Report WP 3.2

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BACKGROUND

Work package (WP) 3.2 aimed to contribute to the third objective of the Transition programme by investigating how transitional healthcare should be commissioned.

'Commissioning' is the process by which public services are organised and contracted to meet population needs. Commissioners follow a generally cyclical process of: assessment of population needs, setting priorities, developing strategies in line with objective outcomes, procuring services and measuring outcomes.[110] The commissioning landscape for health and social care has recently been subject to substantial change. Specifically, changes in policy set out in the Health and Social Care Act which came into force April 2013 and resulted from the White Paper 'Equity and Excellence: Liberating the NHS'.[217] Under the reformed system, the NHS Commissioning Board (now called NHS England) was established within the Department of Health to provide national leadership for commissioning healthcare, to allocate budgets to clinical commissioning groups and to commission specialist services (with the abolition of incumbent PCT commissioners and SHAs).[218]

Commissioning has a pivotal role in ensuring the successful transition of young people with CHN from child-centred to adult-oriented healthcare systems. The need for better discharge of this role was highlighted in the Kennedy report,[12] recommendation 32 which stated: 'Ensuring a smooth transfer between adults' and children's services should be a priority for local commissioners'. Further, the Green Paper[206] highlighted the importance of successful transitional healthcare and proposed that PRIMARY CARE Consortia and Health and Wellbeing Boards should be supported in their commissioning for young people with disability. Further the complexity of transitional healthcare overall, due to its multidisciplinary, interagency nature, is a particular challenge for NHS Trusts, even when the organisation has the strategic will and resources to develop services. User-friendly, effective and efficient health and social care protocols may have little impact on health outcomes of the young people with long term conditions if the service providers are unable to implement the protocols and/or services in other agencies are absent or inadequate. The Government's proposal that more public health and social care service commissioning should be undertaken by Local Authorities is a significant opportunity to ensure services for more comprehensive transitional healthcare are not commissioned in isolation from services in other sectors.

NHS England's Draft Research and Development Strategy 2013-2018 has as its first Objective 'To identify and prioritise commissioning health services research topics and co-ordinate this work with the Department of Health, NIHR, …………'[111] Research is needed to explore and understand the challenges of commissioning for transitional healthcare, and identify successful commissioning practice and guidance within the context of a restructured combined health and social care service.

AIMS AND OBJECTIVES

Aims:

1. To explore and understand the challenges of commissioning for transitional healthcare, focussing on the explicit and implicit organisational structures, processes and relationships which drive commissioning decisions around transition.
2. To explore and understand what constitutes successful commissioning practice for transitional healthcare and identify lessons to inform guidance on commissioning for transition across the NHS, including CCG's; Local Authorities and Health and Wellbeing Boards.

These Aims were addressed in two stages:

Stage 1: Literature review

Stage 2: Semi-structured in-depth interviews with key stakeholders

Stage 3: Case studies

STAGE 1: Literature review of academic, peer-reviewed papers

A systematic review of academic, peer-reviewed literature relevant to commissioning for transition was conducted. The core bibliographic databases used were: Medline (1996 -), Web of Knowledge (WOK) (1996 -) and Scopus (1996 -). A structured search strategy was formulated using controlled search terms, including free text terms and MESH headings were available. Given the complexity and ambiguity of the terms 'commissioning' and 'transition', all alternative terms were used in order to be as thorough as possible. Search terms (Box 4) were applied across databases. To ensure that the literature review remained up to date, searches were conducted regularly over the duration of the review from September 2013 to July 2014. The identified papers were reviewed using explicit exclusion criteria (Box 5).

Box 4. Academic literature search

Commissioning search terms
"Delivery of Health Care" OR [(Contract Services OR Contract* OR Commission* OR fund* OR purchase* OR budget* OR plan* OR provide* OR manage* OR procurement* OR assess*NEAR/1needs) AND healthcare]

Transition search terms
Transition to Adult Care OR Health Transition OR transition* OR continuity* OR pathway OR "service mapping" OR transfer*

AND healthcare AND ('to adult OR 'from paediatric') AND (young person* OR young adult* OR adolescent* OR youth OR child*)

Box 5. Academic literature exclusion criteria
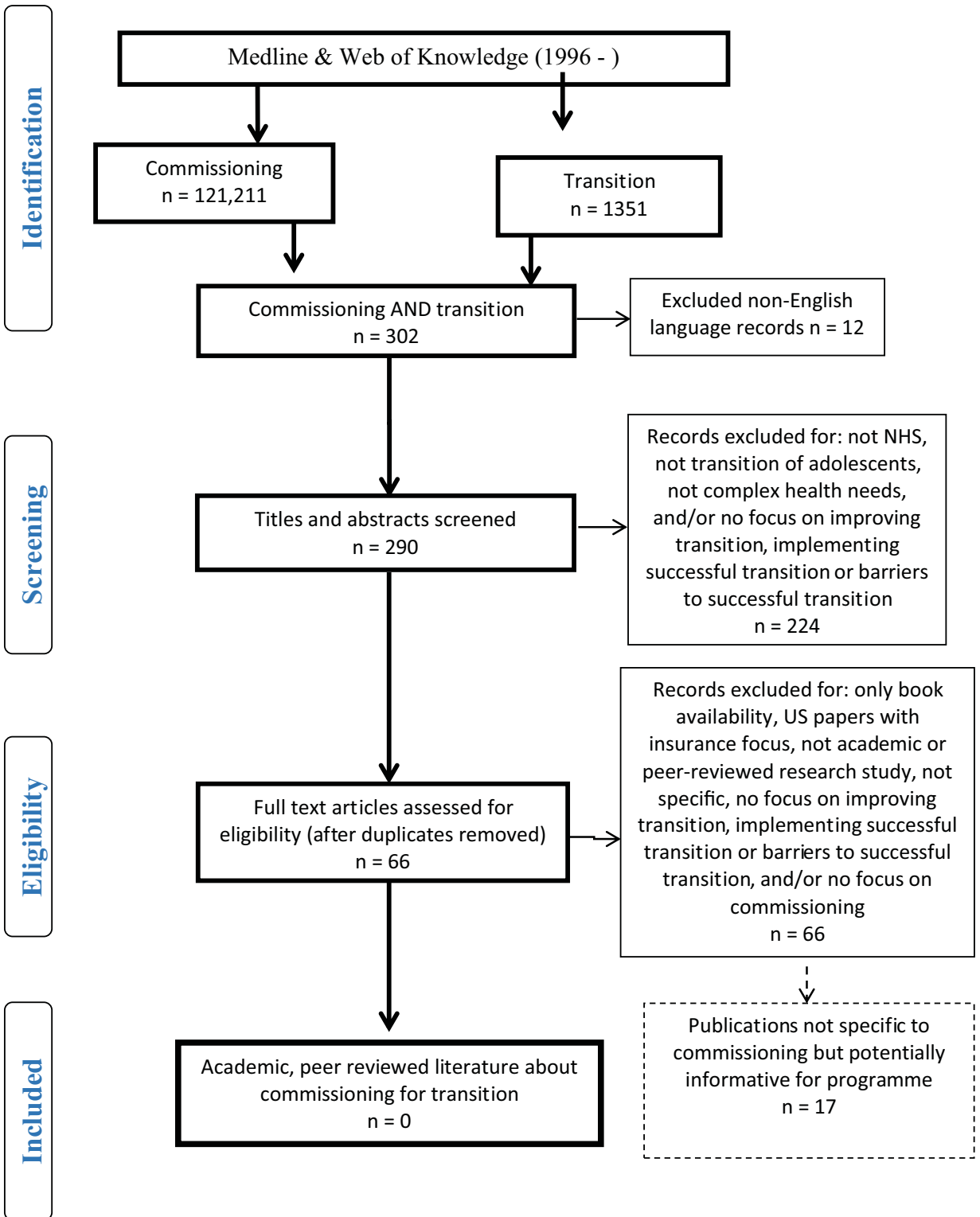

Title and abstract criteria

1. Non-English Language
2. Transitions other than from children's services to adult services
3. Populations other than young people with 'complex health needs' as defined for the research programme
4. Only identify current problems to transition, no mention of approaches to improve transition or barriers to successful transition

Full text criteria
1. It was a book
2. Not an academic or peer reviewed research study
3. Transition papers with no focus on commissioning (or related) processes
4. Focus of the paper not on commissioning or transition processes in the NHS

The PRISMA diagram (Figure 18) shows how the searches of Medline and WOK databases were structured. Separate searches for papers on commissioning and transition identified 302 papers relevant to both topics, which were then screened and assessed for eligibility according to the exclusion criteria. The most common reason for exclusion was that the paper focused only on transition, with no content about commissioning. No academic publications on commissioning for transition were identified. Of the 66 whose full-text was reviewed, 17 were identified as potentially informative for the wider work of the NIHR Programme.

Figure 18: Academic literature PRISMA diagram

Identification

Medline & Web of Knowledge (1996 -)

Commissioning
n = 121,211

Transition
n = 1351

Commissioning AND transition
n = 302

Excluded non-English language records n = 12

Screening

Titles and abstracts screened
n = 290

Records excluded for: not NHS, not transition of adolescents, not complex health needs, and/or no focus on improving transition, implementing successful transition or barriers to successful transition
n = 224

Eligibility

Full text articles assessed for eligibility (after duplicates removed)
n = 66

Records excluded for: only book availability, US papers with insurance focus, not academic or peer-reviewed research study, not specific, no focus on improving transition, implementing successful transition or barriers to successful transition, and/or no focus on commissioning
n = 66

Publications not specific to commissioning but potentially informative for programme
n = 17

Included

Academic, peer reviewed literature about commissioning for transition
n = 0

Results from the academic literature

Our failure to identify any papers about commissioning for transition led us to undertake a grey literature search which will be presented in the next section. However, review of the 17 papers in the academic literature identified three key themes about barriers to and suggestions for successful transition:

1 Consequences of poor transition

2 Barriers to successful transition

3 Components of successful transition

1 Consequences of poor transition

Two key long term consequences from problems in transition were disengagement of young people from adult services and poor health outcomes.;[37, 155, 219-221] Patients often experienced a gap in care which led to disengagement from adult services due to limited accessibility, non-familiarity and non-adherence to follow-up appointments. Poor health outcomes were both physical and psychological, including: patient non-adherence to post-transition medication and increased anxiety described by parents, carers and paediatricians.

2 Barriers to successful transition

The literature outlines structural and process barriers to successful transition, some of which are likely to have implications for commissioners. Barriers were related to challenges in 'communication' and 'implementation/management'.[155, 222] Inadequate patient-provider communication and lack of information sharing between providers proved problematic.[221, 223] Communication barriers also involved lack of appropriate education (between providers) [37, 219, 221, 223, 224] and lack of cooperation between providers.[26] Patients lacked knowledge of self-management and decision-making skills and about how to navigate transition; paediatric providers lacked training in adolescent development and management of transition; adult providers lacked training in paediatric diseases, adolescent development and management of transition. Disagreements and lack of consensus on transition between providers and NHS Trusts led to further complications for management of transition.[155]

Challenges for implementation included process barriers, paucity of resources and insufficient evidence.[37, 221] The challenge of providing a holistic transition process and meeting the needs of a wide spectrum of types of disability were described. Another barrier

was the difficulty in obtaining sufficient funding to allocate resources efficiently for a variety of populations and purposes, such as planning, staffing, infrastructure and training.[26] Further research on testing and evaluation of models is needed to support the development of a generalised transitional plan, skill-assessment techniques and appropriate outcome measurement tools.[155, 219, 223, 224]

3 Components of successful transition

The majority of key issues highlighted in theme 2 are very relevant and addressed by this third theme. Indeed, the literature reviewed provided a number of recommendations that might lead to an improvement of current transition standards, including examples of transition plans and components of successful transitional healthcare. These were related to two key areas: communication/education and planning/processes.

Communication/education

Provider communication barriers may be addressed by increased cooperation between all professionals involved in a holistic transition process and information sharing through written medical summaries.[155, 219, 223, 224] Patient communication barriers may be resolved by peer support groups or use of new IT opportunities such as texting and social media;[53, 219, 220, 222] Provider educational barriers could be resolved by development of training curricula.[222] Patient and carer educational barriers could be addressed by the development of multi-faceted education programmes and provision of appropriate resources materials; including: written checklists, health passports, e-learning and skills assessment. This will further enable the development of required self-advocacy skills as more independent patients are noted to be associated with higher transition success.[53, 155, 221-223]

Planning/processes

Joint transition clinics.[53, 155, 221-224]

Successful transition plans included ongoing preparedness assessments[53, 219, 224]and early meetings with adult clinicians.[53, 155, 219] Successful plans were flexible, personal, appropriately timed and holistic.[53, 155, 219, 224] The planning and other processes were often enabled by a trained and dedicated professional, variously described as a nominated key worker, transition care coordinator or specialist nurse.[159, 220]

STAGE 1 (cont'd): Review of grey literature

Grey literature is defined as "information which is produced on all levels of government, academics, business and industry..., but which is not controlled by commercial publishers". It is more broadly described as material not published commercially or indexed by major databases, e.g. policy papers, discussion papers, briefings not covered in the bibliographic search. The same search terms used for the academic literature were applied wherever possible (Box 5). We hand-searched the following sources: Social Care Institute for Excellence (SCIE), Health Management Information Consortium (HMIC) (Department of Health, Kings Fund), Nuffield Trust, Public Health England (PHE), NHS Evidence (NICE), NHS Institute for Innovation and Improvement, NHS Improving Quality, Health Services Management Centre (HSMC), National Research Register Archive, UK Clinical Research Network, and Google Scholar. These searches were further supplemented using the '360 Review' technique on any key literature, looking at its references, citations and other papers written by same authors. 'Snowball' referencing was used to retrieve references cited in key primary research texts. Papers were also retrieved from email subscription, discussion listings, and supplemented by literature obtained within the wider programme of research. The identified literature was screened for inclusion using exclusion criteria (Box 6). The search of grey literature was completed in June 2014; we decided to keep the search open and update it throughout WP3.2 up to July 2016.

Box 5. Grey literature search strategy

<u>SCIE search terms</u>

'Commissioning for Transition' – simple search box didn't permit combining terms with 'AND' / 'OR' in same manner as Academic database search.

<u>HMIC search terms</u>

'Commissioning' control vocabulary selected:

Locality Commissioning OR General Practice Commissioning Groups OR Practice Based Commissioning OR Commissioning Agencies OR Hospital Commissioning OR Lead Commissioning OR Commissioning

AND

'Transition' control vocabulary selected:

Palliative care OR "Quality of patient care" OR Patient transfer OR transition to adult services OR Mental health services OR Learning disabilities

AND

Management practice OR Primary Care Trusts OR Healthcare OR Primary care OR Organisational culture

AND

'Adults' or 'Young People'

<u>Nuffield Trust and PHE search terms</u>

Hand searched publications on website under Commissioning topic where possible

Box 6. Grey literature exclusion criteria

1. Non-English Language
2. Non-comparative health care system – developing countries
3. Older populations
4. Lower grade cases, or non-disability cases e.g. dentistry
5. Lack of commissioning or lack of transition content
6. Only book availability
7. Focus of the paper not on commissioning or transition processes in the NHS
8. Lack of focus on health care (purely social or educational services)

Figure 19: Grey literature PRISMA Diagram
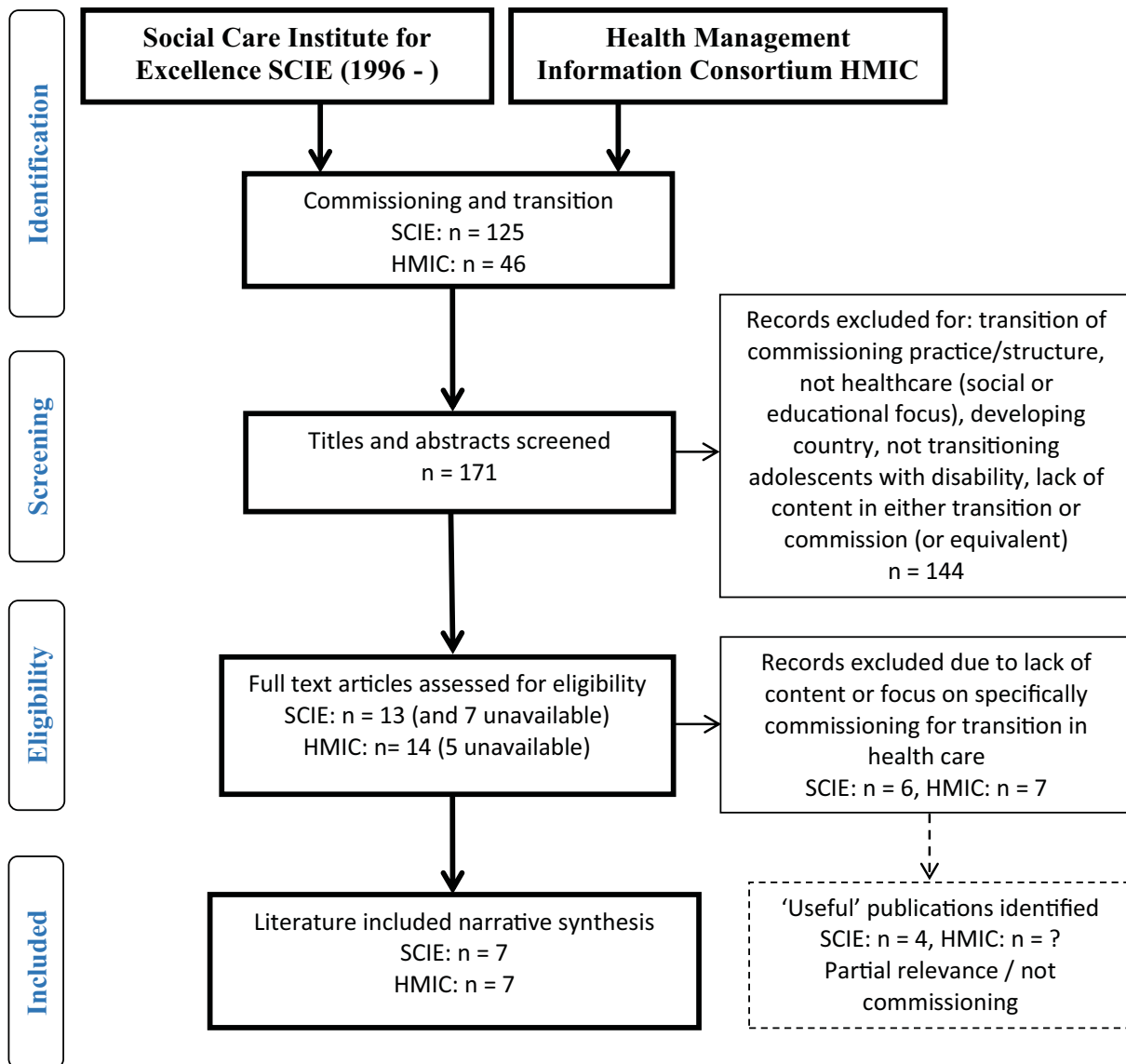
Results of grey literature review

This review identified two main areas with evidence:

1 Commissioning

2 Organisation and delivery of care

1 Commissioning

Within the grey literature, no specific policies relating to commissioning for transition were identified. However, we identified some key themes from policies with a focus on improving outcomes for children and young people, key delivery plans with a focus on personalisation of care, and some commissioning guidelines. Together these themes may provide useful insight into some of the issues which may be relevant for commissioning for transition. The four themes related to commissioning were:

Transition protocols
Clinic structure
Funding
Co-ordination

1.1 Transition protocols

Recommendations were made by the Department of Health for robust or a 'successful and consistent' transition protocol.[225-227] There is currently a lack of joint planning and commissioning and the need to improve this, specifically between children and adult services, was recognised. In order to facilitate this the key responsibilities of commissioners were described as: (i) developing service specifications based on local needs assessments; (ii) stimulating the market place to fill identified gaps in service provision and (iii) stimulating providers to provide best practice services based on research evidence.[227] CQUIN (Commissioning for Quality and Innovation) was suggested as a mechanism to aid effective commissioning practice.[225] Further, the need for a transition protocol to embed the principles of personalised planning as part of the personalisation agenda was highlighted.[226]Finally, there was a practical suggestion that the management of transition in hospitals, primary care and community care should be factored into the overall rating which is calculated as part of CQC inspection models, in order to incentivise improved performance.

1.2 Clinic structure

The 'age conundrum' was identified as a barrier to successful transition.[225] This means that at age 18 a young person is treated in adult services but for children and young people with complex health needs, including learning difficulties and mental health difficulties, this is not necessarily the most developmentally appropriate age to transfer to adult health care providers. Further, age boundaries were perceived to be set arbitrarily and as such considerable variety and inconsistencies existed between different services. There was a variety of suggestions about how this 'age boundary' challenge might be addressed. Some suggested a distinct young person's service, e.g. spanning age 14-25; whilst others suggested a flexible approach to managing transition within the existing structures.[13] Development of young person focussed services in the community were also suggested to provide additional support for children from 11-25.[228]

1.3 Funding

With respect to transition funding, resources were noted to be lacking, and funding arrangements complex. There was at least one suggestion that early investment now would release resources in future

Funding for transition was noted to be complex, fragmented and often not clear. In order to improve this it was suggested that funding responsibilities for equipment and short-term breaks should be agreed earlier between commissioners and providers in order to avoid delays during transition.[13]

Current funding for adolescent health and social care was deemed insufficient, particularly with respect to developmental disorders and mental health, where workloads were perceived to be rising amidst inadequate staffing and resources.[225]

Upstream investment, in terms of commissioning of evidence based preventative measures, and early stage intervention in children and young people services were advocated. This shift in investment was cited as having the potential to enable the child or young person to receive appropriate services more swiftly and for a shorter time and as a means to future savings.[225]

There may be few services suitable for young adults (e.g. a lack of age appropriate short break facilities, few chances of meaningful employment, few residential places that can take

young people with very complex health needs and few health specialists with a holistic approach to a young person's care.[227]

1.4 Co-ordination

Appleton (pages 11, 18-23)[225] argues that effective commissioning practice: depends on important relationships between key groups. "Engagement between commissioners and local clinicians, as well as with young people and their families will be increasingly important in the new commissioning environment. Building relationships has been highlighted in a number of reports as a critical factor in successful transition planning. Commissioner's interest and support for CAMHS and AMHS working together and in partnership with other services are essential". "Commissioners can help services to join up by facilitating a local Transitions Forum, including representatives from CAMHS, AMHS, the voluntary sector and service user groups to review and monitor transition protocols, and provide an arena for debate and service development".

"Current commissioning models often place CAMHS commissioning and AMHS within different frameworks, structures and organisations. Not facilitated joint working across the two sectors and has not enabled a sharing of ideas and solutions. As a result, separate service development has taken place that has not properly addressed the issues relating to transition" (Appleton[225] Pages 10 & 11. "Commissioners should ensure that joint agency planning and commissioning takes place to enable the development of person centred, co-ordinated and integrated packages of care and support for children and young people, to enable smooth transition to adult services and avoid crises".[229]

2 Organisation and delivery of care

2.1 Transition plan (TP)

Transition planning, stated and updated in a document shared with the young person, was recommended by the Department of Health and the Care Quality Commission to start early and continue if necessary into adult care. It will be tailored to the needs of young person and family and be age and developmentally appropriate. It was advised that TP should also include education, social services and voluntary agencies as active partners.[13, 227, 229]

Transition planning is not happening everywhere and opportunities are being missed to focus on employment and housing options at an early stage, for example by embedding career planning in person-centred transition pathways.[226]

There is debate about whether a health passport is implied in a TP or whether it should be a separate document.[13, 230]

2.2 Primary care involvement

It is acknowledged that primary care should take a more active role in transition care for young people.

2.3 Key worker

A key worker is a person who assists an individual to negotiate transition.

A number of papers recommend that patients should have a key worker.[13, 229, 230]

Co-ordination of transitional healthcare is critical and, if this does not already exist, a key worker is ideally placed to oversee a young person's transition, ensuring links with a counterpart within the receiving adult service".[227]

2.4 Transition manager for clinical team

A coordinator is a person working in a service that involves Transition, who works at a managerial level to ensure effective processes such as reminding young people by text of forthcoming clinics, ensuring transition plans are drawn up etc.

Named leader to coordinate, best practice must be followed.[13, 229]

2.5 Holistic care

Key characteristics of an effective holistic transition process include: young person centred, wide age range, informal, flexible, voluntary, confidential, free, independent, early intervention, continuity; support of multiple needs (emotional, mental, personal, physical, social welfare, practical, safeguarding etc.), with complementary interventions delivered under one roof.

Transition is likely to include arrangements for: Independent living, employment, health and social inclusion.[229]

The National Autistic Society lists a range of services commissioners might consider funding.[230]

"A comprehensive local Children's Palliative Care service spans health, social care and education. It is a whole-family approach and has the following characteristics: It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions children's to adult's services. It ensures review of the care plan at key points in transition".[231]

2.6 Effective coordination

The Department of Health recommended that there be a transition lead in every region to support the delivery of a regional multi-agency transition strategy, supported by an implementation group involving all key stakeholders, in particular young people and their families.[232]

CCGs and Local Authorities must listen and learn from young people and their families' experiences.[13]

One of the five ambitions of the NHS pledge - NHS Mandate for 2014/15 is that "services will be integrated and care will be coordinated around the individual, with an optimal experience of transition to adult services for those young people who require ongoing health and care in adult life."[228]

STAGE 2: Interviews with key informants

Design

Semi-structured in-depth interviews with key stakeholders directly involved in commissioning at two sites in the North East of England. The interviews focused on informants' views about what successful commissioning for transition should look like; how commissioning for transition is currently undertaken; and what the barriers and enabling factors to successful commissioning for transition are. NHS Research Ethics (REC) guidance deems interviews with NHS staff to be 'service evaluation' and therefore this part of the research did not require approval from NHS REC. The researcher, SM, obtained a research passport from a local NHS Research and Development Office, and a letter of access from each NHS Trust prior to conducting interviews. We obtained ethics approval from Newcastle University Faculty of Medical Sciences Ethics Committee (ref: 00767/2014).

Sampling and recruitment

Interviewees were selected using a mixture of purposive and snowball sampling methods. The study steering group members were asked to nominate potential interviewees according to role/involvement in commissioning for transition, including representation from CCG, Health and Wellbeing boards and Local Authorities which commission services from the lead NHS Trust, as well as with local general practitioners and the third sector. The nominated interviewees were considered for participation based on their job title. Interviewees who agreed to participate were then also invited to nominate further participants.

We anticipated that around 25 completed interviews would be required to reach theoretical saturation and coverage of a range of views and perspectives at various organisational levels, but we were prepared to conduct more or fewer interviews as necessary. During recruitment, 46 potential interviewees were emailed a letter inviting them to participate. If no response was received to the initial contact then a maximum of three follow up attempts were made by telephone. Where participants declined to participate and provided a reason for declining, the reason was recorded and they were asked to nominate another potential interviewee to participate in their place. Recruitment was continued until new data no longer added content - i.e. to the point of saturation.

Participants were asked to sign a consent form giving permission for the interview to be recorded and transcribed, and confirming that they had read the information sheet. Before asking participants to give informed consent, they were provided with the opportunity to ask questions about the study, or seek clarification on any issue arising from the information sheet.

Data collection

The interview schedule was developed using a modified critical incidence technique, and was informed by grey literature and conversations with the research team and the WP3.2 Steering Group. The schedule was designed to encourage the participants to reflect on successful and unsuccessful practices for commissioning for transition, and to cover topics such as: i) interviewees' perceptions of the organisational structures, processes, relationships, barriers and facilitators related to commissioning for transition throughout the whole commissioning cycle, and ii) interviewees perceptions about the relative influence of policy drivers, past relationships with providers, and external influences on commissioning for transition. The wider research team and Steering Group commented on the schedule. The schedule was further refined in the course of conducting the interviews, based on preliminary analyses.

The interviews were conducted by the second author in a setting chosen by the interviewee, either face-to-face or by telephone. They lasted from an hour to an hour and a half, were audio-recorded verbatim and later transcribed. Data were collected from 22nd April 2014 to 28th August 2014.

Data analysis

The transcripts were analysed using framework analysis. In framework analysis the researchers' initial assumptions are articulated as an initial conceptual framework – this includes assumptions based on any literature read by the researchers and experiential knowledge of the topic. This framework is then expanded and modified, in iterative cycles, throughout the data analysis using the themes emerging from the study. This cyclical process produces a cumulative, refined framework that integrates the initial conceptual framework and the results emerging from the study data.

Researchers from different disciplinary backgrounds and with different expertise contributed to the data analysis. This included the researchers directly involved in the data collection and analysis: Maniatopoulos (GM)-sociology, organisation and management; Kolehmainen (NK)-NHS clinical practice, childhood disability, and implementation science; McCafferty (SM)-healthcare commissioning, health economics. It also included the wider research team Colver-Paediatrics; Le Couteur-Child Psychiatry; Vale-Health Economics; Reape-Health Services Management; and the WP 3.2 Steering Group. The deliberate involvement of the diverse

expertise within this wider research team allowed a nuanced, multifaceted analysis and reconciliation of any tensions in the coding and concepts. The analysis consisted of the four steps which form the framework analysis method:

1 *Familiarisation:* two researchers (GM, NK) familiarised themselves with the data by reading through a sample of transcripts until they felt they had developed an initial sense of the data.

2 *Identifying the initial coding framework:* three researchers (GM, NK, SM,) independently recorded their initial impressions and any deductive themes. Two researchers (GM, NK) then met to discuss these initial impressions; to relate them to their previous knowledge and expertise; and to agree the initial conceptual framework. This process was subsequently repeated for six rounds, with the two researchers reading further transcripts between each discussion round. The discussions consisted of the researchers talking through the emerging issues and themes and relationships between these, and agreeing themes, codes and relationships which were added to the framework. Through this, each round resulted in a refined version of the framework, integrating and dividing themes, and clarifying the concepts in the framework.

3 *Indexing:* Once the framework became stable (i.e. few modifications were required on each round), one researcher (GM) used it to 'index' the remaining transcripts one by one. This involved the researcher 'sifting and sorting' the remaining data and allocating these data into the coding framework. The researcher took notes of any changes to the framework and issues, and these were discussed with a second researcher (NK) to agree further elaborations to the framework. This process was repeated until all data were indexed and the final framework agreed. This final framework summarises the study findings as the "conceptual model to illustrate the process of commissioning for transition" (aim 3 for the overall the work package, see above).

4 *Charting:* Data from the transcripts were summarised according to the themes and codes (i.e. categories) to reduce the data while carefully retaining the original meanings of the interviewees' words. References to illustrative quotations were tagged and managed using Microsoft Word and NVivo10.

Quality assurance

A range of recommended quality assurance techniques were employed to ensure credibility, transferability, dependability and confirmability.[233]

Credibility

- During the data collection, contact was established through demonstrated interest in the responses, attentive listening, understanding and respect for what the participant says.[234] The sequencing and posing of questions was carefully considered, and was dynamic so that the questions promoted positive interaction between the participant and the interviewer and stimulated the participant to share their experiences and points of view. All interviews included an opportunity for participants to comment on any topic covered in the interview, or any new topic which they felt was relevant.[218, 234-236]
- Triangulation: accounts between participants and across two regions were compared and contrasted by the two researchers described above (GM, NK).
- Member-checking: the themes and their content were shared and discussed with the WP3.2 Steering Group.
- Frequent de-briefing: study progress, methods, emerging themes and any issues were reported to and scrutinised by the research programme senior team at regular intervals.

Transferability

- Reporting of the sampling frame and criteria (see above), and the key population characteristics (see Results).

Dependability and confirmability

- Involvement of several researchers helped to ensure that the framework was adapted to reflect the data rather than making the data 'fit' the framework.
- Involvement of new researchers (GM, NK) in the data analysis encouraged further peer examination through critical discussion.
- Audit trail: researchers kept field notes (SM) and a logbook of data analysis (GM), and established an electronic data analysis and synthesis trail of the development of the themes (GM in Word, NK in NVivo).

Results

Overall 29 interviews were conducted (see Table 40). Participants covered a range of roles relevant to commissioning for transition across CCGs, Health and Wellbeing Boards and Local Authorities, local general practitioners, and the third sector.

Table 40: Summary description of the participants

Region	Participant role in commissioning process	Employer
North East of England	Commissioners at different levels of seniority, and related managers (n=4)	Local Authority, Commissioning Support Unit, CCG
	NHS Directors (n=1) and senior clinicians (n=2) General practitioners (n=2)	NHS
	Transition planning workforce (n=2)	Local Authority
	Regional Coordinator	North East Autism Consortium
Bradford	Commissioners and related managers at different levels of seniority, and related managers (n=3)	CCG, Commissioning Support Unit
	NHS clinician (n=2) General practitioner	NHS
	Transition managers and co-ordinators (n=4)	Local Authority
Other regions	National clinical leader (n=2)	NHS England
	NHS clinical leaders (n=3)	Birmingham Mental Health NHS Foundation Trust Sheffield HSCT
	Voluntary sector leaders (n=2)	The J's Hospice, SNOOP

Definition of successful transition

No agreed definition of successful transition care was reported in the participants' narratives. However, some key characteristics of successful transition care emerged. These included that transition care should: (i) be personalised, (ii) be planned, co-ordinated and collaborative, (iii) focus on broad developmental and life participation outcomes, (iv) build pathways from children services to adult services, rather than just relying on individual care packages, (v) ensure co-ordination and continuity of relationships and knowledge across sectors and life domains rather than just a simple transfer of the young person from one service to

another, (vi) use universal services such as primary care where possible, with tailored enhanced support where required.

Box 7. Selected quotes about perceived characteristics of successful transition care

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Personalised, planned, co-ordinated, collaborative and with focus on broad outcomes:

"(…) what all the legislation is telling us, and all the national direction is about, is about personalisation. (…) if we start doing, planning for outcomes. (…) [in current practice] we keep on just focusing on the here and now. What we should be doing is (…) predict what the needs will be in the future (…)" (Commissioner/related manager 1, North East of England)

"(….) a smooth journey and needs met. (…) the much wider picture. So your health needs will impact on your employment outcomes or your education (…) and what you do with your aspirations within your community (…) there's an introduction to that new service, there's someone to coordinate that arrangement (…)" (Member 1 of transition planning workforce, North East of England)

"(…) I think successful transition (…) has to be addressed and introduced as a concept at the age of 14+ school review (…) then the families, and the young people, and the professionals begin, hopefully, to develop some type of joint work between them. So successful transition has to start early. (…)". (Voluntary sector leader, Third sector, Other regions)

Builds pathways, ensures continuity, and uses universal services:

"(…) if the systems were right, so if you had children's services interfaced properly into adult services there was a clear pathway (…) children would just sort of flow through (…)"(Commissioner/related manager 1, North East of England)

"(…) a successful transition is where the person undergoing transition has the change of care seamlessly, without any interruption in their therapeutic relationship, in their treatment strategy, and in their engagement. (…) the aspects of continuity, information continuity, relational continuity, therapeutic continuity." (NHS clinical leader 1, NHS, Other region)

"(…) this concept of universal (…) you might have somebody who's complex and needs CAMHS and learning disability team or whatever, and has some physical needs as well. But still can access the already commissioned services. And if they interfaced well then the transition could be seamless and wouldn't need active commissioning. (…)"
(Commissioner/related manager 1, North East of England)

From the analysis, a range of issues and themes related to commissioning successful transition care emerged. These clustered around four meta-themes:

1 The broad context of commissioning for transition: legislation, policy and wider life transitions

2 Commissioning for transition: structures, processes, pathways and relationships

3 Service-level co-ordination, sign-posting, and relational support
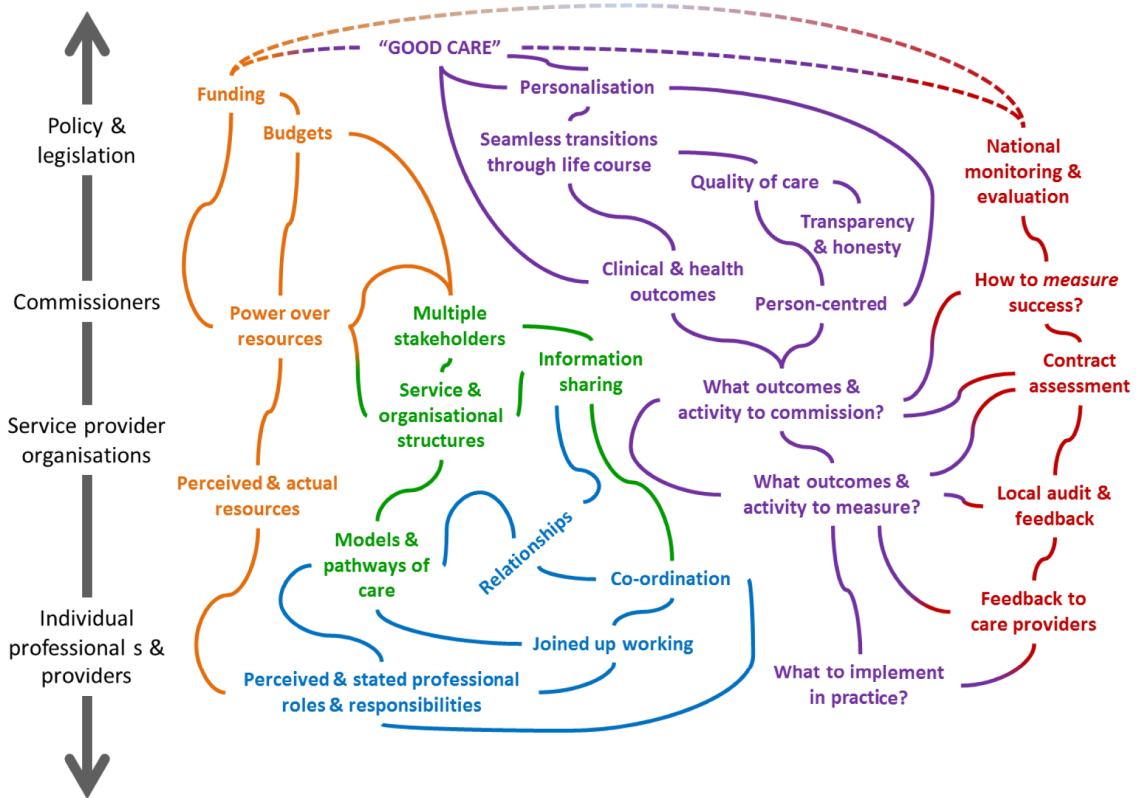
4 Outcomes and contract evaluation

These four meta-themes, with summaries of their key content, are presented below.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews. It is available on request from the authors of the report.

5 A conceptual model to illustrate the process of commissioning for transition

From the analysis, we identified key characteristics of successful commissioning, and developed the first iteration of a conceptualisation of the process of commissioning for transition, as per objective 3 above. This is depicted, visually, in Figure 20. The figure provides a summary output of the results in terms of stakeholders' perceptions of the organisational structures, processes and relationships that drive commissioning for transition. It illustrates the interrelated nature of the themes that emerged, and reflects the complexity of the commissioning process as described by the participants.

Figure 20: A visual summary conceptualisation of the process of commissioning for transition as it emerged from the data analysis

Orange = Financial and legislative. **Green** = the structures, processes, pathways and relationships in commissioning for transition. **Blue** = Service-level co-ordination, sign-posting, and relational support. **Purple** = Outcomes. **Red** = Contract evaluation and feedback.

Implications for the next stage of WP 3.2

In the light of the qualitative analysis of WP 3.2 the following criteria (Table 41) were applied for the next stage of this study to further explore enablers of successful commissioning practice for transition and identify lessons to inform guidance on commissioning for transition across the NHS (including CCG's, Local Authorities and Health and Wellbeing Boards).

Table 41: Criteria for site selection

Derived from the interviews. Potential site-level sampling criteria for commissioning with particular issues relevant to transition	Potential exemplar sites. We seek sites where the criteria are being actively addressed by Commissioners.
1 Commissioning for Quality and Innovation (CQUIN) framework is implemented towards successful transition. *Source theme/subtheme:*	Site identified
2 Commissioning for transition co-ordinators within a framework of Developmentally Appropriate Healthcare, rather than for services. e.g. Diabetes. *Source theme/subtheme: 3.1 and 3.2/2.1*	Site to be identified
3 Joint commissioning i Cross-sectoral joint commissioning - Links to Education, Health and Social Care plans EHSCP. ii Within-health joint commissioning –including with involvement of PRIMARY CARE. *Source theme/subtheme: 3.2*	Site identified Site identified
4 Where Commissioners and Providers effectively commission together *Source theme/subtheme: 2*	Site identified

Further, outcome based commissioning was considered desirable (mentioned often in transcripts) but no-one was clear what the outcomes should be and if and where outcome commissioning is being practiced

Stage 3 Conducting the case studies

Using the findings of the literature review and qualitative analysis of the interviews of Stage1 1 and 2, the criteria in Table 41, sites were then identified for visits.

Research Strategy

A case study approach was followed to collect empirical data from three Clinical Commissioning Groups (CCGs) in England. Yin[237] defines the scope of a case study as "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident".[237] Case studies, by their nature, are sensitive to complexity and can be used to provide in-depth insight into complex social phenomena. As a research strategy, case studies are well suited to addressing explanatory 'how' and 'why' questions.[237] Robson[238] suggests that the case study is an appropriate method towards the "development of detailed, intensive knowledge about a 'case', or a small number of related 'cases'". In this context, one of the most important uses of the case study is "to explain the casual links in real-life interventions that are too complex for survey or experimental strategies to elicit".[237] A case study can be single or multiple. For this study, a number of cases were studied jointly in order to explore local initiatives that address commissioning for transition.

Sampling and recruitment

Participants within selected Case Study sites, were selected using a mixture of purposive and snowball sampling methods. The WP steering group members were also asked to suggest potential sites where one of the criteria (see Table 41) was met.

Within the identified sites, participants were considered for participation based on their involvement in local initiatives that specifically addressed commissioning for transition. During recruitment, potential participants (commissioners and service providers) were invited to participate by a letter sent by e-mail. If no response was received then a maximum of three follow up attempts were made by email or telephone.

Participants were asked to sign a consent form giving permission for the interview to be digitally recorded and transcribed, and confirming that they had read the information sheet. Before asking participants to give informed consent, they were provided with the opportunity to ask questions about the study, or seek clarification on any issue arising from the information sheet.

Data collection

Data collection took place from December 2015 to March 2016 in three areas covered by three Clinical Commissioning Groups (CCGs) in the North West, South East and West Midlands. Across the three sites, a total of 11 semi-structured in-depth interviews were conducted. The interviews aimed to provide a mapping of local initiatives to address commissioning for transition. The breakdown of interviews by site and role is summarised in Table 42. Interviews typically took around one hour and were conducted face to face usually at the workplace of the interviewee.

Table 42: List of participants

Site	Participants/Position	Organisation
NW	General Manager, Child Health, Hospital Trust	NHS provider
NW	Senior Commissioning Manager for Children and Families at CCG	CCG
NW	Quality and Safety Lead, Partnership	CCG/LA
MID	Accountable Officer for the CCG	CCG
MID	Associate Director of Commissioning for Maternity and Children's Services	CCG
MID	Project Manager for age 0 to 25 service, CCG	CCG
SW	Paediatric Liaison and Transition Nurse, Hospital Trust	NHS provider
SW	Assistant Director of Nursing for Specialist Services, Lead Children's Nurse, Hospital Trust	NHS provider
SW	Consultant Paediatrician, Hospital Trust	NHS provider
SW	Service Design and Delivery Manager, Commissioning Department of the CCG	CCG
SW	Quality improvement lead in the Maternity and Children's Strategic Clinical Networks	Strategic Clinical Network

The interviews focused on participants' experiences of local initiatives to address commissioning for transition, in terms of processes relationships, barriers and facilitators, and lessons learnt. We acknowledge that a potential limitation of our study is lack of participants from adult services and lack of voice of any service users.

Data analysis

Interviews were transcribed and analysed inductively, without the aid of a software programme. This process was structured using thematic analysis.[239] Core categories and themes were identified for each participant and then compared within each case. One member of the research team (GM) undertook the analysis of interview data and emerging categories. The themes were then reviewed and discussed within the wider project team meetings. In this report, all participants have been anonymised.

Case Study A. North West: Financial Incentive - Commissioning for Quality and Innovation (CQUIN)

Background

The following case study explores the development and implementation of Commissioning for Quality and Innovation (CQUIN) payment framework to improve transition. In 2009 the CQUIN payment framework was introduced to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care. This means that a proportion of income depends on achieving quality improvement and innovation goals, agreed between the Trust and the commissioners. The key aim of the CQUIN framework is to secure improvements in the quality of services and better outcomes for patients.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study A

In the North West the CQUIN was considered as a necessary first step to quality improvement as it helped to develop a culture, at least within Children's Services, of shared purpose and values around transition. In this context, it was perceived as a useful scheme aiming to standardise the Transition process for young people with long term conditions through the introduction and use of the 'Ready, Steady, Go' forms, a recently developed programme supported by NHS England. Overall, participants reported that the implementation of the CQUIN contributed towards raising the profile and visibility of the transition process. Moreover, it also helped to raise awareness among clinicians of the move to improve transitions and it also contributed towards improved conversations between specific adults' and children's services.

However, a number of barriers were also reported such as a lack of general adult services' engagement in spite of some successes. In some cases, this was compounded with a lack of specific Adult Services for children to be transferred to and the need for some young people to be transferred to other Trusts which participants reported it is more difficult to plan for. Moreover, it was reported that CQUINs focus on numerical indicators and its conceptualisation in terms of finance and targets rather than quality and innovation may actually negate quality improvement. Finally, concerns were raised about the appropriate use of the 'Ready, Steady, Go' programme especially as transition plans extend throughout the life course of transition beyond the timeframe of the one year CQUIN initiative.

Case Study B. South West: Commissioners and Providers working effectively together

Background

The following case study explores the facilitating role of the regional Strategic Clinical Network (SCN) in the South West towards the development and implementation of a regional CQUIN across 14 Trusts related to transitional healthcare (2014-2015). The South West case study provides a novel instance where commissioners and providers worked effectively together through the regional Strategic Clinical Network (SCN). Strategic Clinical Networks, work in partnership with commissioners (including local government/social care), to support their decision making and strategic planning. SCNs facilitate work across the various stakeholder boundaries such as commissioner, provider and voluntary organisations in order

to promote improved care for patients, carers and the public. The following case study further explores the development and implementation of CQUIN in one of the provider Trusts.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study B.

In the South West the Strategic Clinical Network (SCN) did play a central role in facilitating the development and the implementation of the regional CQUIN. The facilitative way of working across the 14 Trusts provided strategic leadership and was an important driver for reconfiguring the commissioner and provider relationships. All participants reported the network played an important role in both raising commissioners' and providers awareness around transition and providing a space for the Trusts to share ideas, knowledge and experience in relation to best practice in transition (shared learning about good practice in terms of transitional healthcare). At a Trust level, the CQUIN contributed towards the development of a Trust wide Transition steering group which was responsible for developing the transition service, ensuring that the transition policy had been followed accurately, and that it was revised as practice evolved. It also provided the opportunity for the appointment of a Transition worker responsible for collaborating with professionals from their own and from other services and developing good working relationships to ensure co-ordination of care for the young person.

However, a number of barriers were also reported such as a lack of general adult services' engagement in Transition steering group meetings and a lack of clarity about adult care commissioners' roles and responsibilities. Evaluating commissioning outcomes for transition through feedback from service users was another challenge for the Trust. Patients' participation and feedback was limited and fragmented across different services. Finally, echoing the findings of the North West case study, conceptualising CQUIN in terms of finance and targets did not necessarily translate into meaningful conversations about quality and innovation.

Case Study C. West Midlands: Joint commissioning (within health and between agencies)

Background

In the West Midlands a partnership was developed between two CCGs and a Local Authority to support the development and procurement of a fully integrated mental health service for 0-25 year olds. This resulted in a change from the previous system through the provision of a seamless service that would include services for the full range of mental health conditions across the age range. Following a tendering process, a partnership led by a Children's Hospital, as the preferred bidder, won a £124m five year contract to deliver mental health services for children, young people and young adults.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study C.

In the West Midlands the overall aim of the partnership was to support the development and implementation of a fully integrated mental health service for 0-25 year olds. The new service addressed problems identified by the commissioners namely disjointed provision of mental health services for individuals up to age 25 years between the different provider organisations. Overall, participants reported that key feature in the development of the new service was the enthusiasm and commitment of commissioners to improve transitional healthcare for young people with mental health problems. Further, participants emphasised the importance of health, social and third sector involvement and co-production with service users of the new service specification. As well as the enthusiasm of stakeholders at a local level, an important feature of the development of the new service was support by a National Children' lead and the regional Collaboration for Leadership in Applied Health and Social Care (CLAHRC). Finally, another key feature was a focus on outcomes through feedback from service users.

However, a number of barriers were also reported such as uncertainty around post-25 years transition and related challenges with adult service engagement. Moreover it was reported that negotiating the decommissioning process with the outgoing provider was a very challenging process. Participants thought also that there was some reluctance to adopt the new service by some stakeholders. Finally, inadequate information sharing procedures were evident following the configuration of the new mental health service.

Interview schedule WP 3.2

Introduction

Summarise ethics considerations – and assure anonymity

Have participant complete consent form.

The purpose of this interview is to gain an in-depth understanding of the commissioning processes which underpin transition of patients from children and young people's services into adult services. Specifically, we are interested in the transition of CYP with complex health needs.

Whilst we are aware that this transition or transfer is often creates challenges or is considered problematic for patients and practitioners alike, what is less clear is

a) What the commissioning processes for transition currently are
b) How the commissioning processes influence or affect transition outcomes

We are keen to gain your specific perspective as <u>provider/ commissioner</u> and to learn about how you have interacted with other <u>providers/ commissioners</u> around the area of transition.

We are also seeking to map commissioning processes and would welcome detail about key relationships, stakeholders and gatekeepers in the commissioning arena.

Interview Topic Guide

Background/ Context

1. Can you tell me what you understand about the term 'transfer' or transition' in health care?
   a. How would you define a "successful transition"?
2. Can you tell me about your role and:
   a. How you are or have been involved in transition?
   b. How you are or have been involved in commissioning?

Probes: key relationships; inter/intra organisational networks; resource allocation; contracting/spending review

Successful Commissioning Outcomes

3. Can you describe an example of when transition (or commissioning) has been undertaken successfully? (Outcomes)

Probes: e.g. new relationships established, the result of the transition, positive patient feedback, quality standards (which ones?) Etc.

Successful Commissioning activities/ actions/ and processes

4. With respect to the example shared can you describe the activities/ actions/ or process that were undertaken to achieve this outcome?

Probes: what activities and actions were undertaken, including key elements of the

commissioning process, key stakeholders and gatekeepers, barriers/ facilitators/

Relationships/ networks/ provision/ politics.

[NB. Labels of 'successful/unsuccessful' are used to encourage discussion on a range of

aspects related to the quality of commissioning rather than to emphasise effectiveness]

Unsuccessful Commissioning Outcomes

5. Can you describe an example of when transition (or commissioning) has been undertaken unsuccessfully? (Outcomes)

Probes: e.g., the result of the transition, difficulties identifying/ engaging a provider?

Negative patient feedback, failure to meet quality standards (which ones?) Etc.

Unsuccessful Commissioning activities/ actions/ and processes

6. With respect to the example shared can you describe the activities/ actions/ or process that were undertaken which resulted in this outcome?

Probes: what activities and actions were undertaken (or neglected), including key elements of

the commissioning process, key stakeholders and gatekeepers, barriers/ facilitators/

Relationships/ networks/ provision/ politics.

[NB. Labels of 'successful/unsuccessful' are used to encourage discussion on a range of

aspects related to the quality of commissioning rather than to emphasise effectiveness]

Any other points

7. Are there any other issue which you consider to be relevant that you would like to discuss?

Close and thanks.