

# Putting Digital Epidemiology into Practice: Prospective Assessment of Incident Health Events within the German National Cohort

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**Background:** Epidemiological data collection is often challenged by low response and poor compliance [1]. For the recording of incident or recurring transient health events, gathering data during the event and immediate response of the participants is crucial to retain good data quality, when biosampling is included it is strictly necessary. To meet these needs, we developed an eResearch system for prospective assessment of incident health events (PIA). The aim was to create a tool that fits into already existing IT structures of the German National Cohort (GNC) is easy to use and flexible to adapt to different research questions and contents. Existing tools do not offer the necessary technical flexibility and thematic modularity either (e.g. “GrippeWeb” [2]) or are not suitable for study management such as documentation of biospecimen, vaccination cards (photograph) or study specific individual feedback (e.g. laboratory results via interface with laboratory and data exchange based on HL7, questionnaire completion proportion). In PIA, such feedback for participants should ensure that participants are willing to use the app for a longer period. Electronic Case Report Form- applications such as SecuTrial® or RedCap offer comprehensive study and participant management and simplify the collection of clinical data [3,4]. However, they do not offer all the specifics mentioned above.

**Methods:** Study participants can use PIA as iOS/Android or web-application. PIA includes complete study management with five different roles: system administrator, research team, participant management, study nurses and participants. Each role has a specific interface, so that different functions e.g. implementation of new questionnaires, administration of biosamples or management of participant contacts can be performed by different personae. For the research team PIA provides flexible adaption of questions and questionnaires to develop an algorithm for displaying a network of conditional questionnaires at specific times and after specific data entry events. It offers the opportunity of biosample collection if a certain case definition applies. A particularly important feature of PIA is the implementation of spontaneous reporting, which enables real-time recording of health events and reduces recall bias.

**Discussion:** PIA is developed for add-on studies of the German National Cohort (GNC) and will be used for the first time in 2019 at the Clinical Research Center (CRC) Hannover [5]. A particular challenge was to create a stand-alone eResearch system that also integrates with the IT and procedural standards and high data protection requirements of an ongoing study like the GNC. In the future, user experience and performance indicators will be evaluated and elements like gamification will be further developed.

[1] Morton LM, Cahill J, Hartge P. Reporting participation in epidemiologic studies: a survey of practice. *American journal of epidemiology*. 2005 Dec 7;163(3):197-203.

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general population of Germany, weeks 35/2011 to 34/2012. Euro Surveill. 2014; 19(4):1–11.

[3] CIO Central Information Office, secuTrial® Data capture. Manual (deutsche Version). [Accessed 28 May 2019]. Available from: [http://www.cio-mr.de/documents/secutrial/oertelw/secutrial-Manual-DataCapture\\_4.9\\_de.pdf](http://www.cio-mr.de/documents/secutrial/oertelw/secutrial-Manual-DataCapture_4.9_de.pdf)

[4] Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support, J Biomed Inform. 2009. 42(2):377-381.

[5] German National Cohort (GNC) Consortium. The German National Cohort: aims, study design and organization. [Accessed 20 February 2019]. Eur J Epidemiol 2014; 29:371–382. <https://doi.org/10.1007/s10654-014-9890-7>

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Der korrespondierende Autor erklärt, dass bei den Autoren folgende Interessenskonflikte bestehen:

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##### Erklärung zum Ethikvotum:

Es liegt ein positives Ethikvotum vor.

##### Erklärung zur Originalität und zum Copyright:

Dieses Full-Paper wurde noch nicht veröffentlicht.

#### Beitragsentscheidung

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