Supplementary Materials 3. Additional content relating to Chapter 5: End-user involvement

Introduction

The inclusion of end-users within healthcare research is encouraged due to the valuable insight they can provide during the research process. {Beresford, 2007 #1916;Boote, 2010 #1917} By incorporating the knowledge and experiences of these groups into each stage of a project's conceptualisation, development, implementation and dissemination of findings, it ensures that the research remains relevant and accessible to the people whom it is intended to benefit.{Thompson, 2009 #1918} Thompson-Coon and colleagues{Thompson Coon, 2015 #1931} conceptualise enduser involvement to include health and social care professionals who may utilise the research findings in their daily practise, in addition to the involvement of service users, carers and service representatives typically considered in the literature patient and public user involvement.{Mockford, 2012 #1920}

In this chapter we outline the involvement of topic experts, including psychiatrists, psychologists, paediatricians, young people and parents at each stage of this project. The impact their experience and insight had on the project is discussed within each section.

Planning stage

Finalising search terms

A list of proposed physical and mental health search terms was circulated by email in January 2016 among the topic experts involved with the project prior to the searches being conducted for Review 1 and Review 2. This contributed towards the creation of detailed search strategies. On the basis of feedback terms including "Crohn's", "fibromyalgia", additional cerebral palsy terms and broad mental health disorder terms like "psychiatric/psychological/emotional disorder" were added.

Defining key terms and refining inclusion criteria

Aim of meeting

A meeting was held for co-applicants and our expert advisory group to remind them of the aim of the project and discuss how we define key terms on 11th February 2016. *Appendix X* lists the topic experts amongst the project team and expert advisory group. Inclusion criteria were also discussed, with any edits to be applied to screening for study selection. The end-user groups represented at this meeting included paediatric psychiatrists, psychologists, researchers and one parent with experience of caring for a child with a long-term physical condition (LTC), whose child was part of our Children and Young People Advisory Group (CYPAG).

Meeting content

One of the key issues addressed at this meeting was the definition of "long-term physical condition" for use in our project. Several definitions of LTC already exist within previous literature, as highlighted in *Chapter 1* of this report. After receiving feedback from a parent of a child with an LTC and topic experts on the various definitions of LTC, including those from the UK Department of Health and Van der Lee and colleagues,{Health, 2012 #1932;van der Lee, 2007 #1186} the project team developed and agreed upon the following definition of LTC:

Diagnosed physical health conditions, with an expected duration of at least three months, where cure is considered unlikely, causing limitations in ordinary activities and necessitating medical care or related services beyond what is usual for age in question.

Discussion extended into consideration of whether LTCs such as chronic fatigue syndrome, chronic pain, fibromyalgia, medically unexplained symptoms and irritable bowel syndrome fit with our agreed definition of LTC. The group acknowledged the key differences between these disorders and other LTCs with clearer physical aetiology, such as cancer. However, it was also acknowledged that regardless of cause, these conditions and associated mental health difficulties were likely to present to and be treated within physical health services. It was agreed that consultation with DSM-5 would provide clarification as to whether any of these conditions are considered primarily as mental health conditions and therefore ineligible for inclusion in the review.

The group also discussed the definition of a mental health intervention in this context. Issues raised included whether to include interventions aimed at parents or those aiming to improve medication adherence. We agreed that interventions were within the scope of the review if explicit reference was made of aims to improve the mental health of children and young people (CYP) with

LTCs. Our parent representative strongly felt that interventions to reduce distress experienced during medical treatments should be included in the study due to the potentially cumulative effect of repeated distress on CYP's long-term mental health. We therefore also included interventions targeting procedural distress during medical treatments.

Impact on project

As a result of the discussions held during this meeting, definitions of LTC and mental health interventions were agreed, which defined the scope of both reviews.

Introducing the project to the Children and Young People Advisory Group

A CYPAG was formed for this project as part of our commitment to patient and public involvement, and met four times over the course of the project. Meetings were held at Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), London. These meetings were arranged and facilitated by Dr Erin Walker (Patient and Public Involvement Lead) and attended by JTC, DM, LS and MN from the University of Exeter. The CYP who attended did so in response to an invitation from EW. Whilst not all of the CYP could attend each consultation event, the core group was deliberately restricted to those who accepted the original invitation to attend. This was to facilitate cohesion and rapport among CYPAG members and the study team, and maintain levels of knowledge about the project within the group across all four meetings.

A group of seven CYP between 12 and 18 years of age attended the first meeting on 20th February 2016. These CYP lived with primarily neurological or rheumatic LTCs (although most had other comorbid physical conditions) and all had experienced issues which affected their mental health and emotional wellbeing.

Aim

The aim of the first meeting was to introduce the project and the research team, provide explanation of challenging concepts, manage expectations of the scope of the project, what it would involve and what it might achieve, and to start to develop rapport within the group. Although at this stage in the project the database searches had been completed for Review 1, we felt it was important to ask the CYP for their views regarding the focus and relevance of this project and the definitions being used, particularly mental health terms.

Structure and content

The two-hour meeting began with an icebreaker activity facilitated by EW. DM gave a short Microsoft PowerPoint 2010 (Microsoft, Redmond, WA, USA) presentation outlining the purpose of the project and our plans for their involvement over the course of the project. An open discussion was held where CYP provided views and insight on the projects focus, drawing upon their own experiences.

Children and Young People Advisory Group views

The CYPAG discussed the inter-relationship between mental and physical health and considered this to vary between individuals. The group did not necessarily recognise the separation between physical and mental health, although one group member felt access to treatment for depression might be easier when already receiving treatment for their LTC. Having a diagnosed mental health condition was considered useful by the group, as it helped explain why they were experiencing certain symptoms and facilitated access to medication or other treatments. However, the group also acknowledged a significant lack of mental health awareness or education in schools. When such education was provided, it was sometimes perceived as unhelpful and failed to reduce the stigma surrounding mental illness.

Participants had experience of a range of mental health interventions, including cognitive behavioural therapy (CBT), medication and meditation. Overall, therapies which worked in the long term and helped with challenges aside from physical and mental health conditions appeared to be favoured. There was recognition that you "can't get it right straight away" [CYPAG member, First meeting] and that individuals may need to try several different treatments for mental ill health.

Impact on project

Ideas put forward by the CYPAG in the first meeting reinforced the importance of acknowledging the link between physical and mental health and how, potentially, interventions aimed at treating one aspect of their wellbeing may impact on another. This strengthened our justification for including all outcomes (in the child mental health domain or otherwise) in the synthesis of Review 1.

Review methods stage

Review 1 Study selection teleconference

A teleconference was held with co-applicants and our expert advisory group on 14th April 2016 to discuss study selection decisions from Review 1.

Aim

To update the team on progress with reviews and make decisions regarding study selection.

Structure and content

DM updated the group on progress with Review 1 and the team discussed specific studies for which inclusion/exclusion decisions ought to be checked with topic experts. The discussions centred around LTCs that may be considered mental as well as physical health conditions, study setting, procedural anxiety interventions, the inclusion of other outcomes and searching for economic evaluations.

For two studies, we discussed the sampled LTC against our defined inclusion criteria.{Brown, 2014 #1585;Masia Warner, 2011 #1563} We agreed that LTCs with a recognised mental health component should be included in the review as distinction on this basis may be unhelpful, therefore both studies were included. We also agreed that a study of sub-syndromal depression should be included as the sample was at risk of depression.{Martinović, 2006 #1310}

Although we were expecting a large number of procedural anxiety studies, we had identified only one relevant study of this nature. Many were excluded due to low anxiety levels at baseline. We also agreed to include the five studies from non-OECD countries. Given the rationale for excluding intellectual and learning disability samples because interventions may be delivered in different forms to accommodate needs, the team agreed to include parenting interventions where a minority of the child sample appeared to have learning disabilities.

We agreed that reporting all other outcomes, but distinguishing between the primary review outcome of CYP mental health and other outcomes, would be preferred. We planned to specifically report if any of the outcomes mentioned in the original Health Technology Assessment (HTA) call (and highlighted by study team and through consultation as important) were not reported in included studies.

At the time of the teleconference, our searches had not identified any economic studies, and furthermore none of the randomised controlled trials identified also reported economic outcomes. Possible solutions were discussed and we agreed to email all corresponding authors of included studies for further information on economic outcomes.

Impact on project

Discussion with clinicians was valuable in refining our interpretation of the inclusion and exclusion criteria for the reviews. By sharing some of the challenges of identifying relevant information at this early stage of the process, we were able to utilise the experience of the entire team in planning alternative approaches.

Feedback on categorisation of interventions and outcomes for Review 1, progress with Review 2 and dissemination planning

The second CYPAG event took place on 10th September 2016. This included six individuals from the first meeting, and one CYP who had been unable to attend the first meeting. At the time of this event, we had preliminary results from Review 1 and the synthesis for Review 2 had just begun.

Aim

As it had been seven months since the group last met, we aimed to update the group on the progress with the study, and to further develop relationships with members. Feedback was sought from the CYPAG regarding how the types of interventions and outcomes from Review 1 were categorised and whether emerging themes from Review 2 matched their experiences. Further plans for how the CYPAG could contribute towards the dissemination of results from the project were also discussed.

Structure and content

This session was two hours long. After a brief reminder regarding the purpose of the two reviews and overview of what was discussed in the previous meeting, CYP were asked to complete two card sorting activities. The card sorting activities facilitated a discussion with the CYP about the types of intervention seen in Review 1 to establish if there were any unexpected findings identified by either review.

For the first activity, the CYP were provided with cards displaying the name of mental health interventions seen in Review 1. They were asked to sort the cards according to how well they thought these interventions would work for CYP with LTCs. For the second activity, the CYP were

presented with cards with common intervention outcomes from Review 1, including: "social skills", "behaviour", "physical condition", "coping", "depression", "anxiety" and "general mental health" printed on them and they were asked to rank them in order of importance. They were also issued with blank cards to write down outcomes which they considered to be important which had not been identified by Review 1.

Figure X illustrates quotes from studies included in Review 2 which were shared with the CYPAG. The CYP were asked to share their views on the anonymised quotes, which were chosen to reflect experiences of the CYP, their parents and professionals across a variety of interventions. Finally, reviewers gave some examples of dissemination from previous projects and asked the group for ideas on potential dissemination routes. We also asked the CYP whether they would like to be involved in the dissemination activities and if so what format this might take.

Children and Young People Advisory Group views

All members of the CYPAG were familiar with CBT. Some had received it and found it useful, others felt it might be more suitable for older participants and those who found it difficult to reflect on thoughts and feelings. The group had varying experience of relaxation techniques, with group members stating they found relaxation activities hard to replicate at times of stress. Physical exercise was perceived to improve mental health and provide a distraction from illness or pain, although prior negative experiences of physiotherapy and pain caused during exercise (e.g. for those CYP who had mobility impairment) had discouraged some CYP from doing physical exercise. Young people felt they needed to be given a rationale regarding why they were being asked to complete exercises, and that they should be able to incorporate exercise into daily life. The relationship with the person leading the intervention was seen as critical to the intervention's success. CYP were surprised that physical exercise did not have more support from included studies and that relaxation had some evidence of effectiveness.

Group members did not like feeling as though they had to "fit in a box" [CYPAG member, Second meeting] of one LTC, or one mental health problem, and discussed how they wanted therapists to listen to them and for mental health interventions to be flexible. The CYPAG believed that the various professionals responsible for their care should understand their multiple needs and work together for the effective treatment of all of their health conditions.

The group discussed how several mental health, physical health and social outcomes were interlinked and how difficulties in one area could lead to problems in another. CYPAG discussed the difficulties associated with returning to school or transitioning between schools and the

importance of understanding relationships with teachers, family and friends. CYP felt that improving social skills could also impact on friendships, symptoms of depression/anxiety and, in the long-term, LTC symptoms. *Figure 1* captures views in response to initial ideas from the synthesis of Review 2.

"What (the intervention) means to me is being away from all of my problems and to be with people that have been through the same thing that I have."

Summary of CYPAG Views:

- Some diseases rare so difficult to find others.
- Not so important [to be with people with same condition], beneficial to be with people.
- People with same condition likely to talk about it so not always a good thing.
- Good to get away from problems.

Summary of CYPAG Views:

- Informed important.
- Knowledge powerful. Often want to know if something concerns them, even when young.
- Want to be empowered.
- Don't want to be treated like a child.

"I'd like to know what could happen, so you've got no surprises later on."

"The truth is that it helped us a lot also because, basically to me it allowed me to not worry so much."

Summary of CYPAG Views:

- If know what to expect can prepare, so less worry.
- Particularly things like side effects of medicines.

Summary of CYPAG Views:

- Lots of nods.
- Would like to meet successful adult with condition, so could get advice on next step.
- Future important.
- Someone who inspires you is important.

"The other thing I would find useful is seeing people who have come through it all and are leading a relatively normal life....A lot of times you get to the point where you think there's just no hope."

Figure 1: Quotes from included studies and responses of CYP

In the discussion of possible dissemination activities, we learned that only some members of the CYPAG would be happy to be filmed, and most preferred the idea of recording audio for a podcast instead. The group were also happy to help edit plain language summaries of review findings.

Impact on project

Meeting activities reinforced the importance of a wide range of outcomes and the impacts of interventions on relationships with friends and family members. CYP emphasised the importance of school attendance and coping with school when one has an LTC. Although very few school-related outcomes were reported in the studies included in Review 1, this discussion highlighted the importance of this type of outcome to CYP and should be considered an important addition to future randomised controlled trials and calls for research in this area. We have highlighted this point in our implications for future research section. We decided to also consider a podcast as a dissemination activity involving the CYPAG and to include time for editing plain language summaries for different end users in the final CYPAG meeting.

Consultation stage

Feedback on preliminary review findings from children and young people and their parents

The third CYPAG event took place on 28th January 2017. Five young people attended. It had been observed at the previous CYPAG meeting that, when parents came to collect their children from the meeting, they spontaneously discussed their experiences of accessing care for their child, and their children's LTCs and mental health problems. Although it was not part of the original patient and public involvement plans for the study, this presented the opportunity to access the experiences and knowledge of these parents, and it was decided to hold a separate parent group meeting, in tandem with the young people's meeting.

Aim of Parent and Children and Young People Advisory Group

We used the two hour group meetings to discuss Review 1 findings, ideas and themes emerging from Review 2, and the Overarching Synthesis. After discussing the emerging findings from the project, both groups were asked about their interest in involvement in future dissemination activities.

Structure and content: Children and Young People Advisory Group meeting

DM and JTC provided the five CYP with a brief project update before introducing the activity. The CYPAG were asked to complete a mind map where they designed their ideal mental health intervention. This activity was based upon questions arising from Review 2 constructs and themes, framing these questions in terms of features the CYP would prefer in an intervention aimed at improving their mental health and why. This activity was introduced prior to communicating Review 2 findings, allowing for feedback on the preliminary results of the review that went beyond presenting findings and seeking agreement. *Figure 2* provides an example of one young person's completed activity.

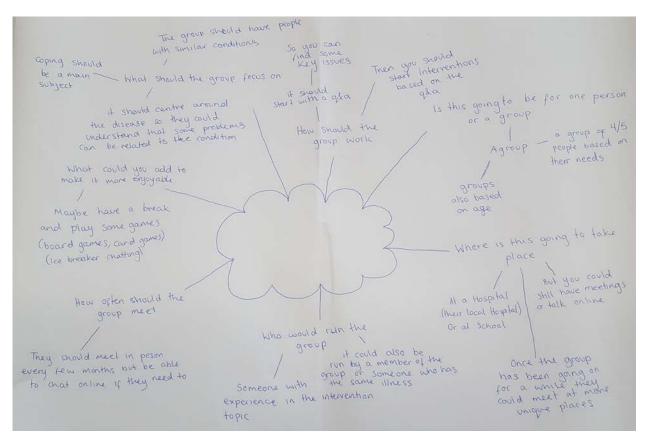


Figure 2: Example of one completed activity from CYPAG meeting

Preferred approaches to mental health interventions varied amongst participants. Some stated a desire for a group intervention, with the ages of participants and conditions kept consistent, although the role of one-to-one interventions was also acknowledged, especially for CYP with unique needs. Confidentiality and clear expectations were valued by CYP, along with the possibility for flexibility with delivery, venue and frequency of sessions. The role of the therapist was the focus of much discussion, with great importance placed on their expertise and ability to create a safe environment. The importance of addressing the links between physical and mental health without it

becoming overwhelming was acknowledged. The group agreed that they did not tend to consider whether the focus of an intervention was on physical or mental health, they just wanted to feel better.

Structure and content: parent meeting

MN and LS facilitated the parent meeting to gain feedback on the preliminary results from Review 2 and the Overarching Synthesis. As the parents had not been involved in the research to date, MN presented a background to the project and summarised the results of Review 1, before LS explained the aim of Review 2 and summarised the line of argument. An open discussion was then held with the parents regarding the results of Review 2 and the Overarching Synthesis.

The difficulties for CYP growing up with a physical and/or mental health condition and how it could impact on other areas of development were discussed. It was widely echoed that transferring to adult services between 16 to 18 years of age is often poorly managed, with several parents discussing their negative transition experience. Empowerment was seen as a key component of mental health interventions. Parents suggested both they and CYP needed information on what to expect regarding possible future physical and mental health needs. They acknowledged the internet as a useful resource for allowing the child to research their condition, although the need for trusted information sources was emphasised. Parents felt that, in order for Skype- or telephone-delivered therapy to work, it was important for the therapist to build up a relationship with CYP before therapy delivery.

Some negative experiences of local child and adolescent mental health services (CAMHS) were discussed, including the impact of long travel times to attend appointments and the perceived "clinical" and non-person-centred environment. Parents felt they did not always receive the support they needed from services or know where to access support within the community. The model of service/intervention delivery used at GOSH was seen as the gold standard, as it enabled a person-centred relationship focused on the child, but also included parents in discussions.

Although reflection on local CAMHS was negative, it was acknowledged that they should not have sole responsibility for managing mental health of CYP with LTCs. Parents agreed that always signposting to CAMHS is not ideal because it becomes crisis care instead of preventative care. Parents appreciated the multidisciplinary skills of the clinicians at GOSH and their willingness to liaise with schools and felt this best practice needed to be filtered down to community settings. The group suggested that GPs and consultants need to be aware of CYP's mental health needs and have multidisciplinary training.

Impact of children and young people advisory group and parent meeting on project

The discussions held with CYP and their parents reinforced ideas which were emerging from the analysis in Review 2, such as the importance of having a voice within the wider community. Some points which challenged the initial synthesis were also raised by members of the CYPAG group. An example of this was the suggestion that mental health interventions should acknowledge that the needs of CYP were serious and therefore did not always need to contain an element of 'fun'. This encouraged the researchers to check the studies included within Review 2 for any refutational data. Ideas from the parent group regarding the impact of school environment, long-term effectiveness of interventions and the need for an age-appropriate approach reinforced ideas presented by the CYPAG, which were drawn upon to inform the analysis for Review 2 and the Overarching Synthesis.

The parent group highlighted the need for interventions to involve systems around the child and the challenges in having the mental health needs of CYP recognised and met by schools and primary care clinicians. This feedback validated the decision to keep 'Availability' as a separate theme within Review 2 and the category 'Holistic Approach' within the Overarching Synthesis. The views of parents and the CYP helped researchers bring together the results from the two reviews within the Overarching Synthesis by providing an alternative viewpoint through which to conduct a secondary interpretation of their results.

Consultation events with interested organisations

Following the completion of the first draft of both Review 1 and Review 2, a series of consultation events were arranged by the project team with a range of interested organisations (*see Table 1*). The purpose of these meetings was to gain feedback on the methods and preliminary results from potential end-users of both reviews and establish links through which the dissemination of results could potentially occur. See *Appendix* for a list of issues raised at these meetings and how they impacted the project. Members of the Children and Young People's Mental Health Coalition (CYPMHC) and clinicians who were involved with the project were key in identifying and supporting these opportunities for consultation.

Table 1: Consultation events held for Review 1, Review 2 and Overarching Synthesis

| Date of | Consultation event description | Attended |
|------------|---|----------|
| event | | by |
| 10/01/2017 | 60 minute meeting with Paula Lavis (Coalition | JTC |

| | Coordinator) and members of the CYPMHC | |
|------------|---|----------|
| 28/01/2017 | 60 minute meeting with the National Institute of Health | DM, LS, |
| | Research Maudsley Biomedical Research Centre Young | EW |
| | Persons Mental Health Advisory Group | |
| 30/01/2017 | 60 minute Skype conversation with Antonis Kousoulis and | JTC, DM, |
| | Josefien Breve from Mental Health Foundation | MN, LS |
| 31/01/2017 | 60 minute teleconference with Helen Gravestock | JTC, DM, |
| | (Research and Policy Manager) CLIC Sargent: Charity | MN, LS |
| | providing support to CYP with Cancer | |
| 02/02/2017 | 2 hour poster presentation at MQ Mental Health Science | MN, LS |
| | Meeting. Attended by academics, clinicians, users of | |
| | mental health services for young people | |
| 03/02/2017 | 15 minute talk during UK Paediatric-Psychiatry liaison | IH |
| | group meeting | |
| 10/02/2017 | 20 minute meeting with Expert Reference Group (ERG): | JTC |
| | Psychological Skills and Knowledge for Multi- | |
| | Disciplinary Team Healthcare Professionals Working | |
| | with Children and Young People with Physical Health | |
| | Conditions | |
| 24/02/2017 | 30 minutes meeting with the Paediatric Psychology | JTC, SB |
| | Network Committee | |
| 14/03/2017 | 60 minute Microsoft PowerPoint 2010 (Microsoft, | MN, LS |
| | Redmond, WA) presentation within the weekly | |
| | Paediatrician Meeting at Royal Devon and Exeter | |
| | Hospital: 60 minutes | |
| 15/03/2017 | 60 minute meeting with PenCLAHRC Patient Involvement | LS |
| | Group member | |
| 15/03/2017 | 60 minute meeting with clinical academic fellow | DM |
| | | |

Summary of content relevant to Review 1

Feedback from the Paediatric Psychiatrist Liaison Group, MQ Mental Health Science Meeting and Paediatric Psychology Network indicated an initial surprise that more studies had not been identified for inclusion in Review 1. Discussions were held around the requirement for Review 1 study samples to have elevated symptoms of mental ill-health at baseline, and how this may have limited the available evidence. The paediatric psychiatrist group felt that they worked in a way

which they considered "preventative", thus many of the studies evaluating mental health interventions that they were aware of may not have been eligible for inclusion in this review. There was an acknowledgement that many already worked in person-centred ways and felt that establishing the effectiveness of these adapted mental health interventions would be hard to formally evaluate.

Summary of content relevant to Review 2

Feedback from the majority of the consultation events suggested that the preliminary synthesis for Review 2 contained material that all the different groups could relate to and felt was important to integrate within mental health interventions. In particular, the Mental Health Foundation and CLIC Sargent felt that the constructs and themes were ones that are consistent with their principles and what young people tell them. Ideas which resonated particularly strongly across groups included the need to provide a 'Therapeutic Foundation', 'Social Support' and 'A Hopeful Alternative'. Practitioner groups felt that they integrated many of the issues raised within the synthesis within their clinical work. The MQ Mental Health Science Meeting provided an opportunity to discuss the findings from this review with an ex-mental health service user, who talked about the impact of opportunities to feel good at something on self-esteem. The clinical academic fellow commented that the constructs might fit interventions for physical health only as well as mental health and wellbeing.

Summary of content relevant to overarching synthesis

The UK Paediatric Psychiatry Liaison group noted that although the research was well-meaning, the original call emphasised the difference between physical and mental health, rather than truly looking at integration. The Paediatric Psychology Network meeting included a discussion around the fact that the usual response to young people with mental and physical health needs is individualised. These ideas fit with overarching categories on adapting interventions and a holistic approach. The National Institute of Health Research Maudsley Biomedical Research Centre Young Persons Mental Health Advisory Group (YPMHAG) also discussed issues relating to the need for a holistic approach. The clinical academic fellow thought that bringing together messages from different reviews which largely included different interventions still provided useful implications.

Impact of consultation events on project

These consultation events highlighted methodological decisions which required additional detail within the write up of this report. For example, feedback from the Paediatric Psychiatry

Liaison Group regarding the importance of considering outcome measures, such as school attendance, meant that the extraction and synthesis of all intervention outcomes in Review 1 needed more emphasis within the written report. The Paediatric Psychiatry Liaison Group suggested some additional studies to check for eligibility for Review 1. All suggested studies had been excluded during screening as they did not meet inclusion criteria. Consideration of the availability of evidence from samples of CYP with learning disabilities was requested by the CYPMHC. At least one young person from the YPMHAG had a precise definition of a mental health intervention as something that is used as a preventative type tool, distinguished from treatment; indicating the need to define intervention in the final report and particularly plain language summaries.

Feedback through consultation events also had some influence on the synthesis for results in Review 2. The interest shown by members of the CYPMHC regarding how much the synthesis of Review 2 focused on CYPs experience of transition between child and adult mental health services resulted in researchers re-examining the data set for relevant information. YPMHAG members assumed there would be differences in experiences of mental health interventions across LTCs and age, highlighting that the methods section should acknowledge how the views of CYP with different LTCs were incorporated into the results.

The presentation of the results of Reviews 1 and 2 at the MQ Science Meeting 2017 provided the opportunity to disseminate our results to an interested audience of clinicians, researchers and CYP who have used mental health services. The author of the blog "The Mental Elf" expressed interest in writing a post about the outcomes of our research as a result of this event, creating a further opportunity to disseminate the results of this project in a format accessible to the wider public.

The consultation process also created opportunities for collaboration with other organisations. The project team shared their methods for Review 2 with the Mental Health Foundation who are undertaking a qualitative systematic review within a similar topic area. CLIC Sargent offered to share the results of several reports they had been working on and requested we share information located through literature searches for Reviews 1 and 2 that could be relevant to the CYP they support. Practitioners and members of CLIC Sargent, the Mental Health Foundation, the ERG, MQ and the Paediatric Psychology Network indicated that they would be willing to provide a platform for the dissemination of the podcasts and plain language summaries produced.

Dissemination stage

Podcast recording and plain language summary editing

The fourth CYPAG event took place on 18th March 2017. As for the previous event, parents also attended. Five parents and five CYP attended.

Aim of event

As this was the final meeting of the group, we aimed to remind CYP and their parents about the completed Overarching Synthesis. We also aimed to co-produce dissemination materials which could be easily accessed by CYP with LTCs and mental health problems.

Structure and content

CYP from our project-specific CYPAG and their parents were invited to take part in the cocreation of a podcast, discussing the results of both reviews and their experiences of being involved in the project. The podcast was produced by Alex Smalley (Science Communication Specialist, University of Exeter).

CYP and their parents also helped edit plain language summaries of the project, including a main summary for publication with the final report and adapted versions for different audiences. Together, these pieces of dissemination aimed to communicate the detail of the project in accessible formats that would be preferred, understood and shared by other CYP with LTCs and mental health problems.

Impact on project

CYP and their parents recorded audio for the podcast and helped to edit plain language summaries.

Impact of consultation and dissemination events on children and young people and parents

One of the main concerns for the project team was to ensure that CYP also benefitted from attending these consultation events. CYPAG members and parents were provided with £20 vouchers following each event to acknowledge their contribution and time commitment. Researchers made it clear that the CYP could contribute towards the project in whatever way was comfortable and meaningful for them. They were invited to be involved in the process of creating

plain English summaries to contribute towards recording a podcast to disseminate the results of the project and to consider presenting about the project at the INVOLVE Conference in November 2017. It was important that the contribution of CYP to this project was acknowledged in a way which they themselves found meaningful and interesting, and that they had a choice in how they wished to be acknowledged.

We also believe the young people benefitted from this research involvement simply by meeting one another through this process. At the first meeting, two of the young people discovered that they shared the same rare physical health condition and each appeared to really value the opportunity to meet someone else with the same condition. This impression was reinforced by email feedback received following the first CYPAG meeting from two group members:

It was good to hear other people's points of view [CYPAG member]

I think it was really helpful having other people who have gone through the same things as you, that understand you [CYPAG member]

Within the parent group, parents also commented how "meetings like this" [Parent, Third meeting] were good for CYP to share experiences and meet people who could "get on with their lives" [Parent, Third meeting]. One example provided was how one young person met an older peer who was in a romantic relationship, which the younger child had thought was a slim possibility for themselves, given their physical condition.

The parents agreed that sometimes it was difficult to get their children out of the house, but that they were always keen to attend these research meetings. Overall, the experience of witnessing how enthusiastic CYP were in having the opportunity to meet each other outside of a treatment setting was extremely powerful for the researchers. This observation later contributed towards the decision to have 'Social Support' as an overarching construct within Review 2, rather than a theme within 'A Therapeutic Foundation'.

Summary and conclusions

This chapter details how the involvement of end-users in each stage of the systematic review process can make a valuable contribution towards the creation of a robust evidence synthesis by incorporating the experience of those whose lives the project intends to influence. As a result of this contribution, this report is grounded in the experiences of CYP with LTCs and mental health problems, and appears to be relevant to their needs. This is reflected by the degree to which the

preliminary findings from Review 2 and Overarching Synthesis appeared to be transferable across different end-user groups and in keeping with practitioners' approaches to providing mental health interventions.

There was agreement across different stakeholders that the separation of mental and physical health when developing interventions was perhaps artificial and unhelpful. The views of the people consulted have also highlighted implications for areas of future research, which are explored in the final chapter of this report.

Appendix: Consultation activities and resulting actions and impacts on project.

Consultation with topic experts

| Consultation Event | Issue Raised | Actions taken | Impact on Project |
|--------------------------------------|---|--|--|
| Whole Team Meeting: 11.02.2017 | Would OECD country restrictions be applied to review 2? | Did not exclude papers during title and abstract screening on the basis of being from non- OECD countries. | It was agreed that reviewers would consider the applicability of any non-OECD RCTs after full text screening for Review 1 and seek views then as needed. |
| | Need to define "Long term condition" inclusion criteria | Agreed a definition of long term condition | After considering definitions from literature, including those from the NHS confederation and the Royal College of Psychiatrists, those present at the meeting agreed that the current working definition used thus far in screening without reference to "cure" could be used: "diagnosed physical health conditions, with an expected duration of at least 3 months, causing limitations in ordinary activities and necessitating medical care or related services beyond what is usual for age in question" |

| Inclusion of LTC's such as chronic fatigue syndrome, chronic pain, fibromyalgia, medically unexplained symptoms and IBS | Preliminary search for existing reviews (including those registered on PROSPERO) in areas such as "migraine", "chronic fatigue" and "abdominal pain" to see if these could be excluded from LTC search terms. Eccleston et al Cochrane Review of psychological therapies for the management of chronic and recurrent pain in children and adolescents included trials of treatment for headache (including migraine), abdominal pain, irritable bowel syndrome and pain associated with sickle cell disease and included depression and anxiety as outcome domains, indicating that studies relevant to these conditions characterised by symptoms of pain have already been reviewed. | Several papers were included in the project where the sample had one of these conditions. For example, a large body of the available evidence in Review 1: Masia Warner et al; Szigethy et al (x2); Wicksell et al; Reigada et al; Gordon et al; Yetwin. |
|---|--|--|
| | Research team consulted DSM-V to see if any of these diagnoses were considered mental health conditions and thus provide a rationale for exclusion as an LTC. | |

Need to define "Mental Health" inclusion criteria Attendees discussed whether we expected every individual in samples in Review 1 to have mental ill health symptoms (on whatever scale was used within study), or for just the average mental health score of whole sample to be above a recognised cut off on a validated scale.

Review 1: It was decided that the average mental health score of the whole sample should be above a cut off indicating elevated symptoms on any mental health measures used. For example, 55+ on Beck Youth Depression Inventory, i.e. mildly elevated would be included. Research team checked scoring systems of scales used within papers identified by searches to interpret mean scores where not otherwise reported. Difficult decisions regarding inclusion/exclusion of studies based upon scores on mental health measures were resolved following consultation with topic experts amongst team.

Discussion regarding how the language used to describe mental health difficulties experienced by children should reflect that used by the papers included in the review. Noted that our write up should be sensitive to terminology and not use a term only because included studies have frequently. It was agreed that "mental distress", "mental illhealth" and "psychological distress" were all acceptable terms to use, although there may be differences in how these terms are defined.

Mental health terminology was discussed in the first meeting (20th February) with the children and young people's advisory group. The co-creation of plain language summaries with the CYPAG and parents also considered preferred terminology and how it may differ between audiences.

| Identifying Intervention Focus | Discussion of inclusion criteria "Intervention must aim to improve child/young person mental health" with reference to examples where it was unclear whether the intention of the intervention is to improve physical or mental symptoms (or both). It was noted that some interventions may not purely be focused on improving mental health. | Intervention should have explicit aim to improve child/young person mental health and that simply measuring a mental health outcome would not necessarily indicate such an aim (e.g. physical treatments that also include depression scores as a secondary outcome). Papers where mental health aim of intervention was in doubt discussed with whole team after full text screening. |
|--------------------------------|--|---|
| | | Team agreed that for studies of interventions to improve adherence to medication for a LTC could only be included in the review if aiming to improve MH of child. |
| | | Interventions that may not have child and young person recipients but are aiming to improve their mental health and measuring this would be included e.g. parenting interventions. It was agreed to amend inclusion criteria for interventions to read: "Intervention can target children and young people's mental health directly (i.e. children and young people are recipients) or indirectly (e.g. parenting interventions)" |
| | Discussion around whether to include papers focusing on treating anxiety associated with a particular treatment procedure for a LTC | Decided that repeated treatments are part of having LTC, therefore anxiety around this should be considered in the project, albeit described separately in reviews. |

| | | e.g. lumbar punctures. | Review 1: Studies focused exclusively on treatment anxiety considered separately and their inclusion discussed with topic experts after full text screening. A preliminary search did not reveal any systematic reviews focused on treatment anxiety in children. |
|---------------------------------|--|--|--|
| Monthly team meeting 14.04.2016 | Inclusion of studies where LTC's may have MH component | Research team highlighted studies where identified LTCs may have a mental health component. Inclusion of Masia- Warner study discussed where functional somatic complaints included; stomach pain, nausea, diarrhoea or constipation, headaches, chest pain. | Reference to previous minutes indicated not necessarily excluding LTC's such as chronic fatigue, inflammatory bowel syndrome etc. CD suggested that other disorders not highlighted like diabetes may include a mental health component so the distinction on this basis may be unhelpful. Agreed Masia-Warner study could be included, so long as we were clear about the difference in condition. Masia Warner (?) circulated for discussion, CD, IH, TF, RS agreed it ought to be included. |
| | Consideration of Acquired Brain Injury as a LTC | We discussed acquired brain injury as a physical long term condition in the Brown 2014, 2015 study | Topic experts agreed ABI meets definition of LTC agreed after the whole team meeting in London, therefore not necessarily be excluded from this definition and study should be included in review. |
| | Review 1: CYP need elevated MH symptoms as measured on validated measure | Martinovic (2006) contradicts what we agreed at whole team meeting about needing a sample mean being over a cut-off. They included a sample selected as subsyndromal depression | Agreed inclusion. RS queried whether there were any other studies with samples "at risk" in the same way as we would want to be consistent if including a study where sample was not above a cut-off. DM confirmed that |

| | | | while there might have been sample means approaching cut-offs used, this was the only study located where the whole sample were all approaching cut-offs, but mean sample score below cut-offs. |
|---------|---|---|---|
| II P | Review 1: Inclusion of Procedural Anxiety study | Only 1 procedural anxiety (Bufalini) identified by through searching and screening process. | Agreed appropriate to include but analyse separately. |
| I | Review 1: Interventions with mixed aims | Only 11/27 papers include an intervention which is reported as aiming to improve only mental health. | IH and RA agreed that we would need to accept mental health aim as stated in individual studies, but consider differences between intervention targets in analysis. |
| | nclusion of non- DECD studies | 5 of 27 papers identified from non-OECD countries | Agreed to include. |
| in le p | Inclusion of ntellectual and earning disability populations | DM said we had not been any more specific in terms of whether whole sample, majority or any ID or LD was cause for exclusion. IH noted that learning difficulties in Brown paper was unlikely to correspond to LD. DM confirmed that although 45.8% of Brown's sample had learning difficulties these were parent-reported rather than measured at baseline and there was no indication of definition used. | Given the rationale for excluding ID and LD samples and that these interventions were parenting programmes it was agreed to include but note these sample characteristics. |
| R | Review 1: Reporting of outcome measures | Discussion around outcomes to be considered for analysis within review 1. The original call mentioned: | All outcome measures extracted. All outcomes mentioned in HTA call reported on in main report. |

| | | Health related quality of life; sleep quality; self-harm; impact on family; adherence with treatment for the primary physical health condition; attendance at school; cost-effectiveness. | |
|--------------------------------------|--|--|---|
| | Review 1: Meta- analysis of Results | Discussion around the LTC groupings, outcomes and intervention categories influenced the structure of the meta-analysis. | Feedback from RV and TF following this meeting advised against assuming acquired brain injury and CP are similar enough to meta-analyse |
| | Identifying economic - evaluations | RA suggested that email authors as well as search for sibling papers asking specifically for any economic evaluations. RA noted that there is likely to be a publication bias with economic evaluations if planned, less likely to be seen or published if efficacy not seen in trial. | MR searched NHS EED using the full search and supplement this with a search in EMBASE since the date that NHS EED stopped being updated using an economic filter in place of the RCT filter. Emailed first authors of all Review 1 included studies to ask for any economic evaluations, qualitative evaluations and other sibling studies related to the trial or intervention, as well as specific questions after our data extraction. This revealed some additional Review 1 papers, but no economic evaluations. |
| Whole Team Meeting: 03.08.2016 | Review 1: Reporting of outcome measures | Discussed how to refer to the outcomes that are not child mental health | Agreed "other" was clearer than "not child mental health" |

| Review 1: Meta- | Group considered | Supplementary analyses of |
|-------------------------------------|---|--|
| analysis | whether, given the broad aim to investigate mental health interventions for LTCs, that meta-analysis across LTCs might be useful, perhaps as a supplementary analysis. The group looked at the LTCs on slide 14 to consider whether it would be feasible to consider the mental health needs and issues as similar across the different LTCs. There was some discussion around whether it made sense to analyse across very different LTCs. MN investigated the possibility of meta-analysing by intervention, across LTC samples. There were some opportunities where this could have been possible (e.g. CBT for depression in Szigethy et al, Martinovic et al, Wicksell et al). | interventions across LTCs were considered, however following later consultation activities, they were not included in the report |
| Review 1: Preliminary Results | Adaptation: The group accepted the logic that an adapted programme might be more effective than a generic one. | The observation that we could separate interventions containing adapted and non-adapted content was described in Review 1 synthesis. It was further discussed in the overarching synthesis, in conjunction with Review 2 findings. |

| | Group discussed four parenting interventions seen in three studies. Can be distinguished in terms of amount of additive components. Trend that the more components seemed to provide more benefit for child behaviour problems. Noted that all three studies only report parent outcomes. Would be interesting to see any information on recruitment success and parent socioeconomic status. MN explored the reporting of trial uptake and socioeconomic status - both were too inconsistently reported to draw conclusions. Furthermore, reasons for poor trial uptake could have been multiple and data only allow speculation. | The components of studies trialling parenting interventions were described, but with the caveat that we can not draw firm conclusions from a small sample of studies. Socioeconomic status was described in Review 1 synthesis where described. Given the lack of detail about trial uptake, this was not described, other than to identify methods of study recruitment. |
|---------------------------|--|---|
| Review 2: Study inclusion | There was discussion around camp and whether it ought to be considered an intervention | Recognition not all papers on camps were included as there needed to be an aim to improve mental health. Camps with an explicit aim to improve mental health, as defined within Chapter 1 of report, remain included. |
| | SB suggested comparing drop out and satisfaction data where reported in Review 1 studies with the Review 2 findings. | Addressed in Overarching Synthesis |
| Consultation plans | Discussion of consultation plans | Expert Advisory group supported project team to identify and access consultation opportunities |

Consultation with children and young people advisory groups and parents.

| Consultation Event | Issue Raised | Actions taken | Impact on Project |
|---------------------------------|---|---|--|
| CYPAG Meeting: 20.02.2016 | Focus of Project | Discussion of focus of project | Highlighted the importance of a broad approach to the project, which is reflected in review searches and inclusion criteria. |
| | Mental Health Terminology | Discussion of mental health terminology used within search criteria | Influenced search terms, helped inform clearly defined mental health terminology, accepting the importance of wider aspects of mental health, such as wellbeing and coping, in addition to the symptoms of disorders such as depression and anxiety. |
| | Experience of mental health interventions | | Influenced definition of mental health intervention, therefore influencing inclusion criteria. Informed definition of Ideas generated used to inform synthesis of results in Review 2. |
| | Treatment/procedur al anxiety | Discussion around how this issue had not been experienced by members of the group. | Ideas generated used to inform synthesis of results in Review 2. Anxiety around procedures still considered worthy of consideration, even though CYPAG members had not personally experienced it. |
| CYPAG Meeting: 10.09.2016 | Review 1: Interventions | Discussion of most common interventions seen in Review 1 | Considered whether CYPAG experiences of interventions seen in Review 1 bore relation to effectiveness data. Ideas generated used to inform synthesis of results in Review 2 and overarching synthesis. |

| | Review 1: Outcomes | Discussion of most common outcomes seen in Review 1 and which CYP viewed as most important. | Perceived importance of a broad range of outcomes by CYPAG confirmed the decision to synthesis all outcomes reported in papers in Review 1. Ideas generated used to inform synthesis of results in Review 2, particularly: importance of social networks for mental health. |
|--|---|---|--|
| | Review 2: Quotes | Discussion around anonymized quotes seen within Review 2. | Ideas generated used to inform synthesis of results in Review 2. |
| | Dissemination plans | Discussion how results of project could be disseminated and how CYP would like to be involved | Involvement of young people in writing Plain English Summaries and creation of podcasts. These were disseminated to relevant organisations. |
| CYPAG Meeting: 28.01.2017 | Review 2: Synthesis of Results | CYP were asked to design their own mental health intervention | The synthesis for Review 2 was re-examined to see if there was more information regarding the following points raised during the discussion: |
| Parent Meeting: 28.01.2017 | Overarching Synthesis: Feedback on categories | Discussions held around categories identified for Overarching Synthesis. Issues relating to 'A Holistic Approach' and 'Adaptability/Flexibilit y' in particular were highlighted. | The synthesis for Review 2 was re-examined to see if there was more information regarding the following points raised during the discussion: Experiences of interventions around points of transition, additional emphasis in write-up of R2/OS on parents being provided with skills to support their children to maintain their mental wellbeing |
| National Institute of Health Research Maudsley | Review 2: Synthesis of Results | Discussed line of argument | Line of Argument not appropriate to appear without written explanation within any dissemination materials. |

| Biomedical Research | | Recognition that whilst Camps were an | Validation of decision to include "Camps" as a type of |
|------------------------|------------------|---------------------------------------|--|
| Centre Young | | American | intervention within Review |
| Persons | | intervention, may | 2. |
| Mental | | have some | |
| Health | | applicability in a UK | |
| Advisory | | setting e.g. respite | |
| Group | | services or camping | |
| Meeting: | | opportunities through | |
| 28.01.2017 | | schools/services | |
| | Dissemination of | Discussion of which | Group recommended |
| | Results | how project results | contacting MQ: to see if |
| | | should be | results could be disseminated |
| | | disseminated and | through email list. |
| | | which platforms e.g. | |
| | | Twitter, email lists, | |
| | | young people | |
| | | accessed. | |

Other consultation activities.

| Consultation | Issue Raised | Actions taken | Impact on Project |
|--------------|--------------|-----------------------------------|---------------------------------|
| Event | | | |
| СҮРМНС | Review 2 | Query regarding whether there | Considered alongside another |
| Meeting: | | were any indications that factors | author query regarding how |
| 10.01.2017 | | that may help or hinder | different themes related to the |
| | | engagement/delivery etc. are | age of recent participants |
| | | different in the 16-25 year age | within the synthesis of |
| | | group? | results. Issue regarding |
| | | | additional support needed at |
| | | | times of transition and how |
| | | | this relates to age raised in |
| | | | Review 2. |
| | Learning | Query regarding how many | Two studies included in |
| | disability | papers we excluded because the | Review 1 (Brown, |
| | exclusion | population met the LD | Whittingham) included some |
| | criteria | definition? Discussion around | children with intellectual |
| | | possibility for future review or | disability in their sample. One |

| | primary research. Examined | exclude does not suggest |
|---------------|-----------------------------------|--------------------------------|
| | excluded papers to determine | need to raise as area for |
| | whether we had excluded any | future review. |
| | for LD alone. Found only one | |
| | for Review 1. | |
| Theory based | Query regarding what project | Examined the possibility of |
| interventions | highlighted about how theory | identifying studies that |
| | driven the interventions are? Can | were/weren't theory driven in |
| | we make any distinction | Review 1, with a view to |
| | between interventions with | comparing effectiveness. This |
| | underlying theory and those | was not realistic given the |
| | without and their relative | range of confounding |
| | effectiveness? | variables and often poor |
| | | description of the basis |
| | | of/theories underpinning |
| | | interventions. |
| Dissemination | CYPMHC keen to help | Reinforce to CYP within |
| | disseminate report findings | CYPAG that project team are |
| | | happy to facilitate |
| | | dissemination of results to |
| | | their schools/individual |
| | | teachers if needed. |
| | | Project team to disseminate |
| | | results at CYPMHC seminar |
| | | in June. |
| | | CYPMHC offered to share |
| | | |
| | | final report and plain |
| | | language versions on their |
| | | website and disseminate to all |
| | | the Coalition members. |

| Mental Health | Review 1 | Any online interventions | Raise implication regarding |
|---------------|---------------|------------------------------------|-------------------------------|
| Foundation | | included in Review 1. How | need to test accessible |
| Meeting: | | many papers did we exclude | interventions. Make clear in |
| 30.01.2017 | | because of poor quality. | review methods that study |
| | | | quality was not a reason for |
| | | | exclusion alone. |
| | Review 2 | Principles from line-of-argument | |
| | | are ones that fit Mental Health | |
| | | Foundation values | |
| | Dissemination | Mental Health Foundation can | Need an accessible version of |
| | | help dissemination | project summary that Mental |
| | | | Health Foundation and others |
| | | | can promote via social media. |
| CLIC Sargent | Review 1 | How many interventions were | Added sentence clarifying |
| Meeting: | | delivered in hospitals versus | setting to Review 1 findings. |
| 31.01.2017 | | other settings. | |
| | Dissemination | Discussion of current | CLIC Sargent's Research and |
| | | dissemination plans, including | Policy manager open to |
| | | role of CYPAG in the creation | receiving and disseminating |
| | | of plain English summaries and | the plain language summaries |
| | | podcast. | and perhaps podcasts |
| | | | developed with our CYPAG |
| | | | which the CYP who used |
| | | | their services would be able |
| | | | to identify with. |
| | | Discussion of project results | Andre Tomlin has offered the |
| | | with Andre Tomlin; the | opportunity to disseminate |
| | | organiser of the 'Mental Elf' blog | the results of the project |
| | | | through the Mental Elf blog. |
| | | | |

| UK Paediatric- | Review 1 | Surprise at small number of | Checked these authors and |
|----------------|-------------|-----------------------------------|------------------------------|
| Psychiatry | | papers eventually selected for | found reasons for excluding |
| liaison group | | quantitative review. Group felt | suggested studies. |
| meeting: | | there were more, good, relevant | Emphasised in Review 1 |
| 03.02.2017 | | papers, but on discussion about | discussion that criteria are |
| | | age range, interventions, | justified given the focus of |
| | | outcomes, and quality - agreed | the review question. |
| | | that ones they had in mind might | |
| | | not meet criteria. | |
| | | Query regarding whether project | |
| | | team should we check again for | |
| | | research regarding: epilepsy, | |
| | | eczema, allergy, Cochrane | |
| | | review on abdominal pain, | |
| | | although these may be physical | |
| | | not mental health outcomes. | |
| | | Check authors: Trudy Chalder, | |
| | | Anne Kazak, Matthew Hodes | |
| | | Thought that if possible we | Research team ensured |
| | | should include outcomes that are | methodology for Review 1 |
| | | proxy for MH outcomes (or | emphasised that all outcomes |
| | | integrate physical and mental) | reported within included |
| | | such as: | studies were reported and |
| | | o Time off school/school | synthesised. |
| | | attendance | |
| | | o Other quality of life | |
| | | measures | |
| | | o Other functional measure | |
| | | e.g. out of wheelchair/mobilising | |
| | | etc. | |
| | Overarching | Overall feeling that the NIHR | The 'holistic approach' |
| | synthesis | call although well-meaning | category in overarching |

| | | emphasises the difference between physical and mental health, rather than truly looking at integration. | synthesis highlights the evidence in favour of integrated and/or collaborative approaches to treatment. |
|--|---------------|--|---|
| Expert Reference Group: Psychological Skills and Knowledge for MDT healthcare professionals working with Children and Young People with Physical Health Conditions: 10.02.2017 | Dissemination | ERG were keen to have outputs they could cite as soon as possible. They won't be able to wait to cite the report. | Let group have Review 1 journal papers once ready. |
| Paediatric- Psychology Network: 24.2.2017 | Review 1 | Why did we decide to answer the question anyway? Who decided it was important? Important to highlight in the report that this is only a subset of the population that PPs deal with and so the findings will only be relevant to a subset of them. | Emphasised the gaps in available evidence, as well as the possible influence of inclusion criteria on study selection |

Discussed 'procedural anxiety' Research group considered and how group may not define importance of adaptation/tailoring/flexibility an issue like that even though within interventions within that may be an aspect of what they are dealing with – CYP are Review 1 and OS. complex and have complex issues – and this is made more complex by the changing nature of e.g. the condition, the growing up of the child, changing dynamics within the family etc. They are continually adapting and tailoring their interventions as issues change. Group discussed that although Ensure that focus is on results indicate from Review 1 findings of effectiveness for indicate cognitive behavioural CBT and gaps for interventions to be studied. therapy is the most promising intervention, this may be because it is an easier intervention to study within an RCT – there may be other promising interventions that haven't been subject to RCTs. Network unsurprised that so Highlighted in implications many outcomes were measured section, Chapter 2 and when the remit of the project Chapter 6. was so wide. The group felt it may be a good idea to have some common outcomes between studies to allow

| | comparison. | |
|---------------|-----------------------------------|--|
| | | |
| | | |
| Review 2 | The potential drawbacks of these | Chapter 3 checked by |
| | interventions were discussed e.g. | research team to ensure that |
| | issues around isolation (i.e. CYP | data highlighting these issues |
| | behind a computer, rather than | was included in synthesis. |
| | going to meet people face to | |
| | face; cyber bullying risks etc.). | |
| | The importance of the facilitator | |
| | was seen as crucial. Risk that | |
| | CYP with mild symptoms may | |
| | interact with CYP with severe | |
| | symptoms, and be scared or | |
| | anxious that they will | |
| | necessarily go the same way. | |
| Dissemination | Group wished to share the | |
| | report, plain language | |
| | summaries and podcasts on their | |
| | website. | |
| Review 1 | It was discussed that best | Considered amongst reasons |
| | practice should involve | for lack of research in Review |
| | clinicians being aware of MH | 1. Mentioned in discussion |
| | complications, and looking out | and conclusion. |
| | for warning signs and dealing | |
| | with them early. May provide | |
| | some explanation for the lack of | |
| | UK research on samples with | |
| | elevated MH symptoms. | |
| | Terminology around | Added to the discussion |
| | tailoring/adaptation of | which led to final definitions |
| | interventions was not seen as | of terminology. |
| | Dissemination | Review 2 The potential drawbacks of these interventions were discussed e.g. issues around isolation (i.e. CYP behind a computer, rather than going to meet people face to face; cyber bullying risks etc.). The importance of the facilitator was seen as crucial. Risk that CYP with mild symptoms may interact with CYP with severe symptoms, and be scared or anxious that they will necessarily go the same way. Dissemination Group wished to share the report, plain language summaries and podcasts on their website. Review 1 It was discussed that best practice should involve clinicians being aware of MH complications, and looking out for warning signs and dealing with them early. May provide some explanation for the lack of UK research on samples with elevated MH symptoms. Terminology around tailoring/adaptation of |

| | Dissemination | important. It was recognised that CBT should be patient-centred and adapted as such, and that altering it for the LTC was seen in the same light. A local meeting of the South West Paediatrics club was mentioned as a relevant dissemination event (http://www.swpc.org.uk/meetin gs.htm). | Team does not appear to be eligible to attend. |
|--------------|---------------|---|--|
| Meeting with | Review1/ | Group member felt adapted vs | Project team considered this |
| PenCLAHRC | Overarching | flexible were too different ideas: | within Review 1 and |
| Patient | Synthesis | Adapted: Different way of | Overarching Synthesis. |
| Involvement | | delivering intervention e.g. | |
| Group | | changing room or venue. An | |
| member: | | external thing. Flexibility: | |
| 15.03.2017 | | therapy being altered around | |
| | | needs of individual e.g. therapist | |
| | | coordinating sessions around | |
| | | exams. | |
| Meeting with | Review 1 | CBT is likely to centre on LTC | Considered as part of |
| clinical | | is it right to make the point that | terminology for Review 1. |
| academic | | it is adapted? | |
| fellow: | Review 2 | When mention ill and healthy | Made clear that ill peers |
| 15.03.2017 | | peers make clear whether ill | refers to similar LTCs in |
| | | peers are those with LTCs or | Review 2. |
| | | mental ill health. | |
| | | Findings from Review 2 are | Made point that Review 2 |
| | | useful but seem to fit any | interventions aim to improve |
| | | intervention not just mental | a range of functioning not just |

| | health. | mental health and wellbeing. |
|--|---------|------------------------------|
| | | |
| | | |