RUNNING HEAD: MY STORY AND ME

My Story and Me: Protocol for the development of a public mental health approach for young women

Long title: Application Development Award – Mental health and wellbeing among young women aged 12-24: Personalised public mental health

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Plain English Summary

Who are we?

We are a diverse team of experts by professional and lived experience.

What do we aim to do and why?

Young women are more likely to experience mental health difficulties than young men because of how society treats them.

We spoke to two groups of young experts by experience: one with eight young women and men and one with seven young women. We discussed how a lack of understanding of a young woman's story hampers positive mental health and wellbeing. It prevents building trusting relationships, talking about mental health and seeking support, and being able to have a say in support.

We aim to produce an intervention for all young women that promotes understanding about their mental health stories. We will focus on the mental health challenges experienced by marginalised groups: Black and minoritised ethnic groups; lesbian, gay, bisexual, trans, queer/questioning, and other communities (LGBTQ+); and neurodiverse groups. In the future, we will do a larger test of the intervention in a bigger study to see whether or not it helps young women's mental health and wellbeing.

The intervention is 'My Story and Me', which has two parts:

1) Watching a video of a young woman's story, created by young women from different ethnic, LGBTQ+, and neurodiverse groups. We will represent intersecting identities by including those from multiply marginalised groups (e.g., neurodiverse trans women).

2) Creating your own story. Young women then record (by speech, video, text, or picture) their own story: 'Who am I? What is My Mental Health Story? How Would I Like to be Supported?'. Only the young woman creating their story will have access to it. There will be guidance on how to talk about your story with others and where to find support.

These videos will challenge stigma and give voice to overlooked experiences. 'My Story and Me' is tailored to be inclusive of young women from marginalised groups. It will help young women to understand and talk about their own mental health stories by hearing the stories of other similar young women, empowering them to seek support at an early stage.

How will we do it?

We will analyse data we already have on large groups of young women to examine different patterns in mental health difficulties and wellbeing for different groups of young women. This will help us to identify the multiply marginalised groups with whom we should be speaking.

We will speak in-depth to 27-30 young women from different ethnic, LGBTQ+, and neurodiverse groups to hear their mental health stories and to create the pre-recorded videos, including the multiply marginalised groups identified from the data analysis. We will hear from larger groups of young women and education, mental health, and community organisations through surveys and discussions. We will understand their views of 'My Story and Me' and of the larger study. This will help us to plan the optimal approach for the larger study.

What do we hope to achieve?

If 'My Story and Me' seems to help, it will be freely available to anyone who wants it. We hope it will be a low cost, sustainable, and inclusive intervention with the potential to help young women at an early stage before developing mental health difficulties. We will amplify the voices of young women from marginalised groups, less often heard in mental health research. With diverse groups of young women, we hope to build a better way to help all young women have positive mental health and wellbeing.

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Abstract

It is known that, throughout the life-course, women are more likely to be disadvantaged by societal structures. Young women experience higher levels of certain mental health difficulties and lower levels of wellbeing. This gap is present in early adolescence and further widens during adolescence. Marginalised groups experience inequity of mental health difficulties and receipt of mental health support. The aim of the research described in the present protocol is to co-adapt an existing, evidence-based intervention to develop 'My Story and Me', a universal personalised public mental health intervention for young women, tailored to be inclusive of young women from marginalised groups: Black and minoritised ethnic groups, LGBTQI+ groups, and neuro-diverse groups. We will conduct three studies. In the first study, we will conduct a secondary analysis of population-level data. This will identify mental health and wellbeing patterns for different groups of young women in the population and which multiply marginalised groups to target for creating content for 'My Story and Me'. In the second study, we will undertake narrative interviews to generate young women's stories in 'My Story and Me'. In the third study, we will co-produce a protocol for a definitive evaluation of the co-adapted intervention, including nested process and economic evaluation, by conducting consultations with young women and educators, mental health, and community organisations. The present research focusses on amplifying the voice of those seldom heard in mental health research, and 'My Story and Me' has the potential to be one piece of the puzzle to redress the mental health equity gap, enabling young women from (multiply) marginalised groups to receive support earlier.

My Story and Me: Protocol for the development of a public mental health approach for young women

The World Health Organization identifies gender as being a structural determinant of mental health (World Health Organization, n.d.). It is known that, throughout the life-course, women are more likely to be disadvantaged by societal structures. This includes socio-economic deprivation, child-bearing and caring responsibilities, discrimination, harassment, trauma, and abuse.

Mental health difficulties for young people are increasing, with 1 in 6 in England having a probable internalising and/or externalising disorder according to self- or parent/carer reported questionnaires in 2021 (Newlove-Delgado et al., 2021). Across countries, adolescent young women (15 years) report lower levels of mental wellbeing than adolescent young men (Campbell et al., 2021). From early adolescence, young women in the United Kingdom (UK) have higher levels of anxiety and lower levels of wellbeing than young men, and this gap widens through mid-adolescence (Deighton et al., 2020). Potential explanations for these differences have been proposed but not well explored. These include for example, navigating the contradicting socialisations of heteronormative gender roles and gender equality, social media and its impact on body image, and differences in experience of academic stress and pressure (Backović et al., 2012). Recent evidence from schools and colleges shows highly concerning levels of sexual harassment, affecting up to 90% of young women (Ofsted, 2021).

The mental health of young women and marginalised groups has been disproportionately affected by the impact of the COVID-19 pandemic (Ford et al., 2021; Jeffery et al., 2021). However, exploration of trajectories of mental health for Black and minoritized ethnic groups, marginalised groups, and multiply disadvantaged groups has been limited, despite evidence of structural inequalities in mental health and receipt of mental health support. For example, young women and men from lesbian, gay, bisexual, trans, queer/questioning, intersex, and other communities (LGBTQI+) groups are at higher risk of depression/anxiety and suicide (Plöderl & Tremblay, 2015; Schulman & Erickson-Schroth, 2019). Neurodiverse needs for young women are often unrecognised or mis-labelled, delaying access to effective support (Lockwood Estrin et al., 2020). Young people and adults from Black and minoritised ethnic groups are more likely to receive mental health care through compulsory routes than voluntary ones, compared to those from White British groups (Barnett et al., 2019; Edbrooke-Childs & Patalay, 2019). Perinatal women from Black African, Asian, and White Other ethnic groups are less likely to receive community mental health support and are more likely to have involuntary inpatient admission than White British women (Jankovic et al., 2020).

A recent systematic review identified a need for public mental health interventions to improve knowledge of mental health problems, increase understanding and expectations of support, and reduce stigma to improve young people's mental health help-seeking (Radez et al., 2021). Young people repeatedly say a key barrier to engaging with adults in the system around them, from schools to specialist services, is not having their voice heard. This is exacerbated for young people from already marginalised groups (Baah et al., 2019). All young people have a legal right to be involved in decisions that affect them (UN Convention on the Rights of the Child). Universal personalised care is a central priority to health and social care as is actively involving young people in their mental health support (NHS, 2019; NHS England & Department of Health, 2015).

A universal personalised public mental health intervention for young women, tailored to be inclusive of young women from marginalised groups, is needed to improve mental health and wellbeing at a population-level. It will promote mental health literacy and psychoeducation, especially about the mental health and wellbeing challenges faced by

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marginalised groups. This will enable conversations and help-seeking at an earlier stage, preventing the development of mental health problems during youth and adulthood.

Based on consultations with young women, theory, and gaps in the evidence, our objective is to co-adapt a widely used evidence-based intervention to personalised health care, 'Ask 3 Questions' (AQUA, 2020). The 'Ask 3 Questions' are: "What are my options? What are the pros and cons of each option for me? How do I get support to help me make a decision that is right for me?" (AQUA, 2020). The intervention on which 'Ask 3 Questions' was based was found to be feasible, practical, and acceptable in a reproductive and sexual health clinic (Shepherd et al., 2016). A randomised controlled trial (RCT) found it to be efficacious in increasing information sharing and patient involvement, according to independent coders of appointments with General Practitioners using unannounced adult actors simulating depression (Shepherd et al., 2011). 'Ask 3 Questions' was adapted from 'AskShareKnow' (Shepherd et al., 2011), who have kindly given us permission to adapt their intervention.

In the present research, we will produce a near-final version of a universal personalised public mental health intervention for young women, 'My Story and Me', in line with guidelines on developing and evaluating complex interventions (Skivington et al., 2021). 'My Story and Me' will be tailored to be inclusive of young women from marginalised groups: Black and minoritised ethnic groups, LGBTQI+ groups, and neuro-diverse groups. The efficacy of 'My Story and Me' for improving young women's mental health and wellbeing will then be testing in a subsequent RCT. We will conduct consultations with stakeholders in the present research to plan the optimum approach to conducting this trial.

'My Story and Me'

'My Story and Me' has two anchor intervention components: 1) watching a video of a young woman's story and b) creating your own story.

1) Watching a video of a young woman's story. We will create videos for this component in this study (see Research Question 2). Videos will be recorded by young women or, if they prefer, a representative of their choosing (e.g., friend) or an actor. Explicit consent for these videos to be in the public domain will be recorded. Videos will have voice-only and text options. Young women will talk about 'Who I am, My Mental Health Story, and How I Like My Mental Health to be Supported'.

Videos will be recorded from representatives of different ethnic, LGBTQI+, and neurodiverse groups, including young women from multiply marginalised groups, reflecting the multiple intersectional influences through which identity and marginalisation are constructed. Participants will choose which video(s) they watch.

Videos will challenge stigmatised attitudes and schemas, inviting more flexible and accepting approaches to understanding the needs of women from marginalised and multiply marginalised groups. The videos give voice to silenced or overlooked experiences and perspectives, shifting power towards the first-person narratives, the heart of 'My Story and Me'. A common identity with the presenter and watcher will increase the authenticity and relevance of the content. Complementing these personal experiences, videos will discuss general mental health/wellbeing patterns for different groups, based on population-level data analysis (see Research Question 1).

2) Creating your own story. Participants then record (speech, video, text, image) answers to three questions, mirroring those in the pre-recorded videos: 'Who am I? What is My Mental Health Story? How would I Like to be Supported?'. Participant recordings will only be accessible by the participant. However, if participants wish, they could use recordings to help structure conversations with parents/carers, educators, or support providers. This would enable the network around the young person to have a better, quicker, and more comprehensive understanding of the young women they are supporting and about how that young person understands their own experiences.

'My Story and Me' supports policy on universal personalised care and empowering young people to be involved in decisions that affect their lives (NHS, 2019; NHS England & Department of Health, 2015). Personalised care is directly support by NICE, such as through shared decision making (NICE, 2021). A person-centred perspective is central to the research, recognising young women's individuality and heterogeneous identities.

'My Story and Me' is a universal personalised mental health intervention for young women, inclusive of young women from marginalised groups. It is based on the theory of mentalisation, which argues that individuals understand behaviour (one's own and that of others) by attributing mental states that drive the behaviour – the thoughts, feelings, and motivations that cause our actions (Bateman & Fonagy, 2016). Our capacity for mentalising, and what mental states we tend to attribute behaviours to, is shaped through our interpersonal relationships during childhood and adolescence. 'My Story and Me' facilitates understanding of one's own behaviour and mental states by learning about how someone else understands their behaviour and mental states. Hearing this from someone with a common identity increases trust in the authenticity and relevance of the speaker and what they are saying (Fonagy et al., 2015). With this increased understanding, the individual is more confident and able to communicate the mental states driving their behaviour to others (see logic model attached).

Evidence gaps

A recent systematic review of film-based interventions to improve mental health education for young people found evidence of promise for reducing stigma and improving attitudes towards help-seeking (Goodwin et al., 2021). This included three RCTs: one in Portugal (Marta et al., 2015) and one in Spain (Vila-Badia et al., 2016), which found that a film + group discussion intervention was superior to no-intervention in reducing stigma; however no effects were found in one RCTs with Arab-American students (Jaber et al., 2015).

'My Story and Me' addresses gaps in the literature - the gap of: 1) RCTs of video-based public mental health interventions for young people in the UK; 2) video-based interventions that enable young people to build their own stories; and 3) video-based interventions that are tailored to multiple marginalised groups, enabling application at a whole population-level.

Aims and research questions (RQ)

To develop 'My Story and Me' and the optimum plan for conducting a full trial, there are three aims of the present research, each with corresponding research questions.

The first aim is to identify mental health and wellbeing patterns for different groups of young women in the population and which multiply marginalised groups to target for prerecorded videos.

- RQ1a) What demographic characteristics are associated with higher levels of mental health difficulties and lower levels of wellbeing in young women?
- RQ1b) What are the mental health and wellbeing trajectories over 4 years for different groups of young women?

The second aim is to include young women's stories in 'My Story and Me'.

• RQ2: What are the narrative experiences of young women aged 12-24 years in the community from diverse ethnic, LGBTQI+, and neuro-diverse groups about their mental health?

The third aim is to plan the full efficacy trial of the intervention.

• RQ 3: What is the optimum approach to conduct the full trial of 'My Story and Me' according to young women and education, mental health, and community organisations?

Research methods and analytic strategy

To answer the research questions of each of the three aims, we will conduct three studies. The research will be overseen internally by a Steering Group (the research team) and a Young People Advisory Group (YPAG) and the two groups will run in parallel. The research will be overseen externally by a Trial Steering Committee (on which the Co-PIs, Edbrooke-Childs and Deighton, will also sit), with responsibility for the overarching conduct and methodological rigour of the research, and a Data Monitoring and Ethics Committee, with responsibility for ensuring the safety of the research, including that adverse events are appropriately and robustly identified, actioned, and reported.

Study 1: to identify mental health and wellbeing patterns for different groups of young women in the population and which multiply marginalised groups to target for pre-recorded videos.

RQ1a) What demographic characteristics are associated with higher levels of mental health difficulties and lower levels of wellbeing in young women?

RQ1b) What are the mental health and wellbeing trajectories over 4 years for different groups of young women?

To identify mental health and wellbeing patterns for different groups in the population, we will a conduct secondary analysis of two recent population-level datasets (UCL Research Ethics Committee approval: 14037/008): $N \approx 35,800$ young women (cross-sectional), $N \approx$ 6,113 young women (separate longitudinal).

Using these data, we will describe the multiple intersecting groups and use this to target pre-recorded videos in 'My Story and Me' to ensure we represent the voice of young women from multiply marginalised groups. Mental health difficulties will be analysed with selfreported Strengths and Difficulties Questionnaire (Goodman, 2001) raw continuous scores and clinical thresholds. Mental health wellbeing will be analysed with self-reported Warwick scale (Vaingankar et al., 2017) raw continuous scores and categorical high/low thresholds.

For RQ1a) correlations, regressions, and multilevel regressions (women within schools within geographical regions) will be explored. For RQ1b): growth mixture modelling, to examine groups and interactions between groups arising from the data, and/or multiple-group growth curve modelling, using a priori groups such as ethnicity, LGBTQI+, and neurodiverse needs (or those based on findings from RQ1a)).

Study 2: Include young women's stories in 'My Story and Me'.

RQ 2: What are the narrative experiences of young women aged 12-24 years in the community from diverse ethnic, LGBTQI+, and neuro-diverse groups about their mental health?

Following further co-adaptation of 'My Story and Me' with the YPAG, we will conduct a narrative inquiry (Polkinghorne, 1989) (UCL Research Ethics Committee approval: 14037/008]). Purposive criterion sampling will be used to recruit 27-30 young women from diverse ethnic, LGBTQI+, and neuro-diverse groups, including young women from multiply marginalised groups identified in RQ1. We will recruit through the team's networks and partners (e.g., Greater Manchester Digital Young Person's Group, Centre for Mental Health, Gendered Intelligence, Racism & Youth Mental Health, Anna Freud Centre (AFC) Young Champions).

Ahead of the interview, young women will be introduced to the project and 'My Story and Me'. Interviews will be directly included in 'My Story and Me' either by the young women, their representative, or an actor. Alternatively, if young women prefer, videos will be produced based on vignettes from different interviews from young women that share similar components of their identity. Stories will be personal, illustrative, and relatable to young women from different ethnic, LGBTQI+, and neuro-diverse groups. A more general perspective will be represented through the inclusion of mental health and wellbeing patterns from the secondary analysis. The topics for the narrative interviews are 'Who I am, My Mental Health Story, and How I Like My Mental Health to be Supported'.

Interviews will be conducted in-person or, if the participant prefers, remotely using video-conferencing software. Interviews will be transcribed and then the researcher and peer researcher will work together to conduct narrative analysis (Creswell, 2013). This will involve reading and re-reading each transcript. Transcripts will then be re-storied so that it is structured according to the three topics. During this stage, the researcher and peer researcher will produce summaries of the transcript that articulate key themes within each topic. These summaries will be discussed with the Steering Group and YPAG to identify priority themes. The researcher and peer researcher will then work together to produce vignettes – narratives across transcripts – that cover the prioritised topics. A reflection and interpretation log will be kept for each interview/transcript.

The pre-recorded stories are not intended to be representative of the heterogenous experiences of all young women of a certain group. An inductive thematic approach with more interviews was considered. Here, pre-recorded stories would comprise the speaker talking about themes common across experiences of young women within a certain group. This approach was not selected for three reasons. First, all young women's stories are unique and a reliance on patterns of similarities may miss relevant data. Second, hearing a personal story, rather than a general story, is important to establish trust in the authenticity of the speaker, in accordance with our underpinning theory. Connecting with the speaker's story, inevitably including some differences to the listener's story, will enable the listener to understand another's experiences and thereby understand their own experiences. Narratives will be checked with the YPAG to ensure they resonate with their lived experiences. Third, hearing personal stories and how mental health challenges and discriminatory experiences have been overcome is empowering. It would also be helpful to share these pre-recorded stories more generally across the system, helping individuals to have meaningful conversations about mental health with others.

Study 3: Plan the full efficacy trial.

RQ 3: What is the optimum approach to conduct the full trial of 'My Story and Me' according to young women and education, mental health, and community organisations?

We will first map stakeholders with interest in and influence on young women's mental health support, in collaboration with the funder, Steering Group, and YPAG. We will conduct a consultation survey and discussions with young women and education, mental health, and community organisations, designing the full trial (UCL Research Ethics Committee approval: 14037/008]). Additional to young people's networks, we will recruit participants from the applicants' extensive networks (e.g., AFC 71,000 network members). Consultations will invite a dialogue with different audiences, reviewing options for the full trial to inform the optimum approach and providing an in-depth understanding of the potential implementation barriers and facilitators. We will map this information on to the Consolidated Framework for Implementation Research (Damschroder et al., 2009) to identify priority areas for the future process evaluation.

Consultation findings will be discussed with the YPAG for interpretation, particularly to resolve divergent views. An additional output will be building a network of diverse audiences with whom we should be engaging when sharing learning from this study and developing the full trial.

We will examine: 1) Numbers of young women (including demographic characteristics) referred to and accessing school and non-specialist community mental health support. 2) Recruitment pathways for the full trial and other personalised public mental health interventions. 3) Young women's views on: acceptability of the intervention; potential intervention outcomes, mechanisms, and time to impact; reasons for non-adherence; optimal dose (e.g., how many videos to present); measures (including those sensitive to the needs of marginalised young women). 4) Implementation barriers/facilitators (research/intervention); 5) Intervention resource implications for future health economics. 6) Suggestions for the full trial and interest in taking part. 7) Any longer term impacts they envisage (e.g., staying in school) and what might happen without the intervention and not having needs identified and met at an early stage.

At this stage, our working design of the full trial is:

Population: Young women living in England aged 12-24; recruitment strategy and sample size calculation based on oversampling of the identified marginalised groups so we are powered to detect subgroup differences as well as whole sample differences. Young

women will be recruited through public and social media advertisements and through schools and community organisations, building on the networks of the applicants' and those extended during the present research. Prospective participants will be directed to the study website where they will record informed consent, be randomized, complete baseline measures, and then access either 'My Story and Me' or the leaflets (see below).

Intervention: 'My Story and Me'. The template for intervention description and replication (Hoffmann et al., 2014) will be agreed by the YPAG and Steering Group, based on learning from this development study, ahead of the full trial. It will be the basis of fidelity monitoring data collection.

Comparator: Information leaflet on talking about mental health and expressing needs. As with 'My Story and Me', leaflets will be provided in range of formats (video, audio, text) and languages and participants will be able to choose different ones tailored to the needs of different ethnic, LGBTQI+, and neurodiverse groups.

Primary outcome: Mental health difficulties according to SDQ Total Difficulties (Goodman, 2001). Secondary mental health/wellbeing outcomes: PHQ-9 (Spitzer et al., 1999), GAD-7 (Spitzer et al., 2006), Warwick scale (Vaingankar et al., 2017); others TBC.

Study design: Pragmatic, single (researcher) blind RCT aligned to best practice (est. 36 months) (Schulz et al., 2010). Randomisation by independent Clinical Trials Unit. There will be an internal pilot with stop/go criteria.

Integration of quantitative and qualitative findings from RQ1-3

Two approaches will be used to combine the quantitative and qualitative analyses. The first is an explanatory sequential design for RQ 1 and 2 (Cresswell & Plano Clark, 2018). The quantitative findings from RQ 1 will identify mental health and wellbeing patterns for different groups of young women in the population and which multiply marginalised groups

to target for pre-recorded videos. This will inform the groups we interview in RQ 2, where we will examine the narrative experiences of young women aged 12-24 years in the community from diverse ethnic, LGBTQI+, and neuro-diverse groups about their mental health.

The second is a triangulation design convergence model for RQ 3 (Cresswell & Plano Clark, 2018). Quantitative and qualitative data will be collected from relevant stakeholders such as young women and education, mental health, and community organisations, through a survey and one-to-one or group discussions. Data will be analysed separately and then interpreted together to answer the question: what is the optimum approach to conduct (i.e., design and implement) the full trial of 'My Story and Me'?

Patient and Public Involvement

A paid peer researcher is a co-investigator and Steering Group member, and they will be supported by the experienced AFC Patient and Public Involvement team and trained to be involved in all aspects of the research. The peer researcher will co-chair the YPAG of 6-8 young women from marginalised groups and/or with lived experience of mental health difficulties. In addition to the peer researcher, two consultations with young experts by experience (1 with 8 young women and men, 1 with 7 young women) directly informed the choice of intervention and research design.

Potential implications

In the present research, we will produce a near-final version of a universal personalised public mental health intervention for young women, 'My Story and Me', tailored to be inclusive of young women from marginalised groups: Black and minoritised ethnic groups, LGBTQI+ groups, and neuro-diverse groups.

We will conduct three studies. In the first study, we will conduct a secondary analysis of population-level data. This will identify mental health and wellbeing patterns for different groups of young women in the population and which multiply marginalised groups to target for creating content for 'My Story and Me'. In the second study, we will include young women's stories in 'My Story and Me', by conducting a narrative inquiry, including young women from the multiply marginalised groups identified in the first study. In the third study, we will plan a definitive evaluation of the co-adapted intervention, including nested process and economic evaluation, by conducting consultations with young women and educators, mental health, and community organisations. The efficacy of 'My Story and Me' for improving young women's mental health and wellbeing will then be tested in a subsequent RCT. We will seek funding for the full trial and funding for complementary projects coadapting 'My Story and Me' for other marginalised groups of young women and for young men.

Potential limitations include low participant recruitment, which we aim to mitigate through the co-design of the methods, recruitment strategy, and materials; the research team has track record of working with marginalised groups. Young people may not want to use 'My Story and Me'. We will examine interest in and acceptability of 'My Story and Me' in the present research, and we also hope that this is mitigated through the co-adaptation of an existing, widely used intervention. Future limitations of the full trial and implementation of 'My Story and Me' are that young women do not have regular, private digital access. There will be both digital and paper formats (freely available) including video transcripts. There may be a possibility that adults do not want to receive information from 'My Story and Me'. Young people will own the information and chose with whom they share it; they will only be able to share it as part of a conversation. Guidance for managing conversations will be included, supporting adults to have such conversations. Risks or needs not otherwise known may be raised in the content participants produce in their stories. 'My Story and Me' provides a guided framework for hearing young women's voices. It will be explicit that no-one else will see it. In terms of risks, it would be no different, for example, to someone writing in a journal. Support signposting will provided.

'My Story and Me' has the potential to be a low cost, sustainable, scalable, and inclusive intervention with the opportunity to reduce the high societal cost of mental illness (during youth and adulthood) for young women from marginalised and multiply marginalised (Suhrcke et al., 2007). This may be one piece of the puzzle to redress the mental health equity gap, enabling young women from (multiply) marginalised groups to receive support earlier. We hope the present research will focus on amplifying the voice of those seldom heard in mental health research.

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Appendix



Figure 1. Logic model with colour.

Figure 2.

Logic model without colour.

