

Personalized preventive child health care

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Impact

The initiative for the presented research project arose from my own professional experiences as a medical doctor working within the preventive Child Health Care (CHC). These experiences ignited the search for efficient solutions for problems concerning accessibility of representative child's health data. The aim was to create direct impact on the CHC-practice by enabling to gain better access to and overview on holistic health data. Quick access and a theoretically structured overview of health data is highly relevant for the interpretation and transfer of holistic health information within a preventive CHC and for the needed transformation toward a more personalized preventive CHC.

Initially, the 360°CHILD-profile was developed to facilitate different stakeholders in the CHC-context (care-providers, parents, youth, managers, policy-makers). However, this tool, as well as the knowledge generated during this thesis, also are relevant for health research and medical education with focus on prevention and personalization of health care.

Relevance of the 360°CHILD-profile for stakeholders within CHC-practice:

This pragmatic research project resulted in delivering a meaningful dashboard for CHC-practice with a valid scientific background, a sufficient user-satisfaction, and a high potential that the intended goals can be reached. To the best of our knowledge, this practice-derived dashboard is unique in providing a holistic and structured display of the actual large and complex electronic CHC-data sets in accordance with the ICF-framework. This multifunctional 360°CHILD-profile is customized to the CHC-context to fit the actual CHC's EMD-data sets.

The potential pragmatic values of the 360°CHILD-profile are:

- providing CHC-professionals, parents, youth and other involved care-providers with:
 - o direct and quick access to holistic health data, collected by preventive CHC from birth until the age of 18.
 - o an appropriate representation of a child's health situation in accordance with international standards (ISO 9241-125).
- enabling the CHC to adequately commit to her legal duty to provide parents and youth with (digital) access to health data.
- supporting preventive clinical reasoning by intuitively guiding thinking processes in line with the desired theoretical concepts of a personalized preventive CHC by:
 - o providing overview on the many factors within child and environment that positively or negatively influence health and development.

- displaying the coherence between different health domains by theoretically structuring data of relevant health variables in line with the biopsychosocial model and the ICF.
- facilitating to gain insight in the complex processes underlying health, including a “growing into deficit” in early phases, when symptoms cannot yet be clustered to a diagnose.
- enabling to identify entry points for pro-actively protecting and promoting health and prevent progression towards a disease.
- empowering parents/youth to actively participate during shared decision-making.
- stimulating a more consistent and structured data registration with more unity in language (in line with ICF)
- enabling the CHC to present structured health data on a population level.

The 360°CHILD-profile’s provision of quick access to relevant EMD-data is highly essential for decreasing the enormous effort and time CHC-professionals currently must put in extracting data of relevant variables from the multiple compartments of the EMD.

Moreover, the overview on personal EMD-data exposes which data are (from a theoretical basis) relevant to assess variables and what relevant data are yet missing within the current EMD-registries. Therefore, CHC-professionals gain direct control (autonomy) over their access to collected health data and improve their data-registration by firstly registering information about the most relevant variables. This supports their multifaceted inquiry during CHC-consultations to map the broad (biopsychosocial) health situation of a child.

Furthermore, the 360°CHILD-profile facilitates the transfer of holistic health information to parents during conversations about their child’s health. The 360°CHILD-profile creates a positive ambience and a situation in which parents and youth look at a set of comprehensible health information together with CHC-professionals. This situation invites and empowers parents and youth to share their perspectives on the child’s health situation and actively get involved in identifying “entry points” for managing health.

During multidisciplinary consultations with other involved care-providers, the 360°CHILD-profile supports parents and youth to take an active role during shared decision-making. Their involvement is crucial for establishing preventive, personalized health plans that are practicable and fit the family’s context and lead to improving a child’s health situation.

The preventive clinical reasoning and shared decision-making processes are rather complex and require simultaneous thinking, which is elicited and supported by the 360°CHILD-profile. In fact, its design intuitively (mostly subconscious) guides the thinking processes of care-providers and parents/youth in line with the preferred theoretical (personalized and

preventive) perspective. This differs from the current situation in which CHC-professionals feel insufficiently supported by the content and theoretical unstructured organization of the EMD's. The actual Dutch standard datasets for the EMD's are not based on a theoretical framework, nor the CHC's preventive and broad perspective on health.

Importantly, the 360°CHILD-profile is suitable for providing parents and youth digital access to a summary of data of relevant health variables, stored in the EMD. Access via the online portal for parents (and children from age of 12) practically can make them in charge of the information because they may provide family members and other care-providers with access to relevant health information. This is not yet possible in the current situation of the online CHC-portal for parents as it only presents the grow-chart and vaccination status.

Access to a personal 360°CHILD-profile via the online CHC-portal, also would enable parents/youth to regularly check their child's health information in the periods between CHC-consultations. In future, they also may add or change information on the 360°CHILD-profile and discuss implications for their child's health situation with CHC-professionals via the online portal. This would provide the CHC with opportunities to be more flexible in offering online and/or face-to-face consultations, depending on the parents and children's possibilities and needs.

The 360°CHILD-profile enables quick and adequate informing other involved care-providers about the child's health situation (by e-mail or by adding it to a referral letter).

By generating a personal 360°CHILD-profile, many health data (including developmental milestones, medical history, family history, life events, environmental factors) are extracted from the EMD. During multi-disciplinary consultations, all involved care-providers gain a holistic overview on the different health domains of a child's health and insight in for which health domain each care-provider is involved. The 360°CHILD-profile provides all involved stakeholders with an adequate level of information and supports the communication and coordination of care.

Implementing the 360°CHILD-profile can be of high interest for CHC-managers. It is promised to be timesaving, support a more efficient data and workflow on a qualitative higher level and facilitate the urgently needed transformation toward a personalized preventive CHC. Thereby, the 360°CHILD-profile enables the CHC to commit to the, since 2020, legal duty to provide parents and youth with online access to a summary of EMD's health data [<https://assets.ncj.nl/docs/416f7354-d0d3-4a6f-85ff-474b2949cc0c.pdf>]. Currently, the CHC is not yet able to commit to this duty, let alone to provide an appropriate representation of a child's health situation in accordance with the international standards for representing health information (ISO 9241-125).

The 360°CHILD-profile's potential to stimulate further professionalization toward more consistent and structured registrations with more unity in language is a prerequisite for the CHC's task to also display standardized and theoretically structured health data on a population level. Although all Dutch CHC-organizations follow the same national guidelines, actually, the CHC cannot yet commit to this duty neither. The latest presentation of Dutch data about child health, were based on databases of the national statistical office, Statistics Netherlands (CBS) and the general practitioners' network. In future, the 360°CHILD-profile based on the ICF offers digital possibilities (e.g., thesaurus or datamining) for automatic transformation of health information, registered in the EMD, toward internationally standardized ICF-codes. This high potential to extract from the EMD's more standardized data of multiple health variables on a population level would enable the CHC to present and exchange valuable health data for national and regional health policy (see figure A).

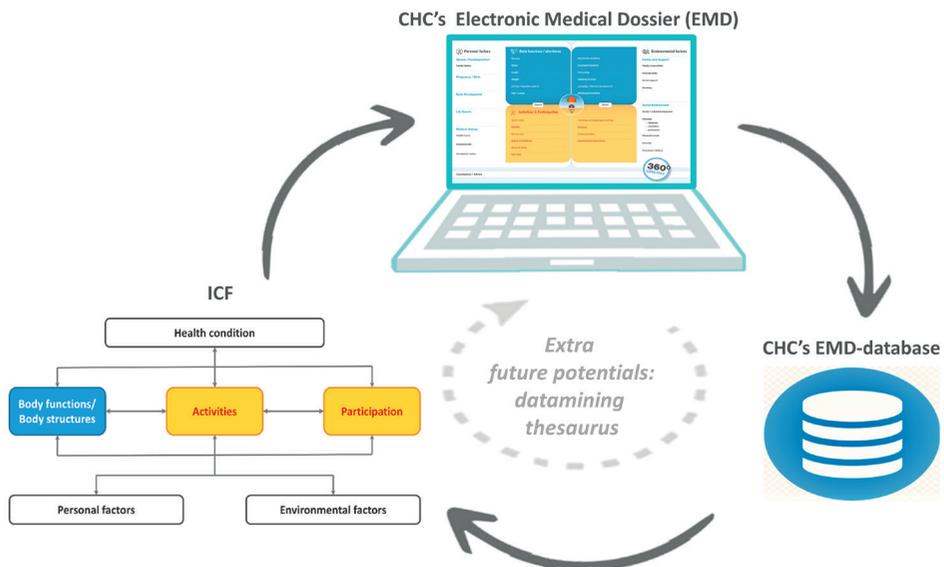


Figure A: potential positive vicious circle towards better access of CHC's health data on an individual and population level based on integrating 360°CHILD-profile in line with the International Classification of Functioning in CHC's Electronic Medical Dossier.

Relevance of the 360°CHILD-profile and generated knowledge for researchers.

The 360°CHILD-profile's potential to realize standardized and structured data-registration and to present health data a population level also would lead to the availability of health data that are suitable for epidemiological research. The theoretical foundation (ICF) facilitates research with focus on gaining better insight in children's functioning and the influence of different interactive health variables on health and development. The foreseen

future possibilities for automatic transforming registered health information toward ICF-codes provide additional opportunities to deliver data suitable for epidemiological research. (see figure A)

This thesis generated valuable knowledge for health research with focus on data-visualization within a health care setting. This research presents an example on how data-visualization and interaction design can be used to reach intended goals within a preventive and heterogeneous health care setting. Furthermore, it shows what opportunities can arise from collaboration with experts within the field of data-visualization and the use of a design model to display and attain immediate digital access to personalized holistic health information.

The integrated quantitative and qualitative findings generated broad insight in how to target the implementation strategy and evaluation of this complex intervention within the preventive CHC-context.

This research project demonstrated the importance of considering the specific CHC-context when proceeding the implementation process and an active role of the management in prioritizing ICT-integration of a tool like the 360°CHILD-profile within an EMD and facilitating professionals. The results also highlighted the importance for implementation to adequately inform all target groups (CHC-professionals, parents, youth, managers, policy-makers) about the benefits of the 360°CHILD-profile for the CHC-context. Implementation on a national level, requires a solid marketing communication plan toward national stakeholders like CHC-professionals (for more bottom-up power) and managers, policy-makers (for more top-down power).

A next project is already initiated with focus on increasing the bottom-up power by communicating the assets of this thesis to Dutch CHC-professionals. This project, granted by ZonMw, includes the development of a website (Home - 360CHILDoc (360child-profile.nl)) and an online course with focus on distributing information about concepts of Personalized CHC and 360°CHILD-profile's research projects and training competencies needed for executing preventive, personalized reasoning.

This research generated valuable knowledge on how to design future studies on performance and effectiveness of the 360°CHILD-profile within CHC-practice.

Insight was provided in how complex it is to perform an RCT within the organizational CHC-context, especially regarding the randomization strategy and appropriate measurement of outcome on 360°CHILD-profile's performance and effectiveness. Therefore, a deliberate,

flexible approach should be considered with alternative designs and Mixed Methods research.

Relevance of the 360°CHILD-profile and generated knowledge for medical education.

Within the current Master of Medicine at Maastricht University, students are educated about preventive CHC during their internship “family medicine and social medicine”. They are trained in essential competencies for preventive consultations (individual and multidisciplinary) and for executing a more preventive, predictive, personalized and participative health care. During lectures and trainings on these topics, I (MW) introduced the 360°CHILD-profile to visualize a case in line with the ICF and visually support the training on communication and preventive clinical reasoning processes.

As prevention is more and more recognized as an essential ingredient of medical care, at the UM, it is decided to address the topic prevention more extensively already within the Bachelor of Medicine. Therefore, prevention and the need for transformation toward personalized CHC is proposed to be covered within the first year of this bachelor and the 360°CHILD-profile is considered as a support tool for addressing these topics.

Regarding post-academic education, the described ZonMw-project that follows this thesis, will result in an online course that is available for professionals working within CHC and adjacent working fields like pediatrics, child psychiatry, child rehabilitation, youth work. Within this online course, the 360°CHILD-profile will be utilized as a support tool. The comprehensible and adequate visual representation of a child’s health situation, based on the ICF especially supports the training of competencies regarding preventive clinical reasoning in line with personalized preventive CHC. The 360°CHILD-profile shows an example of how to gain insight in children’s individual health situation, which is needed for personalizing care. Moreover, the 360°CHILD-profile displays how professionals, together with parents/youth can identify strengths and vulnerabilities and entry-points for pro-active optimization of health and development.