PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (see an example) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Rationale, design and baseline data of a mixed-methods study examining the clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: The DON'T RETARD project
AUTHORS	Hilderson, Deborah; Westhovens, Rene; Wouters, Carine; Van der Elst, Kristien; Goossens, Eva; Moons, Philip

VERSION 1 - REVIEW

REVIEWER	Dr Janet E McDonagh Senior Lecturer in Paediatric and Adolescent Rheumatology University of Birmingham UK
REVIEW RETURNED	23-Aug-2013

GENERAL COMMENTS	This is a much needed concise description of an evidence based transitional care intervention. (i) My main comment is about the aims of the paper. The title states that the paper addresses the rationale, design and baseline data as does the conclusions (on page 2). However references to the longitudinal and comparative analyses having been done in addition to the qualitative work – but no data is presented. This makes reading the paper confusing as so much data is missing. If the data is not to be included in this paper then the paper needs revising and the tenses changed eg "evaluation of the impact of the transition programme is planned applying both longitudinal and comparative analyses. Qualitative data about their experiences will be collected from the adolescents and their parents who participated in the experimental group will be analysed qualitatively using content analysis" . similarly "The primary outcome will be health status….. etc) Page 6 re-iterates the objectives but this time states only 2 but then follows this with "The following hypotheses were tested…." – if the data is not to be included in this paper, this should read "The following hypotheses will then be tested….." If the data is already available it should be stated "data will be presented elsewhere/in a forthcoming publication etc (ii) Article summary Page 3 In the article summary it would useful to include who the second face to face visit is with as well as for whom the adolescent information day is for. Background, Page 4

(iii) adolescents undergo different stages during their life wherein many more than 2 important phenomena occur whether biological (growth, puberty), social, educational etc This sentence is thus somewhat simplistic and would benefit from a rewrite eg “…..2 of the many important phenomena which occur during adolescence include…”

(iv) To further emphasise the difference between transfer and transition, it would be worth considering including the term transition when the “preparatory phase” is defined in line 41

(v) The authors state that since the majority of the studies have been conducted in the UK, this may limit their generalisability to other health care systems. It would be of interest to give an example of what aspects of care they think would be different when making this statement as there are also a significant number of similarities. One obvious difference would be the financing of healthcare.

(vI)One of the justifications for the brief intervention is that existing transition programmes are costly and time consuming. What evidence do the authors have for this? I am unaware of any economic evaluations to date in the literature.

(vii) The authors state the most frequently perceived barriers to transition include time and funding but do not mention unmet training needs which have been reported by other authors. From memory the QUARTT in reference [14] did not specifically consider training which was a limitation of the questionnaire particularly as adolescent health training is not established in many European countries as yet.

Control group.
(viii) Another concern is that the control group (late adolescent and young adult) is a very different group developmentally from the intervention group (mid adolescent developmental stage). The potential impact of this needs to be discussed as may influence the interpretation of data.

(ix) It is unclear why persistent and extended oliogarthritis are combined. It would appear to make more sense to combine the polyarticular with the extended JIA if they actually need combining at all. A young person with a single knee (persistent oligoarthritis) is very different from one with multiple joint involvement (extended oliogarthritis). The rationale for combining these 2 subtypes should be stated.

(x) It is unclear as to what the authors mean by the terms behaviour and psychological control and this needs to be explained for the reader.

Page 6, Transition Programme as a brief intervention

(xi) The transition programme as presented here sounds to be more of a transfer rather than a transition programme. Most guidance proposes that transitional care should start in early adolescence whereas this appears to start in the peritransfer period and it is unclear as to what preparation has been carried out prior to the intervention. This is worthy of discussion in view of the confusion between transition and transfer in the literature.

(xii) What form was the management diary – what did it incorporate?

(xiii) There is surprisingly no mention of opportunities for the young person to be seen independently by the health professionals whether rheumatologist or transition coordinator. Other authors have reported to find these important aspects of transition and are fundamental to adolescent health care

(xiv) I am amazed that the TC could cover all the stated content in 20-30 minutes never mind provide opportunity for the young person to interact! Have these consultations been timed and did the TC always keep to time? Such data would be of great practical interest.

(xv) Why does the TC develop the individual patient transfer plan for each patient rather than doing this collaboratively with the young person?

Methods and design
(xvi) The mixed method approach is very appropriate for such research. However there are limitations with the previous work eg the project is based on qualitative work with a different age group ie adults rather than adolescents. Was that work supplemented by any other evidence eg from the literature?

(xvii) Outcome measures
Secondary outcomes for the parents included various measures relating to autonomy yet autonomy is not specifically measured in adolescents. The rationale for this would be of interest particularly as this aspect has been reported to be important by other authors eg van Staa 2011 who reported that feeling more self-efficacious in skills for independent hospital visits and a greater perceived independence during consultations were found to be most strongly associated with being ready to transfer

(xviii) It is unclear as to how disease activity and clinical remission was measured by the doctor eg visual analogue scale?

(xix) In the definition of usual care there is no mention of whether this included any adolescent specific aspects even if no discussion regarding transfer eg routine psychosocial screening, time alone for the young person etc. The success of these brief transition interventions may also be determined by the quality of their "usual" adolescent rheumatology health care

(xx) There is no mention of assessment of transition readiness in this programme. The rationale for this omission should be stated particularly in view of the increasing interest in this area in the literature (eg systematic review Stinson J 2013)

Minor Points

Consistency of terminology would help the reader. In the draft young people are referred to variably including youngsters, adolescents, young people, patients.

Page 9
The term “mental retardation” is now not recommended for use in some countries such as the UK where it has been replaced by learning disability.

References 18 and 22 are incomplete

REVIEWER	Megan Curran, MD Assistant Professor of Pediatrics Northwestern University Feinberg School of Medicine Attending Physician Ann and Robert H. Lurie Children's Hospital of Chicago Division of Rheumatology I have no competing interests.
REVIEW RETURNED	28-Aug-2013

RESULTS & CONCLUSIONS	The purpose of the article is to describe the content of the transition program and rationale/design of the evaluation, as well as to report baseline data. I understand that results are therefore not the focus of the article but since you are reporting baseline (T0) scores on questionnaires, you should include this and discuss this in the results section of the article, not just in a table. As a reader, I wanted to know more about the results from T1 and T2 - would make it a much more interesting article. Since the data was collected starting in 2011, I assume that results are available but that you are going to describe them in another article.

REVIEWER	Aimee Hersh MD Assistant Professor Pediatric Rheumatology University of Utah I have no competing interests.
REVIEW RETURNED	31-Aug-2013

RESULTS & CONCLUSIONS	This manuscript describes the design and potential outcomes of a brief intervention for transition aged youth with juvenile arthritis. This study provides limited results. I think this manuscript would be strengthened by presenting the results of the intervention if they are available. I do not think a description of the intervention is worth publishing unless the results of the study are available.

VERSION 1 – AUTHOR RESPONSE

Reviewer 1: Dr Janet E McDonagh, Senior Lecturer in Paediatric and Adolescent Rheumato-logy, University of Birmingham (UK)

(Query) This is a much needed concise description of an evidence based transitional care intervention.

(Response) Many thanks to Dr. McDonagh for carefully reviewing our manuscript and providing us with many valuable suggestions and relevant comments that enabled us to improve the quality and clarity of our manuscript.

ABSTRACT

(Query (i)) My main comment is about the aims of the paper. The title states that the paper addresses the rationale, design and baseline data as does the conclusions (on page 2). However references to the longitudinal and comparative analyses having been done in addition to the qualitative work – but no data is presented. This makes reading the paper confusing as so much data is missing. If the data is not to be included in this paper then the paper needs revising and the tenses changed eg "evaluation of the impact of the transition programme is planned applying both longitudinal and comparative analyses. Qualitative data about their experiences will be collected from the adolescents and their parents who participated in the experimental group will be analysed qualitatively using content analysis", similarly "The primary outcome will be health status….. etc)

Page 6 re-iterates the objectives but this time states only 2 but then follows this with "The following hypotheses were tested…." – if the data is not to be included in this paper, this should read "The following hypotheses will then be tested….."

If the data is already available it should be stated "data will be presented elsewhere/in a forthcoming publication etc.

(Response (i))

Since transitional care interventions are seldom described in extent, we intentionally limited this manuscript to the rationale; design and baseline data of the study. We strongly believe that such an article is needed, and will guide clinicians and researchers in future transitional care projects. The final results of the study will be submitted in a forthcoming article. We agree with the reviewer that, therefore, we should express this article more in the future tense, or at least in the present tense. Hence, we reformulated the following parts of our manuscript:

- In the abstract we reformulated the objectives of this methodological manuscript (p2): "This methods paper aimed to describe the content of a transition programme for young people with juvenile idiopathic arthritis (JIA) designed as a brief intervention, as well as the rationale and design of a mixed-methods study evaluating the clinical impact of this transition programme. Since we hypothesized that the transition programme improves the physical, psychosocial, and rheumatic-specific health of adolescents with JIA, baseline characteristics of young people who will participate in the transition programme are furthermore presented."

- Furthermore, we reformulated the objectives in the background section of the paper (p7): "In the present article, we aim (1) to extensively describe the content of a transition programme for young people with JIA that was designed as a brief intervention, (2) to describe the rationale and design of a mixed methods study evaluating the clinical impact of this transition programme, and (3) to report the baseline characteristics of the intervention group on the respective primary and secondary outcomes. We hypothesize that the transition programme would improve the physical, psychosocial, and rheumatic-specific health of adolescents with JIA (primary outcome) [8,18]. Second, we hypothesize that the programme would improve medication adherence, illness-related knowledge, quality of life, threshold to fatigue, and parenting styles in patients who participate in the programme (secondary outcomes). To guarantee transparency and quality of describing this complex intervention, we used the recently published criteria for reporting the development and evaluation of complex interventions (CReDECI) [19]. The results on the clinical impact of the transition programme will be reported in a forthcoming publication."

- And we addressed this comment in the discussion section (p24): "Lastly, the results of the quantitative longitudinal and comparative studies and the qualitative studies will be separately published, and will provide pilot data on the feasibility and impact of a brief transition programme on patient- and parent-reported outcomes in young people with JIA. The data of this forthcoming study can be used to design a randomised controlled trial testing the effectiveness of the programme in a robust way."

ARTICLE SUMMARY
(Query (ii)) In the article summary it would useful to include who the second face to face visit is with as well as for whom the adolescent information day is for.

(Response (ii)) These suggestions were taken into account and extra details were added to the manuscript (p4)
- (2) a second face-to-face visit with the transition coordinator taking place at paediatric rheumatology;
- (3) adolescent-information day for young people and their parents

BACKGROUND
(Query (iii)) Adolescents undergo different stages during their life wherein many more than 2 important phenomena occur whether biological (growth, puberty), social, educational etc This sentence is thus somewhat simplistic and would benefit from a rewrite eg "…..2 of the many important phenomena which occur during adolescence include…"

(Response (iii)) We rewrote this sentence based on this suggestion into the following (p5): "Young people with chronic conditions undergo different stages during their life. Two of the many important phenomena that occur include a developmental transition into adulthood, a phase during which young people evolve from being a dependent child to becoming an independent adult [1]. Second, their setting of care is transferring from a paediatric context to an adult-focused environment. Indeed, a timely and well-prepared transfer to adult-centred care is advocated [2,3]. This transfer is defined as an event or series of events through which adolescents and young adults with chronic physical and medical conditions move their care from a paediatric to an adult health care environment [4]. According to the recent literature, the paediatric-to-adult transfer of care should be preceded by a preparatory transitional phase. Transition is therefore defined as "a process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood" [4].
(Query (iv)) To further emphasise the difference between transfer and transition, it would be worth considering including the term transition when the "preparatory phase" is defined in line 41.

(Response (iv)) Indeed, we changed this into "preparatory transitional phase" (p5).

(Query (v)) The authors state that since the majority of the studies have been conducted in the UK, this may limit their generalizability to other health care systems. It would be of interest to give an example of what aspects of care they think would be different when making this statement as there are also a significant number of similarities. One obvious difference would be the financing of healthcare.

(Response (v)): This suggestion is taken into account (p5): “The vast majority of the studies have been conducted in the United Kingdom [12], which may limit the generalizability of study findings to other health care systems due to e.g., differences in financing and reimbursement of health care expenditures.

(Query (vi)) One of the justifications for the brief intervention is that existing transition programmes are costly and time consuming. What evidence do the authors have for this? I am unaware of any economic evaluations to date in the literature.

(Response (vi)) Following modifications were done to integrate this relevant comment (p6): “Existing transition programmes generally adopt a comprehensive approach, likely contributing to their positive effects. However, they are also perceived as being costly and time-consuming to implement in day-to-day practice, although economic cost-effectiveness studies are currently lacking.”

(Query (vii)) The authors state the most frequently perceived barriers to transition include time and funding but do not mention unmet training needs which have been reported by other authors. From memory the QUARTT in reference [14] did not specifically consider training which was a limitation of the questionnaire particularly as adolescent health training is not established in many European countries as yet.

(Response (vii)) Thank you for this relevant comment, indeed, we did not evaluate training needs in the QUARTT, which is now further discussed in the discussion (p23): “…Shorter time-consuming interventions are in demand, since the current trend is to implement transition programmes through optimal time use and cost-efficacy. However, as pointed out by McDonagh and colleagues, training of healthcare professionals will require additional resources.”

CONTROL GROUP

(Query (viii)) Another concern is that the control group (late adolescent and young adult) is a very different group developmentally from the intervention group (mid adolescent developmental stage). The potential impact of these needs to be discussed as may influence the interpretation of data.

(Response (viii)) Indeed, the age of the young people in the control group is somewhat higher than those of the intervention group. The potential impact of this difference in age will be analysed and discussed in a future paper on the results of the evaluative study. However, we addressed this issue in the discussion on p25: “Finally, since patients who were included in the comparison group are already transferred to adult rheumatology, they are older as compared to the intervention group. In addition, transfer of patients occurred in general somewhat later in the era before our transition programme. This also contributes to the higher age of the comparison subjects. Hence, a matching procedure on age is not possible.”

(Query (ix)) It is unclear why persistent and extended oliogarthritis are combined. It would appear to make more sense to combine the polyarticular with the extended JIA if they actually need combining at all. A young person with a single knee (persistent oligoarthritis) is very different from one with multiple joint involvement (extended oliogarthritis). The rationale for combining these 2 subtypes should be stated.

(Response (ix)) We did follow the classical subtypes of JIA, however, there was no aim to study differences between subtypes when evaluating the impact of the transition programme on our primary and secondary outcomes. However we will consider this suggestion when reporting the results of our evaluation phase in the future.

(Query(x)) It is unclear as to what the authors mean by the terms behaviour and psychological control and this needs to be explained for the reader.

(Response (x)) The section ‘Methods and design’ of our paper provided an overview of the secondary outcomes that were measured in both patients and parents. Furthermore, table 1 listed all the instruments which were used to assess these outcomes in patients and/or parents who participated in this study. On the level of the parents, several secondary outcomes were assessed including four dimensions of parenting. Using parent-reported instruments we assessed (a) the degree to which parents promoted independence, (b) supported autonomy, (c) the degree of behavioral control and (d) the degree of psychological control. Behavioral control is a form of parental monitoring and represents the extent to which parents are perceived knowledgeable about the child’s behavior. Psychological control however is another parenting dimension representing an intrusive and manipulative form of control expressed through the use of tactics such as guilt induction and contingent love. We provided a short description of these two controlling dimensions in the revised manuscript (p12). “Finally in the group of parents, four dimensions of parenting are assessed using parent-reported instruments. Promotion of independence by parents is measured using the Promotion of Independence Scale [31] and support of autonomy is measured using the Autonomy Support Scale [32]. Furthermore, the level of behavioural control (i.e., parental monitoring of child’s behaviour) is assessed using the Parental Regulation Scale [33]; while the aspect of psychological control (i.e., intrusive and manipulative form of controlling) is measured using the Psychological Control Scale [33]. These outcomes are all found to be suboptimal in patients with JIA [23,31,33-35].”

Page 6, Transition Programme as a brief intervention
(Query (xi)) The transition programme as presented here sounds to be more of a transfer rather than a transition programme. Most guidance proposes that transitional care should start in early adolescence whereas this appears to start in the peri-transfer period and it is unclear as to what preparation has been carried out prior to the intervention. This is worthy of discussion in view of the confusion between transition and transfer in the literature.

(Response (xi)) Based on this valuable comment we added a paragraph to the discussion section of the paper on p24: “Furthermore, our brief transition programme might look more as a transfer than a transition programme. The concept of a transition programme may imply more transitional care, starting in early adolescence, whereas this brief intervention starts in the pre-transfer period. Our brief intervention predominantly focuses on counselling and education, rather than skills training. Still, expecting all education needs to be met in the relatively short programme described is ambitious. Moreover, regular assessments of education needs should already be initiated in paediatric care.”

(Query (xii)) What form was the management diary – what did it incorporate?

(Response (xii)) More detailed information is now provided concerning the content of this management diary on p7: “During this first face-to-face visit with the TC, the TC provides the patient and parents with a rheumatology management diary (i.e., a booklet including self-reporting symptoms scales, an overview of scheduled appointments, space for writing down questions, etc.)”

(Query (xiii)) There is surprisingly no mention of opportunities for the young person to be seen independently by the health professionals whether rheumatologist or transition coordinator. Other authors have reported to find these important aspects of transition and are fundamental to adolescent health care.

(Response (xiii)) We apologize for not mentioning this possibility in our paper while in practice young people indeed had the possibility to independently see both the rheumatologist(s) and the transition coordinator during an outpatient visit to the rheumatology department. Now, we have added the following information on p7: “Young people have the possibility to see both the rheumatologist and TC without the presence of their parent(s). This independent visit is strongly encouraged.”

(Query (xiv)) I am amazed that the TC could cover all the stated content in 20-30 minutes never mind provide opportunity for the young person to interact! Have these consultations been timed and did the TC always keep to time? Such data would be of great practical interest.

(Response (xiv)) During the visits, young people were never restricted in time, having the opportunity to elaborate on the aspects which were important for themselves. For example, a young person with oligo- articular JIA, who is in remission off medication, may need less focus on adherence to medication; meaning that each young person was guided according to his/her needs. Hence, the TC did not have a predefined time-lock, and consultations were not timed. However, your suggestion of timing these consultations would indeed be valuable for clinical practice and should be integrated in future research.

(Query (xv)) Why does the TC develop the individual patient transfer plan for each patient rather than doing this collaboratively with the young person?

(Response (xv)) Thank you again to point out the lack of sufficient details on important aspects of our transition programme. However we want to stress that each transfer plan was definitely developed by the TC based on conversations with the young person and the parents. We have now more clearly provided this detailed information on p9: “For the fourth step, an individualized transfer plan is developed by the TC based on conversations with the young person and the parents.”

METHODS AND DESIGN

(Query (xvi)) The mixed method approach is very appropriate for such research. However there are limitations with the previous work e.g. the project is based on qualitative work with a different age group i.e. adults rather than adolescents. Was that work supplemented by any other evidence e.g. from the literature?

(Response (xvi)) It is correct to point out that the preparatory qualitative study captured the perspective of young people with a different age group than the young people included in the intervention group. However, we did not solely rely on our own qualitative findings to determine the content of the transition program. Indeed, we also relied on previously published studies on transitional care to design our intervention. These statements as well as supporting references were added to the manuscript on p10.

OUTCOME MEASURES

(Query (xvii)) Secondary outcomes for the parents included various measures relating to autonomy yet autonomy is not specifically measured in adolescents. The rationale for this would be of interest particularly as this aspect has been reported to be important by other authors e.g. van Staa 2011 who reported that feeling more self-efficacious in skills for independent hospital visits and a greater perceived independence during consultations were found to be most strongly associated with being ready to transfer.

(Response (xvii)) We highly agree with this comment and elaborated further on this issue in the last paragraph of the discussion section (p24): “In addition, we have to bear in mind that the list of outcomes we use to assess the clinical impact of our programme is non-exhaustive. Additional outcomes such as self-efficacy or the level of autonomy of patients might be of interest [52].”

(Query (xviii)) It is unclear as to how disease activity and clinical remission was measured by the doctor e.g. visual analogue scale?

(Response (xviii)) Information on the methods we used to assess these two aspects was indeed currently missing in our manuscript. Disease activity and clinical remission were both evaluated using the criteria of Wallace et al., we added this information on p12: “With regard to disease parameters, we evaluate the clinical status of disease activity and clinical remission on/off medication according to the preliminary criteria of Wallace et al [36].”

(Query (xix)) In the definition of usual care there is no mention of whether this included any adolescent specific aspects even if no discussion regarding transfer e.g. routine psychosocial screening, time alone for the young person etc. The success of these brief transition interventions may also be determined by the quality of their "usual" adolescent rheumatology healthcare.

(Response (xix)) We agree with this comment, and subsequently provided more clarification on p19: “For the purposes of this study, usual care is defined as the care that is currently provided in day-to-day clinical practice. (…) No transition coordinator or formal transition plan is provided to patients in the comparison group who received usual care. ”

(Query (xx)) There is no mention of assessment of transition readiness in this programme. The rationale for this omission should be stated particularly in view of the increasing interest in this area in the literature (e.g. systematic review Stinson J 2013).

(Response (xx)) Thank you for pointing out this omission, transition readiness was indeed not measured in this transition program or study part, which we now included in the discussion (p24) as a shortcoming: “Although we use an innovative embedded experimental design in the DON’T RETARD project, some limitations should be addressed. The assessment of the patient’s transition readiness is no key component of our transition programme. Recently, an increasing number of studies investigated the use of assessment tools such as the Transition Readiness Assessment Questionnaire (TRAQ) [51], an instrument aiming to evaluate a set of skills and developmental tasks that should be fulfilled in order to transfer patients to adult care.”

MINOR POINTS

(Query) Consistency of terminology would help the reader. In the draft young people are referred to variably including youngsters, adolescents, young people, and patients.

(Response) To increase consistency of the terminology and wordings used in this paper we used the term “young people“ throughout our entire paper.

(Query) Page 9 - The term “mental retardation” is now not recommended for use in some countries such as the UK where it has been replaced by “learning disability”.

(Response) The wording “mental retardation” is indeed not the most preferred terminology. However, we think that the proposed alternative “learning disability” does not cover the full meaning of our construct, therefore we reformulated our exclusion criteria as: “a developmental or cognitive disability”.

(Query) References 18 and 22 are incomplete.
(Response) We now provided full details on these references.

Reviewer 2: Megan Curran, MD, Assistant Professor of Pediatrics, Northwestern University Feinberg

School of Medicine Attending Physician Ann and Robert H. Lurie Children's Hospital of Chicago Division of Rheumatology

(Query (i)) The purpose of the article is to describe the content of the transition program and rationale/design of the evaluation, as well as to report baseline data. I understand that results are therefore not the focus of the article but since you are reporting baseline (T0) scores on questionnaires, you should include this and discuss this in the results section of the article, not just in a table.

(Response (i)) We agree with this comment and the reported baseline data (T0) is now integrated in the manuscript (p16). “At baseline, patients reported a median score on psychosocial health of 69.2 (Q1=60.0;Q3=92.9) and 68.8 (Q1=56.3;Q3=89.1) on physical health (PedsQoL). For rheumatic-specific health status (PedsQoL), median scores ranged from 62.5 to 100, with lowest scores for the subscale of ‘pain and hurt’, and best scores for the subscale on ‘daily activities’ (PedsQoL). Furthermore, patients reported a median score for functional status (CHAQ-DI) of 0.3 (Q1=0.1;Q3=0.6) and 73.0 (68.5;90.0) on quality of life (LAS). Regarding fatigue, the motivation subscale was rated worst (7.0).”

(Query (ii)) As a reader, I wanted to know more about the results from T1 and T2 - would make it a much more interesting article. Since the data was collected starting in 2011, I assume that results are available but that you are going to describe them in another article.

(Response (ii)) We would like to kindly thank you for the interest in the results of the evaluative phase of this project. We agree that the findings of the study will be very interesting to clinicians and researchers. Most frequently, when authors are reporting the clinical findings of specific interventions, they do not report the intervention in sufficient details. Hence, researchers who plan to do replication studies, or clinicians who want to implement the interventions into clinical practice, do not have enough information on the specificities of the intervention. This often results in failing effects in day-to-day practice of interventions that has been shown to be efficacious. Therefore, we intentionally limited this manuscript to the rationale; design and baseline data of the study. We strongly believe that such an article is needed, and will guide clinicians and researchers in future transitional care projects. The final results of the study will be described in a forthcoming article.

We admit, however, that we did not clearly state our plan to write a separate results paper. In the revised version of this manuscript we added this information, which increases our transparency to the reader.

(Query) Very well written. The intervention is described well. Please see my written comments and editing suggestions in the attached PDF file.

(Response) Many thanks for carefully reading our manuscript and the many valuable comments and editing suggestions, which we have taken into account.

We provided an overview of the hand-written comments of this reviewer:

ARTICLE SUMMARY
(Query(iii)) Strengths and limitations (p4)

(Response (iii))
- We added the following in answer to your relevant comment: “A transition programme for adolescents with JIA is developed as a brief intervention, which may be less costly and time-consuming than the existing, more comprehensive transitional care interventions.”

- “Enables” refers to all participants involved.

BACKGROUND

(Query (iv)) I believe this is the definition of “transition” and “transfer” described the actual moving of care at the end of the transition process.

(Response (iv)) Thank you for this comment. We now reformulated this sentence accordingly (p5): “According to the recent literature, the paediatric-to-adult transfer of care should be preceded by a preparatory transitional phase. Transition is therefore defined as a process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood [4].”

TRANSITION PROGRAMME AS A BRIEF INTERVENTION

(Query (v)) How do you determine that the patient is ready for transition?

(Response (v)) In this project we did not use or apply a formal checklist to assess the ‘transition readiness’ of participants. At the department of rheumatology in our hospital, there is currently the tendency to start the transition process between the age of 14 and 16 years in patients with a chronic condition. We are however aware of the increasing scientific and clinical interest in instruments aiming to objectively assess the transition readiness of young people with a chronic condition. We addressed this shortcoming in the discussion on p24: “Although we use an innovative embedded experimental design in the DON’T RETARD project, some limitations should be addressed. The assessment of the patient’s transition readiness is no key component of our transition programme. Recently, an increasing number of studies investigated the use of assessment tools such as the Transition Readiness Assessment Questionnaire (TRAQ) [51], an instrument aiming to evaluate a set of skills and developmental tasks that should be fulfilled in order to transfer patients to adult care.”

Furthermore, we described the age range at which the transition process was initiated on p7: “(1) The first step occurs during a scheduled outpatient visit. The paediatric rheumatologist introduces the transition coordinator (TC) to the patient (aged 14-16 years) and his or her parents, and explains the transition programme.”

(Query (vi)) Meaning that the 250-300 patients are all at the age of transition or that while working full time with a caseload of 250-300 patients (of any age), a practitioner could take on the added responsibilities on the transition programme?

(Response (vi)) We estimated that one transition coordinator who is working as a full time equivalent (1FTE) is able to take up a caseload of 250-300 patients through the transition program, during an average period of 1.5 years. This estimation (caseload/FTE) was based on the idea to provide a face-to-face conversation with the TC lasting for 60-90 minutes during each outpatient visit. Furthermore, we included a total of 60 man-hours in our calculation that is needed for the TC, paediatric rheumatologists, rheumatologists of the adult setting, physiotherapists, nurses of adult rheumatology, and the psychologists in order to prepare and organize the activities during the adolescent information day(s). Hence, this one full time equivalent reflects the time and work investment of the team needed to implement the transition programme and guide or support a case load of 250 to 300 transitioning patients.

METHODS AND DESIGN

(Query (vii)) Do any of these instruments measure self-efficacy? A primary goal of a transition programme should be to increase adolescents’ self-efficacy in regards to disease management. A transition programme may not increase an adolescents’ self-perceived health status but should increase their skills in health/disease management.

(Response (vii)) We agree with the reviewer that improvement of self-efficacy is indeed an important outcome of a transition process and programme. Self-efficacy is therefore one of the outcomes of interest when implementing and evaluating the clinical impact of a transition programme. However, in this study, we did not included self-efficacy as one of the outcome measures. We have now addressed this as a possible shortcoming in the discussion section on p24: “In addition, we have to bear in mind that the list of outcomes we used to assess the clinical impact of our programme was non-exhaustive. Additional outcomes such as self-efficacy or the level of autonomy of patients might be of interest.”

(Query (viii)) Table 2: add instrument + score range so readers can better understand what reported numbers mean.

(Response (viii))Table 1 aimed to provide readers with a detailed overview of the variables we measured in the evaluation of the clinical impact of the transition programme. This table described which instruments were used to assess the respective list of variables. Furthermore, additional information on the range of scores and guidance on the interpretation of these scores was provided in table 1. We thought that combining the information reported in table 1 with table 2 would enable the reader to have a full understanding of the reported numbers. However, if the editorial board deems it necessary to repeat these details on the instruments in table 2 as well, we are of course willing to add this information accordingly. Nonetheless, we made some changes to the lay-out of table 2 in order to increase the readability and interpretation of the reported data.

(Query (ix)) Explain rationale for not including results in this article except for baseline data (table 2); why report only the rationale and design without the results?

(Response (ix)) see above (see Query (ii)).

Reviewer 3: Aimee Hersh, MD, Assistant Professor, Pediatric Rheumatology, University of Utah

(Query (i)) This manuscript describes the design and potential outcomes of a brief intervention for transition aged youth with juvenile arthritis. This study provides limited results. I think this manuscript would be strengthened by presenting the results of the intervention if they are available. I do not think a description of the intervention is worth publishing unless the results of the study are available.

(Response (i)) This comment is in line with a comment of the previous reviewer. In contrast, the first reviewer indicated that a description of the transition programme as provided in the present manuscript is highly needed. As we stated in response to the comments of the other reviewers, we strongly believe in the value of this manuscript to guide researchers who plan to do replication studies, or clinicians who want to implement the interventions into clinical practice, because both the content of the intervention is detailed, and the methods for evaluating complex interventions are elaborated on. Since our mixed-methods approach is innovative, and therefore not well known in transitional care research, we think that this paper will add to the body of knowledge by clearly describing all steps and components of this brief transition intervention, and can therefore be a reference for future studies. Admittedly, we have to clarify to the reader that the results of the study will be described in a forthcoming paper. Hence, we added this information in the manuscript.