DMP title

Project Name ID-BODY (C1-project) - DMP title

Grant Title C14/21/052

Principal Investigator / **Researcher** Koen Luyckx

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Description Although the link between oneâ€™s body experiences and identity development has been highlighted repeatedly, little integrative work has been conducted. Further, existing research lacks theoretical and methodological sophistication. To remedy these shortcomings, the ID-BODY project upholds a differentiated and nuanced perspective on identity (processes, statuses, and narrative identity) and the body (body image and embodiment) using longitudinal and mixed-methods designs. The main research question of ID-BODY is: How is the development of identity and the way individuals inhabit their body linked in different community and clinical populations, and how are both sets of variables related to individual functioning and weight- and shape-control behaviors? Different populations will be targeted to capture our core constructs across the normative and clinical range. WP1 assesses community adolescents and emerging adults, focuses on sociocultural and psychological mechanisms linking identity and the body, and how these variables play into functioning and maladaptive behavior. WP2 focuses on chronic illness (type 1 diabetes) affecting how youth see themselves and inhabit their body. We examine how these constructs are related to illness adaptation and generic functioning in the long term, testifying to the clinical relevance of the identity-body link. WP3 assesses individuals with eating disorders, given that in this population identity and the body are strongly compromised. We focus on short-term dynamics to fine-tune the identity-body interplay.

Institution KU Leuven

1. General Information

Name of the project lead (PI)

Koen Luyckx

C1-C2 Project number & title

“My body defines who I am”: An identity perspective on the body (*ID-BODY*)

C14/21/052

2. Data description

2.1. Will you generate/collect new data and/or make use of existing data?

- Generate new data
- Reuse existing data

2.2. What data will you collect, generate or reuse? Describe the origin, type and format of the data (per dataset) and its (estimated) volume. This may be easiest

in a numbered list or table and per objective of the project.

The project consists of three studies (Study I in community adolescents; Study II in type 1 diabetes patients, and Study III in eating disorder patients), and observational data (quantitative data via self-report questionnaires or Experience Sampling Method, and qualitative data via written narrative prompts) will be collected in each study, either through an online tool (e.g., Qualtrics), using paper-and-pencil questionnaires, or using smartphones. Additionally, in Study III, face-to-face interviews are planned with a number of eating disorder patients.

Starting with the study that will also reuse existing data, Study II will extend an existing longitudinal study with three additional yearly datawaves (first wave planned for november 2021); self-report questionnaires and written narrative prompts (the latter only at the second new datawave) will be used (and glycemic control values will be obtained from medical records at each datawave). Hence, besides collecting new data, we will reuse existing data of the first four datawaves that have already been collected. The sample that has participated on at least two of the four measurement waves of this previous longitudinal study will be invited to participate again. Data that will be reused, was collected using self-report questionnaires. Four data waves were initiated in 2014, 2015, 2016, and 2017 (FWO G.0B35.14N; PI: K. Luyckx). Selected from the Belgian Diabetes Registry (BDR), 575 individuals with T1D aged 14-25 years participated at T1. At T2-4, 429, 383, and 324 participated, with 471 participating on at least 2 time-points. Prof. Robert Hilbrands from the VUB is involved in this data-collection as he is afffiliated with the Belgian Diabetes Registry and will help in coördinating the data-collection of Study II. Study I will sample community adolescents through high schools and all participants will be asked to complete self-report questionnaires on the constructs of interest. In sum, the data of Studies I and II will consist of questionnaire data (collected using paper-and-pencil or using a GDPR-approved online platform such as Redcap or Qualtrics); additionally, in Study II, written narrative prompts will be used and glycemic control values will be collected from medical records. Sudy III will sample eating disorder patients and healthy control participants and they will participate in an ESM study (hence, short self-report questionnaires displayed on a smartphone will be used multiple times a day during a period of two weeks). A number of these eating disorder patients will also be invited to participate in an interview study in which interviews will be recorded (for instance, as .mp3-files) and transcribed (MS word format) afterwards. Personal and field notes (on the situation/context of the interview and about personal refflections/experience) during the face-to-face interview (if permitted due to the pandemic) will be written down on paper and later transferred to MS word format. In general, across studies, quantitative data will be collected (or imputed in) mainly in Microsoft Excel and MS Word formats and/or an online format (e.g., Redcap), and at a later stage - for archiving purposes - also as CSV files. All data-files will be embedded in KU Leuven maintained and protected J-Drive and OneDrive for Business (through the use of multi-factor authenticator). Quantitative data will be analysed using SPSS, R, and MPLUS. We expect the total volume of each study not to exceed 1-2 GB.

3. Ethical and legal issues

3.1. Will you use personal data? If so, shortly describe the kind of personal data you will use. Add the reference to the file in KU Leuven's Record of Processing Activities. Be aware that registering the fact that you process personal data is a legal obligation.

Yes.

Privacy Registry Reference: Study II has already been approved by the Ethical Commission Research (Ethische Commissie Onderzoek). The project-number is S65226 and has also been registered at CTC. Study I is part of an overarching project that has been approved by Sociaal-Maatschappelijke Ethische Commissie (SMEC; G-2020-1491-R2(MIN)) and during the months of July-August 2021, we will submit an amendment such that Study I will also be fully covered by SMEC. Study III will happen during the second project year (so starting October 2022) and ethical approval for this study will be obtained during the first project year.

Short description of the kind of personal data that will be used: Following sensitive and/or personal data will be collected from participants themselves across different studies: name, e-mail-address, date of birth, address, height, weight, physical complaints, medical/psychiatric history, medication use, health care utilization, and/or nationality. In Study II, blood glucose values as an indication of glycemic control will be collected from the treating physicians as well through our contacts at BDR. Brief written narratives will also be collected from participants of Study II at the second measurement wave. We will also collect questionnaire data on a variety of constructs but these data are not considered sensitive data according to GDPR standards. In Study III, an ESM study will be conducted and a follow-up interview study in certain ED-patients, which will contain sensitive persoal information. All data collected throughout the project (both sensitive and non-sensitive) will be saved in J-Drive and OneDrive for Business (on encrypted computers and protected through the use of multi-factor authenticator), which can only be accessed by the involved researchers at KULeuven. J-Drive and OneDrive for Business is managed by ICT personnel, bound by the KUL ICT code of conduct. Offline (paper-and-pencil) copies of restricted data and the informed consent forms will be separately archived in a locked room in the office buildings of K. Luyckx. Important to mention is that all sensitive data will be pseudonimized and, as explained, will be stored on J-Drive and OneDrive for Business (through the use of multi-factor authenticator) according to storage guidelines of the Faculty of Psycholoy and Educational Sciences and as implemented in our research center of School Psychology and Development in Context. The use of shared folders (which can be accessed only by certain employee IDs, provided that they were given access) allows for secured storage, management and sharing of files, and avoids loss of data and data breaches.

3.2. Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? If so, add the reference to the formal approval by the relevant ethical review committee(s).

Yes.

Privacy Registry Reference: Study II has already been approved by the Ethical Commission Research (Ethische Commissie Onderzoek). The project-number is S65226 and has also been registered at CTC. Study I is part of an overarching project that has been approved by Sociaal-Maatschappelijke Ethische Commissie (SMEC; G-2020-1491-R2(MIN)) and during the months of July-August 2021, we will submit an amendment such that Study I will also be fully covered by SMEC. Study III will happen during the second project year (so starting October 2022) and ethical approval for this study will be obtained during the first project year. We will update this DMP once everything is finalized.

3.3. Does your research possibly result in research data with potential for tech transfer and valorisation? Will IP restrictions be claimed for the data you created? If so, for what data and which restrictions will be asserted?

No.

The project will generate knowledge that can inform clnical practice (and we will do so through seminars and workshops for practitioners), although designing interventions or preventive strategies based on our findings will not be the goal of the present project.

3.4. Do existing 3rd party agreements restrict dissemination or exploitation of the data you (re)use? If so, to what data do they relate and what restrictions regarding reuse and sharing are in place?

Yes.

The participants themselves are the only third party involved. Agreements as such are part of the Informed Consent form, mentioning the publication of results in scientific communications and the use of data by other researchers.

4. Documentation and metadata

4.1. What documentation will be provided to enable understanding and reuse of the data collected/generated in this project?

Study protocol, a blank copy of questionnaires and informed consent forms, codebooks, flow charts of participant inclusion etc. will be documented as word-files for the different studies. The codebook will contain information on study variables and how these were coded in the data input files, hence a variable list and legend will be provided. Keywords will also be provided for the different studies of the project. All information necessary for secondary analyses will be provided, such as information on accessibility of the dataset (and specific steps that need to be undertaken) and on processing operations on data files.

4.2. Will a metadata standard be used? If so, describe in detail which standard will be used. If not, state in detail which metadata will be created to make the data easy/easier to find and reuse.

There is no formally acknowledged metadata standard available specific to our discipline. In the present project, data-input will be conducted mainly in microsoft excel

within OneDrive for Business (through the use of multi-factor authenticator) and/or online databases (e.g., REDCAP) before data are transported to statistical programs such as R, SPSS, and MPLUS; hence, the metadata characteristic for these programs will be used in the present project and this will ascertain that data will be safeguarded in the long-term in such a way that it is understandable for all collaborators in the project and also for researchers interested in conducting secondary analyses using these data. We may also consult the Data Documentation Initiative to gain more information on metadata and how to describe them at the project level. Keywords for the different studies of the project will also be provided in OSF for researchers interested in obtaining more information about the project and its different studies.

5. Data storage and backup during the C1-C2 project

5.1. Where will the data be stored?

Offline copies of data (paper-and-pencil questionnaires) and informed consent forms of the different studies will be separately archived in a locked room in the office buildings of K. Luyckx. Digital questionnaire data and interview recordings/transcripts will be stored using protected folders in J-Drive and OneDrive for Business (through the use of multi-factor authenticator), which can only be accessed by the involved researchers. As we will work with sensitive personal data, all data will be pseudonimized according to the guidelines forwarded by our Faculty and applied in our research group of School Psychology and Development in Context.

5.2. How will the data be backed up?

The data will be stored on the university's central servers with automatic daily back-up procedures.

5.3. Is there currently sufficient storage & backup capacity during the project? If yes, specify concisely. If no or insufficient storage or backup capacities are available, then explain how this will be taken care of.

Yes.

The data will be stored on the university's central servers with automatic daily back-up procedures.

5.4. What are the expected costs for data storage and backup during the project? How will these costs be covered?

About 50 EUR. Costs will be covered by funds of the PI Koen Luyckx.

5.5. Data security: how will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

Offline copies of data (paper-and-pencil questionnaires) and informed consent forms of the different studies will be separately archived in a locked room in the office buildings of K. Luyckx. Digital questionnaire data and interview recordings/transcripts will be stored using protected folders in OneDrive for Business (through the use of multi-factor authenticator), which can only be accessed by the involved researchers. As we will

work with sensitive personal data, all data will be pseudonimized according to the guidelines forwarded by our Faculty and applied in our research group of School Psychology and Development in Context.

6. Data preservation after the end of the C1-C2 project

6.1. Which data will be retained for the expected 10 year period after the end of the project? If only a selection of the data can/will be preserved, clearly state why this is the case (legal or contractual restrictions, physical preservation issues, ...).

All digital data will be retained for an expected 10-year period after the end of the project (or it will be re-evaluated whether it is necessary to keep them longer at that time), with the exception of the data from the interview study (WP3). Here, due to the sensitive nature of the data, the raw audiofiles will be deleted after publication of the results. Moreover, personal and field notes on paper will be saved together with the interview transcripts in word files. Once the notes have been saved electronically, paper notes will be destroyed.

6.2. Where will these data be archived (= stored for the long term)?

Offline copies of data (paper-and-pencil questionnaires) and informed consent forms of the different studies will be separately archived in a locked room in the office buildings of K. Luyckx. Digital questionnaire data will be stored using protected folders in J-Drive and OneDrive for Business (through the use of multi-factor authenticator), which can only be accessed by the involved researchers. As we will work with sensitive personal data, all data will be pseudonimized according to the guidelines forwarded by our Faculty and applied in our research group of School Psychology and Development in Context.

6.3. What are the expected costs for data preservation during these 10 years? How will the costs be covered?

About 50 EUR for the retention period of 10 years. All costs will be covered by funds of the PI Koen Luyckx.

7. Data sharing and re-use

7.1. Are there any factors restricting or preventing the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions or because of IP potential)?

No.

No factors restrict or prevent the sharing of the pseudonimized questionnaire data.

7.2. Which data will be made available after the end of the project?

A description of the project will be posted on OSF and motivated requests can be made to obtain a copy of the coded, pseudonimized questionnaire data (which are not deposited on OSF) from the PI, such that there will be restricted or controlled access to the data.

7.3. Where/how will the data be made available for reuse?

- In a restricted access repository
- Upon request by mail

The project will be described on OSF and researchers need to send a motivated request if they want to access the pseudonimized, coded questionnaire data.

7.4. When will the data be made available?

- Upon publication of the research results

Once all results have been published on certain data, these questionnaire data can be obtained by researchers in its coded, pseudonimized form.

7.5. Who will be able to access the data and under what conditions?

A motivated request through OSF by other researchers can be made to the PI of the present project for accessing the questionnaire data. Other researchers than the ones directly involved in the project will only have access to the coded, pseudonimized data, and only if they agree with confidentiality rules with respect to the data generated in this project. Data will be only made available upon publication of all results based on these data.

7.6. What are the expected costs for data sharing? How will these costs be covered?

No costs expected.

8. Responsibilities

8.1. Who will be responsible for the data documentation & metadata?

Koen Luyckx (main applicant KULeuven). Laurence Claes, Philip Moons, and Steven Eggermont (co-applicants KULeuven). All four applicants will be involved but Koen Luyckx and Laurence Claes will coordinate this process.

(There will also be three PhD-students, still unknown at present, on the project who will be involved in this process as well. Belgian Diabetes Registry will be involved mainly in the data-collection of Study II.)

8.2. Who will be responsible for data storage & back up during the project?

Koen Luyckx (main applicant KULeuven). Laurence Claes, Philip Moons, and Steven Eggermont (co-applicants KULeuven). All four applicants will be involved but Koen Luyckx and Laurence Claes will coordinate this process.

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(There will also be three PhD-students, still unknown at present, on the project who will be involved in this process as well. Belgian Diabetes Registry will be involved mainly in the data-collection of Study II.)

8.4. Who bears the end responsibility for updating & implementing this DMP?

The PI (Koen Luyckx) bears the end responsibility of updating & implementing this DMP.