Do not read too much into "using a new tool"*

In the words of one of our site members:

> "*…one of the clinicians reflected with me that although she now finds the Bull's-eye really useful it took her a long time to integrate it into her practise. It started with forgetting to take it to the appointment or forgetting to mention it and make time for it. She noted that she had to feel comfortable with it first. We discussed this in the light of her trying to use the Choice cards as she felt a similar process was happening. I thought it was useful learning in preparing people for making this kind of change to practise and not reading too much into 'not using a new tool'.*"

We found this to be a really interesting and insightful reflection into how testing out new approaching for this project is being experienced on the ground. We will be sure to keep this in mind when introducing new tools and approaching to sites, and for wider dissemination also.

3) What risks should they be aware of?
- People in the team leave.
- Professionals in the NHS are accustomed to spreading changes before testing them thoroughly enough!
- Change is an emotional journey- don't be surprised by anything!
- Clinicians take it in turns to lose focus- unless the project is completely embedded into their clinical structures, it is experienced as a burden to do.

4) Where should they target their efforts to enhance their chances of success?

- Focus on small tangible changes.
- Begin with focused activity in one site while you are developing an articulated model of your intervention and then move forward to a collaborative approach to test out clearly defined interventions in different contexts.

5) What should they do to ensure they are successfully measuring the effects of their intervention and producing robust evidence?

- Be flexible and listen to sites in relation to what they say is possible-and meaningful- to collect. Focus on getting this right from the beginning.
- Importance of collecting information at a clinician level.
- Documenting project learning is cumbersome, individuals only appreciate a need for this when they see learning being reflected back to them. Very important to prioritise this to spur momentum
- Infrastructure ideally should be set up to remove any burden associated with data collection

SECTION 7- CONCLUSION

The 'Closing the Gap: Shared Decision Making in CAMHS' project set out to change the relationship between individuals and health providers, in the context of child and adolescent mental health service use. Our approach was based on the premise that effective interactions require both parties to have a shared understanding of purpose and process, and that this could be achieved using a model of SDM. Our intervention involved supporting multidisciplinary teams across 4 locations to test out and implement approaches in SDM. Sites developed a range of tools and resources to facilitate increased SDM.

As a result of this project we have developed a high level conceptualisation of what SDM in CAMHS might look like. This has marked the first attempt to enhance this way of working with young people and families in this context. Our learning indicates the need for adaptation of current models of discrete SDM to make it applicable in the complex environment of mental health and child work where multiple perspectives may be involved, decisions are not one offs and on-going relationships are key.

This conceptualisation consists of 3 elements:

1. SDM is a frame of mind, an ethos and an on-going process that you bring into all of your interactions with young people and their family. This may mean (as discussed above) that at times you are inferring the decision from the young person's behaviour, from contextual factors or from other expressions of communication. The corollary of this is that what SDM is not is a simple process of giving out forms for people to write down choices and those to be followed slavishly – nor is it saying "over to you, the decision is yours". The mode of SDM may change in different context but the ethos remains the same –the key is flexibility of approach.
2. SDM can be seen as a series of steps / stages in the YP's pathway through care and at each stage there are opportunities for SDM and elements that need to be in place if the next step is to happen (e.g. if you haven't agreed what the problem is you can't discuss options).
3. Developing skills in SDM can be seen as a series of stages or states (apprehensions, feeling clunky, integration). We don't know yet if all have to go through these stages or if some are always in one or if people move in and out of these states or stages.

We anticipated and hoped that SDM as a vehicle for change would promote best outcomes for CYP in CAMHS. The specific domains of quality we set out to focus on improving were: effectiveness, efficiency and person-centeredness.

We considered a range of outcome measures and tried hard to look at impact in relation to a range of indicators including DNA rates, service experience and risk behaviours. There is some evidence of impact for individual cases, in particular in relation to risk behaviours on inpatient wards, but it needs to be noted that data quality and capture issues make it hard to make definitive statements about impact at a wider level. Below are our tentative conclusions based on what quantitative and qualitative information we were able to collect:

- In terms of **effectiveness** while we cannot definitively prove that SDM led to better outcomes with young people, clinicians on the ground using this approach felt that they were able to ensure their interventions were maximally aligned to the need of young people and families (e.g. with use of goals or other outcome monitoring measures) with hypothesised impact on outcomes.

- In terms of **efficiency** again while we cannot definitively prove SDM led to greater efficiency, and DNA data proved hard to interpret, clinicians on the ground using this approach noted that they were more able to agree upfront service usage (e.g. agreeing if a young person did not want to use the service rather than offering an appointment that the young person did not attend). In addition data from the inpatient site suggested reduction in incidents which is likely to reduce unhelpful resource usage. One area that was identified as a potential negative effect was challenges raised by burden of admin which may or may not be related to SDM tools specifically.

- In terms of **person centeredness** there was evidence from clinician report and young people with experience of CAMHS generally that they welcomed SDM as a way to facilitate more open conversation and allow young peoples' view to be heard and there was a consensus from those involved in the project that the SDM focus on feedback really aided clinical work (e.g. by use of the bull's eye etc.). The information from feedback collated in PDSAs suggested that SDM may need to be flexibly applied with different groups to ensure maximal benefit (e.g. older versus younger children, those with LD, those with ASD- see discussion in section 3.1.1). The inpatient data suggest that this experience might help reduce stress for young people on the wards.

Thinking ahead to future areas of exploration, directly arising from our learning from Closing the Gap, we would suggest the following:

- Refinement of the range of tools and approaches available to capture SDM in practice in child mental health settings.

- Drawing on learning from PDSA analysis, to develop a tool for measuring extent of SDM in CAMHS clinical interactions and impact of this. In particular we are interested in exploring the relationship between SDM and premature termination of therapy and therapeutic alliance further.

- Use of Brief Focused Recall methodology to explore in detail the lived experience of both clients and clinicians in relation to specific interventions which aimed to promote SDM.

We welcome the opportunity to collaborate with any groups interested in taking these ideas further.