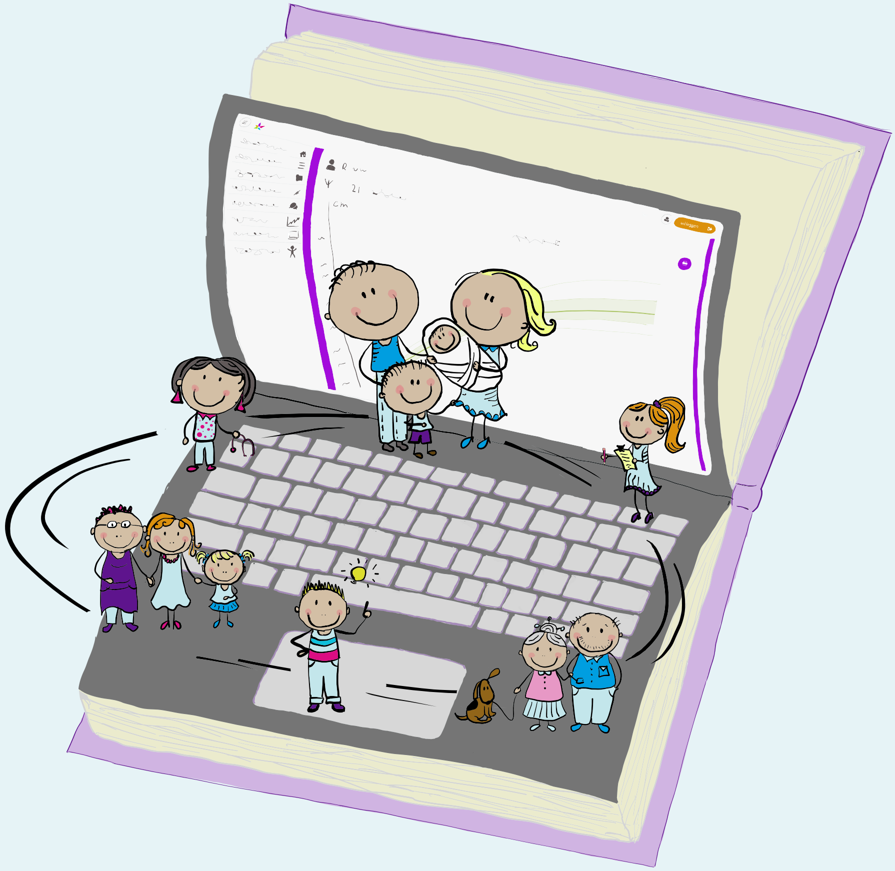
Parent, Child & Professional on the same Page

Implementation and evaluation of a client-accessible health record in Dutch Centers for Youth and Family



Janine Benjamins

Propositions

1. Fully accessible health records for parents and adolescents contribute to person-centred child healthcare and youth care.
   (this thesis)

2. Client-accessible health records bear the potential of reducing health inequalities in society if inequalities in access are removed.
   (this thesis)

3. Knowledge that remains locked in the ivory tower of academia is futile knowledge.

4. The value of new technology is determined by how people use it.

5. Essential ingredients of a co-creative process are patience, perseverance, and pizza nights.

6. In a multi stakeholder process, every participant chooses an approach from a true perspective, yet no-one holds the truth.

7. COVID-19 measures hampered team collaboration.

Propositions belonging to the thesis, entitled
'Parent, Child & Professional on the same Page
Implementation and evaluation of a client-accessible health record in
Dutch Centres for Youth and Family'

Janine Benjamins
Wageningen, 24 November 2023

Parent, Child & Professional on the same Page:

Implementation and evaluation of a client-accessible health record in Dutch Centres for Youth and Family

Janine Benjamins

Thesis comittee

Promotor

Prof. Dr E.W.M.L. de Vet
Professor of Consumption and Healthy Lifestyles
Wageningen University & Research

Co-Promotor

Dr A. Haveman-Nies
Associate professor, Consumption and Healthy Lifestyles
Wageningen University & Research

Other members

Prof. Dr P.J. den Brok, Wageningen University & Research
Dr J. de Wilde, Leiden University Medical Center
Prof. Dr J.J.P. Mathijssen, Tilburg University
Dr R. Crutzen, Maastricht University

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Parent, Child & Professional on the same Page:

Implementation and evaluation of a client-accessible health record in Dutch Centres for Youth and Family

Janine Benjamins

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Janine Benjamins
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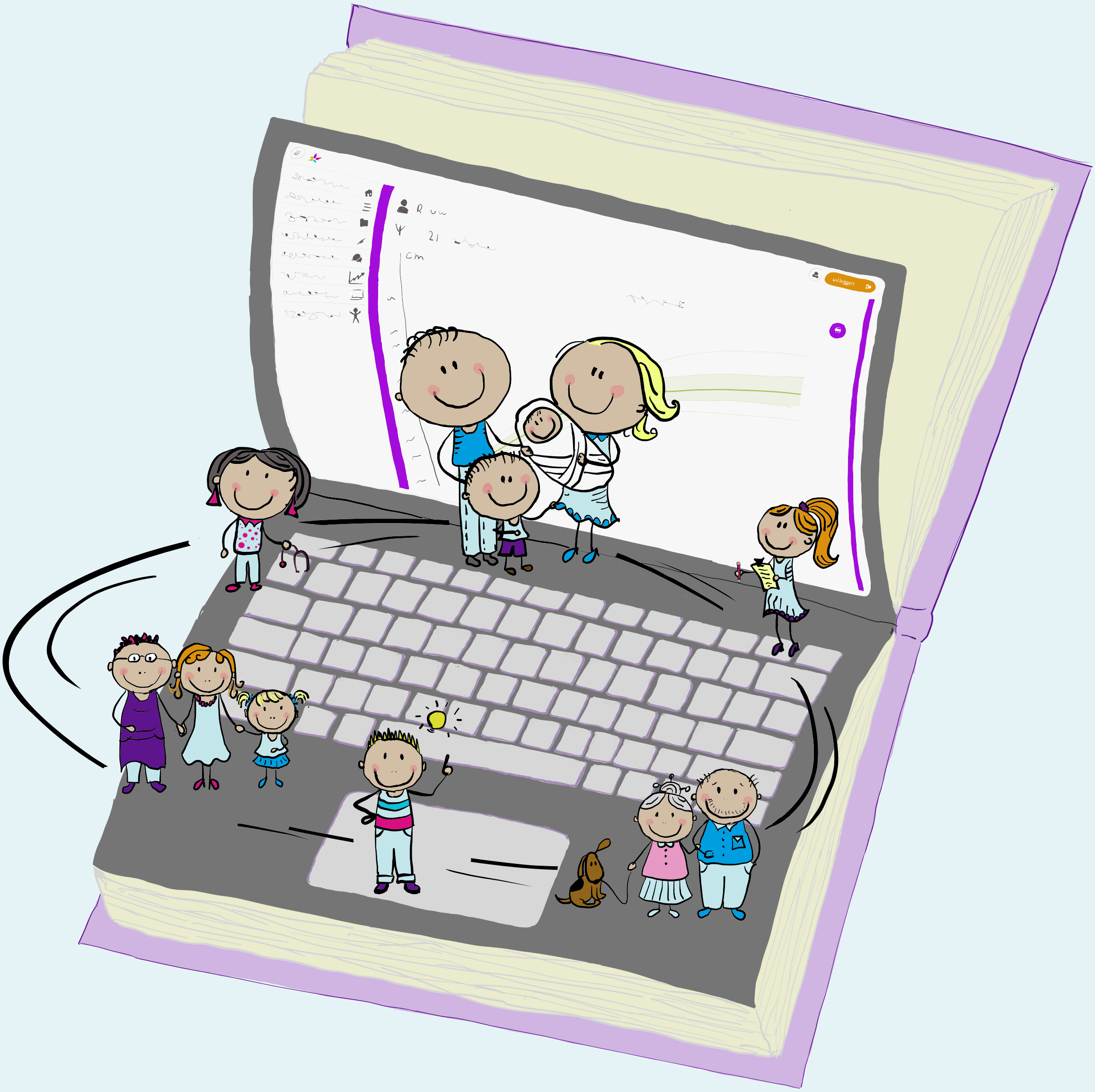
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Chapter 1

General Introduction

> *"For health care to be truly universal, it requires a shift from health systems designed around diseases and health institutions towards health systems designed for people."*
>
> [World Health Organisation,
> Framework on integrated, people-centered health services, April 2016.]

Introduction

Health systems around the world struggle to face the challenges posed by 21st century society (1). Although people's health and life expectancy overall increases, health inequity both within and between countries has increased as well (1). Globally, more than half of all people have no access to essential healthcare (2). Additionally, in high-income countries, increasing life expectancy combined with lower birth rates is leading to ageing societies facing multi-morbidity, long-term chronic illnesses, and rising healthcare costs (3). Fragmentation of healthcare systems makes it difficult to tackle these challenges (3). Therefore, many Western governments are initiating reforms towards integrated care, simultaneously focusing on person-centredness which empowers people to manage their own health conditions and healthcare (3). Integrated person-centred care is expected to increase the quality of care, with lower health care utilization and lower costs as beneficial side-effect (3-10).

Integrated person-centred care

In 2015, the World Health Organisation (WHO) stated that integrated person-centred care should become the standard for healthcare systems all over the world (3). In the WHO definition, integrated person-centred care means "putting people and communities, not diseases, at the centre of health systems, and empowering people to take charge of their own health rather than being passive recipients of services" (1).

Integrated person-centred care is a concept that builds further on the work of Harvey Picker, who developed the Pickers' Principles of Patient Centred Care in 1987 (Figure 1), highlighted in the book 'Through Patients Eyes' (11). Key factors in patient-centred care were responsiveness to the patients' individual needs and preferences, and partnership between care provider and patient in decision making (12-15). Patients were acknowledged as unique human beings, with physical and emotional needs and preferences that should be considered when clinical decisions were made. Ideally, patients were

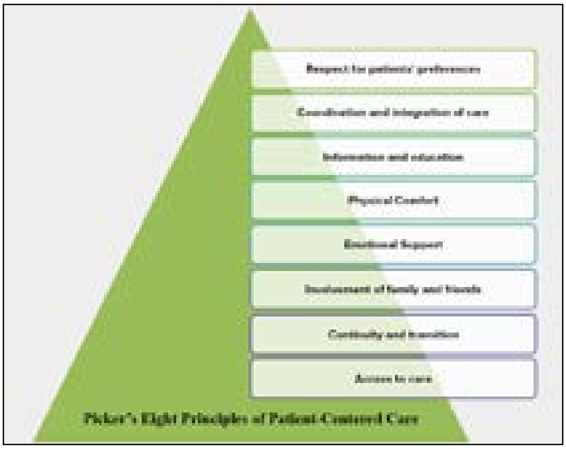


Figure 1: Picker's principles of Patient-Centered Care

involved in taking these decisions and so were family members or caregivers. To deliver patient-centred care, coordination and continuity of easy-accessible care were essential, which made integration of care a crucial element of patient-centredness.

In 2015, the WHO introduced the term ‘person-centred’ care, emphasizing that patients are more than just their health condition and proposing a broadened scope on health and wellbeing (3). The introduction of the term ‘person-centred’ coincided with a paradigm shift from a biomedical model towards the more holistic biopsychosocial model (16). Person-centred care takes into account not only physical and medical needs, but also mental, social and spirituals needs, subsequently broadening the scope for integrated care to both medical and non-medical services (14, 16).

Developments in technology

In parallel to societal changes, also developments in information technology contributed to changes in healthcare (17). In the 1990s, the development of compact and affordable computer systems catalysed the transition from paper-based health records towards computer-based systems throughout healthcare practice (18). It was expected that computers would provide clinicians with faster access to both literature and test results, which could improve decision making. Moreover, the use of reminders and alerts could potentially reduce medical errors (19). At first, electronic health records were used mainly to assist healthcare providers, improving information management, and supporting administrative procedures, financial transactions, and clinical decisions (20). This changed, however, with the emergence of the Internet in the 1990s, and the availability of local area networks providing the public with easy internet access (18, 19).

Patient-accessible Health Records as a tool for person-centred integrated care

Whereas the first electronic health records were built mainly to support healthcare systems locally, new perspectives emerged from the introduction of the Internet. The Internet provided users with access to a vast amount of interactive and up-to-date information (18, 19). When connected to the Internet, electronic health records could be used to exchange health information between healthcare professionals from different disciplines and organisations as well as between health care providers and their patients. Consequently, electronic health records became a possible tool to strengthen both interdisciplinary collaboration and collaboration between doctors and their patients and as such, a possible contributor to integrated person-centred care. In the late 90’s of last century, the first electronic health records with tethered patient portals were developed, allowing patients access to some of their medical information (21). Medication lists and limited test results were shown in these portals, and some could be used to send secure email to the health care team (21). Since then, patient-accessible electronic health records (PAEHR) are being adopted worldwide, varying substantially in design, functionalities and in the degree of transparency (22-26). Based on the hypothesis that full transparency of health records would contribute to a more equal patient-clinician relationship and to better quality of care, a US study from 2010 invited over 10,000 patients to read their doctor's visit notes (24, 27, 28) This was the start of the Open Notes movement, a US-based international organisation that is advocating to allow patients 'access to all their own health data in one place'. Their research contributed greatly to the debate around health data transparency and its relationship with person-centredness (24, 27-32).

Research in adult healthcare shows that the transparency of PAEHRs makes patients feel better informed and more engaged in their own care and hence contributes to patient autonomy and person-centredness (33, 34). Some studies show that using PAEHRs increases a patient's trust in their care provider (28, 35) and improves the communication between care provider and patient (33-37). Furthermore, there is evidence that interdisciplinary use of electronic health records, sharing information and knowledge, and making collaborative care plans, contributes to interdisciplinary collaboration and possibly enhances quality of care (38-40).

Simultaneously, worries have been expressed by healthcare professionals, that reporting in a PAEHR would be more time-consuming for them than before (28, 41). Some healthcare professionals expected to report differently in a PAEHR, which might lead to less accurate reports then before (28, 42). Furthermore, professionals feared that patient-access to health records could cause patient anxiety and misunderstanding of health record content (41, 43, 44). Finally, concerns were raised that people living in vulnerable circumstances, such as people with a migratory background, with a low level of education or with limited literacy, would not be able to benefit from PAEHRs because these groups are known to have less access to and make less use of new information technology than the average population (45-51). Generally, healthcare professionals expressed more concerns about using PAEHRs, and saw less benefits, than patients did (28, 42).

This thesis

Only a few studies can be found on using PAEHRs with parents, children, or adolescents. The reason for this lack of research is, that the development of PAEHRs for children and adolescents has been hindered due to the complexity of confidentiality issues in this age group (52-54). In early childhood, parents are the ones to access their child's PAEHR, being the legal representative of their child. Some studies, mostly in hospital settings concerning children with chronic diseases, report that parents benefit from access to their child's health record (55, 56). In adolescence, contrarily, both adolescents and parents have access rights, which makes protecting the confidentiality of an adolescent's personal information an important issue (56-58). Protecting confidentiality has proved a complex puzzle when developing PAEHRs for adolescents. This puzzle has become even more difficult to solve because legal regulations differ between and sometimes even within countries (59-61). Nevertheless, solving it is important: adolescents report that they only share information with healthcare professionals when they are assured that their confidential information is protected (58, 62). Until now, different solutions have been found in different countries, varying from no access at all in the adolescence phase to case-to-case solutions (61).

Because worldwide development of PAEHRs for parents and adolescents is still in its infancy, evaluating newly developed PAEHRS is important. Evaluating development and implementation of PAEHRS, as well as consequences of using them, generates usable knowledge to tackle barriers that have until now been hindering development. This thesis describes the development of a Dutch PAEHR for preventive child healthcare and youth care and evaluates how this PAEHR, called EPR-Youth, affects integrated person-centred care for parents and adolescents. Before elaborating on the study, however the local context in which EPR-Youth has been developed is outlined.

Context of Dutch youth care

In the Netherlands, person-centredness has taken centre stage in the discussion about quality of care, especially in care for youth (63). The discussion was catalysed by the new Youth Act which became effective in 2015, initiating a transition of responsibilities for several youth care services from central to local government (Figure 2).

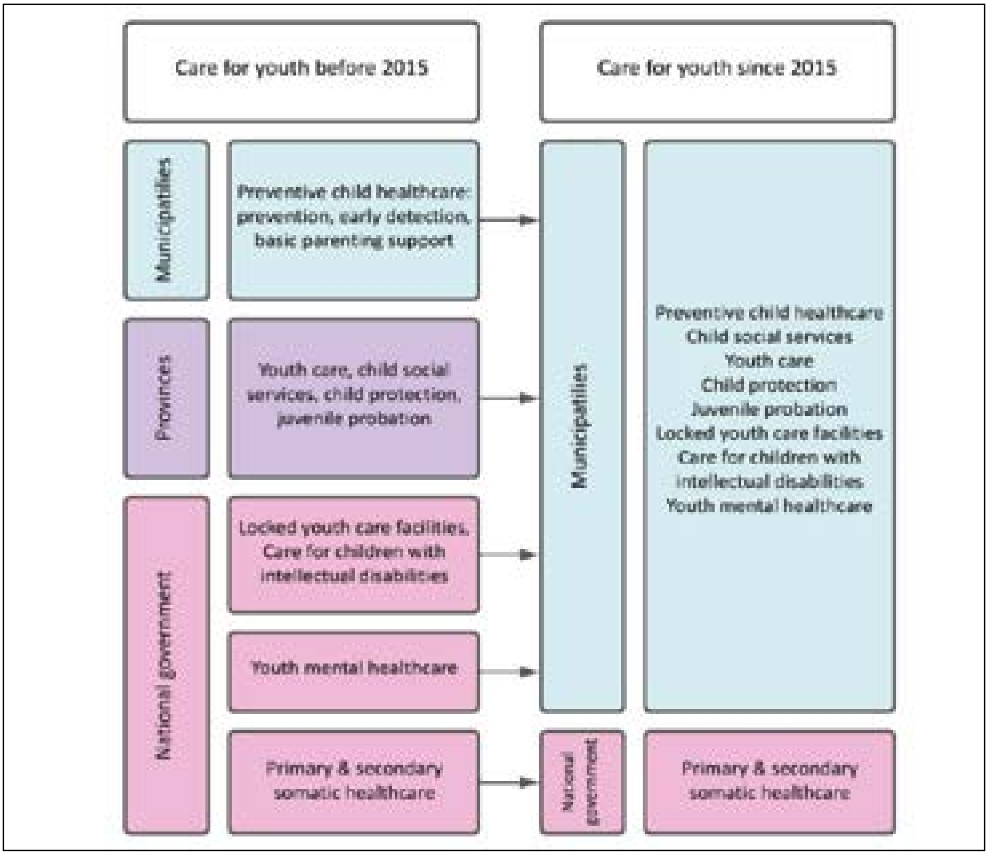


Figure 2: transition of Dutch care for youth from regional and national government to local government.

The Dutch system for child healthcare and wellbeing involves several parties (64). Public health services are offered to all children aged 0-19 years by preventive child healthcare organisations (64). Preventive child healthcare professionals monitor over 90% of all Dutch children in fully free program, focusing on prevention and early detection of both physical and social problems (65). Additionally, youth care organisations and youth social services provide support to children and families when they have parenting issues or are dealing with psychosocial and behavioural problems. Furthermore, children can be referred to youth mental healthcare services in case of psychological problems or suspected mental disorders. Finally, somatic problems are treated by general practitioners, who refer to secondary care when needed (64).

Preventive child healthcare is offered to all children from conception to the age of 18, and to their parents. Parents are actively invited to visit preventive health services with their child: for immunization, for screening on serious physical conditions, and for regular monitoring of health, growth, and development. Parents can get advice on nutrition, parenting and safety, and receive support for mild parenting problems. Youth care is available for all children and families as well but is only initiated in specific situations once issues become more complex and light support is no longer sufficient. Youth care offers support and treatment when children (and their parents) are struggling with psychological problems and disorders, psychosocial and behavioural problems, parenting problems or mild mental or physical disabilities. In the Netherlands, approximately 10% of all children receive some form of youth care (66).

Until 2015, municipalities were responsible for preventive child healthcare, whereas youth care, youth social services and child protection services were the responsibility of regional and national government. Youth mental healthcare and somatic healthcare were the responsibility of the national government as well, through healthcare insurance companies and health offices. With the introduction of the Youth Act in 2015, all care for youth services, except somatic healthcare, was transferred to municipalities (64, 67).

Transformation towards integrated person-centred care

Transferring youth care and youth mental health services to local government was needed because the former youth care system showed various flaws, leading to rising costs, fragmentation of care and insufficient collaboration between professionals involved with children and families. Dutch Inspection for Healthcare and Youth (IGJ) incident reports showed that in complex situations too many professionals were involved, without knowing of each other's involvement (68). When both adult and paediatric mental health care were involved with families, these professionals did not exchange information. Care plans did not meet family's needs. Therefore, more integrated care was needed, not only on care team and organisational level, but also on regulatory, financial and policy level. The assumption was that allocating all budget and responsibilities for care for youth to municipalities would help municipalities to develop an integrated child healthcare policy. As a result of such integrated child healthcare policy, all involved professionals would have to collaborate with each other and the families they supported, executing one plan with shared goals (69).

The transition of youth care also aimed for a transformation towards person-centred care: strengthening autonomy among parents, adolescents, and families, involving them and their network in shared decisions about their care (69). Autonomy was defined as 'organizing or coordinating your own life, aiming for a life that you value as good' (70). For the purpose of our study, we follow this definition and use the term autonomy in line with Self Determination Theory as 'self-governing' or 'regulation of the self' (71). A person is acting autonomous 'when his or her behaviour is experienced as willingly enacted and when he or she fully endorses the actions in which he or she is engaged and/or the values expressed by them' (72). This is an expression of free will, where both intrinsic motivation and exogenic influences are considered to come to decisions. In person-centred care, care providers contribute to this autonomy because they are responsive to a person's individual needs and preferences and make shared decisions with them and their network. Shared decision making can be seen as the process of combining a person's intrinsic motivation and a professional's expertise as exogenic influence, to come to a joint decision.

The new system aimed for each child to grow up in safety and health, with the ultimate goal to become autonomous young people, participating in social and working life as much as possible, according to their level of development (63). In line with the United Nations Convention on the Rights of the Child, parents had autonomy in raising their children, as they were deemed primarily responsible for the upbringing of their children (73). Professionals should support and respect a parent's autonomy and agency, with one exception: when parents failed to live up to their responsibility to raise their children in safety and health, the government and professionals would have an obligation to interfere and to protect the child's interests.

Development of EPR-Youth

In the Dutch North-Veluwe region, six municipalities joined forces with the two regional Preventive Child Healthcare organisations and one Youth Care organisation. They translated the national transformation goals into a regional vision for the transformation of 'care for youth' with four focus areas (74, 75). In the regional vision document, these four focus areas were labelled as: 1) client autonomy and shared responsibility; 2) one plan for one family; 3) do the necessary; 4) connect and share knowledge (74, 75). Based on these focus areas, the municipalities assigned the three organisations to integrate their services into multidisciplinary centres for youth and family (CJGs) providing both preventive child healthcare and youth care. These centres were to become the place where parents and adolescents could go with all questions about health, growing up and parenting. Using the principles of person-centredness, CJG-professionals would collaborate with parents and adolescents to answer their questions, supporting their autonomy and agency.

As a part of the integration assignment, the CJG-organisations were to develop a multidisciplinary and fully client-accessible client-record, 'EPR-Youth'.

The assumptions were: 1) that this multidisciplinary used client health record would contribute to integration of preventive healthcare and youth care working processes, to interdisciplinary collaboration, and to development of interdisciplinary care plans; 2) that client-accessibility would contribute to client autonomy and a shared responsibility for care plans between professional and client; 3) that both would lead to clients experiencing higher quality of care. In other words, EPR-Youth was hypothesized to contribute to all above-mentioned focus areas and consequently to integrated person-centred care. To date, however, research to support these assumptions is lacking for this specific target group.

Developing complex interventions in healthcare

When the development of EPR-Youth started, it was the first Dutch interdisciplinary registration system for preventive child health care and youth care that was fully transparent to both parents and adolescents. This meant that many new challenges had to be met. Functionalities for youth care had to be added to an existing health record for preventive child health care, and data from the three regional CJG-organisations had to be merged into the new system, meaning that working processes of three organisations needed to be synchronized. Additionally, a client portal, offering full access to all data would be developed and then implementation was required among professionals from three organisations and among their clients, both parents and adolescents. Finally, confidentiality had to be protected for both parents and adolescents: In the Netherlands, parents have right of access to their child's record until the child is 16 years old. Adolescents get access rights from 12 years on and are then allowed to deny their parents access. In compliance with laws and regulations, EPR-Youth's patient portal would close automatically to parents when their child turned 12. The portal would then be opened to them when their child granted permission.

As such, developing and implementing EPR-Youth with the aim to contribute to integrated person-centred care could be considered a complex intervention (76). Key to complex interventions is that they consist of multiple components that interact with each other (77). Implementing a technological device in a healthcare context is by definition a complex intervention, requiring adaptations on different levels (78). First, developing and implementing the registration system EPR-Youth required adaptation on a technological level. Second, facilitating a virtual merge between three organisational systems and three different workflows required adaptation on an organisational level. Third, reporting in a fully client-accessible health record, collaborating with both parents and adolescents and with colleagues from other disciplines required adaptation on individual professional level. Fourth, and ultimately, accessing their health records and using the portal facilities to strengthen their autonomy required adaptation among parents and adolescents, on individual client level (78).

Based on system theory, Leeuwis and Aarts endorse that the secret of successful innovation often lies in the integration of ideas and insights of end-users, developers, researchers and other social parties (79). Developing in continuous interaction between these stakeholders and between technical, social and institutional components is referred to as co-creation (79). In this project, EPR-Youth was built in co-creation with professionals, parents, adolescents, researchers, and IT-workers to enhance acceptance among all stakeholders. A project group was appointed, consisting of CJG-professionals from different disciplines, and IT developers. This group, guided by a project leader, was responsible for the development and implementation of EPR-Youth. A consultative group of parents and adolescents advised and co-decided about layout and content of the client-portal.

Aim and research questions

As detailed in the previous parts of this chapter, although PAEHRs have potential for the development of integrated person-centred care, currently insight into the consequences for implementing and using PAEHRs interdisciplinary among adolescents and parents is still lacking. In the present thesis a series of studies has been conducted to fill this gap. The overall aim of the thesis is to generate insight in how using a client-accessible health record in preventive child healthcare and youth care contributes to integrated person-centred care for children, adolescents, and their parents, and to generate insight in barriers and facilitators during the implementation process.

More specifically, in five separate studies we address the following research questions:
1) What is currently known worldwide about experiences of patients and professionals with using a PAEHR, and about whether and how using a PAEHR contributes to patient-centred care, both in general and among specific population groups?
2) To what extent has EPR-Youth been developed and implemented as planned and in accordance with its demanded features, and what were barriers and facilitators in the development and implementation process?
3) How does using an interdisciplinary PAEHR affect interdisciplinary collaboration between professionals working in preventive child healthcare and youth care?
4) How does using a PAEHR in preventive child healthcare and youth care affect experienced autonomy among parents and adolescents?
5) How does using an interdisciplinary PAEHR affect parents' and adolescents' perception of quality of care?

Outline of this thesis

The research project was divided in three parts, each with its specific research questions: In the first part, we explored what was already known and published about the contribution of PAEHRs to person-centre care. In the second part, we evaluated the process of development and implementation of EPR-Youth. Third, we evaluated how using EPR-Youth contributed to client autonomy, to interdisciplinary collaboration between CJG-professionals, and to experienced quality of care. Figure 3 shows how the different chapters of this thesis relate to different phases of project EPR-Youth, highlighting selected outcomes for each chapter in red.

As a starting point for our research, we conducted a scoping review, investigating 'whether and how using PAEHRs contributed to patient-centred care, both in general and among specific population groups'. For the purpose of this review, which is described in **Chapter 2**, we chose the term patient-centred care instead of person-centred care, because the term person-centred care has not yet been commonly used in literature. We assessed patient-centred care based on 10 elements, derived from an integrative model for patient-centred care by Scholl et. al (14). Aiming to include different perspectives, studies were included that investigated experiences of both professionals and patients, and of both a general population and specific populations. Because studies describing experiences of parents or adolescents using a PAEHR were scarce, we broadened the scope of our review to adult healthcare as well.

Chapter 3 describes a process-evaluation, investigating 'whether EPR-Youth was developed and implemented as planned and in accordance with demanded features and questioned what were barriers and facilitators in the development and implementation process'. Evaluating the process of development and implementation was deemed important because the intended effects of EPR-Youth would only be achieved after successful development and implementation of the system. In other words, the developed system should support the envisioned integrated working processes, and professionals and clients should use the new system in the way it was designed for. Using a mixed-methods approach, the process evaluation covered different phases of the project, targeting different levels. The logic model of change in Figure 3 describes the different levels of change for EPR-Youth, distinguishing between organisational, professional and client level and describing what input and activities were planned before and during development and implementation of EPR-Youth, what output was to be delivered and what outcomes were expected after early implementation, in the medium and long term.

The process evaluation focuses on the first phases, including early implementation. A steering committee, project group, and client consultant group were observed during the process of development and implementation, and the delivered output was assessed afterwards.

The intended deliveries from project group and consultative groups were the EPR-Youth system itself, a training plan for professionals and a communication plan including communication materials. The project group reported to a steering committee, consisting of the managers of the CJG-organisations, a medical specialist, and the project leader. The steering committee, as representative of the organisational level, was responsible for directing the transformation, for matching working processes with both vision and

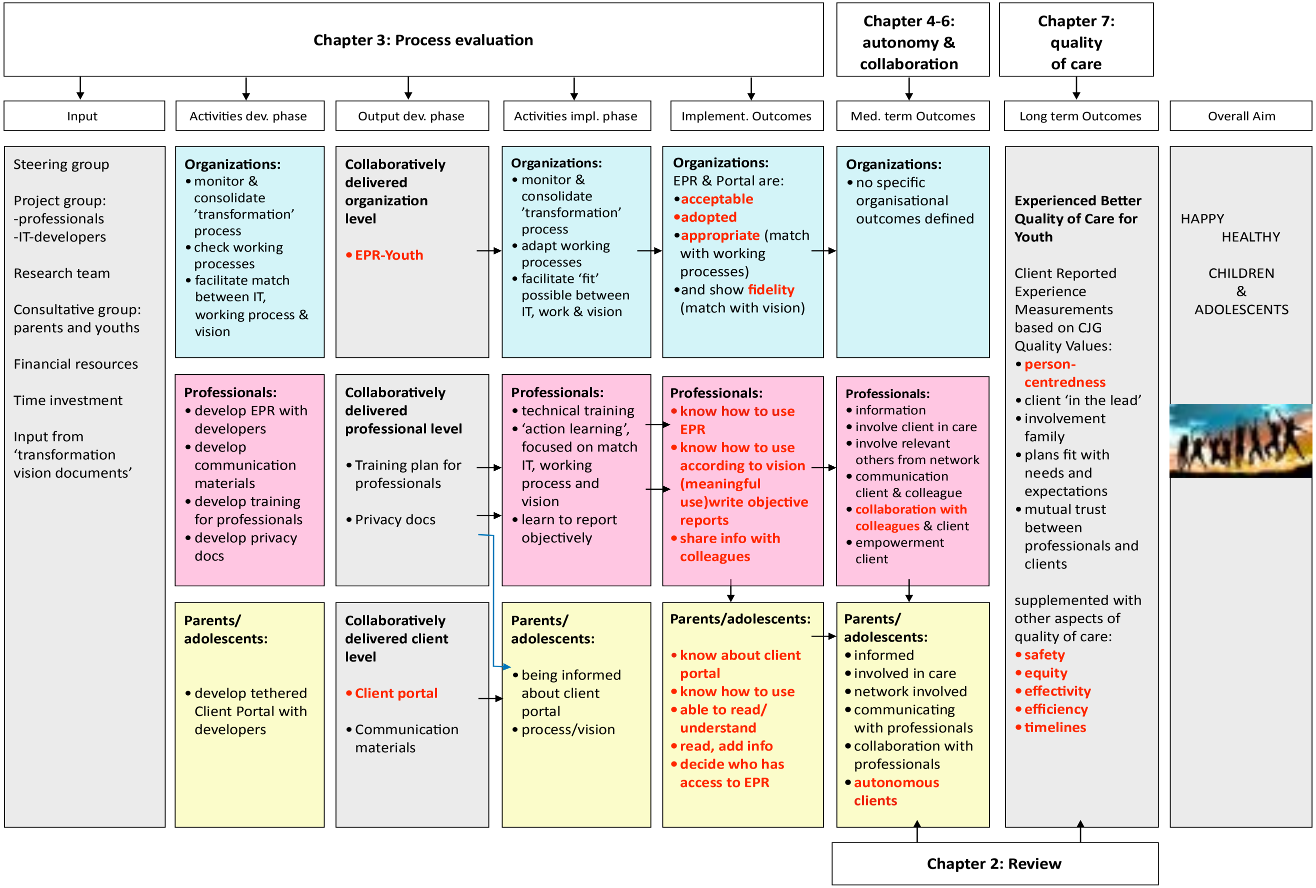


Figure 3: Logic model of change for the development, implementation and intended outcomes of EPR-Youth. In this figure, an overview of all chapters is given as well, in relation with the different phases (development and implementation) and levels of the research program (organisation, professionals, parents and adolescents), highlighting outcome variables that were included in the research in red. Abbreviations: dev. = development; impl. = implementation; med. = medium.

developing EPR-Youth, and for synchronizing working processes. This should result in implementation of a system that was matching with both working processes and the regional vision on youth care, and that was acceptable for and adopted by professionals, parents, and adolescents. On professional level, intended implementation outcomes were knowing how to use EPR-Youth, using EPR-Youth in line with the vision, writing objective reports and sharing information with colleagues. On client level, intended implementation outcomes were: knowing that EPR-Youth existed, knowing how to use the client portal, being able to read all record content, understanding what they read, being able to add information, and deciding who had access to their (child's) health record.

Client autonomy was chosen as medium-term outcome measurement. **Chapter 4** answers the question 'how using EPR-Youth affected client autonomy' (Figure 3). The term client is used because, as opposed to clinical care, preventive healthcare and youth care do not deliver their services to patients who have an illness that needs to be cured. Therefore, client has been chosen as a more appropriate term. To answer the research question in this study, questionnaires and focus group interviews were used, based on a Dutch model by Movisie. This model describes four domains of supporting autonomy from a professional's and a client's perspective: ownership, capability, motivation, and network. From the hypothesis, implied in this model, that professional behaviour would affect client autonomy, we assessed both experienced client autonomy and professional autonomy-supportive behaviour.

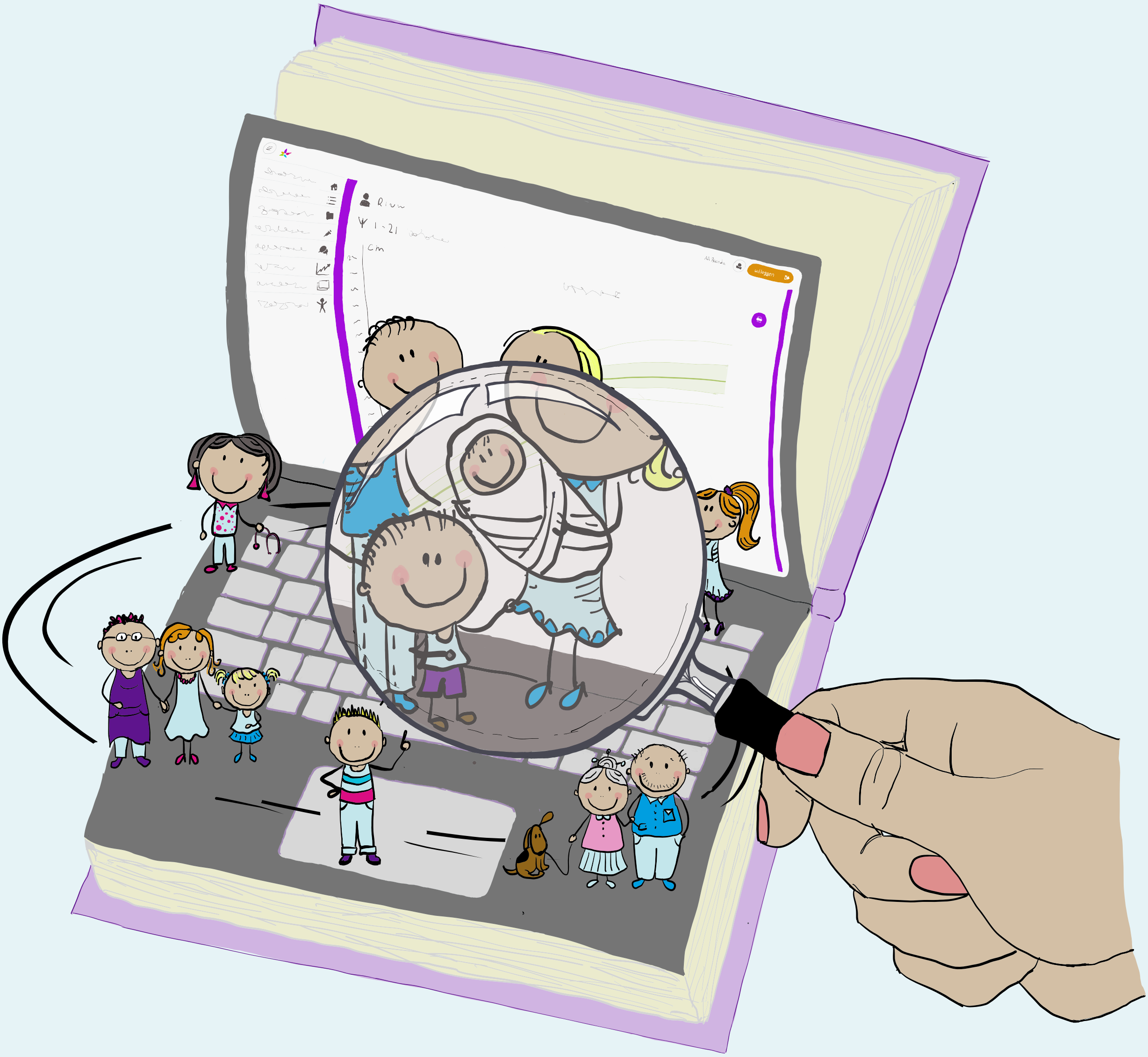
Another medium-term outcome measurement was interdisciplinary collaboration, and an indicator for integrated person-centred care on professional level as well. Before starting the study, an existing American questionnaire about interdisciplinary collaboration was translated to Dutch. This questionnaire, the 'Index for Interdisciplinary Collaboration', had already been validated for US social workers, collaborating with other disciplines (80). The questionnaire was based on a model developed by Bronstein et al, distinguishing five domains of interdisciplinary collaboration: interdependence, flexibility, newly created professional activities, collective ownership of goals and reflection on processes (81). **Chapter 5** describes the process of translating this questionnaire into Dutch and the validation for the context of Dutch youth care.

In **Chapter 6**, the results of this translated questionnaire in combination with focus group outcomes are presented, answering the question 'how using EPR-Youth affected interdisciplinary collaboration between professionals in youth care and preventive child healthcare'. We also explored differences in attitude towards interdisciplinary collaboration between professionals from different organisations, aiming to define characteristics that support or hinder interdisciplinary collaboration.

The final question of this thesis is covered in **Chapter 7**. With the question 'how using EPR-Youth affected perceived quality of care', our study shifts focus to long-term effects of using

EPR-Youth (Figure 3). This question was investigated using a qualitative design. Whereas usually quality of care is being defined from a professional's perspective, in this study the concept was defined and measured from a client's perspective. We used a quality standard that had been previously co-developed with parents and adolescents, which mainly targeted client-centredness as indicator of quality of care. Additionally, the interview guide was complemented with the quality components timeliness, safety, effectiveness, efficiency, and equity. Parents and clients from various backgrounds were included in the study, to ensure that all relevant client perspectives were represented in the outcomes.

Chapter 8 summarizes and discusses the main conclusions and results of this thesis. After a reflection on these findings from a theoretical and methodological perspective, implications for practice, policy, and future research are presented.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Chapter 2

How the use of a patient-accessible health record contributes to patient-centered care: Scoping review

This chapter is published as:

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Abstract

Background: Worldwide, patient-centered care (PCC) is becoming a widely used concept in medical practice, getting more and more attention because of its proven ability to improve quality of care and reduce costs. Although several studies show that patient-accessible electronic health records (PAEHR) influence certain aspects of PCC, the possible contribution of PAEHR implementation to PCC as a comprehensive concept does not seem to be structurally evaluated to date.

Objective: The objective is to review whether and how the use of a PAEHR contributes to PCC both in general and among specific population groups.

Methods: PRISMA-ScR reporting guidelines for scoping reviews were followed. Literature was identified in five databases, using the terms 'patient-accessible medical records', 'patient experiences' and 'professional experiences' as key concepts. A total of 49 articles were included and analysed with a charting code list containing 10 elements of PCC.

Results: Studies were diverse in design, country of origin, functionalities of the investigated PAEHR and target population. Participants in all studies were adults. Most studies reported positive influence of PAEHR use on PCC: patient accessible health records were appreciated for their opportunity to empower patients, to inform them about their health, and to involve them in their own care. There were mixed results for the extent to which PAEHR affected the relation between patients and clinicians. Professionals and patients in mental healthcare held opposing views concerning the impact of transparency, professionals appearing more worried about potential negative impact on the patient-clinician relationship. Their worries seemed to be influenced by a reluctant attitude toward PCC. Disadvantaged groups appeared to have less access to and make less use of patient-accessible records than the average population but experienced more benefits than the average population when they actually used a PAEHR.

Conclusion: The review indicates that PAEHRs bear potential to positively contribute to PCC. However, concerns from professionals about the impact of transparency on the patient-clinician relationship as well as the importance of a patient-centered attitude need to be addressed. Potentially high benefits for disadvantaged groups will be achieved only through easy-accessible and user-friendly PAEHRs.

Introduction

In the last 30 years, patient-centeredness has grown worldwide in relevance in healthcare policy, practice and research. In 1987, Harvey Picker developed the Pickers' Principles of Patient Centered Care, highlighted in the book 'Through Patients Eyes' (11). Thereafter, patient-centered care (PCC) gained increasing prominence in the U.S. when the Institute of Medicine (IOM) advocated PCC as a cornerstone for health care quality (82). In 2015, the World Health Organisation (WHO) stated that PCC should become the standard for healthcare systems all over the world (3, 83).

Key factors in patient-centered care are responsiveness to the patients' individual needs and preferences, and partnership between care provider and patient in decision making. (12-15) Patients are acknowledged as unique human beings, with needs and preferences that have to be taken into account when clinical decisions are made. Ideally, patients are involved in taking these decisions and so are family members or caregivers. This requires clear information to and communication with patients.

PCC has been gaining importance because of the proven ability to increase the quality of care, with lower health care utilization as beneficial side-effect (3, 5-9, 83). The growing importance and the development of the concept in different countries has led to a diversity in models, definitions and terminology. For this review we used an integrative model by Scholl et al (Figure 2), integrating more than 400 definitions and models into a new and comprehensible model for PCC (14).

In the Netherlands, PCC also has taken centre stage in the discussion about quality of care, especially in care for youth (63). To contribute to PCC, three organisations for preventive youth health care and youth social services in the North Veluwe region developed a patient-accessible electronic health record (PAEHR). The assumption that use of a PAEHR contributes to PCC, however, has not been sufficiently proven yet.

Several reviewers investigated effects of a PAEHR by reporting on a variety of outcomes, related to health, quality or patient satisfaction. The aspects of PCC that have been mentioned are, for instance: empowerment of patients, trust in care providers or the clinician-patient relationship. For these aspects, both beneficial (33, 34, 37, 84) and unfavourable or even harmful consequences of the use of a PAEHR (28, 41, 44, 85, 86) to PCC have been reported. Some studies report that disadvantaged groups might profit less from use of a PAEHR than others, since their access to and use of a PAEHR is lower than average (41, 44, 85, 86). To date there is no review published that structurally evaluates the possible contribution of PAEHR to PCC as a comprehensive concept. Doing so would enable us to explore whether PAEHRs could serve as a tool to strengthen this value-based healthcare model.

Since the relation between the use of PAEHR's and the broad concept of PCC has, to date, received limited attention in reviews, a broad overview of recent literature is required, with inclusion of different study designs. With such a broad perspective, a scoping review is more suitable than a systematic review since scoping reviews aim to broadly summarize and synthesize evidence instead of finding answers to circumscriptive questions and including only specified study designs. A scoping review can be helpful to provide direction to future research and search for gaps in knowledge (87, 88). The objective of this review is to provide an overview of recent literature about experiences of patients and professionals with the use of a PAEHR and to investigate whether and how the use of a PAEHR contributes to PCC, both in general and among specific population groups.

Methods

Search strategy and inclusion criteria

Design and reporting of this scoping review were in line with the framework for scoping reviews by Arksey and O'Malley, which was further developed by other authors, finally leading to the PRISMA-ScR guideline and checklist (87-90). Multimedia Appendix 1 contains the completed PRISMA-ScR checklist for this review. The a priori review protocol has not been registered. Key concepts used in the search were 'patient-accessible medical records', 'patient experiences' and 'professional experiences'. Table 1 contains the full electronic search string for the Scopus database. The search was limited to papers written in English or Dutch, being languages all authors understand, and to January 2000 - April 2019. This period was chosen because in a first quick search most articles about PAEHRs appeared to originate from 2000 or more recently. Five databases were searched: Pubmed, Medline, Scopus, Socindex and Psychinfo. The final search was run on April 9, 2019. Search records were uploaded to Endnote X8 to facilitate the article-selection process.

Table1: full search string for Scopus

'Patient-accessible' & 'medical records' & 'Patient experiences' 'physician experiences'	("Patient" OR "Patients" OR "client" OR "clients") AND ("access" OR "online access" OR "accessible") AND ("record" OR "records" OR "file" OR "files")
	AND "Personal health records" OR "Health Record, Personal" OR "Personal Health Record" OR "Record, personal health" OR "personal health records" OR "Personal Health information" OR "Health Information, Personal" OR "Information, Personal Health" OR "Personal Medical Records" OR "Medical Record, Personal" OR "Medical Records, Personal" OR "Personal Medical Record" OR "Record, Personal Medical" OR "Records, Personal Medical" OR "patient portals" OR "Patient Web Portal" OR "Portal, Patient Web" OR "Portals, Patient Web" OR "Web Portal, Patient" OR "Web Portals, Patient" OR "Patient Internet Portals" OR "Internet Portal, Patient" OR "Internet Portals, Patient" OR "Patient Internet Portal" OR "Portal, Patient Internet" OR "Portals, Patient Internet" OR "Patient Web Portals" OR "Patient Portal" OR "Portal, Patient" OR "Open Notes" OR "Electronic health records"
	AND "patient experiences" OR "physician experiences" OR "experiences" OR "experiences, patient" OR "experiences, patients" OR "experiences, physician" OR "experiences, physicians" OR "experiences, professional" OR "professional experiences" OR "outcome assessment (health care)" OR "benefit" OR "satisfaction" OR "patient outcomes"

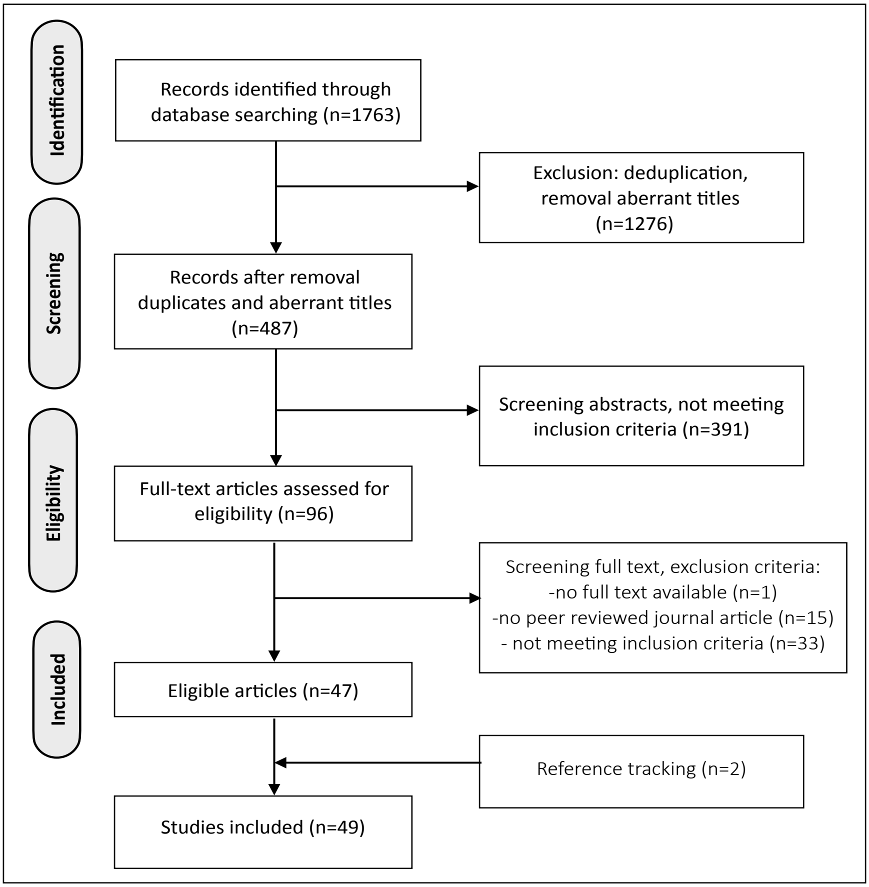


Figure 1: Flow Diagram Article Selection

Searches, deduplication and first screening of titles were performed by SJB. In total, 1763 articles were found and screened for eligibility (Figure 1). Aberrant titles were removed, and abstracts of remaining articles were independently screened by different individuals (SJB, MG and AG), in line with the scoping nature of the review. We included research articles from peer reviewed journals for which full text could be retrieved. The articles were based on original research data. They addressed 'experiences' of professionals or patients/clients using a PAEHR. Articles were screened in three rounds. After every round, different interpretations were discussed between all three screening authors to come to a unanimous decision. If necessary, the inclusion criteria were adapted before the next round to ensure uniform selection. SJB screened the remaining full text articles on inclusion criteria. To exclude articles from predatory journals, every journal was checked against the JournalGuide whitelist (91). The selection process was finalized by reference tracking: all references of selected articles were checked with the inclusion criteria and added when eligible.

Data analysis

Through discussion SJB, AH and EV came to a charting code list (Multimedia Appendix 2). The list contained codes for general article information, study methods, description of the investigated PAEHR and ten dimensions of PCC. The dimensions of PCC were derived from a model, developed by Scholl et al (Figure 2). This model distinguishes fifteen dimensions in three groups: principles, enablers and activities. The principles represent the essential factors of a patient-centered attitude in professionals. The principles and the enablers, which are organisational conditions for patient-centeredness, lay the foundation for the last group, the activities. These are actions and measures by which patient-centered behaviour becomes visible. Assuming that use of a PAEHR would affect the 'activities' from the model, possibly affect the 'enablers' and not affect the 'principles', we included all five enablers and four activities. We did not include the activities 'physical support' and 'emotional support', since we expected not to find any relation with the use of a PAEHR. From the principles, only clinician-patient relationship was included, because we considered this dimension a dynamic one that could be influenced by use of a PAEHR. A separate charting code was created for differences among population groups, since former research suggests that disadvantaged groups might profit less from use of a PAEHR than others (41, 44, 85, 86). The charting process was done by SJB and discussed afterward with the other authors. All charted data were aggregated through group discussion with all co-authors.

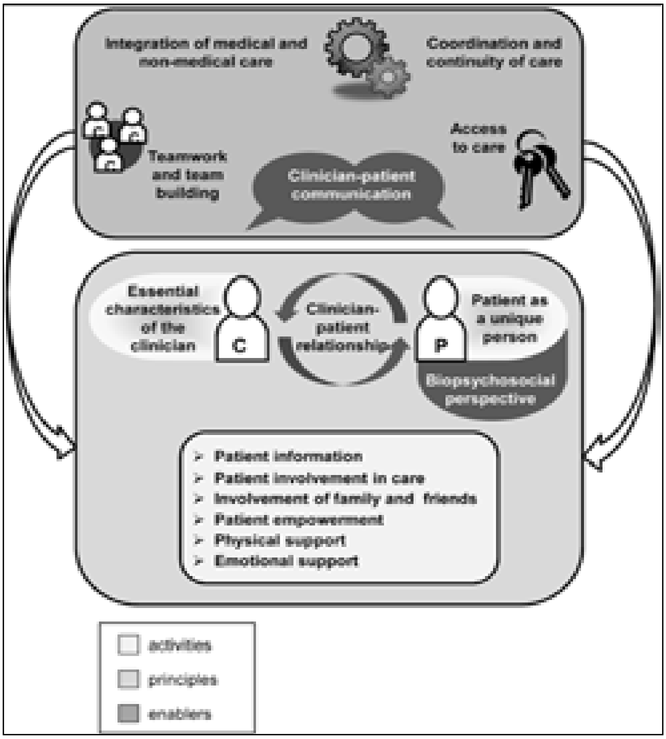


Figure 2: Model PCC by Scholl et al (2014)

Results

Overview

In total, 49 eligible articles were included (22, 23, 28, 35, 45-51, 55, 92-128). Multimedia Appendix 3 presents a brief summary of the articles, with characteristics of each study, functionalities of the studied PAEHR and reported elements of PCC. Multimedia Appendix

4 provides an overview of all outcomes. In this appendix, the articles were divided into three study design groups to facilitate the analysis. The largest group (n=34) consists of descriptive studies, both qualitative and quantitative (22, 23, 28, 35, 46, 48, 49, 51, 55, 93-97, 99-103, 106, 107, 109, 110, 113, 114, 116, 120-124, 126-128). The other two groups contain pre-post-test comparative studies (28, 49, 111, 112, 121, 122, 126, 128) and studies comparing intervention and control groups (45, 47, 50, 92, 98, 99, 104, 105, 108, 115, 117-119, 125). The results of seven mixed methods studies were divided and categorized according to the groups they best matched with (28, 49, 99, 121, 122, 126, 128).

Most articles (n=29) originated from the USA (28, 35, 45, 46, 48-51, 55, 93-96, 98, 101, 102, 104-109, 111, 114, 117, 120, 125, 127, 128). Clustered in 5-year periods, three articles originated from 2000-2004 (49, 93, 117), three from 2005-2009 (97, 118, 119), 15 from 2010-2014 (28, 55, 99, 101, 105, 106, 109, 110, 115, 120, 122, 124-127),and 28 from 2014-2019 (22, 23, 35, 45-48, 50, 51, 92, 94-96, 98, 100, 102-104, 107, 108, 111-114, 116, 121, 123, 128). Duration of experience with a PAEHR varied from 1,5 to 48 months. Population sizes were also diverse, ranging from 9 in a qualitative study to several thousands in an Open Notes survey study (n=29,191) (23, 107). Finally, the type of population varied: most studies included a broad range of patients, e.g. patients in hospitals (45, 93, 111, 123, 128), or in primary care (28, 35, 50, 51, 96-98, 100, 101, 105, 108, 109, 114). Other studies focused on specific patient groups, like cancer patients (45, 94, 102, 110, 113, 126), cardiac patients (49, 117, 125), chronically ill patients (92, 115, 122), HIV-patients (47, 108), psychiatric patients (48, 93, 121), gynaecologic patients (118, 119, 124) and veterans (47, 48, 106, 107, 120, 127). Ten studies investigated experiences of both patients and their care providers (28, 35, 49, 93, 103, 108, 109, 111, 121, 123). Four studies focused on professionals only (23, 95, 112, 116). Respondents in all studies were adults, mostly of no specific age group. Three studies surveyed parents of paediatric patients (55, 94, 103).

Apart from record-access, the most common functionalities of the PAEHR were ‘electronic messaging’ (47, 49, 55, 94, 103, 106, 107, 115, 117, 119-121, 123, 125, 128) and the possibility to add or edit health information (92, 93, 105-107, 109, 113, 116, 121, 123, 125, 126). Six studies investigated a so-called active PAEHR that sent patients ‘personalized health messages’ (92, 93, 109, 114, 118, 119). Other functionalities were ‘give feedback on health information’ (113, 116), ‘download information to share with others’ (45, 96, 109), ‘grant direct access to others’ (106, 113, 127, 128) and administrative tasks like ‘scheduling appointments’ (45, 103, 110), ‘paying bills’ (45) and ‘requesting medication refill’ (45, 123).

One patient-accessible record was paper-based and consisted of a briefcase with all medical information, which was updated after every visit to the clinic (99). Two PAEHRs were electronic but not available online (97, 124). One was an USB-stick containing all medical information, which was revised during every visit to the clinic (124). The other was a kiosk in the clinic’s waiting room, where patients could access all medical info during their visit (97). In one study nine physicians were interviewed about their experiences with PAEHRs in general (45).

Dimensions of patient centeredness

The outcomes for the ten coded dimensions of PCC have been summarized in table 2. In 34 of the studies at least three of these dimensions were explored. None of the studies mentioned the dimensions 'integration of medical and non-medical care' and 'teamwork'. The following paragraphs describe the outcomes for each dimension of PCC. When describing outcomes, we use the term 'effect' both for experienced effects as well as for objective results from comparative studies.

Table 2: Summary of Results for Dimensions of PCC

Dimension PCC	**Number of studies**	**Descriptive studies**		**Comparative studies**		
		Positive	Negative	Positive	Neutral	Negative
Information	N=40	22, 23, 28, 35, 48, 49, 51, 55, 92-95, 98-102, 105, 106, 108, 109, 112, 113, 115, 119-122, 125-127		45b, 47b, 50, 91b, 97, 98, 127	110, 117	111
Involvement in care	N=33	23,35, 49, 92-96, 98-102, 105, 106, 109, 112, 113, 115, 119, 121, 125, 126		47b, 50, 104b	45, 97, 114, 117, 124	110, 111
Empowerment	N=23	28, 48, 51, 55, 95, 98-100, 106, 108, 113, 120, 127		97, 109, 110, 116, 127b	47,49, 111, 118, 120, 121, 125	
Communication	N=22	22, 23, 49, 51, 55, 92, 98, 99, 102, 105, 108, 109, 112, 120, 121, 126, 127		127	107, 116	
Involvement of family and friends	N=14	51, 95, 98, 100, 102, 105, 109, 112, 119, 120c, 121, 123, 127	120c	107		
Clinician-patient relationship	N=22	23, 28, 35,48, 49, 51, 94-96, 101, 109, 112, 113, 115, 121, 122	23[c]	50, 124	107, 121	110, 111
Access to care	N=5	95, 51, 100, 112, 113				
Coordination / continuity of care	N=3	49, 108, 127				
Integration medical/non-medical	N=0					
Teamwork	N=0					

[a] This table represents, for every explored dimension of PCC, whether reported outcomes point in a positive or negative direction. 'Negative' in a pre-post comparative design means 'less positive than expected'. The term 'neutral' refers to the outcome 'no difference' or 'no significant difference', in a pre-post or intervention-control design.
[b] Significant effect
[c] Both positive and negative aspects reported.

Information

Forty studies investigated if and in what way patients felt more informed about their health after use of a PAEHR. We distinguished three different topics: 1) what patients valued in reading records; 2) emotional consequences; 3) understandability. Seven descriptive studies examined reasons for reading medical records (35, 51, 97, 107, 113, 126, 128). Patients valued reading their record because they wanted to know about their health or because they wanted to be sure they understood what the doctor said or because they were curious. Patients valued reading their records most because it improved understanding of health issues (22, 28, 48, 51, 93, 98, 99, 102, 107, 111, 112, 116, 120, 122, 126-128), helped to prepare for next visits (28, 107, 110, 112-114, 116, 122, 126, 128) and helped to remember the care plan (28, 49, 51, 96-98, 101, 102, 107, 112, 128). Reading also helped patients to follow treatment recommendations (23, 48, 55). Six studies compared the difference in health knowledge between intervention and control groups (45, 47, 50, 92, 99, 118). One study found a significantly higher 'self-health management knowledge score' among PAEHR adopters than among non-adopters (P <.01) [30]. Another study found that the intervention group was significantly better informed than the control group about their latest blood measurement levels, including date, time, and trend changes, and about normal lab values (P<.001) (92). A third study found that HealtheVet users were significantly more often able to correctly identify their CD4 counts (fisher= .048) and their viral load (fisher=.003) than non-users (47). The other studies found no significant difference (50, 99, 118). Two pre-post studies compared expectations with experiences (112, 128). After a period of use of a PAEHR, one of them reported better understanding of care plans than expected before (OR =1.39) (128). In the other study, however, interviewed psychiatrists reported less improvement than expected in the extent to which patients understood their medical conditions or remembered their care plans (112).

Reading their record also provided patients with reassurance (55). In four qualitative studies, patients said that transparency reduced anxiety and stress (51, 55, 107, 113). They experienced waiting for news as more stressful than reading notes by themselves. One patient said: "It is easier to break down at home where you are surrounded by family, than at the doctor's office" (113). If reading records caused stress, this was in most cases related to new diagnoses which had not yet been discussed with the professional (55). Stress was also caused if healthcare professionals trivialized a patient's problem in the record (48). Less than 10% of patients often or always experienced worries or confusion after reading their record (28, 48, 107, 108, 128). Three intervention-control studies found no significant difference in anxiety levels or reported worries between users and non-users (99, 104, 108).

Six studies investigated if patients understood everything they read and how they felt if they did not understand (49, 93, 102, 109, 113, 127). Some patients said they would appreciate built-in-definitions and less jargon. On the other hand, one patient added: "I would rather have the doctors just write what they write and me work to understand it, than them writing it for me and leaving something out that I would like to know" (49). Moreover, although patients found some medical terminology too difficult, they managed to find explanations on the internet (109, 113).

Involvement in care

Thirty-two studies described the impact of use of PAEHR on involvement in care. Twenty-three descriptive studies described involvement of patients in their care as a benefit of using a PAEHR (23, 35, 49, 93-97, 99-103, 106, 107, 110, 113, 114, 116, 120, 122, 126, 127). Clinicians in one study said that using a PAEHR resulted in a 'power shift' towards patients. Some of them saw this as a 'move towards PCC, creating better opportunities for collaboration with patients' (95). In intervention-control studies the 13-question Patient Activation Measurement (PAM-13) Questionnaire was most commonly used to measure involvement of patients in their care. Two intervention-control studies found a significantly higher PAM-score in the user groups (47, 105). One study reported a mean PAM-13 score of 47 points in the intervention group vs 45 points in the control group (P=.0014) (105), whereas the other study reported a mean PAM-13 score of 72.5 in the intervention group vs a mean of 63.49 in the control group (P=.03) (47).Three studies found no significant effect on activation score or decision making (115, 118, 125). One study, comparing different user subgroups, reported that less educated and non-white patients were more likely to report that reading visit notes was extremely important to engage in their care than more educated and white patients (98). In the two pre-post comparisons the observation that patients were 'feeling more in control' was slightly lower than expected beforehand (111, 112).

Five studies investigated if patient involvement would result in patients finding and correcting errors in their record (51, 111, 113, 116, 128). One descriptive study reported that six patients in a group of fifteen had found errors but had not requested correction (113). One study investigated a PAEHR with a feedback option (51). Patients valued this feedback option because it helped them to correct errors. Two descriptive studies reported that physicians felt that use of a PAEHR could prevent medical errors and that the PAEHR was used by patients as a means to check for accuracy (116, 128). In one pre-post study patients found less errors than expected, although errors were found and corrected: in a group of 50 patients, three patients reported finding errors in medication, two patients found errors in radiology test reports and one patient found an error in a laboratory test report (111).

Involvement of family and friends

Fourteen studies investigated whether and how family and friends were involved in care through use of a PAEHR. Thirteen descriptive studies reported that patients shared health information with relatives, friends, and health professionals (51, 96, 99, 101, 103, 106, 110, 113, 120-122, 124, 128). Patients said they shared information to answer questions of family and friends and to keep them informed. Sharing information also helped to discuss their disease with relatives or caregivers. The percentage of patients who actually shared notes with others differed among studies, from 15 to 67%. One descriptive study among patients with a bipolar disorder reported that 23% of the 39 respondents considered access to family caregivers preferable, whereas 25% thought it would be harmful (121). One study, comparing HIV patients with other patients in primary care, found that HIV patients were more likely than other primary care patients to share or discuss visit notes with others, both friends and professionals (108). In one mixed-methods study, caregivers especially valued the possibility for a patient to share information with them, because this enabled them to view notes of visits which they had not been able to attend (128).

Empowerment

In 13 descriptive studies patients mentioned that they felt more in control of their health or that they could take better care of their own health due to reading their record (28, 48, 51, 55, 96, 99, 100, 102, 107, 109, 114, 121, 128). In one study patients appreciated the possibility to share a print-out of their record with another doctor (110). Patients also said that their role became more active (51). They experienced more ownership of their own health status (114). Three control-intervention studies reported no significant difference in empowerment between intervention and control groups (47, 117, 119). In seven pre-post studies, six studies found no significant effect on empowerment scores (49, 111, 112, 121, 122, 126). The seventh study reported that patients were more confident in their ability to manage their health information (OR 2.14, 95% CI 1.59-2.89)) and their care (OR 1.48, 95% CI 1.14-1.93) (128).

Communication

Twenty descriptive studies investigated the effect on communication between patient and health care professional and reported an improvement (22, 23, 49, 51, 55, 93, 94, 99, 100, 103, 106, 109, 110, 113, 114, 116, 121, 122, 127, 128). Communication became easier because of the PAEHR, and interaction improved (93, 109). The ability to view health information improved the level of communication during subsequent visits and made it possible to communicate 'on more level playing field' with healthcare professionals (23, 103). The use of a PAEHR also removed barriers: "Because you can ask 'stupid' questions that you wouldn't pick up the phone for" (55). Two intervention-control studies reported on communication and found no significant differences between intervention and control group (108, 117).

One pre-post study reported that caregivers appreciated the possibility to view notes of visits they could not attend, because it improved their communication with care providers [76].Seven descriptive studies investigated the influence of PAEHR use on time investment, five of them reporting no difference (28, 35, 49, 109, 113, 116, 123). One study reported that some professionals needed more time to edit or explain notes. However, they framed this as 'better documentation, a good thing' (28). In one study a professional said that it was improving efficiency: "Finally something to save me time!" (109). One intervention-control study reported that professionals received more messages per patient, but nonetheless did not feel a perceptible change in workload (117). Four pre-post studies investigated expectations of more time investment, but none demonstrated an increasing time investment (28, 49, 111, 112).

Clinician-patient relationship

Seventeen descriptive studies reported on the clinician-patient relationship (23, 28, 35, 46, 48, 49, 51, 95-97, 102, 110, 113, 114, 116, 122, 123). Patients reported that they were feeling better about their doctor after reading their record (35, 48). They appreciated their doctor's expertise more and experienced a more equal relationship (23, 49, 51, 97, 113, 115, 116, 123). They valued the level of transparency, especially when notes were written respectfully (46, 102, 110). Respectfully written notes contributed to their feelings of trust (46, 122). As a result, they felt heard and cared for (51). Three intervention-control studies and one pre-post study reported on the professional-client relationship and found no significant differences (50, 108, 125). Two other pre-post studies, however, found that the experienced increase of trust in physicians was less than expected, both from a patient and a professional perspective (111, 112).

Related to the fear of damaging a therapeutic relationship, some professionals expected that they would report differently if they knew patients could be reading their visit notes. Psychiatrist in one study said: "Sometimes a disbalance occurs, patients 'directing their care' and dictating their doctors how to write their notes" (23). These psychiatrists also feared that transparency of records could damage the therapeutic relationship, especially when notes revealed subjective impressions. Four pre-postintervention studies investigated if clinicians reported differently about sensitive subjects. Professionals appeared to report less differently than they had expected before (28, 108, 109, 112).

Access to care

This dimension was mentioned in five qualitative studies (51, 96, 101, 113, 114). Patients experienced that the PAEHR gave easy and quick access to health information (51, 96, 113). Rapid access was perceived to be advantageous in emergency situations (101). One study also mentioned that immediacy of secure messaging cultivated a sense of ease of access (114).

Coordination and continuity

In two qualitative studies continuity and coordination of care came up (49, 109). Patients mentioned the benefit of being able to bring your health information along to another care provider and to take care of your own medication when you're out of town.

Differences among population groups.

Since former research suggests that different population groups do not profit equally from use of a PAEHR (41, 44, 85, 86), we searched for differences in our review. Seven studies compared the composition of the studied population with national demographic data. They reported that users of a PAEHR were more likely to be white and higher educated than non-users (45-51). Four studies investigated experiences of different ethnic and socio-economic groups (35, 51, 98, 101). One descriptive study found that female, older and high frequency users found reading notes very important to engage in care (51). Another descriptive study reported that older, lower educated, retired, and unemployed patients, as well as patients with a poor self-reported health and participants in other studies were more willing to share visit notes with others (101). A third descriptive study found that disadvantaged groups, like the elderly, non-whites, less educated or patients with a poor self-reported health, reported more often than others that use of a PAEHR made them feel better about their doctor (35). One intervention-control study focused on the importance of a PAEHR to non-white and less educated patients (98). Both non-white and less educated patients reported more often than white and higher educated patients that the PAEHR helped them to understand and remember care plans, feel informed and take decisions concerning their own care. Both non-whites and less educated found reading notes extremely important to engage in care.

Discussion

Summary

This review investigates whether and how the use of a PAEHR contributes to PCC, both in general and among specific patient groups. Overall, the articles in this review support the assumption that patient-accessible records contribute to PCC. In all 34 descriptive studies a positive effect is reported for different dimensions. One descriptive study reported a possible negative effect of PAEHR on the ‘therapeutic relationship’. Five out of 22 pre-post or intervention-control studies reported significant positive effects related to the dimensions ‘information’, ‘involvement of patients’ or ‘empowerment’. No significant negative effects were reported.

The studies in this review included adults only. Four studies found that especially disadvantaged groups experienced benefit from using a PAEHR (35, 51, 98, 101).

Dimensions of PCC

As we expected, the effect on the different ‘activities’ in Scholl’s model was described most often. Although some effects on ‘enablers’ are reported, only two of the ‘enablers’ are mentioned: access to care (51, 96, 101, 113, 114) and coordination /continuity of care (49, 109, 128). Complicating factor in the analysis was the varied use of dimensions and their definitions. For instance: whereas Scholl et al distinguished ‘information’, ‘involvement in care’ and ‘empowerment’ as different dimensions, some studies included ‘involvement’ and ‘knowledge/information’ in questionnaires about ‘empowerment’ (14, 49, 119, 122).

Furthermore, we found topics in our review that were not described by Scholl et al. One topic was that patients contributed to patient safety by finding and correcting errors in their records (51, 111, 113, 116, 123, 128). After discussing this topic, we added the subject to ‘involvement in care’, arguing that patients showed their involvement in care by checking their record for errors. In a recent article by Zeh et al., however, patient safety was added to Scholl's model as a new dimension, based on a Delphi study among patients (129). Patients regarded patient safety as an important dimension of PCC.

Both negative and positive effects were reported for the dimension 'patient-clinician relationship'. Especially professionals in mental healthcare expressed concerns that the transparency of a PAEHR would damage the patient-clinician relationship (95, 112). This is in line with results from other studies. In a recent Norwegian study, professionals in mental health care report significantly more often than their colleagues in somatic care that they change their way of writing in a PAEHR (130). They also discuss significantly more often than their colleagues in somatic care whether patients should be denied access to their record. Dobscha et al reported that only half of the mental health professionals (107/198) considered sharing mental health Open Notes with patients a good idea, while most of them (174/205) supported the idea in general to share medical notes with patients (131).

Opposed to professionals, mental health care patients in our review felt that transparency in a PAEHR strengthened the patient-clinician relationship, given that sensitive information was reported in a respectful way (46, 95). The fact that professionals see this differently could be caused by traditional role expectations, "in which the patient is viewed as someone to 'protect' and for whom the clinician is responsible" (95). These role expectations are at odds with the PCC principle of 'equal partnership between client and professional' and might cause the reluctance towards a transparent PAEHR.

In line with this assumption, another study emphasizes the importance of a patient-centered attitude by offering specific recommendations for mental health professionals to strengthen the therapeutic alliance in the context of patient-accessible records (46). These recommendations focus on the 'principle' dimensions from Scholl's model (14). The findings in these studies strengthen the assumption in Scholl's model, that the 'activity' dimensions only become visible if the 'principles' of PCC, reflected in a patient-centered attitude, have been embraced by professionals.

Differences among population groups

Previous research suggests that disadvantaged groups might profit less from the introduction of a PAEHR than others because they make less use of a PAEHR (41, 44, 85, 86). In our review, seven studies reported that users of PAEHRs were more likely to be white and higher educated than non-users (45-51), probably due to different access possibilities (47). Surprisingly, four other studies found that especially disadvantaged groups experienced benefits from the use of a PAEHR (35, 51, 98, 101). An explanation for this benefit could be the value of rereading information that cannot be absorbed all in once. Moreover, Bell et al state that non-white patients are said to distrust white medical professionals, not expecting them to respect their cultural values. Reading transparent records would prove otherwise and might help them to trust their doctor more (35). These findings show that disadvantaged groups benefit from use of a PAEHR, once they have found their way into the system. This emphasizes the importance to design and implement PAEHRs that are easy-accessible, in order to include disadvantaged groups.

Practice implications

Our review shows that use of a PAEHR could enhance PCC, but the effect can be influenced by factors on professional and patient level. On professional level, adoption of the principles of PC appears to be crucial for a positive impact of use of a PAEHR on the patient-clinician relationship. On patient level, easy access and user-friendliness is important to secure access for all population groups and to facilitate the benefits disadvantaged groups might experience from using a PAEHR.

Strengths and limitations

One of the strengths of this scoping review is that we included all types of designs and we did not focus on 'PCC-specific' search terms. As a result, we created a broad overview on the topic. Subsequently, the analysis was guided by the use of selected dimensions of PCC from Scholl et al., which helped to organize and interpret the information and added strength to the review (14). On the other hand, the analysis in separate dimensions makes it more difficult to explore interaction and dependence between the dimensions and to draw a conclusion about the impact of PAEHRs on PCC as a whole, which is a limitation.Another strength is the combination of searches from five different databases, both from a medical and a social perspective.

A limitation of this review is that, by specifying only 'physicians' in our search terms and not 'nurses', 'nurse practitioners' or non-medical professionals, we could have missed some articles that were relevant to the subject. One more limitation of this review is that we included articles in only English and Dutch and no non-published data or grey literature. For example, no articles from Estonia or Japan could be included, while both countries are very active in E-health and the government of Estonia has implemented a PAEHR that is being used for every citizen of the country.

The strength of the conclusions in this review also depends on the quality of the individual studies. Therefore, we conducted a global quality check, where aspects of study design and population were assessed. Although a thorough quality appraisal is not common in scoping reviews, a more detailed quality check could have added strength to the review. The global check indicated that on average study results could have been biased because of population selection, since virtually all studies included only native speakers and most of them made use of convenient sampling.

Conclusions

The review indicates that PAEHRs bear potential to positively contribute to PCC. However, concerns from professionals about the impact of transparency on the patient-clinician relationship as well as the importance of a patient-centred attitude need to be addressed. Potentially high benefits for disadvantaged groups will be achieved only through easy-accessible and user-friendly PAEHRs.

Appendices

Appendix 1: PRISMA-ScR Checklist, completed for this review.
Appendix 2: Coding or charting list used for analysis.
Appendix 3: Study characteristics, PAEHR functionalities and dimensions of Patient Centered Care. (This appendix can be found online with the published article at https://www.jmir.org/2021/1/e17655/#app3)
Appendix 4: Analysis of outcomes. (This appendix can be found online with the published article at https://www.jmir.org/2021/1/e17655/#app4)

Appendix 1: completed PRISMA-ScR Checklist

(Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews)

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	21
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	22
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	23
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	24
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	24
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	24
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	24
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	24
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	25
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	25, Appendix 2
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	25, App 2
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	26

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	25, fig 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	27, Appendix 3
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	27-33, Appendix 4
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	28, table 2
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	33
Limitations	20	Discuss the limitations of the scoping review process.	35
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	36
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Colofon thesis

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

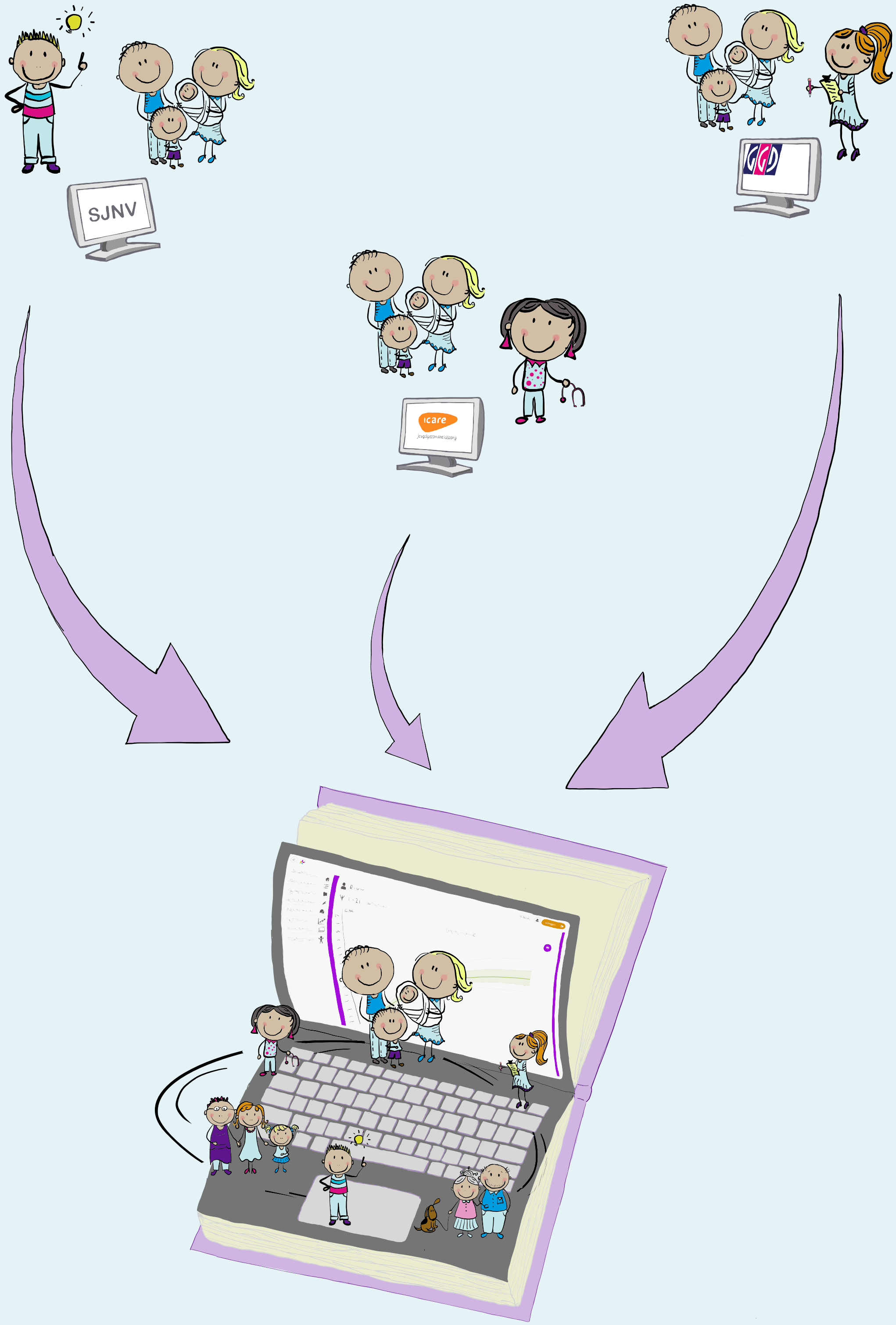
‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

Appendix 2: Coding or charting list used for analysis.

Charting list for analysis

Categories	Item	Subitem	Synonym/specification
Article info	APA reference		
	Year of publication		
	Country where research was done		
	Specific research group	(OpenNotes group, VA mental care, Mental Health My Evet)	
	Aim of study		
Methods	Study design	Qualitative	focus groups; document research; in depth interview
		Quantitative	survey; system data
		Mixed methods	
	Population	Primary care/general practice; public health; paediatrics; HIV; diabetics; chronically ill; asthma; psychiatry	
	Duration of study (months)		
	Number of patients included		
	Number of professionals included		
	Age (in case of patients)	Child/adult	
Description PAEHR	Term for PAEHR		
	Paper/electronic record		
	Active/passive record	Active, passive of semi-active	Active: patient can add information and/ or receive personalized health messages; passive: only read; semi-active: read and use electronic messaging.
	Functionalities of the EPS	Description	
Results	Dimensions PC	Information	(knowledge, insight in health/disease)
		Communication	
		Relationship patient-clinician	(trust, reciprocal, equity, reporting on sensitive subjects)
		Involvement patient	(shared decision making, coordinating own care, participation, error reporting)
		Involvement family and friends	
		Empowerment	
		Access to care	
		Integration medical/non-medical	
		Coordination/continuity	
		Team work	
	Subgroups	Differences between subgroups	Underserved, Disadvantaged, Digital Divide, Youths/adolescents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Chapter 3

Implementation of EPR-Youth, a client-accessible and multidisciplinary health record; a mixed-methods process evaluation

This chapter is published as:

Benjamins J, Duinkerken J-G, den Hamer-Jordaan G, Canfijn R, Koster R, de Vet E, Haveman-Nies A. Implementation of EPR-Youth, a Client-Accessible and Multidisciplinary Health Record; A Mixed-Methods Process Evaluation. ***International Journal of Integrated Care*** 2023; 23(2): 26, 1–16. DOI: https://doi.org/10.5334/ijic.6905

Abstract

Introduction: Client-accessible interdisciplinary health records potentially contribute to integrated care by facilitating collaboration and enhancing clients' involvement in care. To achieve this, three Dutch organisations providing 'care for youth' developed a fully client-accessible electronic patient record (EPR-Youth).

Objective: to evaluate the implementation of EPR-Youth and to determine barriers and facilitators.

Methods: a mixed methods design combined system data, process observations, questionnaires, and focus group interviews. Target groups were parents, adolescents, professionals using EPR-Youth, and implementation stakeholders.

Findings: Client-portal acceptability was high among all clients. Client-portal adoption rate was high and differed between age groups and educational levels. Professionals' doubts about acceptability, appropriateness and fidelity were partly due to lack of system knowledge. Implementation barriers were the complexity of co-creation, lack of clear leadership, and concerns about legal issues. Facilitators were clarifying vision and legal context, setting deadlines, and a pioneering spirit.

Conclusion: The early implementation of EPR-Youth, the first Dutch client-accessible interdisciplinary electronic health record in 'care for youth' was successful. To enhance adoption among clients, group-specific barriers for portal-use should be determined. Professionals need additional training. Further research is needed to gain insight into client-portal access barriers. To benefit more from co-creation, an organisational change towards situational leadership is necessary.

Introduction

During the last few decades, integrated care is worldwide considered a promising solution to reduce healthcare costs, improve patient experiences and enhance the quality of care (132). Integrated care can be defined from different perspectives. For the purpose of this paper a health-system based definition is used, defining integrated care as person-centred care that is delivered in a way that ensures people receive a continuum of all possible different health services according to their needs throughout their life course (3). Within this definition, person-centredness means that health systems and professionals consider individuals and families as participants in organizing care, appreciating a person's health needs and expectations equally as the professional's knowledge and expertise (12, 14, 15).

Integrated care can be supported on a functional level by the interdisciplinary use of electronic health records (133). Research shows that shared use of electronic health records potentially contributes to interdisciplinary collaboration and to better quality of care (38, 134). Moreover, granting clients access to the contents of an electronic health records contributes to person-centred care because the transparency of a client-accessible health record improves communication between client and professionals and enhances a client's involvement in their own care (44, 84, 135).

In the Netherlands, increasing costs and fragmented care in Youth Care have induced a necessary transformation towards integrated care since 2015. In that year, the responsibility for this transformation was transferred from the national to the local government. Six municipalities in the North-Veluwe region commissioned three local organisations to integrate their preventive and youth care services in centra for youth and family (CJG) and to develop a shared client-accessible electronic health record. With the implementation of this electronic health record, 'EPR-Youth', the CJG-organisations aimed for better interdisciplinary collaboration between CJG-professionals, for increasing client autonomy, and for improvement of perceived quality of care.

Developing an interdisciplinary client-accessible health record for care for youth, however, is a complex intervention facing specific challenges. Worldwide, development of client-accessible health records for adolescents has been hindered due to the complexity of confidentiality issues, and little research can be found on this topic (52-54). In the Netherlands, EPR-Youth would be the first system for preventive child health care (PCH) to be fully transparent for both parents and adolescents and to be used interdisciplinary between preventive child health and youth social services. Furthermore, the virtual merging of three different organisation to facilitate shared use of an electronic health record, requiring changes on organisational and individual professional level, enhances complexity.

The intended effects of EPR-Youth will only be achieved after successful development and implementation, meaning that the developed system supports the envisioned integrated working processes, and that professionals and clients use the new system in the way it was designed for. Therefore, an adequate evaluation of the development and implementation of EPR-Youth will add to the knowledge and understanding of delivering integrated care in the context of care for youth. The objective of this process evaluation is to investigate the development and implementation of EPR-Youth and to determine barriers and facilitators in the process.

Methods

Reporting of the process evaluation was guided by the revised Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare (CReDECI2) guideline (76).

Context:

Health system: The Netherlands has established a high-quality preventive child health (PCH) system, underpinned by public health legislation. Over 90% of all Dutch children follow the full free program, consisting of 10 visits in the first year, 5 visits between 1 and 4 years and 5 visits between 4 and 18 years (65). Historically, preventive healthcare for children aged 0-3 years was delivered by private organisations for medical homecare, whereas preventive healthcare for children aged 4-18 years was embedded in municipal health organisations and directed by local government. Local municipalities are financially responsible for the whole preventive child health program. Since 2015, with the introduction of the new Youth Act, responsibility for Youth Care, including youth social services, youth mental health and child protection, was transferred to municipalities as well.

Transformation: The transition of youth care to municipalities was accompanied by a challenge to reduce fragmentation of care within a lower budget. In the North-Veluwe region, six municipalities and three regional organisations for Preventive Child Healthcare and for Youth Care formulated a shared vision on transformation of care for youth, stating that integration of preventive services and youth care was needed, combined with a more client-centred attitude, to limit costs for care for youth (Figure 1) (74). The three organisations should integrate their services, creating multidisciplinary teams in Centra for Youth and Family (CJG's). Part of the integration assignment was the development of a multidisciplinary and fully client-accessible EPR-Youth, facilitating the client-centred approach.

Legal aspects: Due to privacy legislation, sharing electronic record between three different organisations was only possible after explicit and specific approval from a parent or adolescent. Dutch legislation provided adolescents with right of access to their record at the age of 12 (136). Parental access was possible until their child was 16 years old, unless rejected by an adolescent from 12 years based on right to confidentiality. EPR-Youth anticipated on new legislation, expected in 2020, that would oblige healthcare organisations to provide patients with digital access to their health information (137).

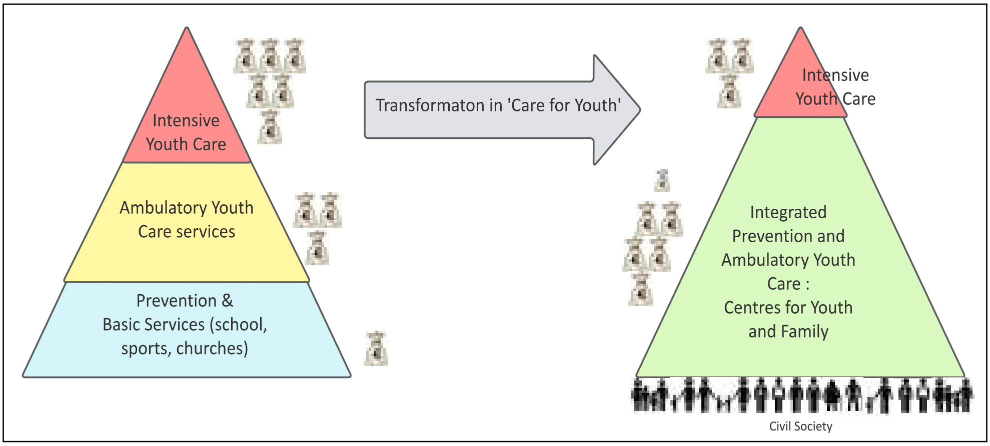


Figure 1: Transformation Youth Care in North-Veluwe region: make use of the strength of the 'Civil Society, invest in prevention and integrate prevention and care to lower costs for intensive youth care. (Benjamins et al, 2015)

Description intervention

EPR-Youth was based on an existing preventive child health system, different from the systems previously used by the regional CJG-organisations. During the development phase, functionalities for youth care were added, as well as a client portal. Information from the existing electronic health records of the CJG-organisations was merged into EPR-Youth. All CJG-professionals, both from youth care and preventive healthcare, reported in EPR-Youth. The client portal provided parents and adolescents visiting the CJG, from now on referred to as 'clients', with full access to their own record. They would be able read all reports, add information, ask questions, and manage appointments.

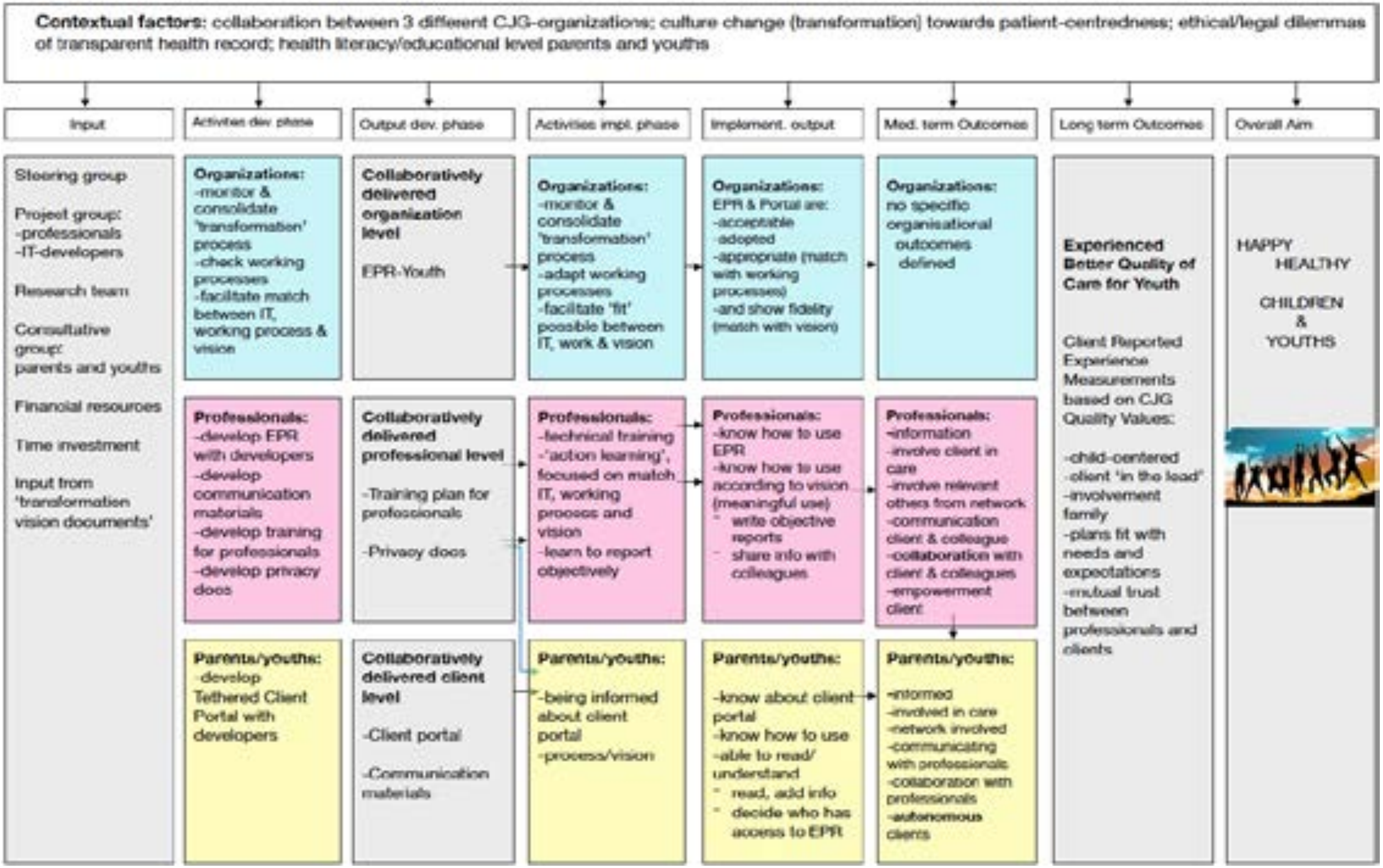
Professionals were authorized to access a child's record when they were involved with that child. Their access to a child's record was visible in the client portal. Parents were given access to their child's record until the age of 12. At the age of 12, the adolescent would get access, and parental access was prolonged only based on their child's approval. Adolescent had the opportunity to keep specific information confidential between themselves and a professional.

The target population of this intervention consists of all 38,000 children aged 0-18 years who live in the region, their parents (52,800 persons) and all CJG-professionals.

Implementation strategy

The implementation of EPR-Youth was a complex intervention, encompassing more than the mere introduction of a new technological tool [20]. Use of EPR-Youth should also support the shared vision on integrated care and facilitate the necessary shift in professional behaviour. Furthermore, an organisational change was necessary, virtually merging working processes of three organisations.

Figure2: logic model of change for EPR-Youth, based on the WK Kellogg Foundation logic model development guide



Contextual factors: collaboration between 3 different CJG-organizations; culture change (transformation) towards patient-centredness; ethical/legal dilemmas of transparent health record; health literacy/educational level parents and youths

Input	Activities dev phase	Output dev. phase	Activities impl. phase	Implement. output	Med. term Outcomes	Long term Outcomes	Overall Aim
Steering group Project group: -professionals -IT-developers Research team Consultative group: parents and youths Financial resources Time investment Input from 'transformation vision documents'	**Organizations:** -monitor & consolidate 'transformation' process -check working processes -facilitate match between IT, working process & vision	**Collaboratively delivered organization level** EPR-Youth	**Organizations:** -monitor & consolidate 'transformation' process -adapt working processes -facilitate 'fit' possible between IT, work & vision	**Organizations:** EPR & Portal are: -acceptable -adopted -appropriate (match with working processes) -and show fidelity (match with vision)	**Organizations:** no specific organisational outcomes defined	**Experienced Better Quality of Care for Youth** Client Reported Experience Measurements based on CJG Quality Values: -child-centered -client 'in the lead' -involvement family -plans fit with needs and expectations -mutual trust between professionals and clients	HAPPY HEALTHY CHILDREN & YOUTHS
	Professionals: -develop EPR with developers -develop communication materials -develop training for professionals -develop privacy docs	**Collaboratively delivered professional level** -Training plan for professionals -Privacy docs	**Professionals:** -technical training -'action learning', focused on match IT, working process and vision -learn to report objectively	**Professionals:** -know how to use EPR -know how to use according to vision (meaningful use) - write objective reports - share info with colleagues	**Professionals:** -information -involve client in care -involve relevant others from network -communication client & colleague -collaboration with client & colleagues -empowerment client		
	Parents/youths: -develop Tethered Client Portal with developers	**Collaboratively delivered client level** -Client portal -Communication materials	**Parents/youths:** -being informed about client portal -process/vision	**Parents/youths:** -know about client portal -know how to use -able to read/ understand - read, add info - decide who has access to EPR	**Parents/youths:** -informed -involved in care -network involved -communicating with professionals -collaboration with professionals -autonomous clients		

Based on system theory, stating that complex interventions will especially succeed if ideas and insights of all stakeholders are included, implementation of EPR-Youth was planned as co-creation between professionals, parents, adolescents, researchers, and IT-workers, including development as the first implementation phase (78, 79). The intended changes and deliveries, from development phase until long-term outcomes, are represented in a logic model of change (Figure 2), at an organisational, professional and client level (138). A group of CJG-professionals, researchers, and IT builders, guided by a project leader, was appointed to develop and implement EPR-Youth together with parents and adolescents. The project group was responsible for the process and were to deliver EPR-Youth, a training plan for professionals and a communication plan including communication materials; The project group reported to a steering committee, consisting of the managers of the CJG-organisations, a medical specialist, and the project leader. The steering committee monitored the process and only intervened when needed. A consultative group of parents and adolescents advised about layout and content of the client-portal.

Evaluation:

Process evaluation design

For this process evaluation, we used a mixed methods design, combining questionnaires, system data, focus group interviews, project documentation and observational reports. Data collection ran from May 2018 to November 2020 (see Table 1 for details). Following the theoretical framework for implementation research by Proctor et al, the early-stage implementation factors adoption, acceptability, appropriateness, and fidelity were chosen to be measured (139).

Table 2: Overview of chosen process indicators and implementation outcomes, corresponding datacollection method, examination period, and target group for the process evaluation of EPR-Youth.

Indicator/outcome	Data	Period	Target group/actors
Delivery process: *Has EPR-Youth been developed as intended and in accordance with the contract?*	Contract between IT-developer and CJG-organisations Document ‘system assessment’ Document ‘system assessment’	Sept ’19 (immediately after implementation)	Not specified
Implementation process and context: *Analysis of legal/ethical, socio-cultural, geographical political and socio-economic contextual aspects that were affecting the implementation process.*	- Verbatim transcripts project group meetings (34x3 hours), steering committee meetings (17x1,5 hours) and consultative group meetings (7x2 hours) - Semi-structured focus group interviews with steering committee (n=6) and project group (n=8), 1,5 hours each. - Project documentation	May ’18-Sept ‘19 June ‘20 Jan ’16-Sept ‘19	- Steering committee, project group, consultative group parents & adolescents - Steering committee and project group

Indicator/outcome	Data	Period	Target group/actors
Acceptability: *To what extent were users, both professionals and clients, satisfied with the intervention? (139)*	- Professionals' questionnaire (n=66): experienced ease-of-use and experienced usefulness	Feb '20	CJG-professionals
	- Questionnaires parents (n=914) and adolescents (n=89): desirability client-access, actual access, and experienced ease-of-use.	Sept-Nov '20	Parents and adolescents that visit a CJG
	- Semi-structured focus group interviews with professionals (n=12), parents (n=8) and adolescents (n=4): how do professionals and clients experience the use of EPR- Youth and the client-portal?	Nov '20	Professionals and clients
Adoption: *To what extent were clients using the client-portal? (139)*	- System data: monthly and total number of clients that logged on to the portal	Sept '19-Dec '20	Clients
	- Questionnaires parents (n=914) and adolescents (n=89): percentage of respondents that logged on to the client-portal	Sept-Nov '20	Parents and adolescents that visit a CJG
Appropriateness: *To what extent does EPR-Youth match with working processes of professionals? (139)*	- Meeting reports of project group and steering committee	May '18-Sept '19	Steering committee and project group
	- Semi-structured focus group interviews with professionals (n=12): Do professionals feel a match between EPR-Youth and their working processes? Meeting reports of project group and steering committee	Nov '20	CJG-professionals
Fidelity: *To what extent are professionals and clients using EPR-Youth and the client-portal as intended, in accordance with the vision on transformation? (139)*	- Semi-structured focus group interviews with steering committee (n=6) and project group (n=8), 1,5 hours each.	June '20	Steering comittee and project group
	- Semi-structured focus group interviews (1,5 hours) with professionals (n=12), parents (n=8) and adolescents (n=4): Do participants experience that EPR-Youth is supporting professionals to work in accordance with the vision on transformation?	Nov '20	Professionals and clients

Target groups and recruitment

The research population consisted of different target groups: parents, adolescents, and professionals that were using EPR-Youth; members of the steering committee, guiding the development and implementation; professionals co-creating EPR-Youth with IT-developers. Table 1 describes which target group was approached in which part of the study. During the development and implementation phase, observational reports were made for every project meeting. One year after introduction of EPR-Youth, all clients visiting a CJG received the clients' questionnaire. From the clients that indicated willingness to participate in a focus group, two focus groups were selected by purposive sampling, including clients from all six municipalities, both parents and adolescents, both male and female, visitors of different CJG-services, and representing different educational levels.

The professionals' questionnaire was distributed among 92 CJG-professionals from all three organisations, representing all available disciplines. For the focus group interviews with professional users and with the project group, purposive sampling was used to ensure that participants represented all disciplines and organisations involved, both sexes and different levels of working experience. In the focus group interview with the steering committee, all members of the steering committee were included. One member was absent and was interviewed separately. Appendix 1 provides an overview of characteristics of all focus group participants.

Measurements

Fidelity of delivery process

To evaluate whether EPR-Youth was delivered as intended, a system assessment was performed by the first author (JB) and members of the project group, comparing EPR-Youths' delivered functionalities and actual timeline of delivery with project documentation and with the project contract.

Implementation process

The first author (JB) participated as participating observer in all steering committee meetings, all project group meetings and all consultative group meetings with parents and adolescents. All meetings were audio-recorded. Project documentation was used for triangulation. The focus groups with project group members and with the steering groups were used to further define barriers and facilitators in the implementation process.

Implementation outcomes

Acceptability, adoption, appropriateness, and fidelity were chosen as implementation outcomes.

Acceptability, meaning 'the perception among implementation stakeholders that a given innovation is agreeable or satisfactory' (139) was assessed among both professionals and clients with questionnaires. Based on the Technology Acceptance Model, the professionals' questionnaire contained questions about 'perceived ease-of-use' from the System Usability Scale (N=9, Cronbach's alpha=0.92) and questions about 'perceived usefulness' from a questionnaire by Davis et al. (N=4, Cronbach's alpha=0.84) (140, 141). The clients' questionnaire was embedded into client satisfaction survey, that was administered to all clients who visited a CJG. The questionnaire contained three questions about 'ease-of-use', two about 'adoption', one about 'desirability of a client accessible EPR'. In both questionnaires, respondents were asked to rate their answers on a 5-point Likert scale, ranging from 'totally agree' to 'totally disagree'(Appendix 2). To match high scores with a positive opinion, all scores were reversed, except for four questions in the professionals' questionnaire, that were reversely worded (figure 4). Results were presented in a descriptive way.

Adoption, meaning ‘intention, initial decision, or action to try or employ an innovation’ (139), was assessed on client level using system data. The number of clients that logged on were counted and presented per month and as a total. To calculate number of log-ons per client, multiple log-ons on the same day were counted as one.

Focus groups were conducted with clients and professionals to assess ***appropriateness***, meaning ‘fit with working processes’, and ***fidelity***, meaning ‘being used as intended’ and to deepen understanding of ***acceptability and adoption*** (139).

Data-analysis

Quantitative data were analyzed using IBM SPSS Statistics 25 and Microsoft Excel. To test for differences in adoption rate based on demographic characteristics, demographic data of portal-using clients were compared with those of the source population using Chi-square tests. Client-portal access percentages, as reported in the questionnaire, were tested for difference according to sex, age or native country with Chi-square or Fisher’s exact tests. Client user experience scores were tested for differences according to educational level and native country. Kruskal-Wallis was used as omnibus test and the Mann Whitney-U as post-hoc test. For professionals’ user experiences, two dimensions were defined: perceived ease-of-use and perceived usefulness. For each dimension, an average score was calculated. These scores were tested for differences according to age and organisation, using one way ANOVA as omnibus test, and Tukey HSD as post-hoc test.

All project meetings, focus group interviews and individual interviews were audio-recorded, transcribed verbatim, and analysed in ATLAS.ti, version 8 and 9. Four researchers working in pairs (RK, JB, RC, GJ) performed a thematic analysis, starting from the themes ‘merging three systems’, ‘client-access’ and ‘general project process’. Based on relationships and cohesion between initial codes, a code tree was built with five main themes (Appendix 3), adding ‘vision’ and ‘bottlenecks, benefits and yield’ as new emerging themes. Finally, interpretation of the themes was discussed with all authors.

Findings

Fidelity of delivery process

After a development phase of 18 months, EPR-Youth was introduced In September ’19 which was six months later than intended. The system could be used by all CJG-professionals. Some adjustments were made during the delivery process (Figure 3).

First, the client-portal started with limited functionalities: clients could manage appointments, ask questions, and had access to vaccination status and growth data. Full access to visit notes was postponed until February ‘20 because the client consultation group had expressed safety worries during the final tests.

Second, all clients were to be informed personally about the client portal. However, the planned mailing to adolescents and parents of school-aged children was cancelled because the start of the COVID-19 pandemic required full attention of the municipal health organisation.

Third, portal access was limited to parents of pre-school children at first because preventive health professionals working with school-age children and adolescents wanted to screen all health records, ensuring nothing was reported about third parties, before sharing the content with their clients. They finished the screening process in June ’20.

Finally, the strict division between medical content, visible only for medical professionals, and non-medical content, visible for all CJG-professionals, was reassessed in May ’20. The reason for this reassessment was that the strict division prohibited youth care workers to see all relevant information about children’s health, which hindered adequate delivery of care.

When these changes in the delivery process were completed, most members of the steering committee and project group considered the implementation of EPR-Youth successful, because adequate interdisciplinary use and full portal access were possible by now. Simultaneously, there was still room for improvement.

Barriers and facilitators in implementation process:

From the qualitative analysis of focus group interviews and project meetings, the following themes emerged as barriers: ‘complexity of co-creation’, ‘lack of leadership’, ‘concern about legal aspects’ and ‘lack of communication’, whereas ‘structuring the process’, ‘clarifying the vision’, ‘pioneering spirit’ and ‘resolving legal issues’ were defined as facilitator. Themes and significant quotes are shown in table 2.

Barriers

Complexity of co-creation: The project proceeded slower than expected, partly due to the complexity of the co-creative change process. Underlying to this complexity were differences between organisations. Whereas the members of the steering committee shared one vision about care for youth, this vision appeared not to be embraced throughout all three organisations, causing recurring substantive and legal discussions and interpersonal tensions in the project group.

Lack of leadership: The project group members felt the project was lacking a plan with clear division of responsibilities. Although the steering committee expected the project group to take ownership over the process , the group had not experienced ownership at the start, nor had the project leader required ownership from them. Maintaining balance between self-organizing as a project group and receiving directions from the steering committee was a recurring theme, both within the project group as between project leader and steering committee. Whereas the project leader urged the steering committee to influence professionals’ attitude and behaviour, they held back instead, emphasizing that change of attitude was a change process that would happen gradually over time. Members of the steering group acknowledged that their reluctance to take leadership might have caused the project group to feel lost sometimes and that they could have intervened earlier, especially in recurring discussions about vision.

Table 3: summary of qualitative themes and sample quotations

Theme	Respondent	Setting	Quote
A1: Implementation process, barriers			
Complexity of co-creation	Project leader	Project group meeting	*We are going to use one EPR-system with three organisations, meaning we're going to merge virtually. I think we underestimated the complexity of that.*
	Preventive health worker	Focus group project members	*We have had a great deal of trouble pretending to be one organisation, while we are not at all…. We are not working from one vision.*
Lack of leadership	IT worker	Focus group project members	*A plan of action was lacking, as well as clarity about everyone's role.*
	Manager	Focus group steering committee	*The steering committee, including myself, too easily assumed that everyone knew the ultimate objective.*
	Preventive health worker	Focus group project members	*The project leader kept saying that we had to ask the steering committee about issues?*
Concerns about legal aspects	Father	Consultative group of clients	*As a parent, I really don't want that my child's medical letters can be downloaded to my computer without warning. That feels unsafe.*
	Preventive health worker	Project group meeting	*Professionals must discuss with an adolescent whether their parents are allowed to access their record, but they must speak with the parents as well.*
	Youth care worker	Project group meeting	*Maybe more medical information should be shown in the general record because some of that is really relevant for youth care workers.*
	Adolescent	Focus group clients	*As a child, especially when you grow up, you want to decide who can access your record and who can read it.*
Lack of information	Preventive health worker	Focus group professionals	*A year ago, information has been added to the invitation letter parents of newborns received, but we did not inform parents of older children.*
	Mother	Focus group clients	*I think you should really explain the client portal to every parent. Don't assume that they will find the client portal by themselves.*
A2: Implementation process, facilitators			
Structuring the process	Youth care worker	Focus group project members	*The deadline when EPR-Youth was delivered had to be met at all costs. Because the deadline was clear we were able to make rigorous decisions.*
	Preventive health worker	Focus group project members	*This is what people had been suggesting for so long: one group should be working on the content, and another on the newsletter, the user's manual etc*
Clarifying the vision	Preventive health worker	Focus group project members	*Once everyone clearly understood the 'why', decisions were quickly made.*
	Medical specialist	Focus group steering committee	*Now that professionals begin to understand the vision, the resistance among them has considerably decreased.*

Pioneering spirit	Youth care worker	Focus group project members	*Having taken up this challenge together that no one had tackled before made the difficult process more tolerable.*
	Youth care worker	Focus group project members	*It's nice to tell that this project is unique in the Netherlands.*
Legal aspects	Medical specialist	Project group meeting	*From July 2020, everybody will be legally obliged to provide digital access to health records.*
	Project leader	Project group meeting	*In my opinion a thorough legal assessment framework has been built already, and a legal guide has been provided.*
B: Implementation outcomes			
Acceptability	IT-worker	Focus group project members	*We have had relatively few start-up problems. Professionals ask practical questions about the record, but nothing like "what a miserable system" or "we can't work with this"*
	Preventive health worker	Focus group professionals	*I really like this system, EPR-Youth is easy to fill in*
	Adolescent	Focus group clients	*When you enter the website, you need to verify in four steps. It really takes time before you are able to read things.*
Adoption	Adolescent	Focus group clients	*Somebody asked if we wanted to complete a questionnaire and then we read about EPR-Youth. Otherwise, we would not have known.*
Appropriateness	Youth care worker	Focus group professionals	*As a youth care professional, it feels as if I am a visitor that is 'allowed' to report in a preventive healthcare record.*
	Youth care worker	Focus group professionals	*Sometimes I think how I am going to report all this, because I feel a 12-year-old should not have to read that.*
Fidelity	Preventive health worker	Focus group professionals	*When a child starts at school, you don't have to transfer the record to the school doctor, because they continue working in the same system.*
	Manager	Focus group steering committee	*With EPR-Youth it is no longer possible to report things that clients are unaware of.*
	Youth care worker	Focus group professionals	*I have a lot of colleagues who still write their referrals in MS Word.*

Concern about legal aspects and privacy: During the development phase, both professionals and clients expressed their concerns about legal issues and about privacy. Client's expressed worries about safety of the client portal, eventually leading to postponement of full opening of the client portal (Figure 3). Professionals were concerned if EPR-Youth was being developed in accordance with new privacy legislation when professionals of three different organisations were allowed to work in the system. Furthermore, professionals had doubts about sharing sensitive information with young adolescents and were unsure how to deal with parents' confidentiality rights in difficult situations, e.g. divorce, child abuse.

Facilitators

Structuring the process: Both the project group and the steering committee acknowledged the benefit of setting strict deadlines. This initiated a division of the project group in smaller task groups, which had proven very helpful and had contributed to the sense of ownership.

Clarifying the vision: The project group valued the process of clarifying the vision, although it was a time-consuming process. They felt this process had eventually enabled them to come to clear decisions. Moreover, the steering committee reported that the process of jointly clarifying the vision had reduced resistance.

Pioneering spirit: Everybody was aware of the pioneering character of this project, realizing that there was no earlier example that could be copied. This awareness created a feeling of pride, both in the steering committee and in the project group, and a strong will to complete the project successfully.

Legal aspects: To manage the doubts that professionals expressed about legal issues, a legal expert was consulted and a 'frequently asked questions' document was written, serving as a guide for both professionals and clients. Furthermore, the steering committee emphasized that the oncoming legislation, obliging every healthcare organisation to digitally share record contents with their clients, contributed to the acceptation of EPR-Youth.

Implementation Outcomes

Acceptability

From the 911 parents and 87 adolescents that completed the clients' questionnaire, 490 parents and 14 adolescents reported they had logged on to the client-portal and responded on the user experience questions (figure 4). Clients were predominantly positive about easy access, comprehensibility, and clear overview. No difference in scores were found according to educational level or native country.

The professionals' questionnaire was completed by 66 of the 92 (72%) invited CJG professionals (figure 4). A statistically significant difference for ease-of-use was found between different organisations, and between age groups. Professionals delivering preventive healthcare to pre-school children experienced EPR-Youth easier-to-use (Mean=3.4, SD=1.0) than youth care professionals (Mean=2.6, SD=0.9), as determined by Tukey HSD post-hoc test ($p<0.001$). Professionals aged 60 years and older experienced EPR-Youth easier-to-use than professionals between 40 and 50 years of age (Mean=3.8, SD=0.7 vs Mean=2.4, SD=0.9; $p=0.02$).

In the focus groups, clients mainly reported that the client-portal was easy to use although adolescents considered the obligatory two-factor authentication time-consuming. Professionals differed in their opinion about ease-of-use, varying from 'easy to fill in' to 'a nuisance'. They particularly appreciated new time-saving functionalities, like automatically generating referrals or indication statements. However, many professionals appeared not to be familiar with all possibilities of EPR-Youth.

Figure 4: Clients' and professionals' user experiences with EPR-Youth. Respondents scored on a 5-point Likert scale, ranging from 'absolutely' (1) to 'not at all' (5) for clients, and ranging from 'totally agree (1)' to 'totally disagree' (5) for professionals. Scores were reversed for all questions, except the ones marked with an asterisk, resulting in low scores representing a negative opinion and high scores representing a positive opinion. In the client questionnaire, Q2-4 were answered only by parents and adolescents that had accessed the client-portal.

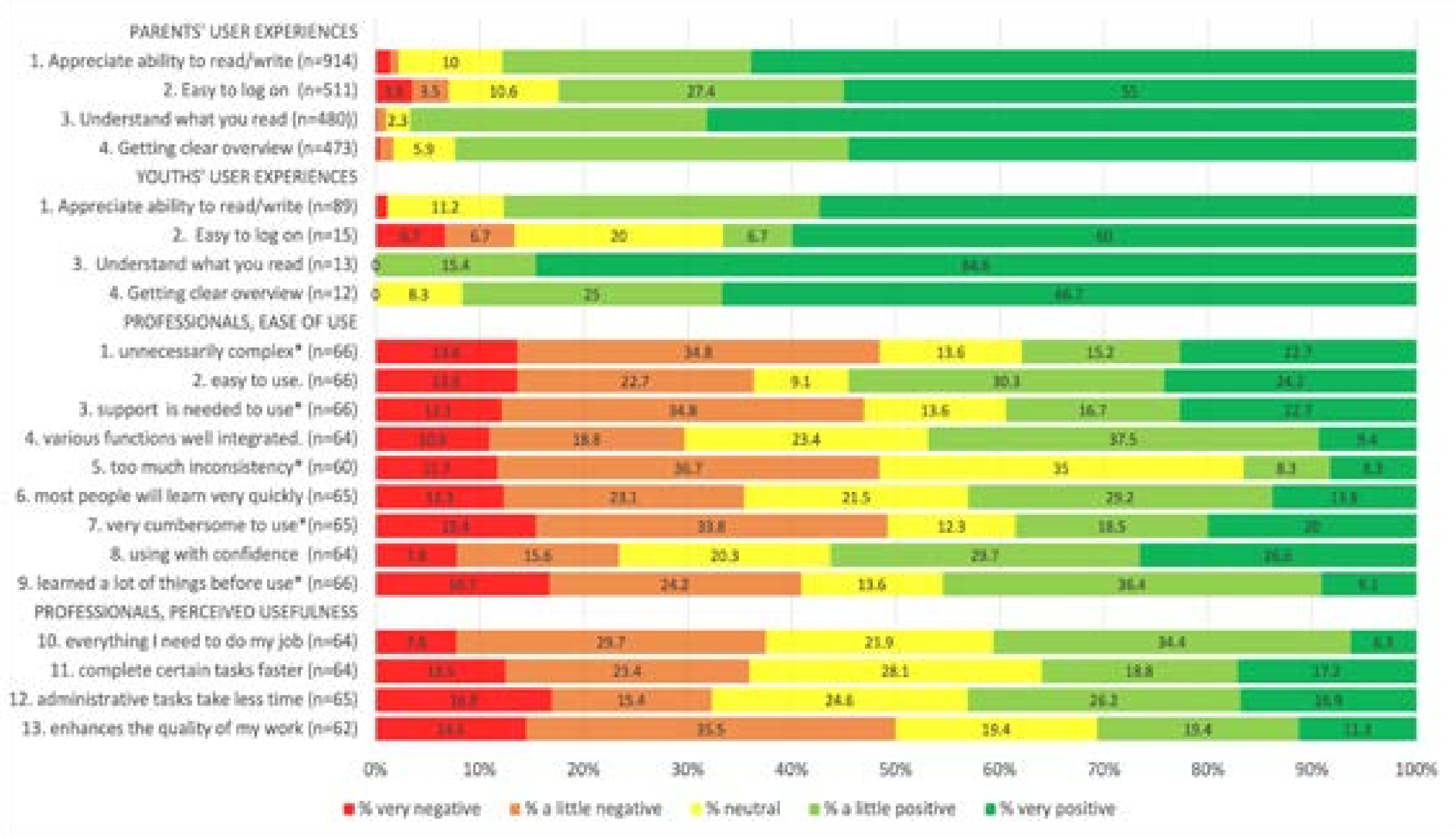


Table 4:Demographic characteristics of portal users (from system data), compared with general population of the North Veluwe region, aged 15 to 65. Source: Dutch Central Bureau for Statistics

TOTAL		**Number of users (percentage)** **5174**	**Percentage among inhabitants North-Veluwe, aged 15-65 years**
Sex[a]	Male	659 (12.7)	50.5
	Female	4509 (87.1)	49.5
	Unknown	6 (0.1)	NA
Age[b]	15-29 years	1107 (21.4)	28.4
	30-44 years	3964 (76.6)	27.6
	45-65 years	102 (2.0)	44.0
Native country[c]	Netherlands	4895 (94.6)	92.4
	Surinam	5 (0.1)	0.2
	Netherlands Antilles	5 (0.1)	0.1
	Turkey	28 (0.5)	1.0
	Morocco	15 (0.3)	0.5
	Europe, North America, Oceania, Indonesia, Japan	105 (2.0)	2.8
	Other country	121 (2.3)	3.1

[a] *Significantly different from North Veluwe population (Chi2-test (1) 2945.942, 2-sided p<0.001)*
[b] *Significantly different from North Veluwe population (Chi2-test (2) 6671.353, 2-sided p<0.001)*
[c] *Significantly different from North Veluwe population (Chi2-test (6) 41.644, 2-sided p<0.001)*

Adoption

System data showed that 5174 clients had logged in to the portal in the period September 2019 until December 2020. In the first five months, the monthly number of portal users slowly increased, then stabilized around 1200 portal users monthly. Table 3 shows that most portal users were women (87.1%), and most users were aged between 30 and 44 years (76.6 %). Compared to the average local population, few portal users were of non-Dutch nativity. The average number of logons per person was 3.68 (Median=2.0; SD 4.1) in 15 months, ranging from 1 to 47 logons. No differences were found in logon frequency, according to sex, age, and native country. The clients' questionnaire showed that logon percentages among parents differed, according to educational level, family composition and children's age (Table 4). These differences did not appear among adolescents. Parents of children aged 0-3 years, reported most often that they had logged on to the client-portal. As reasons to logon to the portal, clients mentioned: checking or managing appointments (72.4%), reading what was discussed (54.3%), asking a question (16.7%) and adding or changing information (2.5%). In the client focus groups, most participants reported they had not been aware of the existence of the client-portal until they were invited to complete the clients' questionnaire.

Table 5: Comparison of login percentages (between brackets) among respondents of the client questionnaire, according to socio-demographic characteristics.

	PARENTS (n=911)				**ADOLESCENTS (n=87)**			
	Logged in n=490 (53.8)	No Portal use n=421 (46.2)	Statistic	2-sided p-value	Logged in n=14 (16.1)	No Portal use n=73 (83.9)	Statistic	2-sided p-value
Educational level								
Low	32(50.8)	31 (49.2)	χ2 = (2) 9.285	**0.01**	6 (15.0)	34 (85.0)	χ2 = (1) 0.671	0.41
Middle	207 (50)	207 (50)			NA	NA		
High	230 (60.5)	150 (39.5)			7 (22.6)	24 (77.4)		
Missing	21	54			1	15		
Family composition								
2-Parent family	452 (58.9)	284 (41.1)	χ2 = (1) 49.523	**<0.001**	5 (16.1)	26 (83.9)	Fisher's exact	**<0.001**
Other situation	16 (18.8)	69 (81.2)			7 (15.9)	37 (84.1)		
Missing	22	36			2	10		
Native country								
Netherlands	431 (54.5)	360 (45.5)	χ2 = (1) 0.447	0.50	12 (17.4)	57 (82.6)	Fisher's exact	0.58
Other country	15 (48.4)	16 (51.6)			0 (0.0)	6 (100.0)		
Missing	44	45			2	10		
Age children								
Children 0-3 y	401 (77.0)	120 (23.0)	χ2 = (1) 264.065	**<0.001**				
Children 4-18 y	67 (20.2)	265 (79.8)						
Missing	22	36						

Appropriateness

When launched in 2019, EPR-Youth supported the most important working processes of CJG professionals. In the professional focus groups, however, preventive health care workers and youth care workers reported different opinions. Whereas preventive health care workers felt that EPR-Youth supported their working processes better than their old system, youth care workers missed a good match with their working processes and sometimes felt as if they were 'visiting' someone else's system. Some professionals experienced difficulties reporting complex family situations, now that adolescents aged 12 and older had full access to their own health record. Before introduction of EPR-Youth, sensitive information considering parents, for instance during a divorce, could be registered without children reading the information. In EPR-Youth, however, information could not be shielded from the adolescents. Consequently, professionals faced difficult decisions what was relevant to report and how to report it.

Fidelity

To investigate implementation fidelity, we discussed with professionals in the focus groups whether the system was being used and implemented as intended. Professionals reported that EPR-Youth facilitated interdisciplinary collaboration, and that the ability to read record content and to plan appointments enhanced parent's involvement in care. One member of the steering committee considered transparency to be the most important achievement because it was no longer possible to report about clients without their knowledge.

Nevertheless, the system was not fully used as intended. For instance, the possibility to manage appointments was offered by only one CJG-organisation. Furthermore, some professionals appeared to lack knowledge of functionalities and struggled to make EPR-Youth work for them, concordant with the regional vision. To increase implementation fidelity, professionals requested additional training.

Discussion

The aim of this comprehensive process evaluation was to investigate the implementation of EPR-Youth and to determine barriers and facilitators. With the implementation of a fully client-accessible health record that facilitated the working processes for three different organisations a strong basis has been created to deliver integrated care. However, client portal adoption differed between subgroups, as did acceptability, appropriateness, and fidelity among professionals. 'Complexity of co-creation', 'lack of leadership', 'concern about legal aspects' and 'lack of communication' proved to be barriers in the implementation process, whereas 'structuring the process', 'clarifying the vision', 'a pioneering spirit' and 'resolving legal issues' proved to be facilitators.

Barriers and facilitators in the implementation process

Complexity of collaboration and lack of leadership were experienced as the most important barriers during implementation. These barriers can be interpreted as a side-effect of the choice to develop and implement EPR-Youth in a step-by-step co-creational process with relevant stakeholders (78, 142, 143). Co-creation is a non-linear process, which is very suitable for innovation (144). In this process, participants must share opinions, acknowledge divergent perceptions, challenge assumptions, and finally work through disagreements (145-147). The members of our project group, coming from three different organisational cultures, discovered they had to go through this time-consuming process to reach the point where they could begin to search for inclusive solutions and come to a deepening sense of connection with each other (146-149).

The disruptive character of co-creational processes requires situational leadership that is adapting guidance of the participants to each phase of the process (150, 151). At the start, the group is in search for direction and objectives. Therefore, leadership needs to be directive, setting clear goals (145, 150). The discussion and polarization phase requires a coaching leadership style, keeping the group focused on the vision, stimulating the search for joint solutions, and creating space and time for renewal processes (152) In the last phase of co-creation, responsibility for shared goals will develop within the group, requiring more facilitative instead of directive leadership (145, 150). The steering committee chose a facilitative leadership style from the start, immediately expecting shared ownership of goals in the project group. Eventually, shared interpretations were formulated, and the feeling of solidarity and commitment within the project group increased. However, situational leadership, adapting to the changing needs and managing the participants' expectations, could have diminished the turbulence of the project.

The awareness of joint commitment to the creation of something new, labelled as 'sense of pioneering', was considered an important ingredient for successful innovation. Senge et al wrote about the importance of joint commitment: "virtually every significant change initiative that we have seen starts with a genuine partnership among a small number of deeply committed individuals" (153). In the context of change management, Clemmer and Warrick use the term 'change champions': individuals in various segments of the organisation who make indispensable contributions to initiating, facilitating, and implementing change (154, 155). Although they did not sense ownership at first, project group members implementing EPR-Youth eventually developed into 'change champions', initiating and supporting the intended change among professionals and clients using EPR-Youth.

Concerns about legal issues and privacy proved a barrier as well, and not only in this project. Development of patient-accessible records for adolescents is hindered worldwide by the struggle of guarding adolescent's rights to confidentiality (52-54). However, we encountered another dilemma, representing the opposite side of the same coin, when professionals expressed concerns about possible violation of parent's privacy due to adolescent record access. The dilemma is caused by a conflict between the adolescents' right of access to their own health record, and the parents' right to confidentiality over their personal information (53). A child's health record contains more information than just about the child's health. Professionals in child and adolescent care, viewing from a biopsychosocial perspective, gather information about family circumstances and parent's health issues as well and report those in the child's record (156, 157). Professionals in our focus groups expressed worries that possibly stigmatizing information about parents would be disclosed that might be harmful for a 12-years-old to read. Literature pays little attention to protection of parent's privacy in relation with client-accessible records for child and adolescent healthcare. The topic, however, certainly needs more attention as Bayer et al rightfully state [14].

Implementation Outcomes

Self-reported client portal adoption was 16.1% among adolescents. Among parents, portal adoption was 53.8%, which is twice as high as internationally reported portal adoption rates in healthcare (158). However, major differences in adoption rate were reported between parents of pre-school children and parents of adolescents and school-aged children. One explanation might be that parents of pre-school children had been informed individually by email, whereas the planned mailing by post to adolescent and parents of older children was cancelled due to COVID-19. Another possible explanation was the higher frequency of preventive check-ups in the pre-school period. Finally, parents of pre-school children were more inclined to access their client-portal because they were offered the opportunity to manage their appointments in the portal, whereas the municipal health service, delivering preventive child healthcare to school-aged children and adolescents and their parents, only offered the option to view appointments.

Client-portal adoption was highest among high-educated and native Dutch clients, which was in line with previous research (41, 45, 85, 86). Unexpectedly, experienced ease-of-use was not related to educational level or native country, which we considered hopeful. Nevertheless, further research will be needed to gain insight in other barriers for portal access, because lower portal adoption rates among lower educated groups and clients of non-Dutch nativity could be a sign of ‘digital divide’, with the possible risk of enhancing socio-economic health differences (159).

Professionals differed in opinion about acceptability, appropriateness, and fidelity of EPR-Youth. Their lack of knowledge of all system functionalities could be explained by the natural differences in any innovation process between early adopters and so-called ‘laggards’ (160). However, professionals also experienced some mismatches between working processes and EPR-Youth, cherishing old habits and refusing to adopt new working methods that were supported by EPR-Youth. These issues go deeper and need to be understood from the nature of complex interventions, generating change on the level of technology, organisation, and people (professionals and clients) (79). Co-creating complex interventions requires interaction over time between the technological, institutional, and social components and their context, in a continuous cycle of feedback and learning (79, 161). Implementing EPR-Youth, the technological development continued as planned, while the changes in professional attitude and adoption of newer working processes were delayed due to the COVID-19 epidemic which put the action-learning program on hold.

In this light, ‘having developed a client-accessible system all professionals can work with’ can be considered a success on technology level. Simultaneously, to complete the implementation on organisational, professional and client level, it is important to continue the cycle of learning and feedback (152). Part of the solution on the ‘people’ level could be the requested training for professionals. On organisational level, a structural change towards situational leadership, knowing when to be directive and when to guide with room for renewal, is important.

Strengths and limitations

The combination of both quantitative and qualitative data from different sources, e.g. system data, project documentation, observation reports, questionnaires and focus group interviews allowed us to view the results from all relevant perspectives.

However, distributing the professional questionnaire only 5 months after introduction of EPR-Youth might have influenced the results for ‘acceptability’ in a negative direction, because professionals still reported insufficient familiarity with all system functionalities. Moreover, including only CJG-colleagues who were already in service when EPR-Youth was introduced, left out possible positive opinions from newer colleagues. In focus group, however, newer colleagues were included, adding their more positive opinions to the overall picture of the systems easiness-of-use.

JB’s active participation in meetings of project group, steering committee and client consultative group can be considered both a strength and a limitation (162). From an empirical positivist perspective, interference with the process is unwelcome, because generalizability of outcomes will diminish, and the researchers’ objectivity could decline (163). In action research, however, knowledge is produced through interaction with the process and its participants (164). Through continuous reflection on the process, delivering feedback to the steering committee and project group, JB contributed to the achievement of project goals (163, 164). The following measures were taken, aiming for intersubjectivity: focus group interviews by an independent reviewer; co-analysing with researchers not involved in the implementation process; member check on both interview transcripts and all quotes in this paper (165).

The earlier mentioned COVID-19 pandemic also influenced the data collection. Professionals’ questionnaires were completed just before the pandemic, whereas client questionnaires that were planned one month later had to be postponed six months. Therefore, the implementation period had been shorter for professionals. That might have caused a lower perception of ease-of-use, due to lack of familiarity with all functionalities, whereas clients reported more positively because they had had more time to adjust.

Conclusion

The first implementation stage of EPR-Youth, the first Dutch client-accessible health record that facilitates both preventive child health and youth care, was successful. However, more time and effort are needed to complete implementation on organisational and personal level. To inform clients about the existence of EPR-Youth, more communication is needed, especially towards groups with lower adoption rate. Further research is needed to gain insight into barriers for client-portal access. To enhance acceptability among professionals, and a better understanding of the match between EPR-Youth, working processes, and organisational vision on care for youth, we recommend additional training.Although co-creation was an essential ingredient to reach project goals, situational leadership with more direction at the start and room for disruption is needed to guide the process.

Appendices

Appendix 1: Completed CreDECI2 Checklist
Appendix 2: Overview of characteristics of focus group participants.
Appendix 3: Client and professional questionnaire about users' experiences .
Appendix 4: Code tree

Appendix 1: Completed CreDECI2 Checklist

Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare.

Topic	**Place in paper**	**When not included: explanation**
1. Description intervention and underlying theoretical basis.	Intervention: methods 2.2 (p 4) Underlying theoretical basis: introduction (p 2)	
2. Description components, characteristics, target population.	Methods 2.2, p 4	
3. Illustration of any intended interactions between components	Methods 2.2, p 4	
4.Context on macro, meso and micro level.	Methods 2.1, p3	
5. Description of pilot test and its impact	Methods, 2.3, p 4	The development process was considered part of the implementation.
6. Description of control condition	Methods, 2.1 context, p 3	
7. Implementation strategy	Methods, 2.3, p 4	
8. description of all materials and tools used for the delivery	Methods, Figure 2	
9. Fidelity of the delivery process with the study protocol	Findings 3.1, p 6,7	
10 description of process evaluation	Methods 2.4, p5&6; Findings 3.2, 3.3 p 7-9	
11. description internal facilitators and barriers potentially influencing the delivery of the intervention	Findings 3.2, p. 7,8	
12. description of external conditions or factors occurring during the study that might have influenced the delivery of the intervention	Findings 3.2, p 7,8	
13 Description of costs or required resources for the delivery of the intervention.	Global description of resources in Figure 2, methods	Not in the scope of this evaluation.

Appendix 2: Overview of characteristics of focus group participants.

Characteristics are shown separately for steering committee (n=6), project group (n=8), clients (n=12), and professional users (n=12).

Steering committee (all members)		**n=6**
Sex	Male	3
	Female	3
Role	Manager	3
	Staff member	2
	Project leader	1
Organisation	Youth care	1
	PCH 0-3	2
	PCH 4-18	2
	Other organisation	1
Setting	Focus group	5
	Individual interview	1
Project group		**n=8**
Sex	Male	2
	Female	6
Profession	Doctor	1
	Nurse	2
	Behavioural scientist	2
	Youth worker	1
	Administrative	1
	Application manager	1
Organisation	Youth care	3
	PCH 0-3	3
	PCH 4-18	2
Clients		**n=12**
Sex	Male	4
	Female	8
Parent or adolescent	Parent	8
	Adolescent	4
Educational level	High	4
	Middle	5
	Low	3
Native country	the Netherlands	12
	Other	0
PCH/ Youth care	PCH	4
	Youth care	8
Professionals		**n=12**
Sex	Male	1
	Female	11
Profession	Doctor	2
	Nurse	3
	Behavioural scientist	1
	Youth worker	3

	Administrative	2
	Screener	1
Working experience	Less than 5 years	4
	5 to 10 years	2
	More than 10 years	6
Organisation	Youth care	4
	PCH 0-3	6
	PCH 4-18	2

PCH = preventive child healthcare
PCH 0-3 = preventive child healthcare for children up to 3 years old
PCH 4-18 = preventive child healthcare for children aged 4 to 18 years old.

Appendix 3: Client and professional user experience questionnaire.

Clients:

(Represented here is the version for parents. In the questionnaire among adolescents, the text 'your child's EPR-Youth' is replaced by 'your EPR-Youth')

1. Do you appreciate the possibility to read and write in your child's EPR?
    - a. I appreciate that very much
    - b. I appreciate that a little bit
    - c. I neither appreciate nor dislike that
    - d. I dislike that a little bit
    - e. I dislike that very much
2. Did you ever log on to your child's record?
    - a. No, never.
    - b. No, I tried but did not manage to get in
    - c. Yes, I logged on to my child's record
3. What was the reason that you logged on to your child's record?
    - a. I wanted to reread what we had discussed
    - b. I wanted to check or change my appointment or plan a new appointment
    - c. I wanted to ask the CJG-professionals a question
    - d. I wanted to add information (e.g., a plan)
    - e. I wanted to do something else……
4. We want you to log on easily to your child's EPR-Youth. Do you manage to do that? *
    - a. I manage easily
    - b. I manage okay
    - c. Neutral
    - d. I manage with difficulty
    - e. I never managed
5. We want you to understand what you read in your child's EPR-Youth. Do you? *
    - a. I always do
    - b. I do, most of the time
    - c. I do, as often as not
    - d. Sometimes, I do
    - e. I never do
6. We want EPR-Youth to give you a clear overview of your child's situation and care plan. Does it? *
    - a. Always
    - b. Most of the time
    - c. Just as often as not
    - d. Sometimes
    - e. Never

**: These questions use a 5-point Likers scale, ranging from one, totally agree, to five, totally disagree. (or an equivalent of these answers, if that matches the formulation of the question better).*

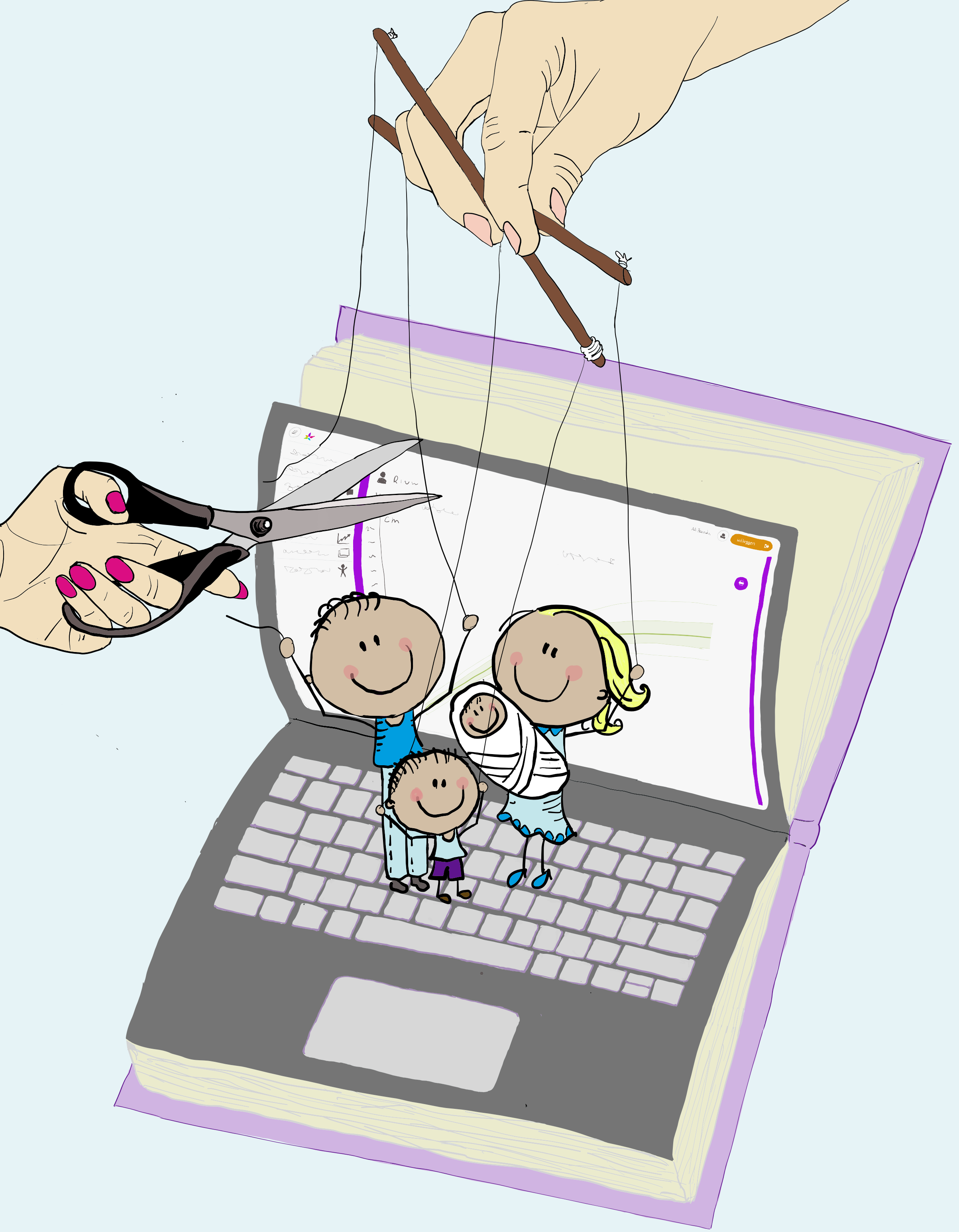
Professionals:
(Questions 1-13 use a 5-point Likers scale, ranging from one,' totally agree', to five, 'totally disagree'.)

1. I find EPR-Youth unnecessarily complex.**
2. I think that EPR-Youth is easy to use.
3. I think I will need the support of a technical person to be able to use EPR-Youth.**
4. I find that the various functions in EPR-Youth are well integrated.
5. I think there is too much inconsistency in EPR-Youth.**
6. I can imagine that most people will learn to use EPR-Youth very quickly.
7. I find EPR-Youth very cumbersome to use.**
8. I feel very confident using EPR-Youth.
9. I needed to learn a lot of things before I could get going with EPR-Youth.**
10. EPR-Youth offers everything I need to do my job.
11. EPR-Youth enables me to complete certain tasks faster than the previous system.
12. EPR-Youth makes administrative tasks take less time-consuming than the previous system.
13. Using EPR-Youth enhances the quality of my work, compared with the previous system.

***: These questions were reverse keyed. The response category 'agree' represents a negative opinion on this aspect of ease-of-use of EPR-Youth.*

Appendix 4: Code tree

This appendix can be found online with the published article at: https://doi.org/10.5334/ijic.6905.s3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Chapter 4

Effect of using client-accessible youth health records on experienced autonomy among parents and adolescents in preventive child healthcare and youth care: A mixed methods intervention study.

This chapter is published as:

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Abstract

Background: Client autonomy is important in Dutch youth care. It correlates positively with mental and physical health and can be strengthened by professional autonomy-supportive behaviour. Aiming for client autonomy, three youth care organisations co-developed a client-accessible youth health record (EPR-Youth).

Currently, limited research is available on how client-accessible records contribute to adolescent autonomy.

Objective: We investigated whether EPR-Youth strengthened client autonomy and whether professional autonomy-supportive behaviour reinforced this effect.

Methods: A mixed methods design combined baseline and follow-up questionnaires with focus group interviews. Different client groups completed questionnaires about autonomy at baseline (n=1404) and after 12 months (n=1003). Professionals completed questionnaires about autonomy-supportive behaviour at baseline (n=100, 82%), after 5 months (n=57, 57%), and after 24 months (n=110, 89%). After 14 months, focus group interviews were conducted with clients (n=12) and professionals (n=12).

Results: Findings show that clients using EPR-Youth experienced more autonomy than non-users; this effect was stronger among adolescents aged 16 and older than younger adolescents. Professional autonomy-supporting behaviour did not change over time. However, clients reported that professional autonomy-supporting behaviour contributed to client autonomy, emphasizing that professional attitude needs addressing during implementation of client-accessible records.

Conclusions: Our findings suggest that using EPR-Youth increased perceived autonomy among parents and adolescents, contributing specifically to ownership, motivation, and capability. Clients considered professional autonomy-supporting behaviour essential to benefit from using EPR-Youth. Therefore, organisations implementing client-accessible records should address professional attitude. Follow-up research with paired data needs to strengthen the association between using client-accessible records and autonomy.

Introduction

Autonomy

Personal autonomy is highly valued in the Western world (166, 167). In line with self-determination theory, autonomy is conceived as ‘acting in accordance with someone’s intrinsic motivation’ and ‘making choices that contribute to a life which is valued as good’ (72, 168). In Western medicine and medical ethics, respect for patient autonomy has become a basic principle (169). Patient autonomy means that patients have a right to make informed decisions about their medical care without healthcare providers trying to steer their (169). Involving patients in their own care positively correlates with mental and physical health and higher levels of health behaviour (170).

Professional autonomy-supportive behaviour

Professionals can strengthen patient autonomy with autonomy-supportive behaviour, characterised by affirming patients’ ownership of their health decisions, following their motivation, showing confidence in their capability, and supporting them to strengthen their network (Figure 1) (168, 171).

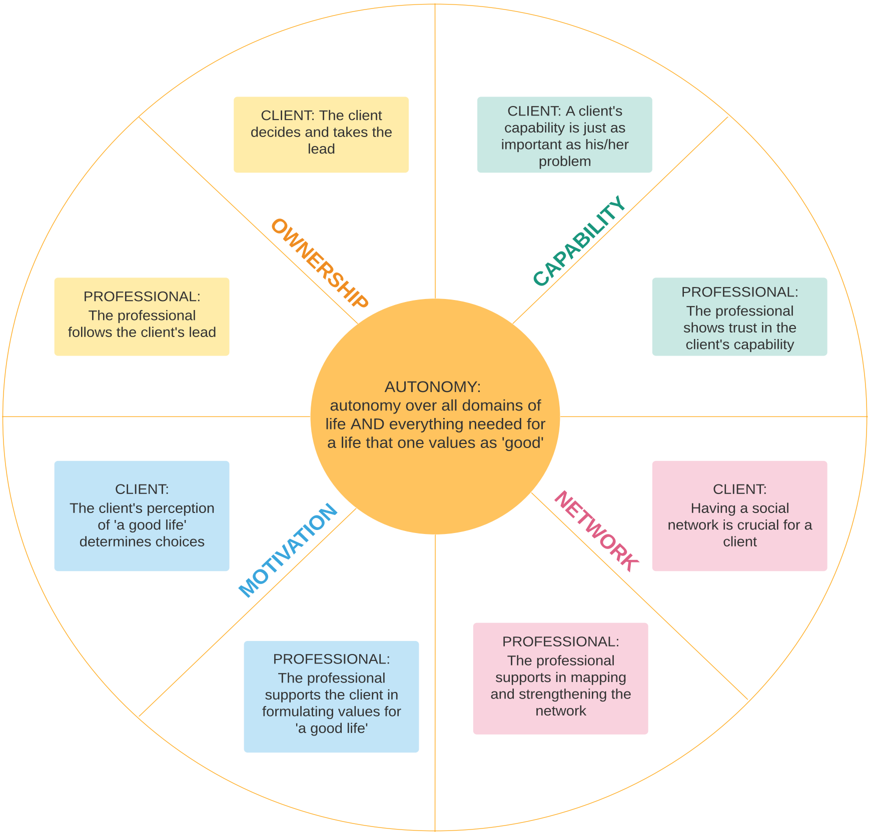


Figure 1: How to contribute to client's autonomy, Movisie 2017 (168)

Autonomy in Dutch youth care

In the Netherlands, since the new Youth Act was introduced in 2015, enhancing client autonomy has been prioritised in 'care for youth', initiating a paradigm shift from professional-centred care towards client- and family-centred care (172). Consequently, to enhance client autonomy, three Dutch organisations delivering youth care or preventive child healthcare (PCH) cooperatively developed a client-accessible electronic patient record for youth (EPR-Youth), accessible to parents of children aged up to 16 years and adolescents aged 12 years and older (173).

Challenges for autonomy among adolescents

In the field of child and adolescent health and well-being, using client-accessible health records to aim for autonomy raises two challenges. First, adolescents' increasing independence has changed a parent's role. Until the age of approximately 12, parents are responsible for their children's' upbringing and development; they exercise autonomy on their children's' behalf (73). However, when adolescents get older, they increasingly gain autonomy over their life and health decisions, and client autonomy becomes a shared domain between parents and adolescents (136). Second, parents and adolescents both have a right to access the adolescent's records and a right to privacy (136, 174).

Gap in knowledge

These challenges have globally hindered the development of client-accessible records for adolescents (52-54). Consequently, little is known about the role of client-accessible records in enhancing autonomy in an age group that is transitioning to adulthood. Research in adult healthcare shows that transparent patient-accessible records make patients feel better informed and more engaged in their own care, which contributes to patient autonomy. (33, 34, 135). Whether the same applies for adolescents yet needs addressing.

Aim

To investigate whether using EPR-Youth in youth care and PCH contributed to experienced autonomy among adolescents and parents and whether professional autonomy-supportive behaviour enhanced the effect of using EPR-Youth.

Methods

Intervention EPR-Youth

EPR-Youth has been built for six municipalities in the North Veluwe region. It facilitates all professionals working in the regional Centres for Youth and Family (CJGs) (173); it comprises three different organisations, one providing PCH to preschool children (PCH 0–3), one providing PCH to schoolchildren and adolescents (PCH 4–18), and one providing youth care. The CJGs provide preventive healthcare to all 39,560 children aged up to 18 years in the region, and additional youth care to children with behavioural or sociopsychological problems (74, 175).

EPR-Youth has a tethered client portal in which parents and adolescents can read everything professionals register. They can manage appointments, ask questions, and write comments. Complying with Dutch legislation, adolescents get portal access after turning 12 (136). Parental access is revoked after a child turns 16 unless rejected earlier by an adolescent aged 12 years or older. Furthermore, adolescents between 12–16 years of age can keep specific information confidential between themselves and a professional.

When EPR-Youth was first introduced in September 2019, a client-accessible EPR was new for most parents and adolescents. Parents of preschool children, however, were already acquainted with a client portal offering limited insight and planning functions.

Research design

A mixed methods research design with an explanatory sequential approach was chosen. Questionnaires were conducted at baseline (prior to introducing EPR-Youth), followed by one follow-up questionnaire among parents and adolescents, and two follow-up questionnaires among professionals. Two months after completing both client questionnaires, focus group interviews were conducted with representatives of all three target groups. Data were collected between November 2018 and September 2021.

Study population and inclusion

The study included three groups in the North Veluwe region: parents of children aged up to 16 years, adolescents aged 12 years and older, and professionals working in the three CJG organisations. Different samples of parents and adolescents were invited to complete an online questionnaire when visiting a CJG at baseline (T0) or 12 months after introducing EPR-Youth (T1) (Supplementary Material 1). All CJG professionals were invited at baseline (T0) to complete an online questionnaire; all responders received a link to a follow-up questionnaire five months later (T1). Because of low response at T1, we broadened the scope for the second follow-up questionnaire after 24 months (T2) and re-invited all professionals.

All CJG professionals were invited for focus group interviews, along with clients who had completed a questionnaire. From those who wanted to participate, two groups of clients and professionals, respectively, were selected through purposive sampling.

Questionnaires

Two different questionnaires were developed for clients and professionals. Both addressed socio-demographic characteristics and elements of client autonomy: ownership, motivation, capability, and, among professionals, networks. These elements were derived from a Dutch model, describing what each element meant from a client's perspective and which professional autonomy-supportive behaviour this was associated with (Figure 1) (168).

Socio-demographic characteristics

The clients' questionnaire contained questions about age, sex, educational level, native country, and family composition because previous findings show that these characteristics might influence portal use (135, 176, 177). Due to a flaw in our online questionnaire instrument, the variable 'native country' was only collected in the follow-up measurement. Questions were equal for parents and adolescents, excluding answering categories for educational level (Supplementary Material 1). For parents, educational level was classified into three categories based on the Dutch Standard Classification of Education (66). For adolescents, an adapted classification was used with two categories. Parents and adolescents were asked what CJG organisations they had visited because of the possible differences in autonomy-supportive behaviour between professionals from different organisations. Both groups were asked if they used the client portal. The professionals' questionnaire contained questions about sex, organisation, profession, and working experience, because of a possible influence on attitudes towards using EPR-Youth.

Experienced client autonomy

Experienced autonomy was measured with five items representing three elements of autonomy (ownership, motivation, and capability). Adolescents and parents were asked to rate on a 5-point Likert scale ranging from 1 (very negative/never) to 5 (very positive/always) to what extent they experienced they could 'choose a plan and solution that fits with you and your family' (ownership), received 'advice that matches your needs' (motivation), or felt encouraged to 'build further on things you already know, capacities you have and things you already do' (capability) (Supplementary Material 1). A self-constructed questionnaire was developed and tested for content validity with experts on Patient Reported Experience Measures and professionals.

Using Maximum Likelihood extraction factor analysis, one factor could be extracted with Eigenvalues above 1.0, explaining 54.9% of all variance (α=0.77). Consequently, we created individual composite scores, calculating individual mean 'autonomy' scores when at least three out of five questions were completed.

Professional autonomy-supportive behaviour

To measure a professional's degree of autonomy-supportive behaviour, we operationalised the autonomy model (Figure 1) into questions about 'capability' (e.g. whether professionals ask clients what is going well), 'network' (e.g. whether professionals ask who else is concerned with a client's well-being), 'motivation' (e.g. whether professionals explores a clients' values for 'a good life') and 'ownership' (e.g. whether professionals let clients decide what they want to keep and what needs to change) (Supplementary Material 2) (168). Professionals reported on a 5-point Likert scale, ranking from 1 ('always' or 'totally agree') to 5 ('never' or 'totally disagree').

Using a Maximum Likelihood factor analysis, one factor was extracted, explaining 42.2% of the variance (α=0.7). Therefore, individual composite scores were created, calculating individual mean 'autonomy-supportive behaviour' scores when at least six out of eight questions were completed.

Focus group interviews

To prevent group bias, an independent and experienced moderator conducted all focus group interviews with clients and with professionals. A semi-structured questionnaire (Supplementary Material 3) guided the interviews, addressing how participants experienced using EPR-Youth contributed to client autonomy, and whether client-professional interaction affected either portal use or client autonomy. An observer assisted the moderator in ensuring that all topics were discussed. To ensure confidentiality, quotes from focus group participants have been pseudonymised in this manuscript.

Statistical analysis

IBM SPSS Statistics 27.0 was used to analyse quantitative data. Descriptive statistics were used to describe participants' socio-demographic characteristics. Assumptions for the parametric tests were tested, and none were violated. Differences in respondents' socio-demographic characteristics between baseline and follow-up were tested using Pearson's Chi-square tests for both professionals and clients. Data from parents and adolescents were analysed separately.

Experienced client autonomy

A linear regression model was used to analyse differences in client autonomy scores between baseline and follow-up. Initially, educational level, sex, native country, family composition, portal use, organisation, and differences between baseline and follow-up were included in the model, as well as relevant interactions between those variables. After backward elimination, for parents, differences between baseline and follow-up, portal use, and organisation were included with fixed main effects, and interaction between the first two variables was included. For adolescents, differences between baseline and follow-up and age, and interaction between them, were included with fixed main effects.

Professional autonomy-supportive behaviour

Changes in professional autonomy-supportive behaviour were analysed using a repeated-measures analysis of variance (ANOVA) over all paired data. Initially, work experience, organisation, profession, and sex were included in the model as fixed factors. After backward elimination, all factors were excluded. To optimise data use, changes in professional contribution to autonomy were also tested using unpaired data of all professionals participating in T0 and T2. We compared all responders at T0 with those who only completed T2 and all responders at T2 with those who only completed T0, using a linear regression model, including organisation with fixed main effect.

Qualitative data analysis

The qualitative data were recorded and transcribed verbatim, and a member check was conducted with all participants to confirm transcript accuracy. Data were analysed using ATLAS.ti, versions 8 and 9. Three researchers (JB, AB, and GJ) performed a thematic analysis based on the Movisie model (168) (Figure 1). Two independent researchers coded each interview transcript combining inductive and deductive coding. Differences in coding were iteratively discussed between coding researchers, and themes were generated. Subsequently, theme interpretation was discussed with all authors, and minor modifications were made.

Data integration

Connecting, building, and merging were used to integrate all data through a narrative approach (Fetters et al., 2013). Questionnaire respondents were recruited to participate in focus groups (connecting), and the focus group interview guide informed the questionnaire outcomes (building). The outcomes from both quantitative and qualitative analyses were combined and compared (merging) to reach conclusions.

Ethics approval

All methods were carried out according to relevant guidelines and regulations of the Netherlands Code of Conduct for Scientific Practice. The research protocol was approved by the Social Sciences Ethics Committee of Wageningen University (approval number: 2018-24-Benjamins). All questionnaire respondents and focus group participants received study information and gave their consent before participation. For minor participants, consent to participate was given by themselves and their parents/guardians.

Results and findings

General characteristics

At baseline, 1202 parents and 202 adolescents completed a questionnaire. A different group of 914 parents and 89 adolescents completed the follow-up questionnaire after 12 months. Completing socio-demographic questions was non-mandatory leading to missing data for different characteristics, which we considered missing at random. Client respondents at baseline and follow-up differed significantly for all characteristics, excluding sex distribution among parents (Supplementary Material 4). Native country was only measured during follow-up. Compared with the source population, parents completing the questionnaire were more often women, highly educated, or native Dutch (175). Among adolescents, native Dutch respondents were overrepresented (175)).

At baseline, 100 (82%) out of 122 invited professionals completed the professional questionnaire, 57 (57%) of the baseline responders completed the first follow-up questionnaire and 122 (89%) out of 137 invited professionals completed the second follow-up questionnaire (Figure 2). Professional respondents’ characteristics did not differ significantly between T0, T1, and T2 (Supplementary Material 4).

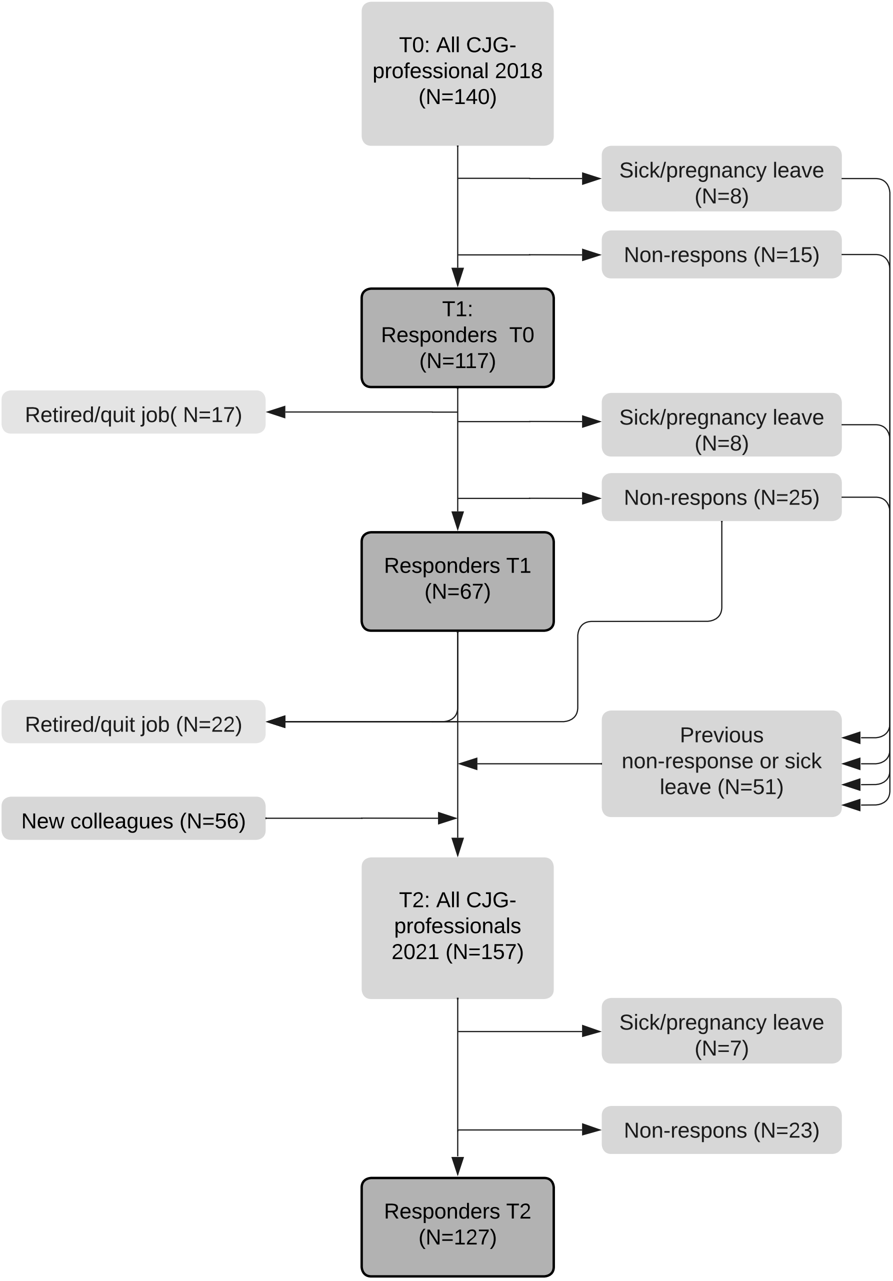


Figure 2: Flow chart inclusion and response professional questionnaire.

Experienced client autonomy

Autonomy scores were analysed for 1129 (94%) and 834 (91%) parents at baseline and follow-up, respectively. At baseline, autonomy scores differed significantly between parents visiting different CJG organisations. Youth Care visitors reported the highest scores (Estimated Marginal Means (EMM) 4.13 95% CI [4.07, 4.20]), and PCH 4-18 visitors reported the lowest scores (EMM 3.82 95% CI [3.75, 3.89]) (Table 1). After 12 months, parents generally showed significantly higher autonomy scores (EMM 4.26 95% CI [4.22, 4.30]) than parents in the baseline group (EMM 4.03 95% CI [3.99, 4.07]). Moreover, portal users (EMM 4.35 95% CI [4.29, 4.41]) reported significantly more experienced autonomy than non-users (EMM 4.17 95% CI [4.11, 4.22]). The difference between PCH 4-18 visitors (EMM 4.12 95% CI [4.05, 4.26]) and Youth Care visitors (EMM 4.28 95% CI [4.21, 4.35]) was no longer significant.

Autonomy scores were analysed for 192 (95%) and 77 (87%) adolescents at baseline and follow-up, respectively. At baseline, all adolescent respondents were portal non-users

Table 1: Client autonomy scores. Estimated marginal means (EMM) for client autonomy at baseline and follow-up, based on a General Linear Model. Organisation and portal use were included with fixed effects among parents, whereas age group and portal use were included with fixed effects among adolescents.

Parents					
	Baseline		Follow-up		Δ
	n	EMM (95% CI)	n	EMM (95% CI)	Baseline/follow-up
Autonomy score	1129	4.03 (3.99-4.07)	834	4.26 (4.22-4.30)	0.23
Portal use (adjusted for organisation)					
No	373	3.99 (3.93-4.05)	375	4.17 (4.11-4.22)	0.18
Yes	756	4.07 (4.02-4.12)	459	4.35 (4.29-4.41)	0.28
Organisation (adjusted for portal use)					
PCH 0-3	882	4.08 (4.04-4.11)	495	4.33 (4.29-4.36)	0.25
PCH 4-18	77	3.82 (3.75-3.89)	169	4.12(4.05-4.26)	0.30
Youth Care	170	4.13 (4.07-4.20)	170	4.28 (4.21-4.35)	0.15
Adolescents					
	Baseline		Follow-up		Δ
	n	EMM (95% CI)	n	EMM (95% CI)	Baseline/follow-up
Autonomy score	196	3.94 (3.82-4.06)	77	4.47 (4.33-4.62)	0.53
Portal use (adjusted for age)					
No	196	3.94 (3.82-4.06)	64	4.36 (4.24-4.49)	0.42
Yes	0	NA	13	4.59 (4.32-4.86)	NA
Age group (adjusted for portal use)					
12-15 years	164	4.07 (3.99-4.14)	33	4.32(4.11-4.52)	0.25
16-17 years	21	3.79 (3.58-4.00)	26	4.44 (4.22-4.65)	0.65
18+ years	11	3.97 (3.68-4.26)	17	4.67 (4.43-4.91)	0.70

PCH 0-3=Preventive Child Healthcare for preschool children up to 3 years old
PCH 4-18=Preventive Child Healthcare for children aged 4 to 18 years old.
NA= Not applicable

because they lacked access prior to introducing EPR-Youth. After 12 months, respondents showed significant higher autonomy scores (EMM 4.47 95% CI [4.33, 4.62]) than respondents in the baseline group (EMM 3.94 95% CI [3.82, 4.06]) (Table 1). No significant difference in autonomy score was found between portal users (EMM 4.59 95% CI [4.32, 4.86]) and non-users (EMM 4.36 95% CI [4.24, 4.49]). Adolescents aged 12–15 years did not experience significantly more autonomy at follow-up (EMM 4.32 95% CI [4.11, 4.52]) than at baseline (EMM 4.07 95% CI [3.99, 4.14]), as opposed to adolescents aged 16–17 years or 18 years and older.

Professional autonomy-supportive behaviour

Overall, professionals reported no difference in autonomy-supportive behaviour when we analysed paired data of T0 (Mean 4.13 95% CI [3.99, 4.28]), T1 (Mean 4.07 95% CI [3.92, 4.21]), and T2 (Mean 4.11 95% CI [3.95, 4.28]) (Table 2). The additional univariate ANOVA, comparing all respondents at T0 (EMM 4.08 95% CI [3.94, 4.23]) with respondents ompleting only T2 (EMM 3.97 95% CI [3.75, 4.18]) and all respondents at T2 (EMM 4.03 95% CI [3.88, 4.18]) with respondents completing only T0 (EMM 3.98 95% CI [3.72, 4.24]), showed no difference over time either (Table 2).

Table 2: Professional autonomy-supportive behaviour. Means of paired data were compared over T0 (baseline), T1 (5 months after introduction of EPR-Youth) and T2 (two years after introduction of EPR-Youth). Significance was tested at the 0.05 level in a repeated Measures ANOVA. Estimated Marginal Mean. of unpaired data were compared in two ways between T0 (baseline) and T2 (two years after introduction of EPR-Youth), using a General Linear Model. Significance was tested at the 0.05 level in a Univariate ANOVA.

Mean professional autonomy-supportive behaviour scores, paired data (repeated measures ANOVA)						
		T0		***T1***		***T2***
	n	Mean (95% CI)	N	Mean (95% CI)	n	Mean (95% CI)
Paired data T0-T1-T2	43	4.13 (3.99-4.28)	43	4.07 (3.92-4.21)	43	4.11 (3.95-4.28)
Estimated Marginal Means for professional autonomy-supportive behaviour scores, unpaired data T0 and T2. (Univariate ANOVA)						
		T0				***T2***
	n	EMM (95% CI)			n	EMM (95% CI)
All T0 vs T2 only, adjusted for organisation	97	4.08 (3.94-4.23)			46	3.97 (3.75-4.18)
Organisation						
PCH 0-3	26	4.08 (3.87-4.30)			8	3.83 (3.34-4.31)
PCH 4-18	10	3.91 (3.57-4.25)			5	3.83 (3.45-4.21)
Youth Care	61	4.25 (4.12-4.39)			33	4.24 (4.06-4.43)
All T2 vs T0 only, adjusted for organisation	36	3.98 (3.72-4.24)			105	4.03 (3.88-4.18)
Organisation						
PCH 0-3	3	3.75 (3.12-4.38)			31	4.11 (3.91-4.30)
PCH 4-18	7	3.95 (3.54-4.36)			8	3.72 (3.34-4.10)
Youth Care	26	4.25 (4.04-4.46)			66	4.27 (4.13-4.40)

However, we found some differences in autonomy-supportive behaviour among professionals from different CJG organisations. In the second follow-up questionnaire round, youth care professionals reported engaging more frequently in autonomy-supportive behaviour (EMM 4.27 95% CI [4.13, 4.40]) than preventive school healthcare professionals (EMM 3.72 95% CI [3.34, 4.10]).

Moreover, professionals responded differently for the four elements of autonomy-supportive behaviour (Supplementary Material 5). The element ‘capability’ scored the highest: on the questions whether they asked clients what was going well and whether they asked how clients had tried to resolve a problem, 88–103 (89–96%) responded with ‘often’ or ‘always’. The element ‘network’ scored the lowest. At T2, 32 (57%) professionals reported that they often or always asked clients who they wanted to involve in their situation, whereas 14 (25%) professionals responded that they sometimes or never asked this question.

Focus group interviews

We conducted two focus group interviews with a mix of parents (n=8) and adolescents (n=4) and two focus group interviews with professionals (n=12). Client focus group participants represented all six municipalities, both male and female participants, with various educational levels, and used different CJG services. Professional focus group participants represented all professions and organisations at different work experience levels. All participants were native Dutch (Supplementary Material 4) and had used EPR-Youth at least once. Four main themes emerged from the thematic analysis: ownership, motivation, capability, and professional-client relationship. Two relevant sub-themes emerged that were linked to capability: adolescents’ capability and balance between client autonomy and professional responsibility.

Elements of autonomy

Ownership: Parents and adolescents highly valued access to EPR-Youth. Reading a report after visiting a CJG enhanced their sense of ownership. Consequently, they were involved in their visit reports, writing comments, or requesting changes. Parents and adolescents considered their right to grant access to their record as an important contributor to ownership.

“Especially as a child, you just want to have ownership,
to decide who can read your record.”
(Adolescent, 17 years)

Professionals also observed an increase in parental ownership. Parents were increasingly giving feedback on reports and planned appointments as needed, whereas professionals initiated prior appointments.

"Reports are always checked with us for accuracy. In the last report, I made some changes."
(Father, two children)

Motivation: Adolescents did not value client portal use for all purposes. For instance, they preferred using WhatsApp messenger instead of logging in to EPR-Youth when they wanted to ask questions or plan a new appointment. They appreciated that they could select a medium that matched their preferences.

"What do you do when you have small questions in between appointments?"
"Oh yeah, most of the time I WhatsApp X"
(Mother, two children, discussing with adolescent, 18 years)

Capability: Both parents and adolescents reported that having 24/7 access to EPR-Youth enhanced their capability, enabling them to manage their own appointments and ask questions at their convenience. Professionals reported enhanced self-management of appointments from using EPR-Youth.

"I like that I can just drop my question whenever it is convenient for me. I don't have to plan a visit because I have plenty of other things to do. I could just describe what I saw, and based on that, we could decide what to do next."
(Mother, one child)

Capability adolescents: Both professionals and parents doubted the feasibility of adolescent portal access at 12 years of age. They expressed concerns that young adolescents were incapable of dealing with confidential information in their record about their parents or about family circumstances. Professionals struggled finding balance between guarding parents' privacy, protecting young adolescents from potentially harmful information, and reporting objectively, especially in difficult situations.

"I definitely don't want my child to read what is reported here. When she's 12 years old, the child would be devastated if she reads what is reported here."
(Mother, two children)

"I really struggle with custody battles. I just keep thinking: How am I going to report this? I don't think a 12-year-old kid should read about this."
(Youth care worker)

Client autonomy vs professional responsibility: Although both professionals and clients valued the fact that clients could become decision-makers and manage their appointments, they also expressed concerns about the counter side of autonomy. For instance, in cases of suspected child neglect, parental autonomy could pose a risk. Participants agreed that client autonomy should not be unlimited. They considered child well-being a shared responsibility between professionals and parents: when parents would not take responsibility, a professional should act upon their responsibility to protect a child.

"In our village, people who mess up don't show up at the CJG. I know someone who has a 3-year-old boy who isn't talking yet. If she had been visiting the CJG regularly, it could have been detected earlier. And that's just it: that freedom can be very dangerous."
(Mother, three children)

Professional-client relationship: Both professionals and clients reported that using EPR-Youth contributed to a more equal relationship and collaboration between them. Collaboration evolved naturally when clients read their health records and became more involved in care processes. Moreover, the professional-client relationship was strengthened because the transparency of EPR-Youth enhanced clients' trust in CJG professionals. Parents emphasised that professional autonomy-supportive behaviour was essential to building a relationship and collaborating on an equal basis.

"If you want people to trust you a bit more…strengthen the bond with parents…if you want to be more on the same page, then I think transparency is important too."
(Mother, two children)
"As a mother with a first child, of course, you are nervous when you visit the CJG. So, when you read afterwards, they thought you were doing a good job… that's reassuring and makes your self-confidence grow."
(Mother, one child)

Data integration

The outcomes of both client questionnaire and focus group interviews show that using EPR-Youth contributes to client autonomy. Moreover, the qualitative findings expand on specific elements where this contribution occurs: ownership, motivation, and capability. Simultaneously, focus group interviews revealed possible limitations of autonomy for young adolescents or parents.

Clients participating in focus groups reported that professional autonomy-supportive behaviour was essential to building a relationship; thus, we expected to find a positive correlation between the extent to which professionals in an organisation reported autonomy-supportive behaviour and the extent to which clients visiting that organisation experienced autonomy. However, questionnaire outcomes did not support this assumption.

Discussion

General

In this study, we investigated whether using EPR-Youth in youth care and PCH contributed to experienced autonomy among adolescents and parents and whether professional autonomy-supportive behaviour added to that effect. We found that using EPR-Youth enhanced experienced autonomy among parents and adolescents, and professional autonomy-supportive behaviour was an important additional factor. Among adolescents, age also contributed to experienced autonomy.

Experienced autonomy

Parents and adolescents experienced more client autonomy 12 months after EPR-Youth was introduced. More specifically, they felt that EPR-Youth contributed to their sense of ownership and to their capability to manage care according to their motivation. Previous research on parent-held child health records shows results comparable to those of our study. Using such records contributed to feelings of empowerment and confidence among parents, helped them make decisions for their children, and strengthened the professional-client relationship (178-181).

Adolescent autonomy

No previous studies have investigated the effect of client-accessible records on adolescent autonomy. In our study, all adolescents perceived more client autonomy over time. Adolescents aged 16 years and older, however, showed a larger increase in autonomy than those aged 12–15 years. This might be a consequence of how Dutch privacy and healthcare legislation (Dutch Ministry of Justice, 2006) supports autonomy during adolescence. Regarding autonomy, adolescents represent a specific group transitioning from childhood to maturity (182). Gaining personal autonomy is part of this transition and is supported by most Western countries' legislation (59, 61, 183). At the age of 12, children supposedly have the capacities for decision-making, and simultaneously may need parental support to facilitate the process (184). Moreover, parents and professionals in our study assumed that 12-year-old children would also require support dealing with sensitive information in their records. Dutch legislation anticipates both capacities and a need for support, granting shared access to medical information to both parents and adolescents aged 12–16 years (136, 172). Consequently, younger adolescents are encouraged to make decisions with parents or legal guardians about their care, whereas adolescents aged 16 and older have more opportunities to make their own choices. Therefore, the stronger effect among older adolescents is probably due to a combination of age-dependent growth of autonomy and changes in legislation and rights from the age of 16.

Vulnerable groups

According to our findings, sex, educational level, native country, and family constitution did not influence client autonomy. Previous research showed, however, that vulnerable groups reported more benefits from using a client portal than average because reading their records increased their understanding of the care process and helped them make decisions about their care (101, 135) and that vulnerable groups particularly valued involvement of family and friends (98, 101, 135). A possible explanation for the difference between our outcomes and earlier research is that lower-educated and clients of non-Dutch nativity were underrepresented in our study and that the last group was not represented at all in our focus groups.

Professional autonomy-supportive behaviour

After 12 months, both portal users and non-users experienced more client autonomy, although portal users scored higher than non-users. This suggests that using EPR-Youth was not the only factor contributing to client autonomy (135). Focus group participants emphasised that an autonomy-supportive attitude was also an important factor, strengthening their sense of ownership and building an equal professional-client relationship. Irrespective of using client-accessible records, when professionals respect a client’s ownership over their care, support clients to use their capabilities, and follow a client’s intrinsic motivation, their behaviour stimulates client autonomy (168, 185). When autonomy-supportive behaviour is combined with client-accessible records, this combination of behaviour and technology enhances the professional-client relationship and helps persons to make better decisions about their care (186).

In line with literature and our qualitative data, we expected to find a correlation between professionals’ scores in one organisation and scores of clients visiting that organisation. This assumption was not supported by our quantitative data, perhaps because client scores could not be linked personally to their own care providers’ score.

Strengths and limitations

With this study, we examined client autonomy from a professional and client perspective and included both parents and adolescents in the client perspective. Combining quantitative and qualitative methods has proved useful in deepening our understanding of client autonomy.

The design, tailored to be feasible in a ‘care for youth’ context, had some limitations. Inviting clients during a regular visit to a CJG location resulted in including different client groups at baseline and follow-up. Consequently, establishing a causal relation between using EPR-Youth and experienced client autonomy proved difficult.

Contrastingly, the paired-measures design for the professional questionnaire would have allowed us to establish a causal relationship between using EPR-Youth and an autonomy-supportive attitude. However, the low response rate at T1, due to increased workload when the COVID-19 pandemic started, drastically reduced the possibility to pair data over three measurements. Therefore, we had to adapt our design and analysis plan, and re-invited all CJG professionals to complete the questionnaire at T2. Combining the analyses of paired and unpaired data, the analyses of unpaired data confirmed the analysis of paired data, leading to a stronger conclusion.

The small number of adolescent respondents and the underrepresentation of vulnerable groups diminished generalisability of our outcomes. Moreover, our study was conducted in a rural area with a relatively low educated population and a small minority with a migrant background.

More research is required, with larger numbers of adolescents and a broader representation of all population groups, to generate more generalisable outcomes in this specific target group. Furthermore, paired data are needed to establish a causal relationship between using client-accessible records and experienced autonomy.

Implications for practice

Our findings support the use of client-accessible records as a tool to enhance autonomy among parents and adolescents. However, when organisations implement client-accessible records with the aim of strengthening autonomy in this target group, two issues need addressing. First, professionals should adopt an autonomy-supportive attitude. Second, the phase between the age of 12 and 16, when parents and adolescents both have access rights, deserves attention. In this phase, adolescents should be encouraged to increasingly exercise their autonomy whereas parents should support their children in this process and gradually step back.

Conclusion

Our findings showed that using EPR-Youth increased perceived autonomy among parents and adolescents, contributing specifically to ownership, motivation, and capability. This contribution was stronger among adolescents aged 16 and older, probably due to different legal rights. Among younger adolescents, the balance between growing autonomy and need for parental support requires attention. Over time, no change in professional autonomy-supportive behaviour was found, although differences were found between professionals from different organisations. Clients considered professional autonomy-supporting behaviour essential to benefit from using EPR-Youth. Therefore, organisations implementing client-accessible records should address professional attitude. Follow-up research with paired data is needed to confirm that the found association between using EPR-Youth and perceived client autonomy is a causal relationship.

Acknowledgements

The authors want to thank all CJG-professionals who invited parents and adolescents to complete a client questionnaire. We further want to thank Klaudia Hoekstra, coach at the CJG's, for her role as focus group moderator; Hester Westerink (HW), medicine student, for her assistance with focus group transcripts and with a part of the qualitative analyses; and Anja Boeve, statistic at Wageningen University, for providing her insights and expertise on the statistical analysis of the quantitative data. Finally, we thank Hanneke Mateman and her colleagues at Movisie for their assistance with translating their client autonomy model.

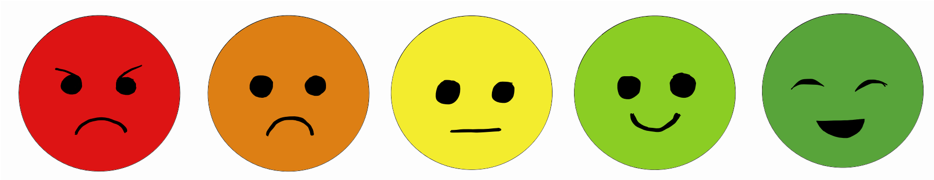
Appendices

Appendix 1: Client's questionnaire, experienced autonomy
Appendix 2: Professional's questionnaire
Appendix 3: Semi-structured questionnaire for focus group interviews
Appendix 4: Tables with demographic characteristics.
Appendix 5: Responses to professional questionnaire on autonomy-supportive behaviour.

Appendix 1: client's questionnaire: experienced autonomy.

With the following 5 questions, three quadrants of the Movisie model for stimulating client's autonomy were operationalized: ownership, capability and motivation. The same questions were used for parents and adolescents.

1. If you have questions, do we build further on the things you already know, the capacities you have and the things you already do? Answering categories: very angry smiley (1) to very happy smiley (5)



2. If you have questions, do we allow you to choose which plan and solution fits with you/ your child/your family?
   1. This never happens
   2. This happens occasionally
   3. This happens as often as not
   4. This happens often
   5. This always happens

3. Do you appreciate the possibility to read and write in your child's/ your record?

   Smiley faces from red (1) to dark green (5)

4. Does our advice usually match with your needs?

   Smiley faces from red (1) to dark green (5)

5. Continue on your own strength: Do our conversations help you/your family to (at a certain point) move on independently?
   1. They never help
   2. They almost never help
   3. They help as often as not
   4. They often help
   5. They always help

6. Portal use: have you ever accessed your client portal/ the client portal of your child?
   1. Yes, I have
   2. I tried, but it did not work (Analyzed as 'no')
   3. No, I have not

Appendix 2: professional's questionnaire: contribution to client's autonomy.

Every quadrant of the Movisie model was operationalized in two statements. Professionals were responding on a 5-point Likert scale, with the answering options as formulated below. To match high scores with positive opinions, all scores from the professional questionnaires were reversed.

Capability:

1. In conversations with parents/adolescents I ask what is going well.
2. In conversations with parents/adolescents I ask what they have already tried to resolve their problem.

Network:

3. In conversations with parents/adolescents I ask who else is concerned about the wellbeing of this adolescent/child and this family.
4. In conversations with parents/adolescents I ask who they want to involve in their situation.

Motivation

5. In solving an issue, I discuss with parents/adolescents what their values are for 'a good life'.
6. In solving an issue, it is most important what the parent/adolescent wants to achieve

Ownership

7. The parent/adolescent usually decides what he/she wants to keep and what needs to change.
8. I only contribute to the solution of an issue when the parent/adolescent indicates that this is necessary.

Answering options questions 1-5:

1 = always

2 = often

3 = 50/50

4 = sometimes

5 = never

Answering options questions 6-8:

1 = totally agree

2 = somewhat agree

3 = neutral

4 = somewhat disagree

5 = totally disagree

Appendix 3: semi-structured focus group interview guide.

Interview scope:

- Professionals – How do professionals experience the impact of using EPR-Youth on client autonomy?
    - » How do professionals feel about a client-accessible health record; what positive and negative connotations do they have?
- Parents/adolescents – How do parents and adolescents experience the impact of using EPR-Youth and its client portal on their autonomy?
    - » How do parents and adolescents feel about a client-accessible health record; what positive and negative connotations do they have?

Topic list:

- ***In general:*** what experiences can you describe, using EPR-Youth or the client portal?
    - » Positive, what is working well; in what way is it helpful?
    - » Negative, what could work better, what is not helping? Do you have any suggestions?
    - » Clients: were you aware of the existence of a client-accessible health record before you were invited to this interview? Have you logged in to the client portal?
    - » Clients: what is your opinion on the possibility to read all registrations?
    - » Clients: Has the care process or the communication with your caretaker altered in any way because of the use of EPR-Youth?
- *Autonomy*
    - » In what way does the use of EPR-Youth contribute to clients' autonomy?
        - ◊ *Clients* (explanation): with the term 'contributing to autonomy' we mean that you are in control of your own care process and make joint decisions with your care provider. We want to create care plans that fit with your personal needs and identity. We want to support that with the development of EPR-Youth. Do you experience that EPR-Youth strengthens your autonomy? What does it contribute to your autonomy that you can:
            - ⬩ Read everything we write.
            - ⬩ Ask questions in the portal.
            - ⬩ Check and manage your appointments.
            - ⬩ See in the view log which professional has been working in your EPR.
            - ⬩ Comment on our registrations
            - ⬩ Add your own information, care plan and hospital letters to EPR-Youth
    - » What is your role in stimulating clients' autonomy?
        - ◊ *Professionals*: informing clients, collaboration, explain view log/planning/questions, discuss registrations, grant access
        - ◊ *Professionals*: do you use all functionalities of EPR-Youth?
        - ◊ *Clients*: Do you use all functionalities of EPR-Youth? If not: why not? Would you want to use them? What would you need to use them?

- » What is needed to enhance autonomy?
- » What could you do?
- » What do you need from managers and staff?
- » What needs to be adapted in EPR-Youth?

Appendix 4: Respondent Characteristics

Table A: Client questionnaire
Table B: Professional questionnaire
Table C: Focus group participants

Table A: *Characteristics of parents and adolescents who completed the client questionnaire, at baseline and follow-up. Absolute numbers are given, and percentages between brackets. We distinguished three educational levels for parents and two for adolescents. For the variables educational level, sex, and native country, distribution within the source population is shown in percentages.*

	Parents		Adolescents		North-Veluwe
	Baseline n=1202 (%)	Follow-up n=914 (%)	Baseline n=202 (%)	Follow-up n=89 (%)	%
Educational level					
Low	150 (12.5)[a]	63 (7.4)[a]	138 (71.1)[a]	40 (56.3)[a]	30%
Middle	543 (45.2)[a]	414 (43.3)[a]	NA	NA	41%
High	509 (42.3)[a]	380 (38.9)[a]	56 (28.9)[a]	31 (43.7)[a]	29%
Missing	0	57	8	18	
Sex					
Male	126 (10.5)	97 (11.3)	95 (47.5)[a]	11 (14.3)[a]	50%
Female	1076 (89.5)	760 (88.7)	105 (52.5)[a]	66 (85.7)[a]	50%
Missing	0	57	2	12	
Native country					
The Netherlands	NA	791 (96.2)	NA	72 (97.3)	92%
Other	NA	31 (3.8)	NA	3 (2.7	8%
Missing	NA	92	NA	14	
Family composition					
2-Parent family	1017 (84.6)[a]	768 (90.0)[a]	147 (73.1)[a]	31 (41.3)[a]	-
Other situation	185 (15.4)[a]	85 (10.0)[a]	54 (26.9)[a]	44 (58.7)[a]	-
Missing	0	61	1	14	
Age children					
Children 0-3 y	949 (79.0)[a]	521 (61.1)[a]	NA	NA	-
Children 4-11 y	168 (14.0)[a]	255 (29.9)[a]	NA	NA	-
Children 12+	85 (7.1)[a]	77 (9.0)[a]	NA	NA	-
Missing	0	61	NA	NA	
Age adolescents					
12-15 years	NA	NA	169 (84.1)[a]	33 (42.9)[a]	-
16/17 years	NA	NA	21 (10.4)[a]	26 (35.1)[a]	-
18+ years	NA	NA	11 (5.5)[a]	17 (22.1)[a]	-
Missing	NA	NA	1	12	

Organisation					
PCH 0-3 yrs	891 (77.6)[a]	495 (57.5)[a]	NA	NA	-
PCH 4-18 yrs	86 (7.5)[a]	187 (21.7)[a]	119 (68.4)[a]	21 (32.3)[a]	-
Youth care	171 (14.9)[a]	179 (20.8)[a]	55 (31.6)[a]	44 (67.7)[a]	-
Unknown/missing	54	53	28	24	
Portal use					
No	415 (34.5)[a]	421 (46.2)[a]	202 (100)[a]	73 (83.9)[a]	-
Yes	787 (65.5)[a]	490 (53.8)[a]	NA[a]	14 (16.1)[a]	-
Missing	0	3	0	2	

[a]: Significant difference between baseline and follow-up group, as tested with Pearson χ^2, $p<0.001$.
NA = not applicable
PCH 0-3 = preventive child healthcare for children up to 3 years old
PCH 4-18 = preventive child healthcare for children aged 4 to 18 years old.

Table B: *Characteristics of professional questionnaire respondents at baseline (T0) and two follow-up moments (T1 and T2, five and 24 months after introduction of EPR-Youth). Percentages of the total number of respondents are represented between brackets. Differences in respondent characteristics between T0, T1 and T2 were tested with Pearson Chi-square, at a 0.05 significance level.*

	T0	T1	T2		
	n=100 (%)	n=57 (%)	n=110 (%)	Pearson χ^2	2-sided p-value
Sex					
Male	9 (9.0)	4 (7.0)	9 (8.2)	0.19	0.91
Female	91 (91.0)	53 (93.0)	101 (91.8)		
Working experience					
0-10 years	35 (35.0)	18 (31.6)	50 (45.5)	6.85	0.14
10-20 years	35 (35.0)	18 (31.6)	38 (34.5)		
>20 years	30 (30.0)	21 (36.8)	22 (20.0)		
Profession					
Behavioural expert	4 (4.0)	1 (1.8)	8 (7.3)	3.46	0.90
PCH Doctor	11 (11.0)	7 (12.3)	10 (9.1)		
Youth Care Worker	58 (58.0)	31 (54.4)	62 (56.4)		
PCH Nurse	25 (25.0)	17 (29.8)	28 (25.5)		
PCH Speech therapist	2 (2.0)	1 (1.8)	2 (1.8)		
Organisation					
PCH 4-18	12 (12.0)	4 (7.0)	12 (10.9)	2.78	0.60
PCH 0-3	26 (26.0)	21 (36.8)	30 (27.3)		
Youth Care	62 (62.0)	32 (56.1)	68 (61.8)		

PCH = preventive child healthcare
PCH 0-3 = preventive child healthcare for children up to 3 years old
PCH 4-18 = preventive child healthcare for children aged 4 to 18 years old.

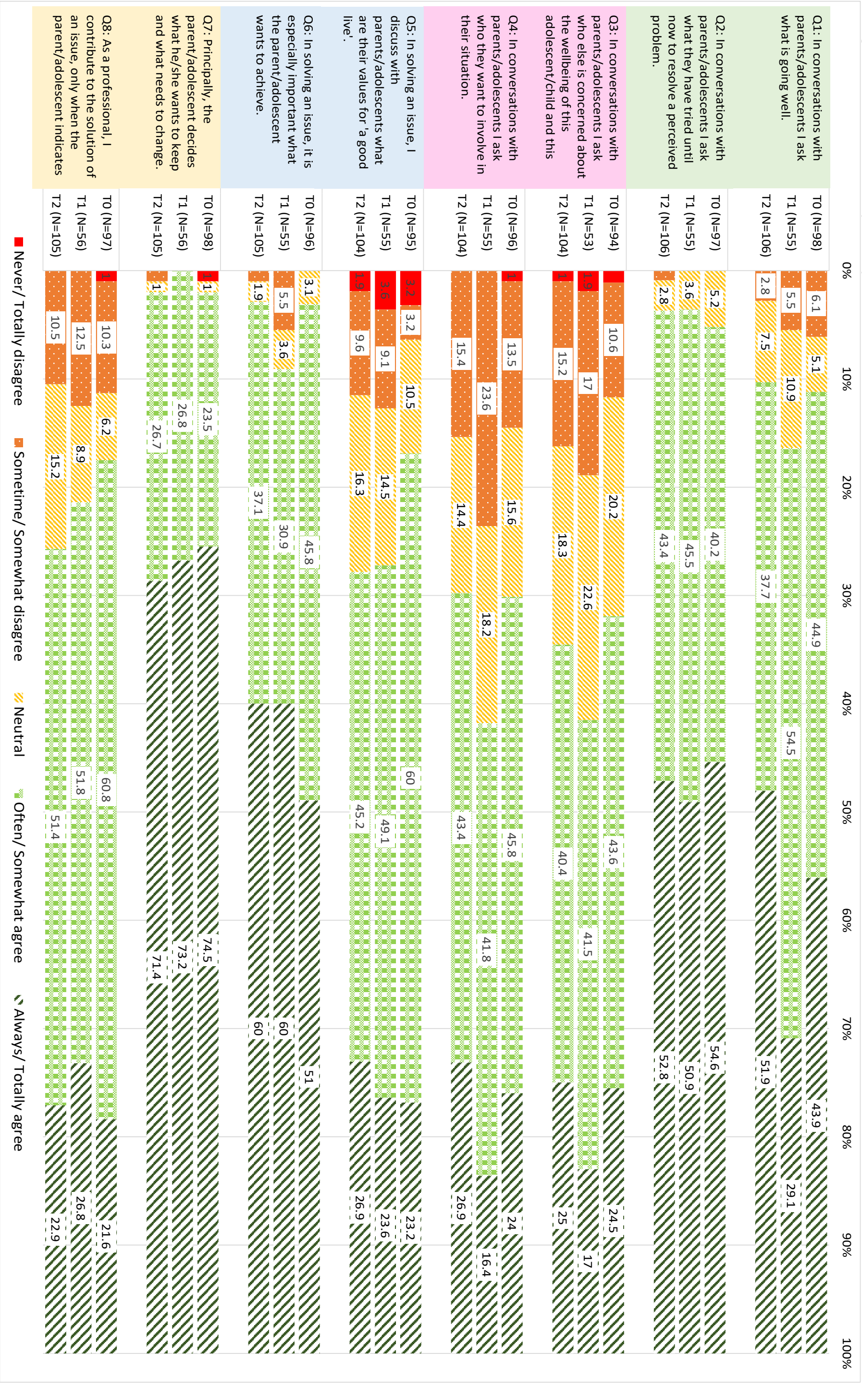
Table C: *Characteristics of focus group participants, separately for clients (n=12) and professionals (n=12). Percentages of the total number of participants from each group are represented between brackets.*

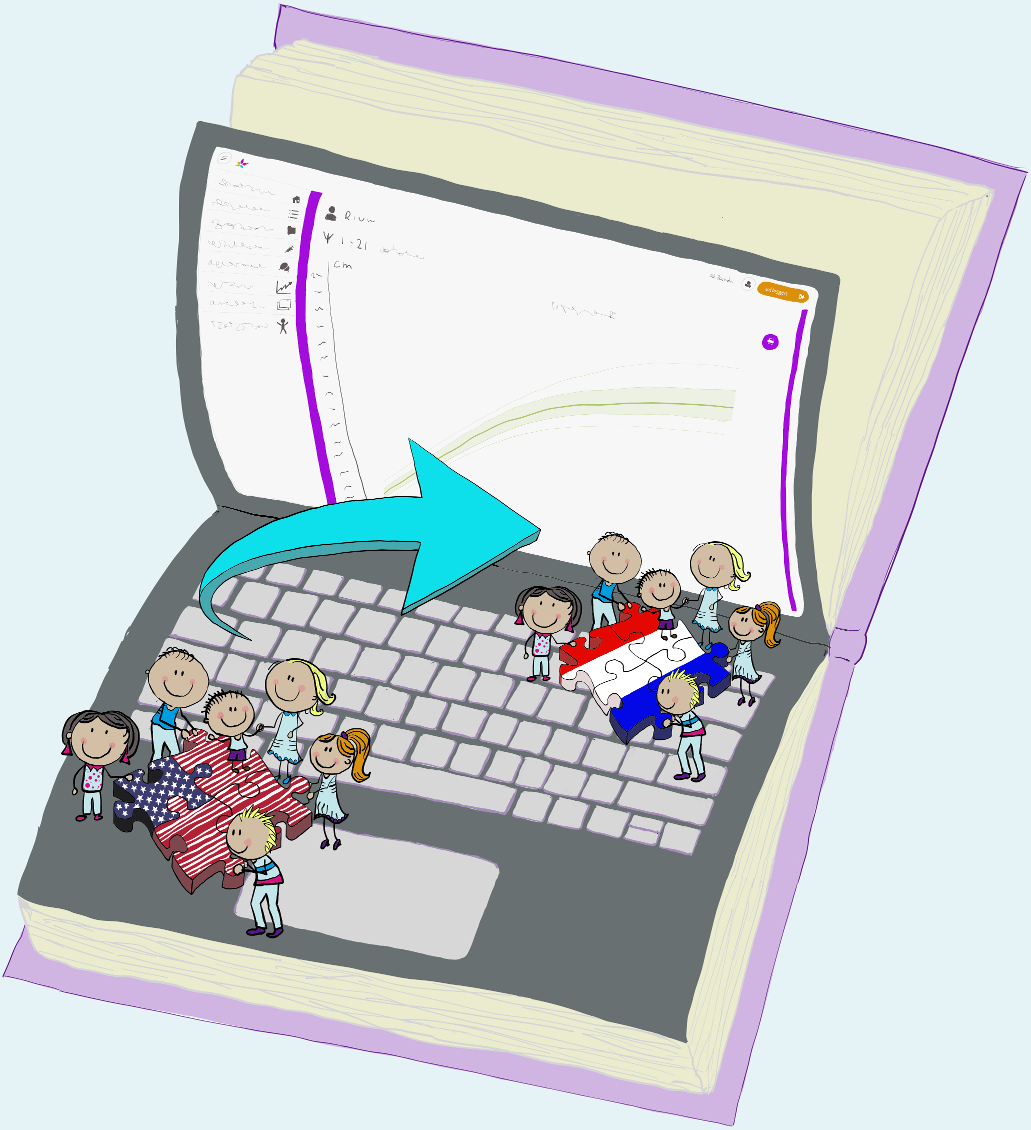
	Clients	n=12 (%)
Parent or adolescent	Parent	8 (67)
	Adolescent	4 (33)
Sex	Male	4 (33)
	Female	8 (67)
Educational level	High	4 (33)
	Middle	5 (42)
	Low	3 (25)
Native country	the Netherlands	12 (100)
	Other	0 (0)
PCH/ Youth care	PCH	4 (33)
	Youth care	8 (67)
	Professionals	n=12 (%)
Sex	Male	1 (8)
	Female	11 (92)
Working experience	Less than 5 years	4 (33)
	5 to 10 years	2 (17)
	More than 10 years	6 (50)
Profession	Doctor	2 (17)
	Nurse	3 (25)
	Behavioural scientist	1 (8)
	Youth worker	3 (25)
	Administrative	2 (17)
	Screener	1 (8)
Organisation	Youth care	4 (33)
	PCH 0-3	6 (50)
	PCH 4-18	2 (17)

PCH = preventive child healthcare
PCH 0-3 = preventive child healthcare for children up to 3 years old
PCH 4-18 = preventive child healthcare for children aged 4 to 18 years old.

Appendix 5: Responses to professional questionnaire on autonomy-supportive behaviour.

For each question, a group of three stacked bars represents the responses given at T0, T1 and T2, distinguishing between never/totally disagree, sometimes/somewhat disagree, neutral, often/somewhat agree or always/totally agree. At the left of each bar, the number of respondents is given. Question 1 and 2 belong to the element 'Ownership'; question 3 and 4 belong to the element 'Network'; question 5 and 6 belong to the element 'Motivation'; question 7 and 8 belong to the element 'Capability'.

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Chapter 5

A tool to investigate interdisciplinary collaboration within Dutch care for youth, translation of the American ‘Index for Interdisciplinary Collaboration’.

This chapter is published as:

van’t Hoff, E. J., Benjamins, S. J., & Haveman-Nies, A. (2020). Een instrument om interdisciplinaire samenwerking te onderzoeken binnen de Nederlandse zorg voor jeugd. JGZ Tijdschrift voor jeugdgezondheidszorg, 52(1), 14-19. doi: 10.1007/s12452-019-00204-4

Abstract

Introduction: Since the transition of youth care, interdisciplinary collaboration in youth care has become increasingly important. In the Dutch North-Veluwe region, the American 'Index of Interdisciplinary Collaboration' (IIC) was translated to examine collaboration within the local Centres for Youth and Family.

Aim: This article describes the process of translation and validation of the questionnaire.

Methods: The IIC consists of 42 questions, divided into five components. The questionnaire was translated into Dutch, followed by back-translation and adaptation to the context of Dutch care for youth. Supplemented with demographic items, the questionnaire was distributed to all 135 CJG staff in the North-Veluwe region. Answers could be given on a 5-point Likert scale. Construct validity and internal consistency were measured by Exploratory Factor Analysis and Cronbach's Alpha.

Results: The questionnaire response rate was 87%. The exploratory factor analysis yielded eight factors, with clear clustering for two of the five components and diffuse loading across multiple factors for the remaining three. All components of the translated IIC showed a high (>0.70) Cronbach's Alpha, except for 'Flexibility' (0.53).

Conclusion: The translated IIC seems to be a useful and valid instrument to measure interdisciplinary cooperation in youth care in the Netherlands. The component 'Flexibility' needs further adjustment. For a stronger substantiation of the validity and usability, additional research is needed, with more and possibly other respondents.

Introduction

Collaboration is an important part of the work of a professional in preventive child healthcare (PCH), and this importance will only increase. Since the transition of Dutch Youth Care became effective in 2015, preventive child healthcare and social youth care increasingly need to collaborate in the case of children and families. This happens under different names and with different constructions: Centres for Youth and Family (CJG), Parent and Child Teams (OKT), Youth and Family Teams (JGT), social district teams, etc. Sometimes preventive child healthcare is part of these teams, sometimes they work in parallel to the teams, but in all cases collaboration is necessary. The Dutch North-Veluwe region has Centres for Youth and Family formed by the regional Municipal Health Service (GGD NOG), Icare JGZ, and the Youth Foundation Noord-Veluwe. GGD NOG provides preventive child healthcare for children aged 4-18 years, Icare JGZ provides preventive child healthcare for children aged 0-4 years, and the Youth Foundation North-Veluwe provides out-patient youth care to young people and families. Together, these organisations provide access to intensive youth care and youth mental healthcare. The local municipalities commissioned them to integrate their services for families and children. In the context of this integration, a shared health record (EPR-Youth) is being developed, fully accessible to parents and young people. A study is being conducted, consisting of a process and effect evaluation. With the effect evaluation we investigate to what extent the use of EPR-Youth contributes to better interdisciplinary collaboration between professionals in the Centre for Youth and Family, and whether the degree of autonomy among parents and adolescents increases when they have full access to the content of their health record.

To examine change in interdisciplinary collaboration, we used an existing and already validated American questionnaire on interdisciplinary collaboration between 'social workers' and other disciplines, the 'Index for Interdisciplinary Collaboration' (IIC) (80, 187). Based on research between social workers, Bronstein et al. developed a model for interdisciplinary cooperation and this questionnaire (Table 1), (81). In her model, Bronstein distinguishes five core components of interdisciplinary collaboration:

- Interdependence; each professional knows himself to be dependent on the other for achieving goals and performing tasks.
- Newly Developed Professional Activities; for example, a method, protocol, or program that arises in collaboration and results in achieving goals that individual disciplines could not have achieved.
- Flexibility; the deliberate occurrence of role blurring. For example, reaching a compromise in the face of disagreement or creatively adapting the professional role to what is needed in a specific situation.
- Collective Ownership of Goals; the shared responsibility to achieve set goals.
- Reflection on the Process; thinking and talking among the collaborating professionals

about the collaborative process: what goes well and what can be improved?
In addition, the model describes factors that can influence interdisciplinary collaboration both positively and negatively, namely professional role, history of collaboration, structural characteristics, and personal characteristics. The questionnaire did not include these influencing factors.

This article describes the process of translating and validating this American questionnaire and examines whether the translated questionnaire is a reliable measurement tool in the context of Dutch youth care.

Methods

The guideline of Beaton et al. was used as a starting point for the translation (188). This guideline describes the different steps that must be taken when adapting a questionnaire for another language and context. Generally, this includes a translation back and forth and a pretest.

Translation

The questionnaire was translated by one of the authors (SJB) and a non-medical colleague. A student with an English Cambridge C2 language proficiency level retranslated the questionnaire. A check was performed by a second student with the same language proficiency level in English. Differences between original and retranslation were compared with the translated questionnaire by the four translators. Through discussion and consultation of English language dictionaries, the most appropriate translation was chosen.

Adaptation to context

As a pretest and to make the questionnaire appropriate for the context of the Centre of Youth and Family (CJG), all questions were discussed with a team of colleagues (a policy officer and three implementing professionals from all three organisations within the CJG). Context-specific terminology such as 'colleague from another discipline' was replaced by more CJG-specific expressions, such as in this case 'my CJG colleague'. The questionnaire was also reviewed for readability. Finally, the modified questionnaire was compared with the original as a final check (SJB and students) to ensure that the modifications had not produced any substantial differences from the original questionnaire.

Measurements

The translated questions were included in an online employee questionnaire along with questions about demographic characteristics (including age, gender, work experience, discipline, and organisation). Comparable with the original questionnaire, respondents answered on a five-point Likert scale, ranking from 1, "totally agree", to 5, "totally disagree”. Additionally, an option 6 (don't know/not applicable) was added, since some of the CJG professionals had an administrative role and therefore might not be able to answer questions related to client contacts or care content.

Data Collection

Data were collected from November 9 to December 30, 2018, using the online survey tool Enalyzer. Both professionals with direct client contact (youth doctors, youth nurses, behavioural health professionals and youth and family workers) and administrative professionals (assistants, screeners, planners, and secretaries) from all CJG locations in the Noord-Veluwe region received an invitation to complete the questionnaire. A link to the questionnaire was distributed via e-mail, followed by reminders two and six weeks later.

Statistical Analysis

Factor Analysis

The Statistical Package for the Social Sciences (SPSS), version 25, was used to perform the analyses. First, an Exploratory Factor Analysis (EFA) was performed on the translated questionnaire. A Maximum Likelihood extraction with Promax rotation was used to gain insight into the structure of factors in the data. The Kaiser-Meyer-Olkin (KMO) test and Bartlett's test were performed to investigate whether the use of a factor analysis was justified. With a value of 0.85, the KMO remained above the cut-off value of 0.5. Together with a statistically significant Bartlett's test ($p \leq 0.001$), this supported the use of a factor analysis. Questions 26, 36, and 41 were excluded from the analysis because they did not cluster with other questions (anti-image correlation <0.5). Eight factors were identified with eigenvalues above 1.0 and were retained in accordance with the Kaiser-Guttman criterion. All assumptions of the EFA (normality, homogeneity of variance, and outliers), except sample size, were met.

Cronbach's Alpha analysis

Internal consistency was determined using a Cronbach's Alpha analysis for both the full set of questions on collaboration and for the five components of interdisciplinary collaboration separately.

Results

The translated and adapted questionnaire (Table 1) was distributed to 135 employees. Of these, 117 employees eventually completed the questionnaire in full (response rate of 87 %). This group consisted of 108 women (92%) and 9 men (8%). The group of employees between 50 and 60 years old was the largest age group (30%).

Table 1: Translated and context-adjusted questionnaire about interdisciplinary collaboration. The original IIC-questionnaire can be found in the article by Bronstein et al. (1,2) The names of the five components are in italics. All answers were categorized on a 5-point Likert scale: totally agree(1), agree(2), neutral(3), disagree(4) and totally disagree(5). An additional option 'not applicable' (6) was added.

Questions in Dutch	Questions IIC, adapted to care for youth context
Onderlinge afhankelijkheid	Interdependency
1. Ik maak gebruik van de specifieke expertise van mijn CJG-collega's.	I utilize my CJG-colleagues for their specific expertise.
2. Ik geef consequent feedback aan mijn CJG-collega's.	I consistently give feedback to my CJG-colleagues.

3. Mijn CJG-collega's maken voor verschillende taken gebruik van mij en mijn vakgenoten.	My CJG-colleagues utilize me and my colleagues for a range of tasks.
4†. Samenwerking met mijn CJG-collega's is niet belangrijk voor mijn mogelijkheden om jeugdigen en ouders te helpen.	Teamwork with my CJG-colleagues is not important in my ability to help parents and adolescents.
5†. Mijn CJG-collega's en ik communiceren zelden.	My CJG-colleagues and I rarely communicate.
6. Mijn CJG-collega's begrijpen het onderscheid tussen mijn rol en hun rol goed.	The CJG-colleagues with whom I work have a good understanding of the distinction between my role and their role(s).
7†. Mijn CJG-collega's verwijzen ouders en jeugdigen niet voor de passende redenen door naar mij.	My CJG-colleagues make inappropriate referrals to me.
8. Ik kan aangeven op welke terreinen mijn professionele rol zich onderscheidt van die van CJG-collega's.	I can define those areas that are distinct in my professional role from that of the CJG-colleagues with whom I work.
9. Ik zie het als een deel van mijn professionele rol om anderen met wie ik werk te ondersteunen in hun rol.	I view part of my professional role as supporting the role of others with whom I work
10. Mijn CJG-collega's verwijzen vaak naar mij.	My CJG-colleagues refer to me often.
11†. Samenwerken met CJG-collega's maakt geen onderdeel uit van mijn taakomschrijving.	Cooperative work with colleagues from other disciplines is not a part of my job description.
12†. Mijn CJG-collega's behandelen mij niet als een gelijke.	My CJG-colleagues do not treat me as an equal.
13. Mijn CJG-collega's vinden dat zij zonder mij en mijn vakgenoten hun werk niet even goed kunnen doen.	My CJG-colleagues believe that they could not do their jobs as well without the assistance of social workers.
Nieuw ontwikkelde professionele activiteiten	Newly created professional activities
14. Uit het gezamenlijk werk van de verschillende disciplines binnen het CJG komen nieuwe onderscheidende programma's voort.	Distinct new programs emerge from the collective work of all colleagues within the CJG.
15. Protocollen en werkafspraken binnen het CJG weerspiegelen dat er samenwerking plaatsvindt tussen de verschillende disciplines/organisaties.	Organisational protocols within the CJG reflect the existence of cooperation between professionals from different disciplines
16. Er bestaan formele procedures om de dialoog tussen professionals van de verschillende disciplines te faciliteren (bijv. In gestructureerde gezamenlijke overleggen of casusbesprekingen).	Formal procedures/mechanisms exist for facilitating dialogue between professionals from different disciplines (e.g. in structured dialogue sessions or case discussions)
17†. Ik ben me er niet van bewust dat er in mijn CJG (of op regionaal niveau) een project, task force of commissie is ontstaan vanuit gezamenlijke inspanning tussen de disciplines/organisaties.	I am not aware of situations in my CJG (or regionwide) in which a coalition, task force or committee has developed out of interdisciplinary efforts
18. Werken met CJG-collega's leidt tot resultaten die we alleen als vakgenoten niet hadden kunnen bereiken.	Working with CJG-colleagues leads to outcomes that we could not achieve alone.
19. Uit mijn werk met CJG-collega's komen creatieve resultaten voort die ik niet had kunnen voorspellen.	Creative outcomes emerge from my work with CJG-colleagues that I could not have predicted.
Flexibiliteit	Flexibility
20. Als het belangrijk is, ben ik bereid taken op te pakken die buiten mijn taakomschrijving vallen.	I am willing to take on tasks outside of my job description when that seems important.
21†. Ik ben niet bereid autonomie in te leveren om bij te dragen aan het gemeenschappelijk oplossen van problemen.	I am not willing to sacrifice a degree of autonomy to support cooperative problem solving.
22. Ik gebruik formele en informele manieren om met mijn CJG-collega's problemen op te lossen.	I utilize formal and informal procedures for problem solving with my CJG-colleagues.
23†. Mijn CJG-collega's houden op een rigide wijze vast aan hun taakomschrijving.	The CJG-colleagues with whom I work stick rigidly to their job descriptions.

24. Mijn CJG-collega’s en ik werken op veel verschillende manieren met elkaar samen.	Creative outcomes emerge from my work with CJG-colleagues that I could not have predicted.
Gezamenlijke verantwoordelijkheid voor doelen	Shared ownership of goals
25. CJG-collega’s waar ik mee samenwerk moedigen betrokkenheid van familieleden bij begeleiding of hulpverleningstrajecten aan.	CJG-colleagues with whom I work encourage family members’ participation in the care process.
26†. Mijn CJG-collega’s zijn niet gemotiveerd om samen te werken.	My CJG-colleagues are not committed to working together.
27. Mijn CJG-collega’s spannen zich met mij in om conflicten te exploreren en op te lossen.	My CJG-colleagues work through conflicts with me in efforts to resolve them.
28. Wanneer collega’s van verschillende disciplines samen beslissingen nemen onderzoeken ze gestructureerd verschillende oplossingsrichtingen.	When CJG-colleagues make decisions together they go through a process of examining alternatives.
29. Het contact met mijn CJG-collega’s vindt plaats in een klimaat waar ruimte is om van elkaar te verschillen en het oneens te zijn.	My interaction with my CJG-colleagues occurs in a climate where there is freedom to be different and to disagree.
30. Onze klanten (ouders/jongeren) nemen deel aan interdisciplinaire overleggen die hen betreffen.	Our customers (parents/adolescents) participate in interdisciplinary planning that concerns them.
31. Professionals van alle verschillende disciplines nemen verantwoordelijkheid voor het ontwikkelen van inhoudelijke werkwijzen en protocollen.	Colleagues from all professional disciplines take responsibility for developing care plans.
32†. Bij het implementeren van inhoudelijke werkwijzen en protocollen doen niet alle disciplines binnen het CJG mee.	Colleagues from all disciplines do not participate in implementing care plans.
33. Professionals van de verschillende disciplines zijn rechtdoorzee als ze informatie delen met klanten (ouders/jongeren).	My CJG-colleagues and I are straightforward when sharing information with parents and adolescents.
Reflectie op werkproces	Reflection on process
34. Mijn CJG-collega’s en ik bespreken regelmatig verschillende strategieën om onze werkrelatie te verbeteren.	My CJG-colleagues and I often discuss different strategies to improve our working relationships.
35. Mijn CJG-collega’s en ik spreken over manieren om andere professionals bij ons werk te betrekken.	My CJG-colleagues and I talk about ways to involve other professionals in our work together
36†. Mijn CJG-collega’s doen geen moeite om een positief klimaat te creëren binnen onze organisatie.	My CJG-colleagues do not attempt to create a positive climate in the CJG.
37. Ik ben optimistisch over de mogelijkheden van mijn CJG-collega’s om met mij te werken aan het oplossen van problemen.	I am optimistic about the ability of my CJG-colleagues to work with me to resolve problems
38. Ik help mijn CJG-collega’s om conflicten met andere professionals rechtstreeks bespreekbaar te maken.	I help my CJG-colleagues to address conflicts with other professionals directly.
39. Als er belemmeringen zijn om succesvol samen te werken is het net zo waarschijnlijk dat mijn CJG-collega’s dit aan de orde stellen als dat ik het doe.	My CJG-colleagues are as likely as I am to address obstacles to our successful collaboration
40. Mijn CJG-collega’s en ik spreken over onze professionele overeenkomsten en verschillen, zoals onze rol, competenties en stereotypes.	My CJG-colleagues and I talk together about our professional similarities and differences including role, competencies and stereotypes.
41†. Mijn CJG-collega’s en ik evalueren ons werk niet samen.	My CJG-colleagues and I do not evaluate our work together
42. Ik bespreek samen met mijn CJG-collega’s in welke mate ieder van ons betrokken moet zijn bij een bepaalde casus.	I discuss with my CJG-colleagues the degree to which each of us should be involved in a particular case.

†These questions have been worded reversely, to minimize the possibility of response bias.

Table 2: Explorative Factor Analysis. Pattern matrix. The table shows on which factor each item (V1-V42) is loading. Maximum Likelihood Extraction, Promax Rotation with Kaiser Normalization.

	Factor							
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
V1		0.553						
V2		0.715						
V3		0.618						
V4			0.939					
V5			0.608					
V6		0.651						
V7			0.725					
V8		0.671						
V9		0.373						
V10		0.664						
V11			0.622					
V12			0.378		0.546			
V13	0.507							
V14	0.841							
V15	0.645							
V16	0.677							
V17				0.687	0.415			
V18						0.960		
V19				0.474			0.322	
V20						0.319		
V21			0.395					
V22							0.437	
V23					0.731			
V24							0.962	
V25	0.434			0.352				
V26†								
V27				0.304				
V28	0.650							
V29		0.464						
V30				0.627				
V31	0.617							
V32					0.476			
V33	0.616							
V34								0.826
V35				0.528				0.330
V36†								
V37		0.357					0.347	
V38				0.625				
V39	0.666	0.365						
V40	0.536							
V41†								
V42	0.556							

Factorloadings <0.30 are not showed in this table.

Factor analysis

The eight identified factors together explained 64% of all variance, with the first factor explaining 33% of all variance. The remaining seven factors explained a smaller portion of the variance, namely: factor 2: 7.4%; factor 3: 5.4%; factor 4: 5.0%; factor 5: 4.3%; factor 6: 3.5%; factor 7: 3.2% and factor 8: 2.7%. Table 2 presents the pattern matrix with the clustering of the 42 items on the eight factors. The items of Interdependence (items 1-13) predominantly loaded on factors 2 and 3; the items of Newly Developed Professional Activities (items 14-19) loaded on factors 1 and 4; Flexibility (items 20-24) loaded on factors 3, 4, 5, 6 and 7; Collective Ownership of Goals (items 25-33) loaded on factors 1, 4 and 5 and Reflection on the Process (items 34-42) loaded on factors 1, 2, 4, 7 and 8.

Cronbach's Alpha

Table 3 shows the results of the Cronbach's Alpha analysis for both Bronstein's complete 42-item questionnaire and each individual core component of the IIC. Cronbach's Alpha was 0.92 for Bronstein's 42-item questionnaire. For the individual components, the Cronbach's Alpha was between 0.72 (Newly Developed Professional Activities) and 0.82 (Reflection on the Process). Only the Flexibility component scored lower at 0.53. The analysis showed that no question in the translated questionnaire increased Cronbach's Alpha after removal.

Table 3: Internal consistency, measured with Cronbach's Alpha, for the whole questionnaire. and for each component separately.

Component	N items	Cronbach's Alpha
Full IIC Questionnaire	42	0.921
Interdependency	13	0.788
Newly Developed Professional Activities	6	0.724
Flexibility	5	0.534
Collective Ownership of Goals	9	0.776
Reflection on Process	9	0.822

Discussion

The purpose of this study was to test the reliability of the translated IIC in the context of youth care in the Netherlands. The components 'Interdependence' and 'Newly Developed Professional Activities' showed good internal consistency and construct-validity in both EFA and Cronbach's Alpha. The components 'Collective Ownership of Goals' and 'Reflection on the Process' also scored well in the Cronbach's Alpha analysis but showed diffuse loading on several factors in the EFA. Flexibility scored lowest of all components in both the Cronbach's Alpha analysis and the EFA. The diffuse loading of aforementioned three components on different factors was the most striking difference from Bronstein's findings.

Translation

With the translation of the questionnaire, we deviated slightly from the guideline: the forward-translation was made by two people together, rather than independently. The translation back was performed and checked by two students with the highest level of proficiency in English (Cambridge C2), rather than native speakers. The guideline recommends independent translations and a back-translation by a native speaker to achieve the most consistent translation possible. A study of interdisciplinary collaboration between occupational physicians and mental health physicians by Holwerda et al. translated the same questionnaire, although in a different context (189, 190). In this study, a forward translation was performed by two researchers, followed by a discussion with a third researcher and a pretest among ten professionals. A comparison between the two translations did not reveal any significant differences in the content of the questions, although both translations were not performed strictly according to the guidelines.

Factor Analysis

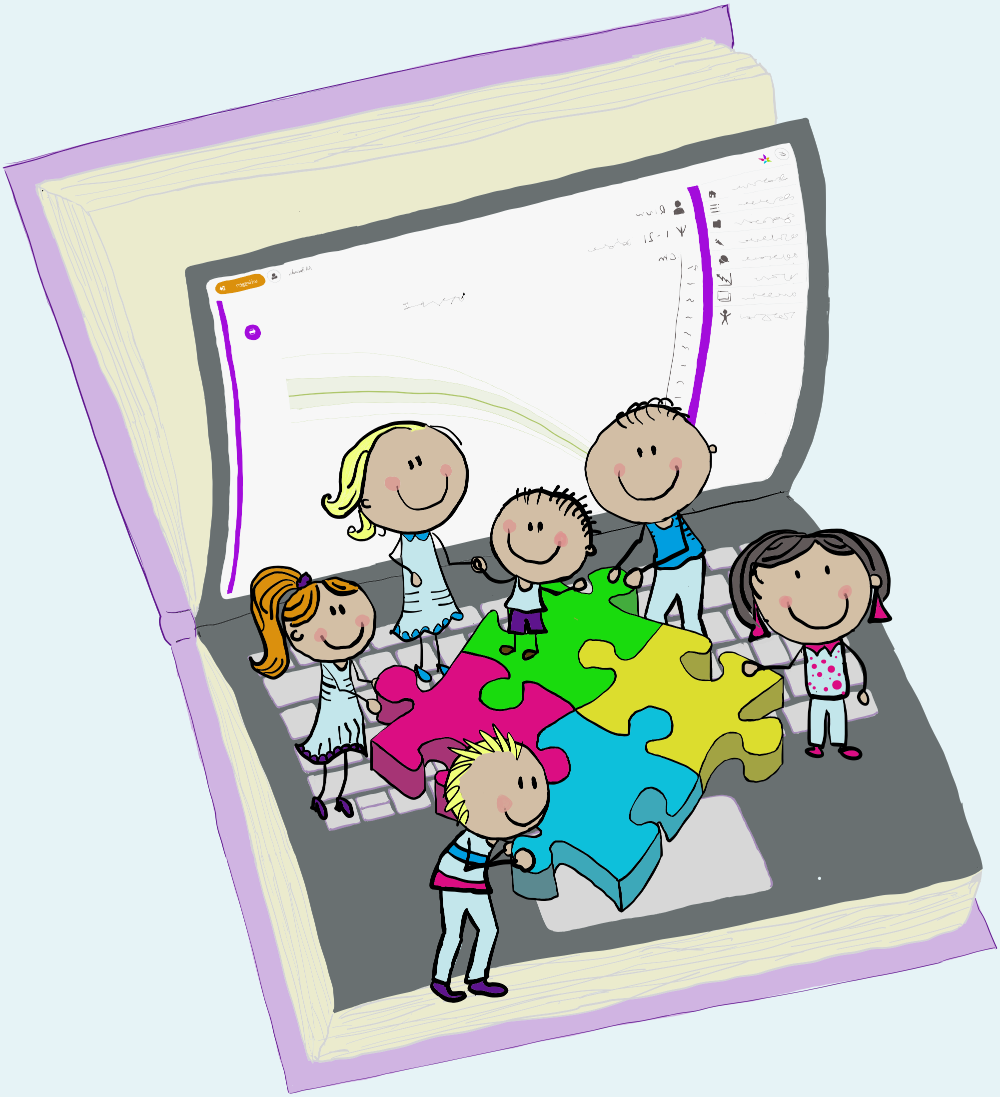
The factor analysis revealed eight factors, where Bronstein et al. identified five. Among these, the questions on "Interdependence" loaded on factors 2 and 3 and the questions on "Newly Developed Professional Activities" loaded on factors 1 and 4. The other components loaded diffusely across several factors. In Bronstein's study, the five components loaded more clearly on 1 factor, or at most on 2 factors. We can think of a few explanations for these differences. First, a different rotation method was used to that in Bronstein's study: we used the Promax instead of the Varimax. The reason for this is that we expected the factors to correlate. When applying other rotation methods, no better approximation of Bronstein's results was found. Second, Bronstein's questionnaire surveyed only non-administrative professionals while this study also included administrative professionals. This choice was made because they are seen as an essential part of the multidisciplinary team. However, this made it necessary to add a response option 'don't know/not applicable'. Both this addition and the inclusion of administrative professionals could have affected the factor analysis. When repeating the factor analysis with the exclusion of support staff or labelling the response category 'don't know/not applicable' as 'missing', however, the result did not approximate Bronstein's results better. Finally, and this seems the most likely explanation for the difference, the sample was not very large. A good EFA requires a sample with at least 5 respondents for each individual item in a questionnaire. This meant that the number of respondents should have been at least 210, while the number of respondents was 117. Because it was not certain that the factor analysis was sufficiently reliable based on this small sample size, and there was also no possibility to increase the sample size, we decided to adopt the factors and corresponding division into components from Bronstein’s study. For these five components, the Cronbach's Alpha was calculated.

Cronbach's Alpha

The Cronbach's Alpha scores were high and were in high agreement with the scores from Bronstein's study. Low Cronbach's Alpha scores were found for the component 'Flexiblity' in the translated (0.53) and original (0.62) questionnaires. If the Cronbach's Alpha is lower than 0.70, the internal validity of the construct is insufficient. After closer inspection of the questions in this component, it seems that not one, but two constructs are being measured. The questions not only address flexibility in task perception, but they also address flexibility in solving issues. Flexibility in task perception is partly determined by the space professionals are allowed by managers to deal with their tasks in a flexible way. The CJGs employ many professionals who, although they are supposed to be self-managing, come from a culture where they had to account for everything to managers and supervisors. Flexibility in solving issues is more person-dependent, although organisational culture plays a role as well. We agree with Bronstein's conclusion that flexibility as a construct should be better elaborated in the questionnaire. In other studies where the IIC was also used, 'Mutual Dependence' and 'Flexibility' were often merged(5, 6). However, this is not supported by Bronstein's factor analysis.

Conclusion

This research indicates that the IIC has been consistently translated and adapted to the context of youth care in the Netherlands and that the translated questionnaire is a reliable instrument to measure interdisciplinary cooperation in youth care. The outcomes of the baseline measurement support this assumption. Although the results cannot be shared at this stage of the research, the outcomes proved to be largely in line with how CJG-professionals currently experience their interdisciplinary collaboration. With this translated questionnaire an instrument is available with which an important aspect of quality of care can be visualized, both by preventive child healthcare organisations and other organisations in youth care. Regarding the component 'Flexibility', further modification of the questionnaire is necessary, since the internal consistency is too low, and merging Flexibility with Interdependence does not seem to be the best solution. In addition, repetition of the EFA and Cronbach's Alpha with a larger research group is needed to make a definitively positive statement about the construct validity of the translated questionnaire. The final steps in the process would be to further test validity and usability.



Chapter 6

Enhancing interdisciplinary collaboration between youth care professionals using an electronic health record; a mixed methods intervention study.

This chapter is submitted as:

Benjamins J, de Vet E, Haveman-Nies A. (2023) Enhancing interdisciplinary collaboration between youth care professionals using an electronic health record; a mixed methods intervention study.

Abstract

Objective: The aim of this study was to investigate whether using a shared electronic health record (EPR-Youth) strengthened interdisciplinary collaboration between professionals in youth care and child healthcare.

Methods: In a mixed methods design, two partly overlapping samples of professionals completed questionnaires before introduction of EPR-Youth (n=117) and 24 months thereafter (n=127). Five components of interdisciplinary collaboration (interdependence, newly created professional activities, flexibility, collective ownership of goals, and reflection on processes) were assessed. Midway through the study period, focus group interviews were held with 12 professionals, examining how EPR-Youth contributed to interdisciplinary collaboration.

Results: Professionals reported significantly more positive on flexibility after introduction of EPR-Youth than before. For the other components of collaboration, professionals scored slightly, but not significantly, more positive. Focus group participants reported that using EPR-Youth strengthened their sense of 'interdependence' and 'collective ownership of goals', and contributed to 'newly created professional activities'. At baseline, levels of interdisciplinary collaboration differed between organisations. Focus group participants confirmed these differences and attributed them to different facilitation of interdisciplinary collaboration.

Conclusion: This study suggests that using EPR-Youth can foster interdisciplinary collaboration. Organisational differences underline that implementing an EPR alone does not suffice: a shared vision and organisational facilities are needed to further strengthen interdisciplinary collaboration.

Introduction

Interdisciplinary collaboration is considered crucial in healthcare and social care to deliver high quality care. Most western countries face an increasing complexity of health problems that can only be effectively addressed in collaboration between different medical and non-medical professionals (191). Approaching complex problems from each domain separately might cause scattered care accompanied by rising costs. This risk arises in adult health care, where comorbidity requires a multidisciplinary approach. In healthcare and social care for children, however, interdisciplinary collaboration becomes urgent as well: children and families meet complex problems that are interconnected across different live domains, such as school, family and community systems (192).

Interdisciplinary collaboration in healthcare can be defined as an interpersonal process between healthcare professionals from multiple disciplines, with shared objectives, decision-making, responsibility, and power, working together to achieve goals that would not be achievable by one team member alone (193, 194).

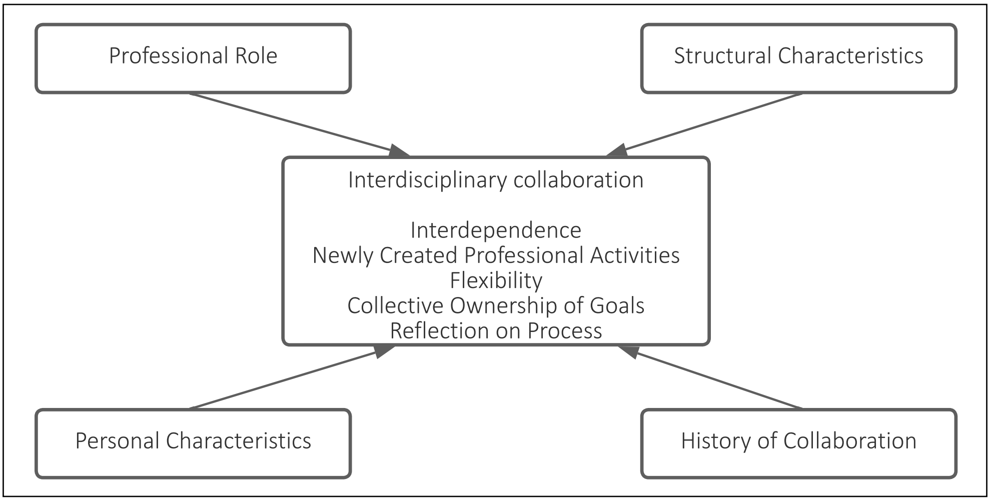


Figure1: Model for interdisciplinary collaboration [Bronstein, 2003]

Different models have been developed to explore interdisciplinary collaboration. For the purpose of this paper we apply the much-cited model by Bronstein et al, which was developed in the US context of social work (81). This model (Figure 1) is based on perspectives of multidisciplinary collaboration theory, services integration, role theory and ecologic systems theory, and distinguishes five core components of interdisciplinary collaboration: 1) interdependency, referring to professionals being dependent on each other to reach their goals. For example, when a child is diagnosed with attention-deficit/hyperactivity disorder (ADHD), a doctor prescribes medication in addition to parent training in behaviour management (PTBM), given by a behaviour therapist, and classroom interventions performed by teachers (195). 2) Newly created professional activities, referring to collaborative programs or structures that help professionals achieve things they could not have achieved independently. In case of ADHD-patients, multidisciplinary guidelines help professionals to keep track of each other's role and make use of each other's competencies (195). 3) Flexibility, referring to deliberate role-blurring. As opposed to strictly following the guidelines, professionals can also choose to do something extra or something different, when that would be helpful for this specific patient at this specific moment. 4) Collective ownership of goals, referring to a shared sense of responsibility to reach goals. A collective goal can be the health of the group of patients that professionals collaboratively care for, each one from his own perspective. 5) Reflection on process, referring to professionals thinking and talking about their collaboration in order to enhance the process (81). Bronstein's model defined four factors that could influence the degree of interdisciplinary collaboration: 1) how professionals experience and define their 'professional role'; 2) the structural characteristics of a professional's job, such as workload, a collaboration-supportive culture, professional autonomy and how organisations facilitate collaboration with time and space; 3) personal characteristics of professionals; 4) whether professionals have a history of and positive experiences with interdisciplinary collaboration.

Research shows that interdisciplinary collaboration can be strengthened by interdisciplinary use of electronic health records. More specifically, sharing information and knowledge, and drawing collaborative care plans in such an interdisciplinary used electronic health record could enhance the quality of care (38-40). On the other hand, some studies point out that electronic health records can inhibit collaboration as well, due to improper registration or a mismatch with working processes (196, 197).

Although there is a growing body of literature about the effect of using electronic health records, there are few studies about using interdisciplinary electronic health records among adolescents, mainly due to privacy issues associated with using electronic health records in this age group (52). In the Dutch North Veluwe region youth care organisations have, however, joined forces to tackle these privacy issues and build an interdisciplinary health record for youth care and preventive child health care. This Electronic Patient Record, further referred to as EPR-Youth, aims to integrate regional care for children and adolescents. In the Netherlands, interdisciplinary use of an electronic health record between preventive child healthcare (PCH) and child social care is unique, and so is a fully transparent child and adolescence health record. Although EPR-Youth provides an unique opportunity to combine registration by different disciplines in one client-accessible system, it remains unknown whether the use of EPR-Youth will strengthen collaboration between those disciplines.

The aim of our study therefore is to investigate whether the use of EPR-Youth contributes to interdisciplinary collaboration between professionals in youth care and child healthcare. Furthermore, we aim to contribute to the body of knowledge about interdisciplinary use of electronic health records among families and adolescents.

Methods

Context

The Netherlands has established a preventive child healthcare (PCH) system, strongly underpinned by public health legislation (65). Over 90% of all Dutch children follow the full free program, consisting of 10 visits in the first year, 5 visits between 1 and 4 years and 5 visits between 4 and 18 years. Professionals in public health have a role in prevention and early detection of both physical and social problems, referring when needed to primary or secondary healthcare, to mental healthcare or to (social) youth care. Approximately 10% of all children receive Youth Care, in case of mental disorders, psychosocial problems, or behavioural problems (66). Dutch municipalities provide both preventive child healthcare and youth care to all children.

In the North Veluwe region, six municipalities commissioned two organisations providing preventive child healthcare (PCH) and one organisation providing Youth Care to integrate their services in Centres for Youth and Family (CJGs). Jointly, they provide preventive healthcare to the 38.000 children aged 0-18 years in the region and provide additional Youth Care when needed. One PCH organisation provided services to children aged 0-3 years (PCH 0-3), the other organisation provided services to children aged 4-18 years (PCH 4-18). During this study, 58 professionals were working in PCH 0-3 and 18 professionals were working in PCH 4-18. The number of Youth Care workers increased from 60 to 80 professionals, due to an increasing demand for Youth Care. CJG-professionals were a mix of child health doctors, child health nurses, youth care workers with varying backgrounds (e.g. social work, mental healthcare or child protection services), further referred to as 'non-administrative professionals'. The CJG-teams were completed by administrative professionals such as child health assistants, secretaries, screeners, and planners.

Intervention

To facilitate the integration of preventive child healthcare and youth care, an electronic client record had been developed (EPR-Youth), that was used by all CJG-professionals. Professionals only had access to records of children with whom they were involved. In the health record, they had specific access to information that was relevant to do their job. Parents and adolescents aged 12 years and older had access to a client portal where they could read the full content of their record. The client portal offered a view log where parents and adolescents could see which professional had accessed their record.

Research design

A mixed methods research design with an explanatory sequential approach was chosen. All CJG-professionals were invited to complete a pre-test questionnaire prior to introduction of EPR-Youth, followed by post-test questionnaires at 5 and 24 months after implementation. Because of low response due to COVID (n=67), the first post-test questionnaire was eventually excluded from the study. Halfway through the study, two focus group interviews were held with a selection of professionals. Data were collected between November 2018 and September 2021.

Study population and inclusion

We included all professionals working in the CJGs (N=135) and invited them to complete the online pre-test questionnaire. Two years after introducing EPR-Youth, all CJG-professionals (N=157) were invited to complete the post-test questionnaire. Due to staff turnover, the samples were partially overlapping.

For the focus group interviews, all CJG professionals were invited. From the participants who expressed their interest, two groups (n=12) were selected through purposive sampling, ensuring that focus groups represented all professions and organisations involved, both men and women, with different work experience levels.

Measurements

To measure interdisciplinary collaboration, we translated the Index for Interdisciplinary Collaboration (IIC), a 42-item validated questionnaire by Bronstein et al (80, 198). The original questionnaire was developed and validated among social workers to investigate interdisciplinary collaboration with other disciplines. The questionnaire was based on Bronstein's model for interdisciplinary collaboration (Figure 1), including Bronstein's five components of collaboration: interdependency (13 items), newly created professional activities (6 items), flexibility (5 items), collective ownership of goals (9 items) and reflection on process (9 items) (80). For the present study, the questionnaire phrasing was adapted to the context of Dutch care for youth [see Additional file 1] (198). In the original questionnaire, all components showed good internal consistency (α=0.75-0.82) except flexibility (α=0.62). Because Cronbach's alpha scores in our study were similar to Bronstein's study, we calculated mean scores for each of the five components and one for the entire questionnaire. Mean scores were calculated when at least 2/3 of the questions for that component were completed (198). The translated IIC used a 5-point Likert scale, ranking from 1 ('totally agree') to 5 ('totally disagree'). Several items were worded negatively to reduce agreement bias among respondents (80). All scores for positively worded items were reversely coded to ensure that higher scores reflected a more positive attitude towards interdisciplinary collaboration. We also added the answering category 'not applicable'.

One open-ended question about collaboration experiences, and questions about socio-demographic characteristics like sex, age, organisation, profession and working experience, were added to the questionnaire.

Focus group interviews

A semi-structured questionnaire [Additional file 2], based on Bronstein's model for interdisciplinary collaboration, guided the interviews (81). The questionnaire addressed experiences with EPR-Youth in general as well as the relation between using EPR-Youth and interdisciplinary collaboration. For instance, whether and how using EPR-Youth impacted exchange of information, harmonisation of working processes, task flexibility and shared ownership of goals.

To limit moderator bias, an experienced moderator, who was familiar with the organisational vision without being part of the development process of EPR-Youth, guided the focus group interviews (199, 200). She was assisted by the main author as observer and a research assistant as note taker. The duration of both focus group interviews was approximately 90 minutes. The interviews were audio-recorded and transcribed verbatim. Afterward, a member check was conducted with all participants to confirm transcript accuracy.

Data analysis

Quantitative data collected in the online questionnaire were analysed by using IBM SPSS Statistics, version 27. Descriptive statistics were used to describe participants' socio-demographic characteristics. Differences in the respondents' socio-demographic characteristics between pre-test and post-test measurements were tested using Pearson's Chi-square tests.

Missing data patterns were analysed and compared between administrative and non-administrative professionals, showing that administrative professionals responded significantly more often with 'not applicable' then non-administrative professionals (8.4 vs 2.5 times in the 42-item questionnaire, $p<0.001$). Furthermore, most administrative professionals reported that the questions were not relevant to them because they were not collaborating with their colleagues. Therefore, administrative professionals were excluded from further analyses.

Subsequently, a linear mixed model was used to analyse the difference between pre-test and post-test results for non-administrative professionals, including organisation, municipality, time and the interaction between time and municipality and between time and organisation as fixed factors. Respondent ID was included as a random factor. Although function, discipline, and working experience appeared to relate to influencing factors in Bronstein's model (Figure 1), these variables did not contribute to the model and were therefore not included (81).

Qualitative data were analysed in Atlas Ti, version 8 and 9. Three researchers performed a thematic analysis, based on Bronstein's model for interdisciplinary collaboration.

Two independent researchers coded each interview transcript using a combination of inductive and deductive coding. In an iterative process between coding researchers, differences in coding were discussed, and themes were generated. Subsequently, theme interpretation was discussed with all authors, and minor modifications were made.

Data integration

Data were integrated using a narrative approach, connecting and merging data, and building further on former outcomes (201). Data were connected by recruiting questionnaire respondents to participate in the focus groups (201). Data building happened when questionnaire outcomes informed the focus group interview guide (201). We merged data by combining and comparing outcomes from quantitative and qualitative analyses to reach conclusion (201).

Ethical considerations and ethics approval

All methods were carried out in accordance with relevant guidelines and regulations, complying with the Netherlands Code of Conduct for Scientific Practice. On these grounds, the research protocol was approved by the Social Sciences Ethics Committee of Wageningen University, approval number 2018-24-Benjamins. All respondents to questionnaires and participants in focus groups received an invitation beforehand with information about the study. Respondents to the questionnaire gave a written informed consent after information of the study was given. Participants in the focus groups gave an explicit verbal informed consent at the beginning of the focus group interview. Each interview was recorded and transcribed verbatim, including the verbal informed consent. Both procedures were approved by the ethics committee.

Results

General sample characteristics

The response rates in pre-test and post-test were 87% (n=117)and 81% (n=127) of all professionals, respectively (Figure 2). A group of 73 professionals completed both questionnaires.

Although the professional population had changed significantly during the 2-year period, due to a high turnover rate, respondent characteristics were mostly similar for both measurements (Table 1).

Self-reported interdisciplinary collaboration

Comparing the overall mean score, non-administrative professionals reported slightly more positive about interdisciplinary collaboration after introduction of EPR-Youth (n=106, Estimated Marginal Means (EMM)=3.93, 95%CI=3.82-4.04) than before (n=97, EMM=3.85, 95%CI=3.74-3.95), although the difference was not statistically significant F (1, 105.9)=1.70, p=0.19 (Table 2). Comparable outcomes were found for the separate components of interdisciplinary collaboration. Professionals reported significantly more positive about flexibility after introduction of EPR-Youth (n=106, EMM=4.00, 95%CI=3.86-4.14) than before (n=97, EMM=3.79, 95%CI=3.65-3.92), F (1, 100.7)=1.97, p=0.05, whereas rating of the other components improved slightly but not significantly.

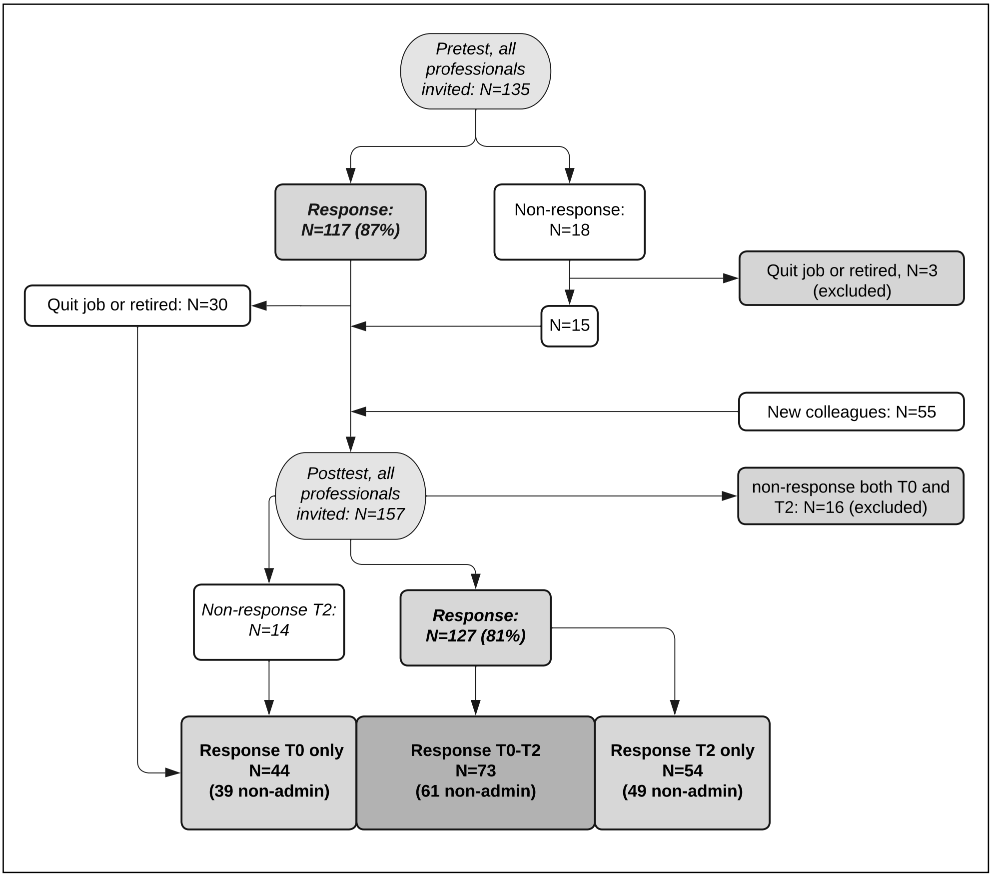


Figure 2: inclusion flow diagram for questionnaire respondents

Significant differences in self-reported collaboration were found between organisations, F(2, 134.0) = 7.17, p=0.001, and between municipalities, F(4,130.8) = 3.80, p=0.006, before introduction of EPR-Youth. Professionals in preventive child health care among schoolchildren and adolescents reported significantly less positive (EMM=3.57, 95%CI=3.31-3.82) about interdisciplinary collaboration than youth care workers (EMM=4.05, 95%CI=3.94-4.15). And professionals from the municipality Oldebroek showed a more positive attitude toward interdisciplinary collaboration (EMM=4.14, 95% CI=3.93-4.36) than professionals from the municipalities Nunspeet (EMM=3.69, 95% CI = 3.48-3.90) and Harderwijk (EMM=3.69, 95% CI=3.53-3.85). No significant differences in overall mean score and separate components between pre-test and post-test were found for any single organisation or municipality.

Table 1: Characteristics of respondents, in pre-test and post-test, with absolute numbers and percentages.

	pre-test N=117 (%)	post-test N=127 (%)	df, Pearson χ²	Two-sided p-value
Sex			0.33	0.86
male	9 (7.7)	9 (7.1)		
female	108 (92.3)	118 (92.9)		
Working experience			2, 2.85	0.24
0-10 years	41 (35.0)	57 (44.9)		
10-20 years	45 (38.5)	45 (35.4)		
>20 years	31 (26.5)	25 (19.7)		
Profession			7, 1.52	0.98
Assistant[a]	12 (10.3)	11 (8.7)		
Behavioural expert	4 (3.4)	8 (6.3)		
PCH Doctor	11 (9.4)	10 (7.9)		
Youth Care Worker	58 (49.6)	62 (48.8)		
PCH Nurse	25 (21.4)	28 (22.0)		
PCH Speech therapist	2 (1.7)	2 (1.6)		
Screener[a]	3 (2.6)	3 (2.4)		
Team administrator[a]	2 (1.7)	3 (2.4)		
Discipline			2, 0.127	0.94
Administrative[a]	17 (14.5)	17 (13.4)		
Youth care	62 (53.0)	70 (55.1)		
PCH	38 (32.5)	40 (31.5)		
Organisation			2, 0.01	0.97
PCH 4-18	14 (12.0)	15 (11.8)		
PCH 0-3	41 (35.0)	44 (34.6)		
Youth Care	62 (53.0)	68 (53.5)		
Municipality			5, 1.44	0.92
Oldebroek	17 (14.5)	24 (18.9)		
Elburg	18 (15.4)	18 (14.2)		
Nunspeet	20 (17.1)	24 (18.9)		
Harderwijk	37 (31.6)	39 (30.7)		
Ermelo	21 (17.9)	18 (14.2)		
Putten	4 (3.4)	4 (3.1)		

[a]: Non-administrative professionals, invited for questionnaire and excluded afterwards based on missing data pattern analysis.

Table 2: Total and component scores of interdisciplinary collaboration before and after introduction of EBPR-Youth, presented by organisation, municipality and the total research population.

	Pre-test		Post-test		Difference pre-test/ post-test
	n	**EMM* (95% CI)**	**n**	**EMM* (95% CI)**	**F (df numerator, df denominator), p-value**
Collaboration overall	97	3.85 (3.74-3.95)	106	3.93 (3.82-4.04)	1.70(1, 105.9), 0.19
Interdependence	98	4.02 (3.92-4.13)	107	4.08 (3.97-4.18)	0.60(1, 110.2), 0.44
Newly created professional activities	92	3.70 (3.54-3.86)	101	3.80 (3.65-3.95)	0.94(1, 126.7), 0.33
Flexibility[a]	97	3.79 (3.65-3.92)	106	4.00 (3.86-4.14)	1.97 (1, 100.7), 0.05
Collective ownership of goals	91	3.82 (3.65-3.98)	102	3.93 (3.78-4.09)	1.38 (1, 112.7), 0.24
Reflection on process	96	3.72 (3.56-3.87)	104	3.93 (3.68-3.98)	1.49 (1, 119.6), 0.23
	n	**EMM* (95% CI)**	**n**	**EMM* (95% CI)**	
Organisation					
PCH 4-18[bc]	10	3.57 (3.31-3.82)	12	3.74 (3.50-3.98)	
PCH 0-3[b]	25	3.92 (3.76-4.09)	26	4.00 (3.84-4.16)	
Youth Care[c]	62	4.05 (3.94-4.15)	68	4.06 (3.96-4.16)	
Municipality					
Oldebroek[de]	14	4.14 (3.93-4.36)	22	4.06 (3.86-4.25)	
Elburg	15	3.91 (3.69-4.12)	15	3.95(3.72-4.17)	
Nunspeet[d]	16	3.69 (3.48-3.90)	20	3.81 (3.62-4.01)	
Harderwijk[d]	30	3.69 (3.53-3.85)	34	3.80 (3.65-3.94)	
Ermelo/Putten	22	3.80 (3.61-3.99)	15	4.00 (3.82-4.24)	

[a]: significant difference between pre-test and post-test measurement, 2-sided p-value=0.05, as tested with Bonferroni post-hoc
[b–e]: significant difference between these subgroups, 2-sided p-value<0.05, as tested with Bonferroni post-hoc
**: Estimated marginal means (EMM)were calculated in a mixed model analysis, including organisation, municipality, time, interaction between time and municipality, and interaction between time and organisation as fixed factors, and ID as random factor.*

Focus group interviews and qualitative questionnaire outcomes

Analysing the qualitative data, we found that using EPR-Youth contributed to three out of five components from Bronstein's model. 'Interdependence', 'collective ownership of goals' and 'newly created activities' were affected by using EPR-Youth, whereas 'flexibility' and 'reflection on process' were not affected by using EPR-Youth. Additionally, the contributing factor 'structural characteristics' emerged as a relevant theme as well.

Interdependence: Professionals reported that the use of EPR-Youth strengthened their sense of interdependence, mostly in a practical way. Because the system facilitated the sharing of necessary knowledge and information, professionals felt that they became more aware of each other's expertise and knowledge. As a result, they found themselves better able to complement each other in the care process. Having direct access to relevant information about 'who is doing what in this case' contributed to efficiency, and so did the possibility to transfer information between disciplines without contacting each other. Some professionals, however, did not utilize all information in EPR-Youth since they did not feel free to read information that was added by other disciplines.

“It is important that we as colleagues in the Centre for Youth and Family know each other and know each other’s work and professional roles, to make use of each other’s expertise, involve each other when needed, and contribute to each other’s strength.”
[Youth Care Worker, Pre-test questionnaire; 6:41]

“I don’t need to transfer the record to PCH 4-18 when a child is 4 years old. And when I need information about an older child, I don’t need to mail to my PCH 4-18 to ask her, because I can find it myself with permission from parents.”
[PCH Nurse, Focus group interview 1; 2:4]

Newly created professional activities: Developing and implementing EPR-Youth together with all different disciplines in the CJG-teams was considered a very impactful newly created professional activity. Focus group participants reported that developing and using EPR-Youth helped them realize how working processes and procedures were differing between the three organisations. Consequently, they felt an urgency to develop more newly created professional activities, such as synchronizing working processes and registration habits, and clarifying and describing each other’s role and tasks in those processes.

"Sometimes they (nurses) report client questions in EPR-Youth and sometimes they don’t. We have no clear agreement about this. I would very much like to have a guide in which we have made some statements: this is how we agreed to work together."
[PCH doctor, Focus group interview 2; 4:195]

Collective ownership of goals: Because EPR-Youth provided the opportunity to create a shared care plan for a child or a family, in which different disciplines could be involved, professionals felt that EPR-Youth contributed to a collective ownership of these care plans. Every professional could register his own actions and add them to the same plan. This was in line with the regional aim to create ‘one plan for each family’ instead of separate plans from each professional’s own perspective. Moreover, professionals considered the transparency of a fully client-accessible health record supportive for the working relation between client and professional, creating more equality and rendering more responsibility to clients then before. Consequently, ownership of care plans and goals was shared not only between different professionals, but between client and professional as well.

"I think it (EPR-Youth) can be a very powerful instrument to collaborate with parents and to leave the responsibility where it belongs."
[Youth Care worker, Focus group interview 1, 2:67]

Flexibility: Changes in flexibility, as described by focus group participants were rather related to organisational facilities than to using EPR-Youth. Youth care professionals reported a lack of flexibility among PCH colleagues when planning interdisciplinary meetings. Attending these meetings was not mandatory and was not facilitated equally for each involved organisation.

> *"PCH 4-18 colleagues have fixed working days and schedules that are not flexible. That means that we as youth care workers must be even more flexible, coming to the office on our day off."*
> *[Youth care worker, Post-test questionnaire, 8:31]*

Reflection on process: Using EPR-Youth had not initiated any reflection on using EPR-Youth itself or on integrating the use of EPR-Youth in collaborative working processes. However, the need for reflection became clear during the focus group interview, when participants concluded that they lacked knowledge about the match between system, vision on care for youth and actual working processes. They unanimously felt that this lack of knowledge limited EPR-Youth's potential to strengthen interdisciplinary collaboration.

> *"That confirms the need for training, not only about how the system works, what buttons you need to press, but also how we use it. How do we synchronize our working processes, how do we report correctly."*
> *[Behavioural Scientist, Focus group interview 2, 4:131]*

Structural characteristics: Barriers reported by professionals were mainly associated with the factor 'structural characteristics' in Bronstein's model. Overall, professionals mentioned lack of time as an important barrier for interdisciplinary collaboration. Especially in the questionnaires, professionals reported (n=14) that their collaboration with PCH 4-18 professionals was limited, because these colleagues were facilitated less by their organisation to collaborate with other disciplines than PCH 0-3 professionals and youth care workers. Professionals felt that the PCH 4-18 organisation did not provide their professionals with enough time, nor with flexibility in their working schedules, to join meetings with their colleagues from other disciplines. Moreover, PCH 4-18 professionals were mainly working at schools and not at the office, which was reported as another barrier for interdisciplinary collaboration due to lack of meeting opportunities.

Finally, 'being part of multiple teams' was reported to be a barrier for collaboration since professionals had to divide their attention between different teams and between different interacting systems.

"Working in the same building helps to find each other faster and to know each other's qualities. I find it difficult that there are parent companies behind the three organisations that shape their working processes
in a different way than the Centre for Youth and Family does."
[Unknown, Post-test questionnaire 8:23,24]

Discussion

General

With our study we investigated whether the use of EPR-Youth contributed to interdisciplinary collaboration between professionals in youth care and child healthcare. Although a significant effect of using EPR-Youth on interdisciplinary collaboration was found only for the component flexibility, the overall slightly positive trend was confirmed by the focus group interview outcomes. These indicated that using EPR-Youth contributed to a professional's sense of 'interdependence', 'collective ownership' of care plans, and 'newly created professional activities'. Additionally, the qualitative data confirmed the differences between organisations and municipalities that were found in the questionnaires and expanded on reasons for the difference between organisations, which could for instance be found in their facilitation of interdisciplinary collaboration.

Comparison with previous research

Except for the component 'flexibility', no component was rated significantly higher after introduction of EPR-Youth than before, although all components showed a slightly positive trend. Contrastingly, Fukkink and van Verseveld investigated growth in interprofessional collaboration between childhood care, primary education, and youth care, analysing four components of Bronstein's IIC, and found a significant increase for the components 'interdependence', 'reflection on process' and 'newly created professional activities' (202). Another Dutch study used the Index of Interprofessional Team Collaboration for Expanded School Mental Health, an adaptation of the IIC for use in schools (203), to assess changes in interdisciplinary collaboration between primary and secondary school teachers and youth care workers, finding a significant increase for the components 'interdependence' and 'flexibility' (204). A possible reason for the stronger effects in these two studies might be that these focused fully on interdisciplinary collaboration as a new intervention, whereas in our study CJG-professionals had been collaborating for four years, and we were assessing what introducing EPR-Youth added to the existing interdisciplinary collaboration.

Impact of COVID-19

Two factors could have attenuated the effect of using EPR-Youth on interdisciplinary collaboration:

First, the COVID pandemic started shortly after introducing EPR-Youth. Due to the pandemic, face to face team meeting opportunities were reduced to a minimum. Moreover, PCH 4-18 professionals had to prioritize working in COVID-teams (performing tests, tracking contacts and vaccinating) over their regular work. Research shows that meeting only virtually as a team impedes the development of shared mental models, conceptual frameworks, and personal relationships. (205-207) This explains why professionals in our study were progressing slowly with the 'creation of new professional activities', such as the synchronization of working processes and registration habits, although they felt this was urgent. Most likely, the COVID-19 pandemic impeded the process of interdisciplinary collaboration in general, and the effect of ERP-Youth on interdisciplinary collaboration more specifically. Therefore, we expect the contribution of EPR-Youth to interdisciplinary collaboration to increase now that the impact of the COVID-19 pandemic on working conditions is decreasing.

Organisational differences

Second, the significant differences in attitude toward interdisciplinary behaviour between professionals from different organisations suggest that organisations play a role in supporting interdisciplinary collaboration. Bronstein's model confirms this, describing 'structural characteristics' as facilitating factors provided by organisations that contribute to interdisciplinary collaboration (81). These include a collaboration-supportive agency culture, space for professional autonomy, and facilitation of collaboration with time and space. The found differences between attitudes of professionals from different organisations might be caused by different organisational views on collaboration. Questionnaire respondents said that PCH 4-18 professionals were provided with less space and time to collaborate with their colleagues in the centres for youth and family than other professionals. Literature distinguishes between multidisciplinary collaboration and interdisciplinary collaboration (208). In multidisciplinary collaboration, different disciplines work alongside each other, performing their jobs independently and only sharing information with each other (209, 210). Multidisciplinary teams consult with the same client but do not develop a cohesive care plan as each team member uses his or her own expertise to develop individual care goals. In interdisciplinary collaboration, on the other hand, goals can only be achieved through the interactive effort of the involved professionals (81, 208). This type of collaboration requires a higher level of communication, collective decisions and goal setting, and mutual planning. This also requires a shift in organisational behaviour, away from traditional identities, leadership models and decision-making roles, towards new behaviour needed for the facilitation of participation in and decision-making with interdisciplinary interorganisational teams (211).

Differences between municipalities

In this study we also found differences between professionals working in different municipalities that we could not explain from differences in structural characteristics, such as workload and facilities, or differences in team composition. However, Bronstein's model contains more factors that influence interdisciplinary collaboration, such as 'a strong sense of professional role', 'personal characteristics' and a 'history of collaboration' (81).

Other authors also describe different factors on professional or team level contributing to interdisciplinary collaborations, like leadership, transparent team roles and interactive communication (212, 213). These factors, on which we have not elaborated in our study, possibly hold an explanation for the differences between professionals working in different municipalities. However, further research would be needed to identify the relevant factors.

Strengths and Limitations

The mixed methods design with qualitative data expanding on repeated quantitative measurements was a strength, generating a complete overview of different perspectives on interdisciplinary collaboration. We were limited by the necessary exclusion of one measurement due to COVID-19 and a high turnover in CJG-professionals causing a limited number of professionals who completed the questionnaire twice. Using a mixed model analysis, we optimized data use and were able to keep all responding participants included in the study.

Another limitation was the lack of a control group. However, there was no Dutch region with a similar context, where preventive child healthcare and youth care collaborated in a similar fashion without the use of a shared health record.

Conclusions

Our study suggests that using EPR-Youth can foster interdisciplinary collaboration. The different levels of interdisciplinary collaboration between organisations underline that implementing an EPR alone does not contribute to interdisciplinary collaboration: a shared vision and organisational facilities are needed to strengthen interdisciplinary collaboration.

Acknowledgements

The authors want to thank all CJG-professionals who participated in the study by completing a questionnaire or participating in a focus group interview. We further want to thank Klaudia Hoekstra, coach at the CJG's, for her role as focus group moderator; Claudia Laarman, master student, for her assistance with focus group transcripts and with a part of the qualitative analyses; and Gerrit Gort, statistic at Wageningen University, for providing his insights and expertise on the statistical analysis of the quantitative data.

Appendices

Appendix 1: Questionnaire, based on Index of Interdisciplinary Collaboration.
Appendix 2: Interview guide, used in the focus group interviews with professionals.

Appendix 1: Questionnaire, based on Index of Interdisciplinary Collaboration.

Explanatory text: when you read ‘my CJG-colleagues’ (mijn CJG-collega’s), we specifically mean the colleagues working for the two CJG-organisations that are not your own. Youth care professionals: think of all PCH-professionals, PCH-professionals: think of your Youth Care colleague and your PCH-colleague who is working in the other PCH-organisation. When you read ‘my colleagues; (mijn vakgenoten), we mean the colleagues with the same profession that you have (e.g. doctor, nurse, youth care worker, screener).

Interdependency

1. I utilize my CJG-colleagues for their specific expertise.
2. I consistently give feedback to my CJG-colleagues.
3. My CJG-colleagues utilize me and my colleagues for a range of tasks.
4. * Teamwork with my CJG-colleagues is not important in my ability to help parents and adolescents.
5. * My CJG-colleagues and I rarely communicate.
6. The CJG-colleagues with whom I work have a good understanding of the distinction between my role and their role(s).
7. * My CJG-colleagues make inappropriate referrals to me.
8. I can define those areas that are distinct in my professional role from that of the CJG-colleagues with whom I work.
9. I view part of my professional role as supporting the role of others with whom I work
10. My CJG-colleagues refer to me often.
11. * Cooperative work with colleagues from other disciplines is not a part of my job description
12. * My CJG-colleagues do not treat me as an equal.
13. My CJG-colleagues believe that they could not do their jobs as well without the assistance of social workers.

Newly created professional activities

14. Distinct new programs emerge from the collective work of all colleagues within the CJG.
15. Organisational protocols within the CJG reflect the existence of cooperation between professionals from different disciplines.
16. Formal procedures/mechanisms exist for facilitating dialogue between professionals from different disciplines (i.c. at structured dialogue sessions or case discussions).
17. * I am not aware of situations in my CJG (or regionwide) in which a coalition, task force or committee has developed out of interdisciplinary efforts.
18. Working with CJG-colleagues leads to outcomes that we could not achieve alone.
19. Creative outcomes emerge from my work with CJG-colleagues that I could not have predicted.

Flexibility

20. I am willing to take on tasks outside of my job description when that seems important.
21. * I am not willing to sacrifice a degree of autonomy to support cooperative problem solving.
22. I utilize formal and informal procedures for problem solving with my CJG-colleagues.
23. * The CJG-colleagues with whom I work stick rigidly to their job descriptions.
24. My CJG-colleagues and I work together in many different ways.

Collective ownership of goals

25. CJG-colleagues with whom I work encourage family members' participation in the care process.
26. * My CJG-colleagues are not committed to working together.
27. My CJG-colleagues work through conflicts with me in efforts to resolve them.
28. When CJG-colleagues make decisions together they go through a process of examining alternatives.
29. My interaction with my CJG-colleagues occurs in a climate where there is freedom to be different and to disagree.
30. Our customers (parents/adolescents) participate in interdisciplinary planning that concerns them.
31. Colleagues from all professional disciplines take responsibility for developing care plans.
32. *. Colleagues from all professionals disciplines do not participate in implementing care plans.
33. My CJG-colleagues and I are straightforward when sharing information with parents and adolescents.

Reflection on process

34. My CJG-colleagues and I often discuss different strategies to improve our working relationships.
35. My CJG-colleagues and I talk about ways to involve other professionals in our work together.
36. My CJG-colleagues do not attempt to create a positive climate in the CJG.
37. I am optimistic about the ability of my CJG-colleagues to work with me to resolve problems.
38. I help my CJG-colleagues to address conflicts with other professionals directly.
39. My CJG-colleagues are as likely as I am to address obstacles to our successful collaboration.
40. My CJG-colleagues and I talk together about our professional similarities and differences including role, competencies and stereotypes.
41. *. My CJG-colleagues and I do not evaluate our work together.
42. I discuss with my CJG-colleagues the degree to which each of us should be involved in a particular case.

Respondents were choosing from the following answering categories: totally agree (1), agree (2), neutral (3), disagree(4), totally disagree (5), not applicable(6)

* These questions have been worded reversely, to reduce respondent agreement bias.

Appendix 2: semi-structured interview guide for focus groups

Interview scope:
How are professionals experiencing the impact of the use of EPR-Youth on interdisciplinary collaboration?
How do professionals feel about a client-accessible health record, what positive and negative connotations do they have?

Topic list:
In general: what experiences can you describe, using EPR-Youth?

- Positive experiences: what is working well, in what way is EPR-Youth helpful?
- Negative experiences: what could work better, what is not helping? Do you have any suggestions for improvement?

Collaboration:

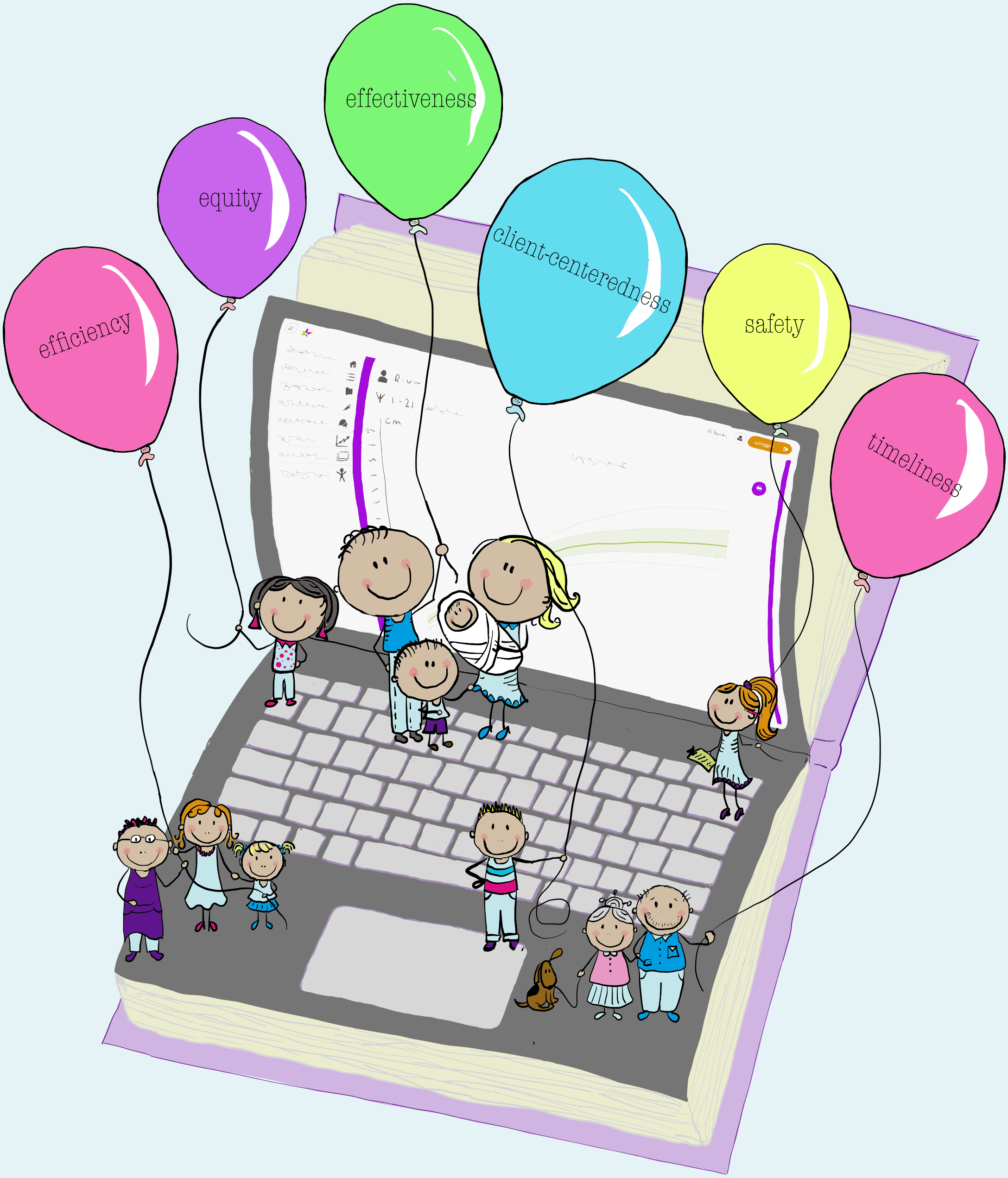
- Does the use of EPR-Youth contribute to interdisciplinary collaboration? In what way?
- Impact on sense of interdependency (e.g. exchanging knowledge and information, making use of each other's expertise)
- Impact on newly created professional activities (e.g. harmonizing working processes, new interprofessional working agreements)
- Impact on flexibility (e.g. shifting tasks from one discipline to another when needed)
- Impact on shared ownership of goals (e.g. shared care plans)
- Impact on reflection on process (e.g. interdisciplinary meetings to reflect jointly on cases or working agreements)
- Impact on communication
- Impact on efficiency

How do you use EPR-Youth?

- Read information that others wrote?
- Inform clients about interdisciplinary shared use?
- Communicate with colleagues through the system?
- Disclose relevant information for colleagues if it is only visible for you?
- What could be needed to enhance collaboration?
- What could you do?

What do you need from managers and staff?

What needs to be adapted in EPR-Youth?


efficiency
equity
effectiveness
client-centeredness
safety
timeliness

Chapter 7

How using a client-accessible health record contributes to perceived quality of care among parents and adolescents: a qualitative study.

This chapter is submitted as:

Benjamins J, de Vet E, de Mortier C, Haveman-Nies A. (2023) How using a client-accessible health record contributes to perceived quality of care among parents and adolescents: a qualitative study.

Abstract

Introduction/Background: Patient-accessible electronic health records are assumed to enhance quality of care, expressed in terms of safety, timeliness, efficiency, effectiveness, equity, and person-centredness. However, research on the impact of PAEHRs on perceived quality of care among parents, children, and adolescents is largely lacking.

Aim: This study assessed whether and how using a client-accessible interdisciplinary health record contributes to experienced quality of care, from a client's perspective.

Methods: A qualitative design with a phenomenological approach was chosen to explore how parents and adolescents perceived the impact of using EPR-Youth on quality of care. In-depth interviews with one to three persons simultaneously were conducted in 2021. A total of 13 parents and seven adolescents were included in the study, representing both sexes, different educational levels, different native countries, and all participating municipalities. Within this group, seven parents had not previously been informed about the existence of a client portal. Their expectations of using the client portal, in relation to quality of care, were discussed after a demonstration of the portal.

Results: Parents and adolescents perceived that using EPR-Youth contributed to quality of care, because they felt better informed and more involved in the care process than before the introduction of EPR-Youth. Moreover, they indicated to have more control over their health data, had faster and simpler access to their health information and found it easier to manage appointments or ask questions at their convenience. Parents from a migratory background, of whom six out of seven had not previously been informed about the client portal, expected that portal access would give them a better understanding of and more control over their care processes. Although portal usability was regarded high, parents expressed concerns about equity, because parents from a migratory background might have less access to the service. Furthermore, both parents and adolescents saw room for improvement in broader interdisciplinary use of EPR-Youth and in the quality of reporting.

Discussion/conclusions: Using EPR-Youth can contribute to client-experienced quality of care, more specifically to perceived person-centredness, timeliness, safety, efficiency, and integration of care. However, some quality aspects, such as equity, still need addressing. In general, client information about the portal needs to be improved, with a specific focus on people in vulnerable circumstances, such as those from migratory backgrounds. Additionally, to maximize the potential benefit of using EPR-Youth, a person-centred attitude among professionals is important. Considering the small number of adolescent participants (n=7), adding quantitative data from a structured survey could strengthen the available evidence.

Introduction

In implementation and optimisation of healthcare services, assessing quality of care is an important topic. Quality of care is a broad concept and encompasses various aspects of healthcare. Most commonly used is the Institute of Medicine's (IOM) definition of quality of care, which distinguishes six different domains: safety, timeliness, efficiency, effectiveness, equity, and patient-centredness (82). Patient safety refers to the notion that provided care should prevent patients from harm (82). Timeliness refers to delivering healthcare services on time (82). Efficiency deals with how well resources are used and about avoiding waste (82). Effectiveness reflects the use of appropriate interventions and treatments (82). Equity ensures everyone has equal access to the best possible care independent of personal characteristics or geographical location (82). Patient-centredness is about tailoring care to the unique patient's needs and preferences, engaging them and their proxies in decision-making (82, 214). Traditionally, quality of care has been approached from a professional's perspective, aiming to increase the likelihood of desired health outcomes. In 2015, the WHO reformulated the term patient-centredness into person-centredness, emphasizing that patients are more than just their health condition, and proposing a broadened scope on health and wellbeing (3). With this pivot-shift from conventional biomedical healthcare models to a more holistic approach, patient experiences have become an important healthcare quality outcome and patient-reported experiences have evolved into important indicators for quality of care (215, 216).

Patient-accessible electronic health records (PAEHRs) are assumed to enhance quality of care because they provide users with information about their health and healthcare (33, 135). Information can be provided in a one-way manner, sharing health data in a patient portal, or interactively when the system supports messaging between patient and care provider (34, 49, 93, 217). Either way, providing patients with their own health data promotes empowerment and enhances people's engagement in their own care plan (33, 135). Consequently, health consciousness, therapy adherence, and self-management of health improve, contributing to better health outcomes (49, 218-220). Moreover, transparency of patient-accessible records is reported to enhance patient safety, for instance because patients can identify errors in their health record and have them corrected (34, 44).

The growing body of literature reporting about the effect of using PAEHRs on quality of care predominantly stems from adult healthcare. Because the development of PAEHRs for children, adolescents and their parents is lagging behind, research on the impact on quality of care when using PAEHRs for these target groups is limited (59, 221). Based on reported outcomes in adult healthcare, we could assume that PAEHRs among minors and parents will affect quality of care the same way, because aspects like equity, timeliness, efficiency, and effectiveness are not age specific. For the aspects person-centredness and safety, however, impact of using PAEHRs will probably be different because age-specific ethical issues regarding autonomy and confidentiality need to be addressed (52, 53). During early childhood, the focus of person-centredness is on parents as legal guardians of their children, while during adolescence this focus gradually shifts to the increasingly autonomous adolescent. This gradual shift means that, during a certain period, parent and adolescent are equally involved in discussing care plans. Consequently, during this period both have a right of access to the adolescent's health information, and both have a right to confidentiality (52, 53). Protecting the rights of both parties brings up challenges that have affected development and implementation of PAEHRs for this age group negatively (52, 53). Meeting these challenges, however, and investigating what using a PAEHR then contributes to perceived quality of care, is relevant for an age group that is evolving towards autonomous adulthood. In the Netherlands, a PAEHR named EPR-youth has been developed for this age group and their parents. EPR-Youth is used interdisciplinary in preventive child healthcare and youth care and is accessible to adolescents aged 12 and older, and for parents of children aged 0 to 16 years. Investigating the impact of using EPR-youth on perceived quality of care among adolescents and parents will contribute to undiscovered knowledge.

Objective

The aim of this study was to investigate how Dutch parents and adolescents visiting preventive health care and youth care perceived the impact of using a client-accessible interdisciplinary health record on quality of care, exploring both experiences of active users and expectations or first impressions of non-users.

Methods

Intervention and context.

The Dutch North-Veluwe region consists of six municipalities. These municipalities commissioned two organisations providing Preventive Child Healthcare to children aged 0-3 years and children aged 4-18 years and one organisation providing Youth Care to integrate their services in Centres for Youth and Family (CJG). Since 2015, the CJGs provide preventive healthcare to all 38.000 children aged 0-18 years in the region and provide additional Youth Care for children and families with behavioural or sociopsychological problems (74). Using a participatory approach, the CJG's in 2016 developed a quality standard for their services, following the European 'Quality 4 Children' protocol (222). In dialogue sessions with parents and adolescents, they jointly defined quality of care from a client's perspective.

To support the integration of services, the electronic health record 'EPR-Youth' was built that facilitates the working processes of all professionals working in the CJGs. Furthermore, to support client autonomy and collaboration between professionals and families, EPR-Youth includes a tethered client portal in which parents and adolescents can read everything professionals register. They can manage appointments, ask questions and comment on written reports. Compliant with Dutch legislation, adolescents get access to the portal at the age of 12 (136). Parental access is possible until their child is 16 years old, unless rejected by an adolescent from 12 years. Furthermore, adolescents between 12 and 16 years old have the possibility to keep specific information confidential between them and the professional. EPR-Youth was introduced in September 2019.

Research design

A qualitative design with a phenomenological approach was chosen to explore how parents and adolescents perceived the impact of using EPR-Youth on quality of care (223). Twelve in-depth interviews with 1-3 persons simultaneously were conducted between October 11 and November 25, 2021. We reported our qualitative study according to the consolidated criteria for reporting qualitative studies (COREQ) (224). Multimedia Appendix 1 contains the completed COREQ checklist for this study.

Study population and inclusion

The study included parents of children aged 0-16 years, and adolescents aged 12 years and older, living in the North Veluwe region, further referred to as clients. Clients that visited a CJG in September 2021 were invited personally by CJG-professionals. Clients who expressed interest to participate were contacted by email or phone to explain the nature and purpose of the interview and to make an appointment. Where feasible, clients were invited to join interview group sessions at a CJG-location. Those unable to attend a group session were offered an individual or dual interview, at the location of their choice, live or online. Purposive sampling ensured a varied group representing both sexes, parents and adolescents, various educational levels, with both native and migratory backgrounds, both visitors of preventive health care and youth care, and inhabitants from all participating municipalities. We included both active users of EPR-Youth and non-users. In total, 12 interviews were conducted, with 20 participants. Apart from seven individual interviews, two double and three triple interviews were conducted.

Measurements

To create an interview topic guide (Multimedia Appendix 2), a working session was convened with an interdisciplinary expert panel of eight professionals. Based on the CJG quality standard and the overarching IOM framework (82), they explored what aspects of client-perceived quality of care could be influenced by using EPR-Youth. Table 1 shows the main topics from the interview guide.

All participants were interviewed once, by an experienced female interviewer (JB). For the first six of the 12 interviews, a research assistant (CM) assisted as an observer and note-taker. Individual interviews lasted 30-60 minutes, double and triple interviews lasted 90 minutes on average. When participants were not acquainted with the client portal, the first part of the interview was used to demonstrate its functionalities, followed by the main interview which then focused on expectations and first impressions instead of on experiences. Every interview was audio recorded, supplemented by note-taking, and by videorecording for online interviews.

Table 1: Client interview main topics.

Domain of quality of care	Topics
General	Are participants acquainted with EPR-Youth? How have their experiences been in general? If they were not acquainted, what are their first impressions?
Equity	How do participants experience ease of access and ease of use? How do participants experience comprehensibility of record content? Were participants informed about the existence of EPR-Youth?
Person-centredness	To what extent do participants perceive an influence of using EPR-Youth on client-professional collaboration/communication? To what extent do participants perceive an influence of using EPR-Youth on equal relationship? To what extent do participants perceive an influence of using EPR-Youth on sense of ownership?
Safety	How do participants feel about security of their data? How do participants feel about detecting errors? How do participants value the view log?
Efficiency	How do participants experience collaboration between disciplines through EPR-Youth? How do participants experience the use of interdisciplinary shared care plans?
Effectiveness	How do participants experience completeness and understandability of reports in EPR-Youth? How do participants value professional expertise?
Timeliness	How do participants experience the possibility of 24/7 access to their health data? How do participants experience the possibility to manage their own appointments? How do participants experience the possibility to ask questions at their convenience?

Data analysis

All interviews were transcribed verbatim for analysis. A member check was conducted with all participants to affirm transcript accuracy. Data were analysed in Atlas Ti, version 9. Based on the topic list with the six domains of quality of care as a framework, a preliminary codebook was written. In accordance with best practices, data collection and analysis were conducted in an iterative cyclical process, checking for data saturation. The interviewing authors (JB, CM) conducted a thematic analysis, re-reading and coding all transcripts independently (225, 226). After coding a full transcript, the two researchers discussed discrepancies in coding until consensus was reached. Simultaneously, in a continuous process, additional codes were added to the codebook, coding definitions were refined, and transcripts were recoded when necessary. Saturation was discussed during analysis and had been reached after 12 interviews. Subsequently, JB and CM grouped all codes into major themes and discussed interpretation of themes with all authors.

Research team and reflexivity

The interviews were conducted by a researcher working as a policy advisor in the CJG's and a research assistant, both trained in qualitative research. Although one interviewer worked in the CJG, no working relationship had been established with any of the participants prior to the study. Every interview started with an introduction of the interviewers, their personal motivation, and the study goal. Combining an experienced researcher with inside knowledge of the CJG and EPR-Youth with a young researcher from outside the CJG had two advantages: first, when present during the interviews with adolescents, the younger researcher could identify easily with the participants and vice versa; second, during analysis, comparing observations and discussing interpretations from both inside and outside perspective enriched the process of interpretation and limited the chance for bias.

Ethical approval, consent to participate and availability of data

The study was carried out in accordance with relevant guidelines and regulations, complying with the Netherlands Code of Conduct for Scientific Practice. On these grounds, the research protocol was approved by the Social Sciences Ethics Committee of Wageningen University, approval number 2018-24-Benjamins. All participants received an invitation beforehand with information about the study and gave an explicit verbal consent at the beginning of the interview. Each interview was recorded and transcribed verbatim, including the verbal consent. Since interview transcripts contained sensitive information, these will not be published in a separate dataset.

Results

General characteristics

In total, 13 parents and seven adolescents were interviewed individually (n=7), in pairs (n=4) or in triplets (n=9). Initially, 23 participants had been included of which 3 dropped out due to agenda mismatches. Participants represented both sexes, parents, and adolescents, from different educational levels, of Dutch and non-Dutch nativity, from all involved municipalities and making use of PCH and Youth care services (Table 2). Seven participants were not acquainted with the client portal before the interview, six of them were from a migratory background. From the participants that were acquainted with the client portal, six participants had received information from a CJG professional, seven participants had discovered the portal through a questionnaire about EPR-Youth. Six participants came to the CJG office, ten were interviewed in their own home and four interviews were held online.

Table 2: Characteristics of participants in the client interviews

	Number of participants (N=20)
Sex	
Male	4
Female	16
Parent/adolescent	
Parent	13
Adolescent	7
Educational level	
High	5
Middle	7
Low	8
Native country	
Netherlands	13
Kosovo	1
Syria	1
Afghanistan	2
Thailand	2
Sudan	1
Municipality	
Oldebroek	2
Elburg	1
Nunspeet	3
Harderwijk	8
Ermelo	5
Putten	1
Visiting PCH or Youth Care	
PCH	10
Youth care	10
Acquainted with portal	
Yes	13
No	7

CJG = Centre for Youth and Family
PCH = Preventive Child Healthcare

Interview outcomes

A code tree (Multimedia Appendix 3) was created with branches for all six aspects of quality of care: person-centredness, equity, efficiency, effectiveness, safety and timeliness (82). One additional theme emerged, related to professional attitude and behaviour. Because this theme linked with person-centredness, we divided the theme person-centredness in in two subthemes: client perspective and professional attitude. Most expressions from the participants could be coded in the domain person-centredness, followed by safety and equity, whereas effectiveness was mentioned the least (Figure 1). When experiences across quality-of-care domains were compared, it appeared that positive experiences were expressed for person-centredness, timeliness and safety, whereas the domains equity and effectiveness evoked predominantly expressions of concerns. Participants expressed mixed feelings for the domain efficiency. In the following paragraph, more in-depth analyses of participants' reflections on individual dimensions of quality of care will be presented.

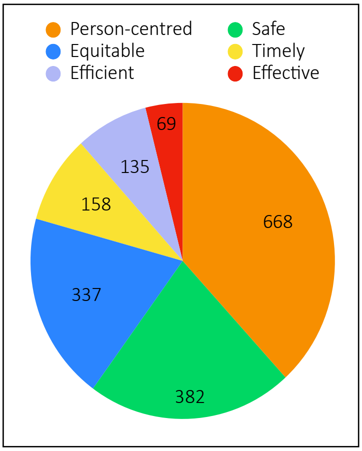


Figure 1: Number of codes for each domain of quality of care.

Person-centredness

Subtheme A: Client perspective

Clients reported that rereading information in the client portal contributed to person-centredness, because this helped them to recollect what had been discussed during a visit, to get overview over a longer period, and to prepare for a next visit.

"Sometimes it is so crowded in my head. Then I start thinking: what was it all about?"
[mother, 2 children, R7.2]

"It's more like when I am struggling with something that we have discussed earlier that I think: Hey, wait a minute. Didn't we already talk about this once? And I can reread our conversation."
[female adolescent,17 years, R10]

Using the client portal to get overview was even more important for parents with a migratory background, although only one of them had been using the portal before the interview. However, after watching the portal demo and accessing their own child's health record, all parents from a migratory background considered access to the client portal to be very valuable. They expected that both rereading and reading with others would be vital. Rereading, using an online translation tool when they did not comprehend the Dutch text, would help them to get a better understanding of what was discussed during a previous visit. Some mothers with a migratory background had partners who understood Dutch better than they did. Rereading together after a mother's visit to the CJG would provide the father with all relevant information and would help the mother to recollect what was discussed or provide her with information that she had not grasped yet during the visit.

"This one (client portal), this is good! My husband always is asking: 'How big was his head, how tall was he and how many kilos?'
And then I go: 'Oh my goodness, I forgot! Do I need to memorize that?'
Now I can say: 'Hey, you can log in and see for yourself what has happened.'"
[mother, 1 child, R2.1]

Involving relatives in your care was an aspect of person-centredness that not only parents with a migratory background reported as a benefit from access to the client portal. Most parents valued that a partner who had not been present at the doctor's visit could read the notes afterward. For adolescents, it felt easier to have parents read a visit report than to recall the whole conversation themselves, although they also valued the possibility to actively withhold information from their parents if they wanted to. Finally, rereading with relatives or friends was reported as helpful as well, when preparing for a next visit, or when decisions had to be made about the care process.

"I have a Syrian friend who does not speak Dutch. Her daughter has a growth problem. I helped her and we took the information from the growth chart in this portal, bringing it with us to the hospital."
[mother, 3 children, R11]

Being able to reread information, clients felt well informed and engaged in their own care plan. They also valued being part of the reporting process, discussing beforehand what should be reported and how. The combination of reporting together and rereading information enhanced their sense of ownership and contributed to equal client-professional collaboration.

"Now I know, because I can check myself, when my children need vaccinations"
[father, 5 children, R3.2]
"You construct the report together, so to speak, and you can both navigate the plan a little."
[mother, 2 children, R7.3]

Both parents and adolescents would like to have more ownership than was facilitated by the client portal. Some parents expressed the need to add more information to EPR-Youth, to create a full overview of all health and welfare issues concerning their child. Adolescents wanted to be more in control of who accessed their health record: they wanted to actively give access to professionals or at least be able to see beforehand who had access to their record instead of reading afterward in their view log who had accessed their health information.

"At least I want to see beforehand which professional is authorized to access my health record, instead of seeing who has accessed my record afterward."
[male adolescent, 17 years, R5.1]

Subtheme B: Professional attitude.

Different participants emphasized that professional attitude was an important underlying condition to deliver person-centred care and to experience the possible benefits of using EPR-youth. The transparency of EPR-Youth contributed to a sense of trust, but only if professionals reported respectfully, showing that they did take clients seriously. Being able to see in a view log who accessed your health record was considered reassuring and enhanced trust. On the other hand, if professionals did not report respectfully, or showed that they did not respect a client's privacy, trust could be damaged. One parent had experienced so often that healthcare professionals were speaking about her, that she decided to not access the client portal to protect herself from losing trust in her current care provider.

> *"You should consider very carefully how you report, because you are inviting me: 'go ahead, read it.' You are giving full access to the health record."*
> *[mother, 2 children, R7.3]*
> *"I have decided that I trust 'X' completely. Why should I read my health record when I do not really need to and take the risk to read something that might harm that trust?"*
> *[mother, 2 children, R9]*

Safety

Participants were satisfied about the security of their health data and about the way professional authorisation was organized. They generally valued the possibility to see in their view log who accessed their health record. Adolescents valued their right to decide about access for their parents. Knowing how safety was warranted was an important factor contributing to their trust in the system.

> *"This afternoon I saw that someone had accessed my daughter's record. But I remembered I gave approval for that person. It's nice to know that my approval is needed beforehand."*
> *[mother, 4 children, R7.1]*
> *'I had problems with my parents, and I don't know if that's still in all those documents. Then it is nice indeed that you can decide, what they can and can't see.'*
> *[male adolescent, 17 years, R5.1]*

However, not everybody was well informed about the privacy and data security measures, and not everybody knew where to find the view log. For one client the view log was a reminder that professionals were discussing her situation without her being present, which she did not appreciate.

> *"Can other people (outside the CJG) see my child's record? How do I know that you don't give it to other people? Because everything is online."*
> *[mother, 1 child, R2.1]*
> *"Although I like seeing who has accessed my health information, it also gives me stress. Because once they discussed my condition in a meeting with several people and I was not there. They were talking about me without me, so to speak, and that's not okay. When I check the view log that situation comes back in mind."*
> *[female adolescent, 18 years, R5.2]*

Correcting errors is generally considered a part of the element ‘safety’ (34). Throughout some of the interviews, registration errors or missed appointments without follow-up were found when clients checked their portal. They said identifying errors did not upset them. Quite the reverse, they appreciated the possibility to detect errors, report them and have them corrected. Moreover, being able to correct mistakes increased a client’s sense of ownership over their care process.

“Sometimes things go wrong. For example, E had missed a vaccination. So now we can check the record ourselves and see which vaccination he needs.”
[father, 5 children, R3.2]

Equity

Independent of native country and educational level, participants thought very positive of the client portal’s usability. The portal was experienced as easy-to-use, and intuitive. Client could log on to the system easily using digital ID (DigiD), because people had familiarised themselves with this verification procedure during the COVID-19 pandemic. Usability on mobile phones was also considered good.

“Logging in with DigiD makes things easier actually, solving the whole hassle of passwords.”
[mother, 4 children, R7.1]
“For me, it must be well-organized and then it’s good. The way it is constructed right now, it’s clear, uncluttered and you can read everything. I think I will look more often.”
[mother, 2 children, R7.3]

Clients considered also considered most record content comprehensible. However, some portal features, e.g. vaccination overview and planning appointments, required explanation and clients sometimes encountered jargon or incomprehensible abbreviations

“I understood most things I read. But I thought about some information from when I was a little kid, some expressions: that must be only for doctors.”
[female adolescent, 18 years, R12]

The most serious concerns expressed by parents was that not all clients were informed equally about the existence of EPR-Youth. Seven out of twenty participants had not received any information about EPR-Youth before the interview, six of them being from a migratory background. One parent from a migratory background did use the client portal to manage appointments but was not aware that she could also reread visit reports. Parents presented many options for improvement of communication. Emphasizing the importance of more equal information to all population groups, one parent offered to participate in information meetings with mothers from migratory backgrounds.

"If I had not been here, I would not have known anything about it at all,
and that's a shame."
[mother, 1 child, R2.3]
"Some mothers (with a migratory background) are unsure
about their language proficiency. For them it is easier to do it through the internet."
[mother, 3 children, R11]

Timeliness

The client portal's 24/7 accessibility did not contribute to faster access to care. It did, however, provide clients with the opportunity to ask questions or schedule appointments easily and at their own convenience. Clients valued this opportunity as timesaving, as well as the immediate access their own health information without the interference of a CJG professional.

"Suppose I get very anxious during the weekend about certain behaviour I observed.
I would prefer to search information right then and there, instead of sending an email
and wait several days until someone responds.
I think it's a plus that I can check the client portal and ask my questions immediately."
[mother, 2 children, R7.3]
"I rescheduled my appointment once through the portal. Very convenient and timesaving!"
[mother, 2 children, R7.2]

Efficiency

In EPR-Youth, all CJG-professionals had access to all relevant information stored in the same place, which was considered an advantage contributing to efficiency. Consequently, parents and adolescents did not have to repeat their story when visiting a new professional in the CJG.

"I think it is very convenient when you visit several people in the same period that all
information is in one place. So, they can make use of each other's information."
[female adolescent, 15 years, R6]

However, participants saw room for improvement in expanding EPR-Youth towards other care providers and in a more active role for themselves in uploading information from other care providers in their client portal. They felt that if all their health data would be stored in one place and accessible for all their care providers, it would be easier for both care providers and clients themselves to create a clear overview and manage their care.

"I really hope lines between all professionals will be shorter.
Eventually, I hope my children will have all their health data in this record,
that this will be their complete and only health record."
[mother, 2 children, R8.3]

Effectiveness

Participants did not associate using EPR-Youth with effectiveness. Although a fully accessible health record gives clients the opportunity to engage in the management of their care process, none of the participants commented on the actual care process and whether right choices had been made.

Participants did comment on the process and quality of reporting: they felt that reporting quality could be improved. Some reports contained mistakes, and some were incomplete or missing. One parent expressed the concern that reports were prejudiced sometimes, elaborating on risk factors, and neglecting protective factors.

> *"They only report what is wrong. You know what could really help? If you would read in your child's record what is going well, if someone would write down what a lovely little boy he is"*
> *[mother, 2 children, R9]*

Discussion

Principal findings

With this study we explored how parents and adolescents visiting preventive health care and social care perceived the quality of care when using EPR-Youth. Both experiences of active users and expectations or first impressions of non-users were included. The results suggest that using EPR-Youth contributed to some, but not all aspects of quality of care. On the positive side, parents and adolescents felt better informed and expressed more engagement in the care process than before introduction of EPR-Youth. They felt more in control of their health data, reported to have faster and simpler access to their health information and found it easier to manage appointments or ask questions at their convenience. Portal usability and data safety were regarded high, and interdisciplinary collaboration in EPR-Youth was considered to enhance efficiency. Parents from a migratory background expected that portal access would give them a better understanding of and more control over their care processes.

Parents, however, expressed concerns about possible inequal access due to lack of information to parents from a migratory background. Furthermore, both parents and adolescents saw room for improvement in broader interdisciplinary use of EPR-Youth. Finally, they felt that effectiveness could be improved by more complete reporting, regarding protective factors as well as risk factors.

Comparison with prior work

Overall contribution to quality of care

Previous research investigating quality of care in relation with using PAEHRs predominantly focused on adult healthcare. These studies reported largely the same outcomes as our study, although described from a care provider's perspective. Using a PAEHR was reported to contribute to person-centredness (135, 227, 228), safety and efficiency (220, 227, 228). Contrary to the present study, prior studies also show a positive impact of using a PAEHR on effectiveness (220, 227, 228). Some studies report that patient portals enhance timeliness through messaging functionalities or quicker access to results (51, 101, 113, 114, 229).

Person-centredness, professional perspective

Some participants emphasized the importance of a person-centred professional attitude, which they considered fundamental for EPR-Youth's contribution to quality of care. When professionals reported respectfully in EPR-Youth, this enhanced the client's trust in their care providers, whereas earlier experiences with professionals not respecting a client's privacy damaged that trust. An extensive review by Scholl et al. generated a patient-centred care model that places a professional's attitude central in the delivery of person-centred care (14). In this model, delivering patient-centred care relies on professionals embracing a person-centred attitude, characterized by respecting a patient's unique preferences and needs, building a professional-patient relationship based on equality, and viewing a patient's health from a biopsychosocial perspective (14). Leeuwis et al state that complex interventions, such as technological innovations, usually require change on different levels (78). These changes, on technological, organisational and professional level, are considered to be interdependent (78). In this case, implementing a PAEHR with the aim of enhancing person-centredness is not only about introducing the technological tool: the implementation needs to address professional attitude and behaviour as well. In turn, changes in professional behaviour and attitude require adjustments at the organisational or institutional level. These interdependencies should be anticipated when organisations start implementing a PAEHR, and the necessary changes on organisational and professional level should be planned and facilitated in addition to the development and implementation of the tool itself.

Equity

Equity emerged in this study as an issue of concern, because most participants with a migratory background appeared to be unaware of the existence of a client portal, opposed to one participant with a native background. Diving a bit deeper into this, anecdotal evidence may suggest that professionals hesitated to inform clients about the existence of the client portal when they noticed that a client's knowledge of Dutch was limited. Unawareness of the existence of a patient portal has been reported as a main barrier for using a patient portal (230, 231), and could be resolved by provider encouragement, which is an important contributor to portal use (232-234). However, when providers selectively encourage certain people groups to use a patient portal and neglect others, they could enhance disparity. Previous research shows that persons living in vulnerable circumstances, (e.g., persons with lower levels of education, or persons from a migratory background), make less use of patient portals than average (44-47, 50, 85, 235, 236). Literature on the digital divide reports that social exclusion can lead to digital exclusion, and that the introduction of new technology then might unintentionally reinforce already existing health disparities (237-239). Two studies investigating a provider’s role in patient portal use reported that healthcare professionals play a role in this reinforcement: higher educated and white patients were more likely to report being encouraged by healthcare providers to use a client portal than lower educated patients and patients from migratory backgrounds (232, 233). Antonio et al stated in a review that ‘healthcare providers’ prejudgments may further exclude populations that are already underserved’ (240).

This is an important issue to address because research shows that especially people living in vulnerable circumstances experienced benefits from using a PAEHR (35, 98, 101, 235). In our study, parents from migratory backgrounds reported that rereading their health information and sharing it with family members or friends would provide them with a better understanding of the care process and would increase their engagement in care. We concluded that ensuring that all clients are equally informed about the existence of a client portal is not only necessary to prevent further disparities but could possibly even diminish existing disparities (241). This may require adapted measures for specific population groups. Additionally, professionals need to be made aware of the risk of digital divide, and of their crucial role in conquering this phenomenon.

Confidentiality

Based on the known bottlenecks to develop PAEHRs for adolescents (52, 53), we expected data safety, confidentiality, and privacy an issue of concern for at least some of our participants. Surprisingly, however, participants did not express concerns about their data safety. Adolescents did value highly how their right to confidentiality was protected and reported that this contributed to their trust in their care provider. Previous research that compared professionals’ general concerns about using PAEHRs beforehand with experiences after a period of using a PAEHR shows, that expectations were not always lived up to. For example, an expected increase in workload and excessively anxious patients did not occur after introducing PAEHRs (28, 111, 112). One recent review investigated experiences of parents and adolescents using a PAEHRs or and expectations of parents and adolescents without access to a PAEHR (242). The authors found that parents and adolescents without access to a PAEHRs anticipated confidentiality issues when using a PAEHRS, whereas adolescents and parents using a PAEHR did not experience these issues (242).

Confidentiality issues could have been one of the problems expected by professionals that was not to evolve. Another explanation of the contrast between expected bottlenecks and real experiences may be that the explicit focus in literature on confidentiality issues has initiated specific awareness for this topic during development of EPR-Youth and has led to implementation of successful solutions.

Integrated care

Participants considered the interdisciplinary use of EPR-Youth a contribution to efficiency, and even expressed a need to expand the use of EPR-Youth to other disciplines, outside the CJG. This would give them the opportunity to view all their health data in one place. Parents and adolescents stated that, in their opinion, this would contribute to efficiency. With their remarks, however, participants draw upon an additional aspect of quality of care, integrated care, that the World Health Organisation (WHO) has added recently (82, 243). The WHO defines integrated care as 'providing care that is coordinated across levels and providers and makes available the full range of health services throughout the life course. Parents and adolescents even challenged the CJG-organisations to extend opportunities for interdisciplinary collaboration within EPR-Youth and facilitate them to gather all their health information here. With that challenge, parents and adolescents confirmed the value of the Dutch aim for integrated care in child healthcare and youth care (75). This aim also reflects in the recently established Agreement on Healthy and Active Living, between Dutch government, municipalities and public health association (GALA) (244), although it is not yet common practice throughout the country.

Strengths and limitations

Recruiting a well-balanced group of participants in this qualitative study was a strength of this study, compared to our previous studies on EPR-Youth, where adolescents were represented in small numbers and participants with migratory background could not be included (245, 246). The inclusion of all relevant groups in this study enabled us to explore different client perspectives. Choosing a qualitative research design made it possible to collect rich, in-depth information about client's expectations of and actual experiences with using EPR-Youth.

Due to COVID-19, organizing focus groups proved difficult. Although some triple interviews could be organized, most participants were interviewed individually or in couples. Consequently, our study lacked some of the interaction that usually is generated in bigger groups, which could be considered a limitation (247). We partly managed to overcome this limitation because we collected and analysed data in a continuously iterative process.

This meant that topics that were brought up in the first interview could be explored further in the following interviews.

Because JB had a role as policy advisor in the CJG's she was able to introduce participants to EPR-Youth who were not yet acquainted with the client portal, which gave us the opportunity to include more parents with a migratory background, and to add valuable information to our data. However, combining a portal demo with an interview about how clients perceived quality of care using this portal might have created a respondent bias: The interviewer's positive attitude towards the client portal could have evoked socially desirable answers. To enhance trustworthiness, the interviewers followed the interview guide as closely as possible, although allowing some adaptation to the conversational flow. A member check was conducted, transcripts were co-analysed with a researcher with no connections with EPR-Youth or the CJG, and reporting followed the consolidated criteria for reporting qualitative studies (224, 248).

Conclusion

Using EPR-Youth is expected to contribute to perceive quality of care from the perspective of parents and adolescents specifically to the aspects person-centredness, timeliness and safety. Parents and adolescents feel better informed, experience more sense of ownership, and are satisfied about data security and portal usability. Clients also report that using EPR-Youth contributes to integrated care. Some quality aspects, however, such as equity in portal access, still need addressing. In general, client information about the portal needs to be improved, with a specific focus on people in vulnerable circumstances, such as those from migratory backgrounds. Additionally, to maximize the potential benefit of using EPR-Youth, a person-centred attitude among professionals is important. With our study, we have investigated parent's and adolescent's perspectives regarding all domains of quality of care. However, considering the small number of adolescent participants, adding quantitative data from a structured survey could strengthen the available evidence.

Appendices

Appendix 1: Completed COREQ checklist
Appendix 2: Interview topic list
Appendix 3: Code tree

Appendix 1: completed COREQ checklist.

Consolidated criteria for reporting qualitative studies. (224)

No	Item	Guide questions/ description	Remarks	Section, subsection
Domain 1: Research team and reflexivity				
Personal Characteristics				
1.	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Main author JB led all interviews and focus groups CdM participated in 3 focus groups and 3 interviews as observer and notetaker	Methods, data collection
2.	Credentials	What were the researcher's credentials? E.g. PhD, MD	JB: MD, public health. CdM: MSc, Health Biology and Education.	Appendix 1
3.	Occupation	What was their occupation at the time of the study?	JB: medical policy advisor in preventive child health care, PhD-candidate CdM: postgraduate research assistant	Methods, data collection.
4.	Gender	Was the researcher male or female?	JB: female CdM: female	Methods, data collection, Appendix 1
5.	Experience and training	What experience or training did the researcher have?	JB has several years of experience in qualitative research. CdM followed workshops about qualitative research and analyzing data with Atlas.TI	Methods, research team and reflexivity
Relationship with participants				
6.	Relationship established	Was a relationship established prior to study commencement?	Both JB and CdM had no professional-client relationship with any of the participants.	Methods, research team and reflexivity
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	At the start of each interview, JB explained the purpose of developing EPR-Youth, her drive to do this research and the purpose of this interview.	Methods, research team and reflexivity
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	As a policy advisor, JB was very well informed about the functionalities of EPR-Youth and its patient portal, which was helpful when participants were not yet acquainted with the system.	Methods, research team and reflexivity; discussion.
Domain 2: study design				
Theoretical framework				
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis.	A thematic analysis was conducted from a phenomenological perspective, with an aim to determine what using EPR-Youth meant to clients in terms of quality of care.	Methods, research design

Participant selection				
10.	Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive sampling, aiming for a presentation of both sexes, parents and adolescents, different educational levels, both native and migrant background, coming from all participating municipalities and visitors of both preventive health care and youth and social care.	Methods, study population and inclusion.
11.	Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Face-to-face invitation by a professional, followed by phone/ email from one of the researchers to make appointment.	Methods, study population and inclusion.
12.	Sample size	How many participants were in the study?	20 participants were included, 13 parents and 7 adolescents	Results, general characteristics. Table 1: 'characteristics participants client interviews'
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	3 adolescents dropped out because of agenda mismatches (initially, 10 adolescents were recruited)	Results, general characteristics
Setting				
14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Where feasible, small group at CJG-Office. If not, location of client's choice. Three interviews were conducted at the CJG office, and five interviews were conducted at a client's home address.	Methods, study population and inclusion.
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No	n/a
16.	Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Demographics (sex, adult/ adolescent, educational level, native country and municipality), interview setting and acquaintance with client portal have been represented in table 2	Results, table 2
Data collection				
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	An interview guide was written, based on the six pillars of quality of care, defined by the Institute of Medicine (1999). The interview guide was written after a group session with professionals, discussing how using EPR-Youth could affect the way parents and adolescents experienced quality of care in each of these six domains.	Methods, data collection
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No	n/a
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio recorded. The online meetings were video recorded as well.	Methods, data collection

20.	Field notes	Were field notes made during and/or after the interview or focus group?	No	n/a
21.	Duration	What was the duration of the interviews or focus group?	Individual interviews ranged from 30 to 60 minutes, while group interviews took approximately 90 minutes.	Methods, data collection
22.	Data saturation	Was data saturation discussed?	Yes	Methods, data analysis
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	All transcripts were returned to participants for a member content check.	Methods, data analysis
Domain 3: analysis and findings				
Data analysis				
24.	Number of data coders	How many data coders coded the data?	Two authors (JB and CdM)	Methods, data analysis
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Yes	Multimedia Appendix 2, Methods, interview outcomes.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were identified in advance. The major themes were derived from the IOM definition of Quality of Care.	Methods, data analysis
27.	Software	What software, if applicable, was used to manage the data?	Atlas.TI, version 9, was used.	Methods, data analysis
28.	Participant checking	Did participants provide feedback on the findings?	No comments or corrections were returned. Eight participants responded that they had no comments.	Results, interview outcomes
Reporting				
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g., participant number	Yes, identified by gender, parent/adolescent, number of children (parents) or age (adolescent), and respondent number. The respondent number is indicated as R followed by the number of the interview, and if more participants were present at the interview a decimal to indicate this specific participant. e.g., R7.3 is the third participant in interview nr 7.	Results, interview outcomes
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes	Results, interview outcomes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes	Results, interview outcomes
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	One major theme was divided in two subthemes. In the discussion, an additional theme ‘integrated care’ was proposed.	Results, interview outcomes; discussion.

Appendix 2: topic list quality of care

Interview scope
This topic list guides the interviews with parents and adolescents about their perceptions of quality of care in relation to the use of EPR-Youth (Jeugddossier).

Each interview starts with a short introduction
- Introduction round interviewers and participants.
- What is today's topic: what is EPR-Youth and what is its purpose?
- Explanation about research topic and methods, about data management and privacy; request permission to record the meeting; explanation of member check afterwards.

General questions
- Are you acquainted with EPR-Youth and do you use it?
  - » If participants are not yet acquainted with EPR-Youth, continue with a 10-minute demo of the client portal.
- What are your experiences? Do you read, ask questions, plan, and manage your appointments? Did you experience that you can decide who has access to your (child's) record? If so, what does that mean to you?
  - » If participants are not acquainted with EPR-Youth yet, discuss their first impressions with them.

Continue the conversation, approaching the different domains of quality of care.
- **Equity**
  - » Did you manage to access the client portal? How easy was it? Did you need any help?
  - » After accessing the client portal: Did you understand what you read? Could you find everything that you are looking for?
  - » If you have never accessed the client portal before: did you know about the existence of EPR-Youth? How would you like to be informed about the existence of EPR-Youth?
- **Client-centeredness**
  - » How did the ability to read the EPR-Youth affect the collaboration and/or communication between you and CJG professionals? (keywords: transparency, honesty, trust)
  - » In dialogue with parents and adolescents, we stated that as CJG professionals we find it important to take our clients serious. Did EPR-Youth contribute to that? How does it affect the sense of equality?
  - » If you ask questions in the client portal, we would like to collaborate with you to find an answer that matches your needs. We consider you the 'owner' of your

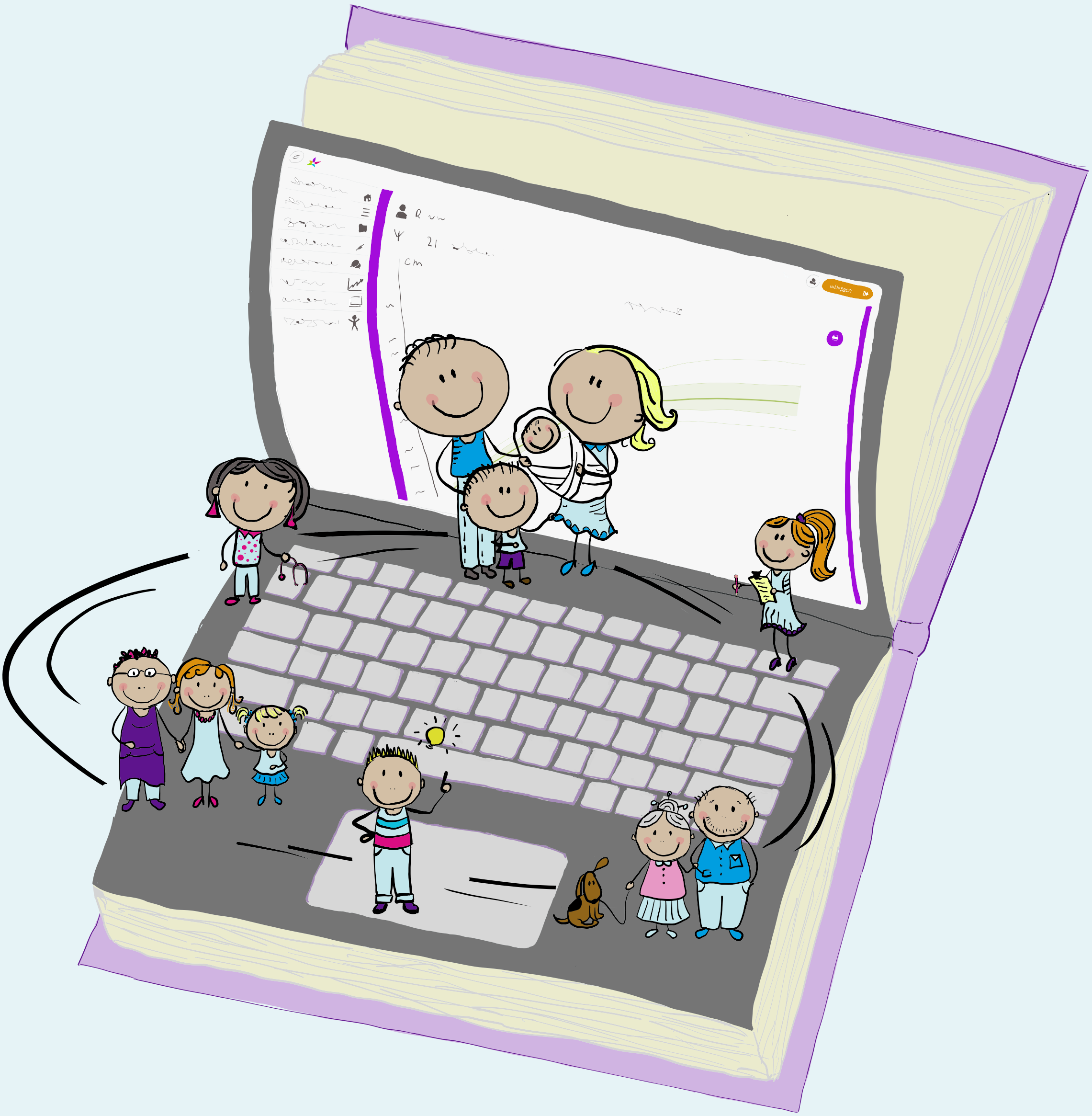
question, therefore you are the one who should choose the solution and who should decide when you have reached your goals. Did EPR-Youth contribute to that feeling of ownership of questions, solutions, and goals? Did it change your sense of involvement?

- **Safety**
  - How did you feel about the security of your data in EPR-Youth? Did that feeling change in comparison with the former health records? (Each organisation uses their own health record, without client access)
  - Did you have any concerns about things going wrong with your data and what would that be?
  - Did you ever discover flaws in our reports when reading your (child's) record? If so, what did you do, and with what positive/negative consequences?
- **Effectivity and Efficiency**
  - How did reading reports influence your view of our professional expertise?
  - We work with the '1-family-1-plan' principle: preventive child healthcare professionals and youth care workers report in the same record although they work in different organisations. They can read each other's reports, which would help them to work more effectively and efficiently. Did you notice any differences because of their shared access?
- **Timeliness**
  - You have 24/7 access to your client portal; therefore, you can ask questions and manage appointments anytime. Did that increase the speed of getting answers to your questions and did you get appointments faster?
  - How did you value the opportunity to ask questions 24/7 in the portal?
  - How did you value the opportunity to check and manage your appointments 24/7? This opportunity only exists for parents visiting preventive health care for preschool children. If you visited preventive healthcare for older children or youth care, would you value the opportunity to check and manage appointments?

Appendix 3: Code tree 'quality of care

Codetree for perceptions of quality of care, reported by parents and adolescents using EPR-Youth.
The main themes are derived from the IOM framework for quality of care, each theme in a different color
- *Client-centered (orange)*
- *Safe (green)*
- *Timely (yellow)*
- *Efficient (purple)*
- *Effective (red),*
- *Equitable (blue)*

Codes with a higher density are represented in a larger circle and larger font.
Cursivated codes indicate a mainly negative association with quality of care.
Bolded codes indicate a mainly positive association with quality of care.
Codes in normal font are associated both positively and negatively with quality of care.
Some codes are connected between themes. If possible, the connection is made with a line from one theme to another. When themes are on opposite sides of the codetree, a code is added to the other theme in the color of that theme and outlined in the color of the original theme. E.g.: 'incorrect information' is a code under the green theme 'Safe', and is added under 'Effective' in red with a green outline.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Chapter 8

General Discussion

"All interventions are complex, but some are more complex than others."

Graham F Moore et al, July 2017. (249)

General aim

The general aim of this dissertation was to improve the understanding of how using a PAEHR in preventive child healthcare and youth care contributes to integrated person-centred care for children, adolescents, and their parents, and to generate insight in barriers and facilitators during implementation. As outlined in the introduction, a growing body of literature exists about the use of patient-accessible health records. Most of these studies, however, did not include minors or their parents and hardly any study has investigated client-accessible health records in the context of public health or social work. Especially studies among adolescents using patient-accessible health records are lacking, which is mainly attributed to ethical challenges when dealing with confidentiality issues of both parents and adolescents.

In this final chapter I will provide an overview of the main findings for each chapter and reflect on the results at the level of client, professional and organisation. Subsequently, I will discuss methodological issues of this work and the implications of the findings for policy, practice, and future research, after which I will present the final conclusions of this work.

Summary of main findings

This thesis started (Chapter 2) with a scoping review of literature about the contribution of PAEHRs to patient-centred care, both in general and among specific patient groups. No studies could be found about the effect of using a PAEHR among adolescents on patient-centredness. Only a few studies reported about parents' experiences with access to their child's health record. Based on literature on primarily adult health care, we found that PAEHRs possibly contribute to patient-centred care. Although generally both patients and professionals reported positively about the use of PAEHRs, professionals in mental health care expressed concerns about the impact of transparency on the patient-professional relationship. These concerns appeared to be stronger when professionals were not embracing a person-centred attitude. People from vulnerable groups, such as older or less educated persons, patients with a chronic disease, or people with a migratory background, reported to benefit more from using PAEHRs than average, although PAEHR adoption rates were lower among these groups.

A process evaluation of development and implementation of EPR-Youth (Chapter 3) concluded that the first implementation stage of EPR-Youth could be considered successful: a fully client-accessible health record had been delivered that facilitated the working processes of all professionals from three different organisations. With this implementation, a strong basis had been created to deliver integrated person-centred care. At the same time, issues remained to be addressed that could mitigate medium-term effects of EPR-

Youth. Factors that could limit these effects were familiarity of adolescent and parents of school aged children with the client portal and limited user skills among professionals. Figure 1 depicts EPR-Youth's logic model of change and shows what output had been delivered and evaluated and what where implementation outcomes. As output from the development phase, the system EPR-Youth and its tethered client portal were delivered and evaluated (in green in the model). On organisational level, the implementation outcome variables acceptability, appropriateness, and fidelity were rated as 'sufficient' during evaluation (in green), whereas 'adoption' still needed addressing (in orange). On professional level 'sharing information with colleagues' was rated as sufficient, and 'knowing how to use EPR-Youth', 'knowing how to use the system in accordance with the vision' and 'writing objective reports' still needed addressing. On client level 'knowing about client portal' still needed addressing. Contrastingly, users who did know about the portal knew how to use it. They were able to understand what they read, to add information and to decide who had access to their EPR. Therefore, these implementation outcomes were rated as sufficient. As follow-up strategy, improved information, targeting clients from all different backgrounds, was advised, as well as additional training for professionals.

The effect evaluation of EPR-Youth was divided in two phases and focused on three topics: in the first year after introducing EPR-Youth, the contribution of EPR-Youth to enhancing client autonomy (Chapter 4) and to strengthening interdisciplinary collaboration was assessed (Chapters 5 and 6). Client autonomy and interdisciplinary collaboration are shown in Figure 1 as medium-term outcomes. Two years after introducing EPR-Youth, impact on client perceptions of quality of care (Chapter 7) was investigated, as a first measurement of long-term outcomes (Figure 1).

In Chapter 4 we found indications that parents and adolescents using EPR-Youth experienced more autonomy than non-users. This effect appeared stronger among adolescents aged 16 and older than among younger adolescents. During this study period, professional autonomy-supportive behaviour did not change although clients reported that professionals could enhance the effect of using EPR-Youth on client autonomy with autonomy-supportive behaviour, emphasizing the importance of addressing professional attitude when implementing a client-accessible health record.

To investigate the effect of using EPR-Youth on interdisciplinary collaboration, the Index of Interdisciplinary Collaboration (80), a questionnaire from the US, was translated to Dutch. The 42-item questionnaire consisted of five components of interdisciplinary collaboration: interdependence, newly developed professional activities, flexibility, collective ownership of goals and reflection on the process. After the first round of questionnaires, reliability tests (Chapter 5) concluded that the translated questionnaire could be a useful and valid instrument to measure interdisciplinary cooperation in youth care in the Netherlands, although one component showed low internal consistency and requires further adjustment in the future.

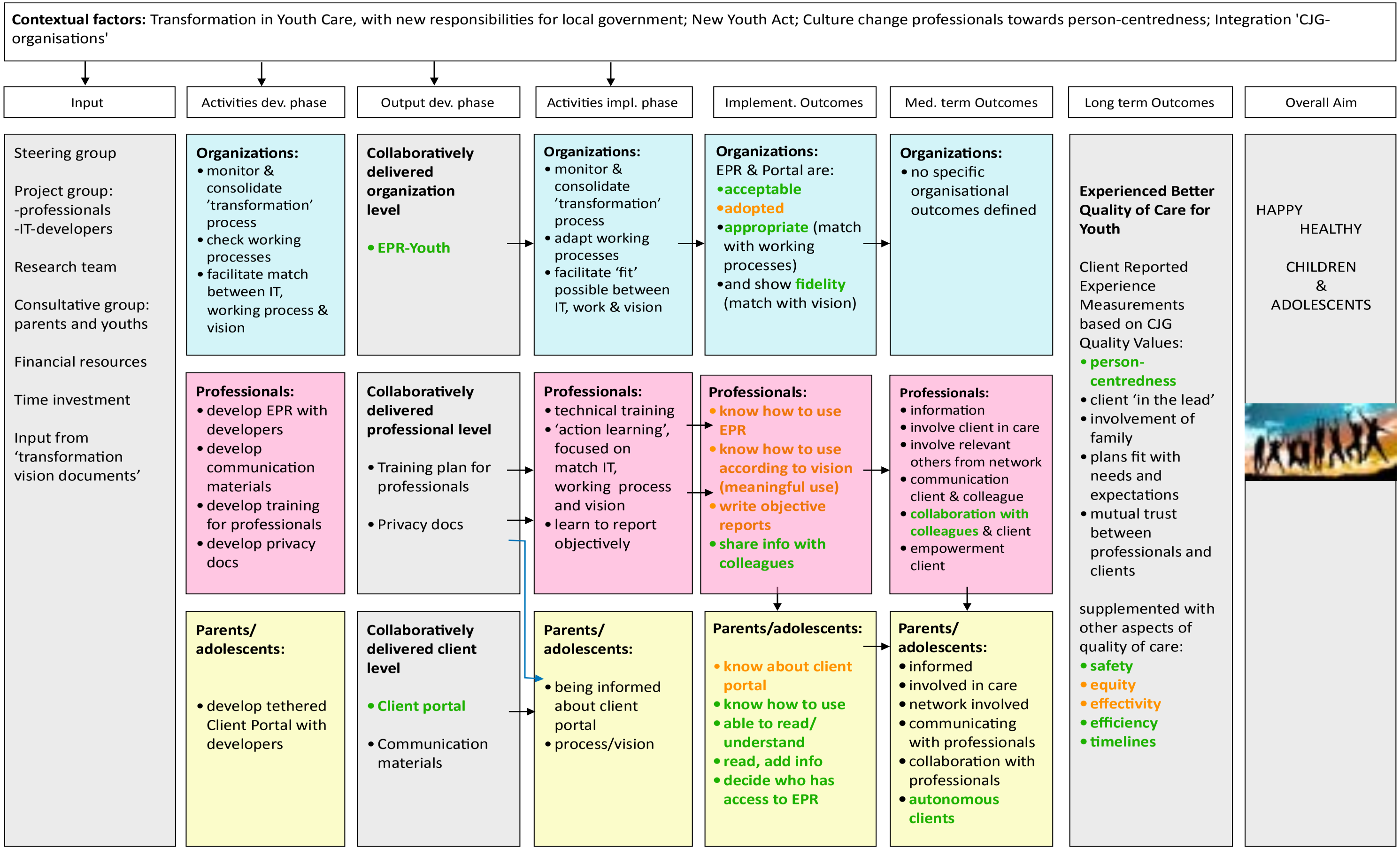
The effect evaluation suggested that using EPR-Youth fosters interdisciplinary collaboration (Chapter 6). Although a significant positive effect on interdisciplinary collaboration was found for only one of five components, the overall slightly positive trend was confirmed by focus group interview outcomes, suggesting that using EPR-Youth contributed to a professional's sense of 'interdependence', to 'collective ownership' of care plans, and to 'newly creating professional activities'. Differences in levels of interdisciplinary collaboration between professionals from different organisations suggested that other factors, such as developing a shared vision on collaboration among participating organisations, are important for fruitful interdisciplinary collaboration.

Finally, the effect of using EPR-Youth on quality of care was investigated (Chapter 7). We found that using EPR-Youth contributed to client-experienced quality of care, more specifically to perceived person-centredness, timeliness, safety, and efficiency. Parents and adolescents using EPR-Youth felt better informed and more engaged in the care process and experienced more sense of ownership than before introduction of EPR-Youth. Parents and adolescents were satisfied with data security and portal usability. Most participating parents from migratory background had not previously been informed about the client portal. Nonetheless, they expected, that portal access would give them a better understanding of and more control over their care processes. To achieve this, professionals need to be aware that these parents must be better and more specifically informed. Ultimately, both parents and adolescents appreciated the interdisciplinary use of EPR-Youth and expressed the hope that one day they could store all information about their health and well-being in this record, and that they could collaborate in it with all their care providers.

Reflection on main findings

To our knowledge, this is the first study investigating the implementation and use of an interdisciplinary client-accessible health record among professionals, parents, and adolescents. Overall, our work delivers first proof that using a client-accessible health record in the interdisciplinary context of preventive child healthcare and youth care potentially contributes to integrated person-centred care in a similar way as patient-accessible health records do in adult healthcare. Together our work provided first indications that parents and adolescents using EPR-Youth may experience more client autonomy, professionals using EPR-Youth may experience a positive effect on their interdisciplinary collaboration, and as a result, parents and adolescents using EPR-Youth may experience positive effects on quality of care. Our work also illustrates that implementing a client-accessible health record in a multidisciplinary context involves more than just implementing the tool, requiring change on client, professional and organisation level (Figure 1). We further discuss our findings in relation to those levels.

Figure 1: Logic model of change EPR-Youth. In bold are output and outcomes that have been assessed during this project. In green are the output that had been delivered before the evaluation and the outcomes that were associated positively with using EPR-Youth, in orange the topics that still needed addressing.



Contextual factors: Transformation in Youth Care, with new responsibilities for local government; New Youth Act; Culture change professionals towards person-centredness; Integration 'CJG-organisations'

Input	Activities dev. phase	Output dev. phase	Activities impl. phase	Implement. Outcomes	Med. term Outcomes	Long term Outcomes	Overall Aim
Steering group Project group: -professionals -IT-developers Research team Consultative group: parents and youths Financial resources Time investment Input from 'transformation vision documents'	**Organizations:** • monitor & consolidate 'transformation' process • check working processes • facilitate match between IT, working process & vision	**Collaboratively delivered organization level** • **EPR-Youth**	**Organizations:** • monitor & consolidate 'transformation' process • adapt working processes • facilitate 'fit' possible between IT, work & vision	**Organizations:** EPR & Portal are: •**acceptable** •**adopted** •**appropriate** (match with working processes) •and show **fidelity** (match with vision)	**Organizations:** • no specific organisational outcomes defined	**Experienced Better Quality of Care for Youth** Client Reported Experience Measurements based on CJG Quality Values: • **person-centredness** • client 'in the lead' • involvement of family • plans fit with needs and expectations • mutual trust between professionals and clients supplemented with other aspects of quality of care: • **safety** • **equity** • **effectivity** • **efficiency** • **timelines**	HAPPY HEALTHY CHILDREN & ADOLESCENTS
	Professionals: • develop EPR with developers • develop communication materials • develop training for professionals • develop privacy docs	**Collaboratively delivered professional level** • Training plan for professionals • Privacy docs	**Professionals:** • technical training • 'action learning', focused on match IT, working process and vision • learn to report objectively	**Professionals:** • **know how to use EPR** • **know how to use according to vision (meaningful use)** • **write objective reports** • **share info with colleagues**	**Professionals:** • information • involve client in care • involve relevant others from network • communication client & colleague • **collaboration with colleagues** & client • empowerment client		
	Parents/ adolescents: • develop tethered Client Portal with developers	**Collaboratively delivered client level** • **Client portal** • Communication materials	**Parents/ adolescents:** • being informed about client portal • process/vision	**Parents/adolescents:** • **know about client portal** • **know how to use** • **able to read/ understand** • **read, add info** • **decide who has access to EPR**	**Parents/ adolescents:** • informed • involved in care • network involved • communicating with professionals • collaboration with professionals • **autonomous clients**		

Client level

Confidentiality

In our review, we had found that development of patient-accessible records for adolescents had been hindered worldwide by the struggle of guarding adolescent's rights to confidentiality (52-54). In our study, in the development phase of EPR-Youth, parents and adolescents had expressed worries about data safety and confidentiality in general, which was a reason to postpone the release of full record content in the client portal for five months. Furthermore, because preventive child healthcare doctors worried about protecting the confidentiality of their clients' personal information towards youth care professionals, EPR-Youth was built with a strict division between medical and non-medical information. During implementation, professionals and clients determined that this division was artificial and hindered adequate interdisciplinary collaboration. Therefore, the division was reassessed and adjusted, with the aim that every professional could read all information that was necessary to do their work. A FAQ document was posted on the EPR-Youth portal website, written in understandable language for parent and adolescents, explaining rights, regulations and working procedures concerning use of EPR-Youth.

One year after the introduction of EPR-Youth, parents, adolescents, and professionals using EPR-Youth expressed little or no worries about the protection of the adolescent's right to confidentiality. They felt that the system protected these rights adequately, closing the portal for parents when a child turned 12, reopening it after permission from the adolescent and then still leaving the option to keep specific information confidential between adolescent and professional. Adolescents valued highly that they could share their story in confidence without professionals sharing it among each other, that youth care professionals only accessed an adolescent's health record after permission from that adolescent, and that they could see in a view log which professional had accessed their health record. This strengthened their confidence in the professional.

Meeting worries before introduction of a PAEHR and finding these worries have diminished or disappeared after a period of using the PAEHR has been reported by several studies (28, 49, 111, 112, 116). In these studies, professionals worried beforehand that reading notes would cause patients to worry more about their disease (111, 112, 116), cause confusion among patients because they did not understand what they read (49, 111,112). Professionals also expected beforehand that as a result their workload would increase (28, 49, 112), that they would report differently about sensitive subjects (28), and that the patient-clinician relationship might be hampered by a PAEHRs transparency. These worries had diminished or disappeared after a period of using a PAEHR. One recent review investigated experiences of parents and adolescents using a PAEHRs or and expectations of parents and adolescents without access to a PAEHR (242). The authors found that parents and adolescents without access to a PAEHRs anticipated confidentiality issues when using a PAEHRS, whereas adolescents and parents using a PAEHR did not experience these issues (242). Therefore, addressing confidentiality issues during development of PAEHRs is important. Nevertheless, we may have confidence, based on previous research, that the experience of using well-built PAEHRs helps mitigating confidentiality concerns. In our study, for example, the measures taken during development and implementation have possibly solved the problems that were causing parents and professionals to worry about confidentiality.

It is important to note that we did encounter a different confidentiality issue: in our studies on client autonomy and on quality of care, parents and professionals expressed their worries that parental privacy might be violated when adolescents accessed their own record at the age of 12. In a similar vein, parents and professionals were concerned that some of the information that adolescents would encounter in their own health record might be harmful to themselves.

The first concern receives little attention in literature, although many other countries have legislation that give both parent and adolescent right of access to the adolescent's health information during a certain period (59, 61, 183, 252). This shared right of access has been created to support the transitional phase adolescents are in: from a state of dependence on parents towards autonomous adulthood (182). In the beginning, the child is considered old enough to begin making their own decisions, but still at an age that they require a lot of support from parents, teaching them how to exercise their newly acquired rights (184). Gradually they will learn, and the need for support will diminish, until they have grown old enough to make their own decisions independently and get sole access to their health record (184). In our study, the adolescent's right to confidentiality was well protected because they were allowed to keep specific information confidential even when they had allowed their parents access to their health record. Parental privacy, instead, was not protected in the same way, because the information in the health record about parents is considered relevant to the adolescent's health and therefore it is the adolescent's right to see this information (53). This sometimes involved highly sensitive information, concerning matters like parental lineage, diagnosis and treatment of sexually transmitted diseases, substance abuse, domestic violence, or mental health. Parents may not have disclosed and may not want to disclose such information to their child. A recently published case study illustrates how relations between professional, parent and adolescent could be hampered if such information is disclosed anyhow, and shares recommendations how to ensure confidentiality with adolescent minors and their caregivers (253). Recommendations include clear information to parents and adolescents about functionalities of a PAEHR and its privacy settings, discussing what information has to be shared with whom, and emphasizing the importance of involvement of adolescents in their own care (253). A key recommendation when reporting in a PAEHR is to always bear in mind that parents and adolescent can read it afterwards. Therefore, use clear language, highlight strengths, and progress, and document all important information in an objective and discrete manner.

Handling these situations requires professionals to be alert and attentive. In our study, in response to the process evaluation results, professionals received additional training in objective reporting, and received instruction how to protect parental privacy adequately. This means discussing carefully with parents about what and how to report in EPR-Youth about their current situation. It also means that parents are allowed to scrutinize their child’s record before the child turns 12, and that previously reported sensitive information will be rephrased if necessary or even deleted if no longer relevant for the child’s health.

Digital divide and equality

On client level, we found that using PAEHRs in general, and using EPR-Youth specifically, potentially contributes to person-centred care. Clients in our study experienced more autonomy and higher quality of care when using EPR-Youth. Our review showed that patients living in vulnerable circumstances benefit even more from using patient portals than average. Parents with a migratory background in our study on quality of care expected high benefits from using EPR-Youth as well. Contrastingly, we found in both the review and the evaluation studies, that people in vulnerable circumstances showed lower portal adoption rates than average. In the North-Veluwe region, clients of non-Dutch nativity and less educated clients were underrepresented among portal users. Our study on quality of care showed that parents with a migratory background were not utilizing the client portal to its full potential. Both findings are in line with earlier research. On one hand, there are studies reporting that people in vulnerable circumstances benefit more than average from using a PAEHR, because they felt better about their doctor after reading their notes, because it helped them to remember their care plan, and because it facilitated them in making care decisions (35, 98, 101, 235). Using a PAEHR was important to them to engage in their care (98). On the other hand, people in vulnerable circumstances are known to show lower than average PAEHR adoption rates (44-47, 50, 85, 235). In a systematic review, Grossman et al. found more than 100 studies reporting differences in portal adoption rates that were related to health inequities (236). For instance, lower adoption rates were found among persons with low socioeconomic status, persons with low health literacy, or persons from racial minorities (236). This discrepancy between potential benefits and actual use among people in vulnerable circumstances means that introducing a PAEHR could enhance existing health inequities instead of diminishing them. This raises the question how differences in portal adoption can be reduced.

Differences in adoption of technology are usually referred to as ‘digital divide’. This term was introduced in the nineties to describe the gap between those who readily adopt new technology, and those who do not. The digital divide was originally mainly attributed to unequal physical access to technology: the difference between the ‘haves’ and the ‘have nots’ (254). Since 2002, numerous researchers have been investigating the ‘digital divide beyond access’ and currently three levels have been distinguished. First-level digital divide refers to lack of physical access to technology, second-level digital divide refers to limited digital skills and knowledge to use technology (41, 85). Third-level digital divide focuses more on the consequences of introducing new technology for already existing inequalities, on the relationship between social inequality and digital inequality, and on the match between technology and people’s lived experiences (238, 239, 241). In our last study, parents with a migratory background had no previous experience with EPR-Youth because they had not been informed about its existence. Unawareness of the existence of a patient portal has been reported as a main barrier for using a patient portal (230, 231), and such lack of knowledge could be labeled as second-level digial divide (41, 85). However, the finding that mainly parents with a migratory background were unaware of the existence of EPR-Youth suggests that professionals have selectively informed clients about the portal, which can be considered third level digital divide. Previous studies have reported the same selective information patterns among healthcare professionals (238, 240). For instance, doctors who expect their elderly patients not to be digitally proficient might not want to burden them with information about a patient portal. Or a health provider meeting patients from migratory background with limited language skills, assessing that it is not worth informing them about a PAEHR because they will not be able to understand what is written. This matches with a third-level digital divide because a person’s characteristics, such as in our study native background or language skills, influenced the professional’s decision whether or not to share information about the PAEHR. In third-level digital divide, social and digital inequalities are linked and can reinforce each other (237). Professionals can play either a contributing or limiting role in this process, enhancing or diminishing equity as such. Antonio et al. stated in a review that ‘health care providers’ prejudgments may further exclude populations that are already underserved’ (240). It is important for professionals to be aware of the more than average benefits that have been reported by people in vulnerable circumstances when using a PAEHR. Moreover, professionals need to be aware of the position they have in promoting portal adoption. They need to be trained to specifically address people in vulnerable circumstances when providing information about availability of a PAEHR.

Professional level

Autonomy-supportive behaviour and relational autonomy

Professionals not only play their part in informing clients about a client portal, but also in supporting client autonomy. In our study on autonomy, parents emphasized the importance of an autonomy-supportive professional attitude, to build an equal professional-client relationship, and to further strengthen client autonomy, when using EPR-Youth. Similarly, in our review we found that adoption of a patient-centred attitude by professionals appears to be crucial for a positive impact of using PAEHRs on the professional-patient relationship. Scholl’s model for patient-centred care (14) emphasizes the importance of building an equal professional-patient relationship as underlying principle to come to shared decisions and deliver patient-centred care.

Why autonomy-supportive professional behaviour and building an equal professional-patient relationship is so important in the development of client autonomy is explained by the concept of relational autonomy (252). From the perspective of relational autonomy, contrarily to what the liberal approach to autonomy states, individual persons can not make decisions of their own free will, independent from others, solely based on information they gathered. Relational autonomy theorists argue that autonomy evolves in the context of significant social relationships, scaffolded by social conditions (252). When autonomous decisions are being made in such a context, both intrinsic motivation and exogenic influences play a role. In a healthcare process, healthcare professionals are part of the exogenic influences. Their contribution to client autonomy is not solely to share information with someone and let them decide independently. Health care professionals should, from the eyes of relational autonomy, actively engage with clients and their relatives and act as facilitators of the decision-making process, defending their client's best interests (256).

This theory explains the significance of professional autonomy-supportive behaviour. At the same time, it places a responsibility on professionals to handle this properly. In a professional-client relationship, the professional's knowledge, needed to solve the client's problem, inevitably creates inequality (257). In an attempt to even out this inequality, procedures such shared decision-making and tools like PAEHR have been developed. However, the initiative to even out inequality lies with the most powerful, the professional. It is important for professionals te be aware that building an equal relationship with clients, especially those in vulnerable circumstances, contributes to client autonomy and, eventually, to better health. Professionals in our study were aware that EPR-Youth was a powerful tool to promote equal collaboration between them and clients. Less clear was their awareness that professional attitude and behaviour played an equally important role, a reason to address the topic during further implementation.

Organisational level

Barriers in interorganisational collaboration

Both in the process evaluation and in our study on collaboration we found differences between the three involved organisations and in the way they facilitated their employees to participate in the process of development and implementation and in interdisciplinary collaboration. This means that we can neither speak of 'the' organisational culture, structure, and vision, nor of 'the' way professionals were facilitated by their organisation. The variation in culture, structure and facilitation raised issues that emerged in both the process evaluation and the study on interdisciplinary collaboration. Organisational cultures differed, among other things, in leadership styles and degree of self-management of teams, which resulted in different expectations regarding project leadership. The three organisations had implemented the shared vision on integrated care for youth in different ways, resulting in many and recurring discussions about the project's goal and purpose. Structurally, each organisation has its own geographic working area, partly outside the

North-Veluwe, and the challenge to match regional interorganisational collaboration with the broader organisational direction. Moreover, preventive child healthcare and youth care are secured in different laws, creating different task perceptions. Finally, there was a difference in how workload was organised, and consequently in time available to spend on interdisciplinary collaboration. From previous research we know that such differences arise when aiming for integrated care. Delivering integrated care requires boundary-crossing activities between not only professionals from different disciplines, but between organisations as well (258). Crossing boundaries between organisations is about learning to speak each other’s language, about getting to know each other’s work and working conditions, and defining shared goals (258, 259). Research shows that this process can be hindered by a whole range of factors, related to broader organisational priorities and workforce arrangements (260). Although we found an explanation for the interorganisational frictions arising during development and implementation, we did not yet find clear answers to the question how to facilitate the process of co-development and collaboration, and what factors can promote boundary-crossing activities. Given the fact that the extension of integrated care across the boundary of medical care is relatively new, it would be relevant for future research to provide further understanding of promotors and barriers in interorganisational collaboration, and define pathways to strengthen such collaboration.

System change: change on all levels.

In a logic model, we described the required change on client, professional and organisational level when implementing EPR-Youth (Figure 1). We found, however, that change on one level is often connected with change on another level. For instance: EPR-Youth is reported to contribute to client autonomy, and professional autonomy-supportive behaviour adds to this effect. In other words, a change in professional attitude is needed to maximize the impact of EPR-Youth on client autonomy. When developing and implementing complex interventions, such connections between levels of change are inevitable and even beneficiary. Leeuwis et al state that in co-creational processes, such as the development and implementation of EPR-Youth, different elements on different levels mutually reinforce each other (79). To introduce new technology in a proper way, changes are needed on all levels, and can be initialized through co-creative platforms where all stakeholders are represented (79, 261). Consequently, it is important to be aware of the interaction between levels during the implementation process, to eventually be able to deliver the intended outcomes.

Methodologic reflections

The research methodology selected is subject to limitations. In the following section, the strengths and weaknesses of the study design, samples and measures are discussed. Next, the research is placed in a broader context of practice-based research and in a broader time frame of health care research during a pandemic.

Strengths and weaknesses

Design

In this thesis the development and implementation of PAEHR was evaluated in a process and effect evaluation on client, professional and organisational level, including adolescents, parents, and professionals. This holistic multi-level approach, combining qualitative methods (e.g., observations, focus group interviews and document analysis), with quantitative methods (e.g., surveys) added strength to this work (262), because the data from different sources complemented each other, and allowed us to evaluate the process from different perspectives.

To evaluate how using EPR-Youth affected client autonomy, professional autonomy-supportive behaviour, and interdisciplinary collaboration, we used a pre-test post-test designs with 12- and 24-month follow-up. Such a longer-term follow-up is also a strength of the study. Unfortunately, it was not possible for all outcome measures to include entirely the same cohort across measurements over time, due to the use of anonymous client questionnaires, and high turnover among professionals. Also, it should be noted that a control group was not included, because there was no suitable comparable Dutch region, offering a similar context, in which preventive child healthcare and youth care collaborated in a comparably integrated fashion towards a transformation of youth care. These methodological limitations limit the certainty with which the positive changes can be attributed to the introduction of PAEHR/EPR-youth.

Nevertheless, we tried to estimate the isolated effect of using EPR-Youth on experienced client autonomy, comparing the difference between portal users and non-users. It is possible, however, that mainly persons who experienced more autonomy accessed their client portal, which would have created a selection bias. Yet, adding focus group interviews to the design allowed us not only to deepen our understanding how using EPR-Youth affected interdisciplinary collaboration and client autonomy, but also to discuss with participants to what extent the changes that we had found could be contributed to the use of EPR-Youth or to other factors. Although the findings from the qualitative studies substantiated the indications found in the quantitative evaluation, it is important that future research is conducted to replicate the findings.

Participants

Target groups for our study were all parents, adolescents, and professionals that were using EPR-Youth. For the process evaluation, members of the project group and steering committee that guided the development and implementation were additional target groups. Including professionals from all three organisations and from all different disciplines was a strength of this work, as well as covering the perspectives of clients, professionals, and organisation. The high questionnaire response among professionals in the pre-test and second post-test was also a strength, resulting in outcomes that are representative for this region.

Among clients, however, not all relevant subgroups were equally represented, which limits the external validity of the research. Only a small number of adolescent portal users were included in the client questionnaire, and parents with lower educational level or with migratory backgrounds were underrepresented.

The small number of adolescent portal users made it difficult to detect potential differences between pre-test and post-test as significant, making it likely that some (either positive or negative) changes remained unnoticed due to a lack of power. Yet, the differences that were identified can be considered relevant. We conducted a power analysis to estimate how many paired samples would be needed to detect an effect size of 0.3 on client autonomy. Assuming a power of 80%, a level of significance of 5% and a SD of 0.8, 90 paired samples need to be included (263). Which means that, with an average portal use of 20%, and an estimated loss to follow-up rate of 25%, a total of 600 adolescents would have to be included in the pre-test. In our study, with different samples in pre-test (n=202) and post-test (n=89), the samples would have had to be even larger.

As opposed to the study on client autonomy, we managed to include a well-balanced representation of all relevant client subgroups in our qualitative study on quality of care. This added value to our complete work because we were able to elaborate on topics from previous parts of the study, such as equity in portal access, portal usability among different subgroups, and the role of professional attitude, from perspectives that we had not covered yet in former interviews.

Measurements

To measure client autonomy, professional autonomy-supportive behaviour, interdisciplinary collaboration, and the implementation outcome ‘acceptability’, questionnaires were used. Interdisciplinary collaboration and acceptability were measured with existing questionnaires. The questionnaires about client autonomy and professional autonomy-supportive behaviour were self-developed. Both were carefully developed based on the underlying model, developed by Movisie, describing in four elements what autonomy meant from a client’s perspective and which professional-autonomy-supportive behaviour this was associated with (168). The high Cronbach’s alpha scores suggested a good reliability for all questionnaires, except for the component Flexibility in the professional questionnaire on interdisciplinary collaboration. This had been an issue in the original questionnaire as well (80), which might have been caused by the multidimensionality of the items in the domain flexibility, measuring two constructs instead of one. However, because we considered every item in the domain Flexibility as relevant to the construct and we did not want to hamper the validity of the questionnaire by taking questions out, the questionnaire data were included consistent with the originally developed scale. This enabled us to compare our results with other studies using the same questionnaire.

Practice-driven research

This thesis has been practice-driven from the start: our work has been focused on a question from professional practice, intending to gain new knowledge with implications and operational significance for this professional practice. The aim of our work has been to deliver practice-based evidence, as opposed to evidence-based practice. From the evidence-based viewpoint, interventions should be developed in an academic setting, based on theory, and implemented after building a thorough foundation of evidence (264-266). Practice-driven research in many cases is conducted with a group instead of on a group. As such, practice-driven research can take an action research approach, ‘learning by doing’, combining research, reflection and change in an iterative process (163, 267, 268). Performing practice-driven research brings up specific methodologic limitations and strengths.

The researcher’s role and position

One possible weakness is that a practice researcher can become too involved with practice to remain objective (163). In our work, an action research approach was chosen for the evaluation of the development and implementation of EPR-Youth. The observing practice researcher produced knowledge through interaction with the process and fellow professionals, which could create a researcher bias. At the same time, specific measures were taken to prevent such a bias (164). Examples included the involvement of an independent moderator who guided most interviews, joint coding of all qualitative data with researchers who were not involved in the practice situation, and conducting a member check for all interview transcripts (165). All analyses and articles were thoroughly discussed with the members of the supervision team, who were not involved in the practice situation either.

Learning by doing

The strength of this type of practice-driven research is that through continuous reflection on the process and delivering feedback to the persons responsible for the project, research findings can be used to contribute to the project goals. In this study, the iteration of research, reflection and adjustment supported the process of further developing and implementing EPR-Youth, created broad support among professionals and initiated a learning cycle (163, 164). For instance, based on process evaluation outcomes, new trainings were developed for professionals. And in the study on client experienced quality of care, feedback from participants was used to make flyer texts more understandable and to organize information meetings for parents with migratory backgrounds.

External validity of practice-driven research

Generalisation of practice-driven research and action research is often at stake. Action research, for instance, will by nature not provide results with a high statistic-probabilistic generalizibility, which has historically been the ultimate goal in quantitative research (269). Due to its focus on generating knowledge for a specific situation, generalisability is not a primary goal of practice-driven research, which does not mean that its findings have little value (267). At first glance, the generalisability of our findings is limited: we conducted our research in a mainly rural area with one small town (47,000 inhabitants) and a few little villages, with relatively few higher educated inhabitants and a small minority of inhabitants from migratory background. Furthermore, implementation of EPR-Youth was initiated by a group of highly motivated managers and professionals. However, making use of thick descriptions, integrating qualitative and quantitative outcomes with each other and taking contextual factors into account during the analyses strengthen the possibility that the outcomes of our study can be applied to similar contexts.

Impact of COVID-19

Finally, in practice-driven research, the real-life context sometimes poses unforeseen challenges that hinder the study in different ways. In our study, the COVID-19 pandemic proved to be that challenge. EPR-Youth was introduced in September 2019, five months before the pandemic started, and full record content was visible for parents and adolescents from February 2020. One month later, the first lockdown started in the Netherlands, with a huge impact on all citizens, including the CJG professionals and the families they were supporting. One of the CJG organisations was the Municipal Health Service, who provided preventive child healthcare to school children and who also had a central role in fighting the pandemic. They regrouped all their professionals including the preventive child health care workers, prioritizing the work in COVID-teams (performing tests, tracking contacts and vaccinating) over their regular work. The workload of the remaining CJG professionals increased and at the same time, due to COVID-19 measures, opportunities to meet face to face with clients or with each other minimized. This had several consequences. Firstly, the professional questionnaire that was planned in this period was distributed on schedule, but due to increased workload the response rate was low and eventually this first follow-up questionnaire was excluded from the study. Secondly, due to limited face to face meetings with clients the follow-up client questionnaire had to be postponed for six months. Thirdly, the communication round, that was planned by the Municipal Health Organisation to inform parents and adolescents about the new possibility to read their full health record, was cancelled because the full focus of this organisation had shifted to combatting COVID-19. Lastly, because face to face meetings between professionals were minimized, interdisciplinary collaboration and its enhancement through use of EPR-Youth was mitigated. This last effect was even stronger because the professionals who delivered preventive child healthcare to school-aged children were temporarily absent due to responsibilities in the combat against COVID-19. Concluding, COVID-19 impeded communication with clients and between professionals, and limited data collection, which hindered the planned process of implementation and might have attenuated the intended effects of using EPR-Youth.

Implications for policy, practice, and research

Our findings have several implications for practice and policy on using PAEHRs among parents and adolescents as contributors to person-centred care. The finding that a client-accessible health record contributes to person-centredness in child and adolescent care in a similar fashion as in adult healthcare is relevant because person-centred care is on the political health policy agenda for all ages and access to personal health data is one of the topics on that agenda (244, 270). Since Huber in 2011 introduced the concept of 'positive health', defining health as 'people's ability to deal with physical, emotional and social challenges in life', and emphasizing that people should be 'in charge of their own affairs whenever possible', both the biopsychosocial perspective and patient autonomy are being incorporated in the Dutch discourse about health and healthcare (271). Recently, the Dutch government has established important agreements concerning health and healthcare, such as the integral care agreement (IZA) and the 'healthy and active life' agreement (GALA) (244, 270). IZA, an agreement between the Dutch national government, healthcare providers, public health organisations and health insurance companies, explicitly states that 'in 2025 Dutch citizens must have digital access to their own health information, through personal health platforms' (270). This is an extension of the 'Supplementary Provisions on Processing Personal Data in Healthcare' Act, which was enacted from July 2020. Under this Act, citizens already have a right to digitally access their health information, but 24/7 access through patient portals is not obligatory yet. Delivering the information later suffices as well, provided that digital transport media are used. This loophole allows healthcare providers to share only partial health record content, or to extract a pdf file from the health record upon a patient's request and send this via secure email connection. Signing IZA, parties in healthcare have committed to jointly developing a personal digital health environment in which citizens have 24/7 access to all their health data (270). Looking at experiences in countries like Sweden and the US, whom are ahead of us in developing patient-accessible health records, legislation and national regulations have accelerated the process of developing client-accessible health records. In Sweden, the national PAEHR 'Journalen' was introduced in 2012, following the introduction of the Patient Data Act in 2008, which made it possible for patients to access their health record online (272, 273). This Act was followed in 2017 by a National Regulatory Framework of the PAEHR, ensuring that 'Journalen' would be used in all 20 county councils, and that all Swedish residents of 16 years and older would have full online access to their health information (273, 274). As a result, since 2018 all regions are connected to a national Health Information Exchange infrastructure (274). In the United States, two consecutive laws together served the same purpose. The Health Insurance Portability and Accountability Act, re-enacted from 1996, gave patients the legal right to access their medical record and was followed in 2009 by the American Recovery and Reinvestment Act, which required the development of patient portals that allowed patients to view, download and transmit health information. Based on those experiences, we can expect legislation to accelerate the process of developing client-accessible health records for all Dutch citizens as well.

GALA, the other recently signed agreement, between Dutch national organisations, focuses on 'healthy and active living' and on integrated person-centred care (244). With the slogan 'equity in all policies', this agreement advocates reducing health inequalities and targeted investment for equal opportunities. Equal opportunities require healthcare that is available and accessible for all groups of people, in a physical, geographical, financial, and cultural sense. This means, among other things, that communication is geared to the language and education level of patients (275). The positive expectations towards using EPR-Youth expressed by parents with a migratory background should, in combination with findings in our review, contribute to the awareness that introducing PAEHRs can help reduce health inequalities. It is important, though, that IT developers and healthcare organisations keep in mind that introducing eHealth instruments such as EPR-Youth, requires not only designing user-friendly systems (100), but also co-designing with all different kinds of end-users in order to match with their lived experiences (239).

Because this study is one of the first globally to investigate use of a PAEHR with adolescents and parents, and probably the first in the context of preventive child healthcare and social care, the findings are relevant for healthcare organisations working with children, parents, and adolescents worldwide. The finding that adolescent confidentiality rights can be protected could help lower threshold for development of client-accessible health records for adolescents.

Contrastingly, the dilemma that we encountered about the need to protect parental confidentiality rights in a child health record as well, has not gained much attention yet in literature and has not been sufficiently covered in our study either. In our research, possible solutions were mainly found in training for professionals on communication and reporting skills. Although this appeared to be a useful approach within the scope of this study, future research should be aiming somewhat broader: to find an adequate balance between reporting relevant parental information in a child's record and protecting a parent's privacy, communication and reporting skills are important to address. Nonetheless, a thorough exploration of this topic from legal and ethical perspective will be needed as well. I would recommend to co-develop technological solutions, with all end-users, based on legal and ethical standards and aiming to adequately protect everyone's rights during the different stages of childhood.

Finally, it is important for healthcare organisations who plan on implementing a PAEHR with the aim to strengthen person-centred care to acknowledge the complexity of such an intervention. Leeuwis et al. state that such technological innovations require not only technological change, but institutional change and changes in behaviour patterns and culture as well (79). Organisations will have to incorporate both technological knowledge and knowledge of change management to anticipate in their implementation plans on initiation and facilitation of change on all different levels.

Conclusion

The general aim of this dissertation was to improve the understanding of how using a PAEHR in preventive child healthcare and youth care contributes to integrated person-centred care for children, adolescents, and their parents, and to generate insight in what barriers and facilitators can be expected during implementation.

With this first Dutch study into the implementation and evaluation of a client-accessible health record among adolescents, parents, and professionals, we provided initial support for the hypothesis that using a PAEHR in these target groups contributes to integrated person-centred care. Although no causal conclusions can be drawn from this thesis, our results indicate that using a PAEHR contributes to client autonomy among both parents and adolescents, and to parents’ and adolescents’ positive perceptions of the quality aspects person-centredness, safety, efficiency, and timeliness. The findings in this dissertation further suggest that interdisciplinary use of a PAEHR can foster interdisciplinary collaboration between professionals from different organisations. However, the development and implementation of EPR-Youth was somewhat hindered by the complexity of co-creation between three organisations and by the COVID-19 epidemic. As a result, not all parents and adolescents were informed about the existence of EPR-Youth and professionals were not fully acquainted with all functionalities of the system, which might have impeded effect evaluation outcomes in turn. This underlines the importance of an adequate implementation to achieve the desired medium-term and long-term outcomes.

Three issues are important to address when developing, implementing, and using PAEHRs as tools to deliver integrated person-centred care: firstly, we noted that people in vulnerable circumstances reportedly benefit more than average from using a PAEHR. Therefore, PAEHRs should be developed in co-creation with these population groups to limit the possibility of a digital divide; secondly, professionals play an important role both in promoting client portal adoption and in supporting client autonomy. Consequently, professional attitude should be addressed during implementation of PAEHRs; thirdly, organisations have a responsibility to develop an organisational policy and create facilities for their staff to deliver integrated person-centred care. Until now, research into using PAEHRs with parents and adolescents was largely lacking. With this first evaluation of development, implementation, and use of an interdisciplinary PAEHR in Dutch preventive child health care and youth care, we hope not only to lower barriers for implementing PAEHRs elsewhere for children, adolescents, and their parents, but also to contribute to the knowledge about possible benefits of using PAEHRs among these target groups.

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List of abbreviations

CJG = Centrum voor Jeugd en Gezin (Centre for Youth and Family)
CReDECI = Criteria for Reporting the Development and Evaluation of Complex Interventions in Healthcare
COREQ = Consolidated criteria for Reporting Qualitative studies.
COVID-19 = Official name for the disease caused by the SARS-CoV-2 (2019-nCoV) coronavirus.
EPR = Electronic Patient Record.
EPR-Youth = Electronic Patient Record for Youth
GALA = Healthy and Active Living Agreement
IIC = Index for Interdisciplinary Collaboration
IOM = Institute of Medicine
IZA = Integral Healthcare Agreement
PAEHR = Patient-Accessible Electronic Health Record
PCC = Patient-Centred Care
PCH = Preventive Chld Healthcare
PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews
WHO = World Health Organisation

Summary

Samenvatting

Summary

Health systems worldwide are grappling with the challenges posed by an aging population, rising healthcare costs, and health inequities. Integrated person-centred care reforms are being implemented in many Western countries to address these issues. Integrated person-centred care means personalized, holistic care that considers patients' diverse needs and preferences, and involves patients and their close ones in making shared decisions about their care.

Since the late 90's of the last century, patient-accessible health records (PAEHRs) have emerged as a potential tool to support integrated person-centred care. Previous research from adult healthcare indicates that PAEHRs can improve patient autonomy, engagement, and trust in care providers, as well as enhance communication and collaboration among healthcare professionals.

Despite this proven potential in adult healthcare, currently insight into the consequences for implementing and using PAEHRs interdisciplinary among adolescents and parents is largely lacking.

This thesis aimed to fill this research gap by investigating how using a newly developed client-accessible health record in Dutch preventive child healthcare and youth care (EPR-Youth) affects integrated person-centred care for children, adolescents, and their parents. The aim was also to generate insight in barriers and facilitators during the implementation process.

The research project consisted of three parts: a literature review, an evaluation of the development and implementation process of EPR-Youth, and an assessment how using EPR-Youth affected client autonomy, interdisciplinary collaboration, and quality of care.

The review in **Chapter 2** provides an overview of what is currently known worldwide about experiences of patients and professionals with using a PAEHR, and about whether and how using a PAEHR contributes to person-centred care, (in this review we used the more common term 'patient-centred care') both in general and among specific population groups. We identified literature in five databases, using the terms 'patient-accessible medical records', 'patient experiences' and 'professional experiences' as key concepts. A total of 49 articles were included and analysed with a charting code list containing 10 elements of patient-centred care. A diverse range of studies on PAEHRs revealed a potentially positive contribution to patient-centred care. Using PAEHRs empowered patients, provided them with health information, and involved them in their care. The influence on the patient-clinician relationship varied, with mental healthcare professionals expressing more concerns than other healthcare professionals. People living in vulnerable circumstances made less use of PAEHRs but experienced greater benefits when using PAEHRs. These outcomes underline that promoting a patient-centred attitude, and ensuring easy accessibility and user-friendliness are crucial for maximizing the potential benefits of PAEHRs, particularly for people in vulnerable circumstances.

Chapter 3 describes a process-evaluation, investigating whether EPR-Youth was developed and implemented as planned and in accordance with demanded features. The process evaluation also determined barriers and facilitators in the development and implementation process. This evaluation was deemed important because the intended effects of EPR-Youth, as further described in the chapters 4, 6 and 7, would only be achieved after successful development and implementation.

Using a mixed-methods approach which combined system data, process observations, questionnaires, and focus group interviews, the process evaluation covered various phases of the project, and targeted client, professional and organisational level. The client-portal was highly acceptable to clients, and adoption rates varied among different age and education groups. Professionals had doubts about acceptability, appropriateness, and fidelity, partly due to a lack of system knowledge. Implementation barriers included complexity in co-creation, lack of clear leadership, and legal concerns. Facilitators included clarifying vision, legal context, setting deadlines, and fostering a pioneering spirit. Our outcomes suggested that enhancing client adoption required addressing group-specific portal access barriers and providing additional professional training. We also recommended organisational change towards situational leadership to improve co-creational efforts.

Chapter 4 answers the question how using EPR-Youth affected client autonomy. A mixed methods design combined baseline and follow-up questionnaires with focus group interviews. Different client groups completed questionnaires about autonomy at baseline and after 12 months. Professionals completed questionnaires about autonomy-supportive behaviour at baseline, after 5 months, and after 24 months. After 14 months, focus group interviews were conducted with clients and professionals. Findings show that clients using EPR-Youth experienced more autonomy than non-users; this effect was stronger among adolescents aged 16 and older than younger adolescents. Professional autonomy-supporting behaviour did not change over time. However, clients reported that professional autonomy-supporting behaviour contributed to client autonomy, emphasizing that professional attitude needs addressing during implementation of client-accessible records.

Chapter 5 describes the process of translating and validating an existing American questionnaire (IIC) about interdisciplinary collaboration into Dutch. The questionnaire consisted of 42 questions, divided into five components. These components were: interdependence, newly created professional activities, flexibility, collective ownership of goals, and reflection on processes. The translated questionnaire was distributed to all professionals working in the North-Veluwe Centers for Youth and Family. Exploratory Factor Analysis yielded eight factors, with two components showing clear clustering and three components showing diffuse loading across multiple factors The translated IIC showed a high reliability (Cronbach’s Alpha >0.70) for all components except for 'Flexibility' (0.53). The questionnaire therefore appeared to be a useful and sufficiently valid tool for measuring interdisciplinary collaboration in Dutch youth care.

Consequently, we investigated in **Chapter 6** whether using EPR-Youth strengthened interdisciplinary collaboration between professionals in youth care and child healthcare. In a mixed methods design, two partly overlapping samples of professionals completed questionnaires before introduction of EPR-Youth and 24 months thereafter. Midway through the study period, focus group interviews were held with 12 professionals, examining how using EPR-Youth affected interdisciplinary collaboration. This Professionals reported significantly more positive on flexibility after introduction of EPR-Youth than before. For the other components of collaboration, professionals scored slightly, but not significantly, more positive. Focus group participants reported that using EPR-Youth strengthened their sense of 'interdependence' and 'collective ownership of goals' and contributed to 'newly created professional activities'. These outcomes suggest that using EPR-Youth can foster interdisciplinary collaboration. At baseline, levels of interdisciplinary collaboration differed between organisations. Focus group participants confirmed these differences and attributed them to different facilitation of interdisciplinary collaboration, which underlies that a shared vision and organisational facilities are needed to further strengthen interdisciplinary collaboration.

In **Chapter 7**, a qualitative design was chosen to explore how parents and adolescents perceived the impact of using EPR-Youth on quality of care. In-depth interviews were conducted with a total of 13 parents and seven adolescents, representing diverse backgrounds. The participants reported that using EPR-Youth improved their perceived quality of care by increasing their knowledge, involvement, control over health data, and convenience in managing appointments and inquiries. Parents from migratory backgrounds, who were previously unaware of the client portal, expected better understanding and control of their care through portal access. However, concerns were raised about inequitable access and the need for improved information dissemination, particularly for vulnerable populations. Both parents and adolescents identified areas for improvement, including interdisciplinary use of EPR-Youth and the quality of reporting. Overall, using EPR-Youth possibly enhances client-centeredness, timeliness, safety, efficiency, and integration of care. However, equal access requires attention, and a person-centred approach among professionals is crucial.

Conclusion

With this study we provided initial support for the hypothesis that interdisciplinary use of a PAEHR among parents, children and adolescents contributes to integrated person-centred care. Although no causal conclusions can be drawn from this thesis, our results indicate that using a PAEHR contributes to client autonomy among parents and adolescents, and to parents' and adolescents' positive perceptions of the quality aspects person-centredness, safety, efficiency, and timeliness. The findings in this dissertation further suggest that interdisciplinary use of a PAEHR can foster interdisciplinary collaboration between professionals from different organisations. However, developing and implementing EPR-Youth was somewhat hindered by the complexity of co-creation between three organisations and by the COVID-19 epidemic. As a result, not all parents and adolescents were informed about the existence of EPR-Youth and professionals were not fully acquainted with all functionalities of the system, which might have impeded effect evaluation outcomes. This underlines the importance of an adequate implementation to achieve the desired medium-term and long-term outcomes.

Three issues are important to address when developing, implementing, and using PAEHRs as tools to deliver integrated person-centred care: firstly, because people in vulnerable circumstances reportedly benefit more than average from using a PAEHR, they should always be involved in development of PAEHRs to limit the possibility of a digital divide; secondly, because professionals play an important role both in promoting client portal adoption and in supporting client autonomy, professional attitude should be addressed during implementation of PAEHRs; thirdly, organisations have a responsibility to develop an organisational policy and create facilities for their staff to deliver integrated person-centred care.

Until now, research into using PAEHRs with parents and adolescents was largely lacking. With this first evaluation of development, implementation, and use of an interdisciplinary PAEHR in Dutch preventive child health care and youth care, we hope to lower barriers for implementing PAEHRs elsewhere for children, adolescents, and their parents. Furthermore, this thesis contributes to the knowledge about possible benefits of using PAEHRs among these target groups.

Samenvatting

De gezondheidszorg worstelt wereldwijd met uitdagingen als een vergrijzende bevolking, stijgende zorgkosten en sociaaleconomische gezondheidsverschillen. Om deze uitdagingen het hoofd te bieden wordt in veel Westerse landen gestuurd op geïntegreerde persoonsgerichte zorg. Geïntegreerde persoonsgerichte zorg wil zeggen: oog hebben voor de hele mens en niet alleen de ziekte, rekening houden met de unieke behoeften en voorkeuren van elk persoon, en op basis daarvan met die persoon en diens naasten samen beslissen over benodigde zorg. Zorg wordt dan geboden door een netwerk van professionals en organisaties uit zorg en welzijn.
Sinds de 90-er jaren van de vorige eeuw komen patiënt-toegankelijke medische dossiers (ook wel open dossiers genoemd) in beeld als potentieel hulpmiddel om geïntegreerde persoonsgerichte zorg te bevorderen. Eerder onderzoek onder volwassenen wijst erop dat open dossiers de autonomie en betrokkenheid van patiënten kunnen verbeteren, net als hun vertrouwen in zorgverleners en de communicatie en samenwerking met en tussen zorgverleners. Er is echter weinig onderzoek naar de gevolgen van het (interdisciplinair) implementeren en gebruiken van open dossiers onder kinderen, jongeren en hun ouders. Het proefschrift wat voor u ligt heeft ten doel dit kennistekort op te vullen. Het beschrijft een onderzoek naar Iuvenelis, een nieuw ontwikkeld cliënt-toegankelijk jeugddossier voor JGZ en jeugdhulp. Onderzocht werd hoe gebruik van Iuvenelis geïntegreerde persoonsgerichte zorg voor jeugd beïnvloedt. Ook was het doel om inzicht te krijgen in belemmerende en bevorderende factoren tijdens de implementatie van dit dossier.
Het onderzoek bestond uit drie delen: 1) een literatuuronderzoek, 2)een procesevaluatie van de ontwikkeling en implementatie van Iuvenelis en 3) een evaluatie van het effect van gebruik van Iuvenelis op autonomie onder ouders en jongeren, op interdisciplinaire samenwerking en op ervaren kwaliteit van zorg.

De review in **Hoofdstuk 2** beschrijft wat wereldwijd bekend is over ervaringen van patiënten en professionals met open dossiers, of en hoe een open dossier bijdraagt aan persoonsgerichte zorg (of 'patiëntgerichte zorg'), zowel in algemene zin als onder specifieke bevolkingsgroepen. We zochten literatuur in vijf databases, met als zoektermen 'patiënt-toegankelijke medische dossiers', 'patiëntervaringen' en 'professionele ervaringen'.
In totaal werden 49 artikelen geselecteerd en geanalyseerd aan de hand van een codelijst met 10 elementen van patiëntgerichte zorg. Een divers palet aan onderzoeken beschreef een mogelijk positieve bijdrage van open dossiers aan patiëntgerichte zorg. Door het gebruik van open dossiers werden patiënten mondiger, voelden ze zich beter geïnformeerd en werden ze beter betrokken bij hun zorg. De invloed op de patiënt-arts relatie werd verschillend beschreven, waarbij vooral GGZ-professionals zich hierover zorgen maakten, meer dan andere zorgverleners. Dit leek verband te houden met de mate van patiëntgerichtheid. Mensen in kwetsbare omstandigheden maakten minder gebruik van open dossiers, maar ervoeren grotere voordelen bij het daadwerkelijk gebruik ervan. Deze

uitkomsten benadrukken dat het bevorderen van een persoonsgerichte houding belangrijk is om maximaal te kunnen profiteren van open dossiers. Maar ook de ontwikkeling van gebruikersvriendelijke en gemakkelijk toegankelijke klantportalen is cruciaal, met name voor mensen in kwetsbare omstandigheden.

Hoofdstuk 3 beschrijft een procesevaluatie, waarin werd onderzocht of het EPD-Jeugd volgens plan en met de gewenste functionaliteiten was ontwikkeld en geïmplementeerd. De procesevaluatie bracht ook belemmerende en bevorderende factoren in het ontwikkel- en implementatieproces in beeld. Deze evaluatie was belangrijk omdat de beoogde effecten van Iuvenelis, zoals beschreven in de hoofdstukken 4, 6 en 7, afhankelijk waren van een succesvolle ontwikkeling en implementatie.

Voor de procesevaluatie werd gebruik gemaakt van een ‘mixed methods’ onderzoeksdesign, in een combinatie van systeemdata, procesobservaties, vragenlijsten en focusgroep interviews. De evaluatie beschreef verschillende fasen van het project vanuit het perspectief van de client, de professional en de organisatie. Zowel gebruiksvriendelijkheid als daadwerkelijk gebruik onder ouders en jongeren waren hoog, maar de mate van gebruik varieerde op basis van leeftijd en opleidingsniveau. Professionals spraken hun zorgen uit over gebruiksvriendelijkheid, en over een goede match van Iuvenelis met werkprocessen en met de regionale visie. Dit bleek deels te worden veroorzaakt door gebrek aan kennis van het systeem. Belemmeringen bij de implementatie waren onder andere complexiteit van co-creatie, gebrek aan duidelijk leiderschap en zorgen over juridische aspecten. Bevorderende factoren waren onder andere het verduidelijken van de visie, verhelderen van de juridische context, het stellen van deadlines en pionieren aanmoedigen. Onze resultaten wezen erop dat professionals aanvullende training nodig hadden, en dat er gericht aandacht besteed moest worden aan groepen ouders en jongeren die het klantportaal minder gebruikten. Ook adviseerden we de organisaties om gebruik te maken van situationeel leiderschap als er in co-creatieve projecten gewerkt werd.

Hoofdstuk 4 geeft antwoord op de vraag wat de invloed was van Iuvenelis op ervaren eigen regie onder ouders en jongeren. We gebruikten een mixed methods design, met vragenlijsten als nulmeting en vragenlijsten gevolgd door focusgroep interviews als nameting. Verschillende groepen ouders en jongeren vulden vragenlijsten over eigen regie in, voor aanvang van het project en 12 maanden na livegang van Iuvenelis. Professionals vulden vragenlijsten in over ’eigen regie’ bevorderend gedrag, voor aanvang van het project, na 5 maanden en na 24 maanden. Na 14 maanden werden focusgroep interviews gehouden met ouders, jongeren en professionals. De uitkomsten laten zien dat ouders en jongeren die Iuvenelis gebruikten meer eigen regie ervoeren dan niet-gebruikers; dit effect was sterker bij jongeren van 16 jaar en ouder dan bij jongeren onder de 16. De mate waarin professionals eigen regie bevorderden veranderde niet in de loop van de tijd. Ouders en jongeren vertelden dat naast het gebruik van Iuvenelis de houding van professionals invloed had op de mate waarin zij eigen regie ervoeren. Dit geeft aan dat tijdens implementatie van open dossiers de houding van professionals ook aandacht behoeft.

Hoofdstuk 5 beschrijft de vertaling (en validering) naar het Nederlands van een bestaande Amerikaanse vragenlijst (IIC) over interdisciplinaire samenwerking. De vragenlijst bestond uit 42 vragen, onderverdeeld in vijf componenten. Deze componenten waren: wederzijdse afhankelijkheid, nieuw ontwikkelde professionele activiteiten, flexibiliteit, gemeenschappelijk eigenaarschap van doelen, en reflectie op processen. De vertaalde vragenlijst werd verspreid onder alle professionals in de Noord Veluwse Centra voor Jeugd en Gezin (CJG). De vertaalde IIC liet een hoge betrouwbaarheid (Cronbach's Alpha > 0,70) zien voor alle componenten behalve voor Flexibiliteit (0,53). De vragenlijst bleek daarom een bruikbaar en voldoende valide instrument voor het meten van interdisciplinaire samenwerking in de Nederlandse jeugdzorg.

Vervolgens onderzochten we in **hoofdstuk 6** of het gebruik van Iuvenelis de interdisciplinaire samenwerking tussen professionals in jeugdgezondheidszorg en jeugdhulp versterkte. In een mixed methods design vulden twee deels overlappende groepen professionals vragenlijsten in vóór de invoering van Iuvenelis en 24 maanden daarna. Halverwege de onderzoeksperiode werden focusgroep interviews gehouden met 12 professionals om te onderzoeken hoe het gebruik van Iuvenelis de interdisciplinaire samenwerking beïnvloedde. De professionals rapporteerden significant positiever over flexibiliteit na de invoering van Iuvenelis dan daarvoor. Voor de andere onderdelen van samenwerking scoorden professionals iets, maar niet significant, positiever. Deelnemers aan de focusgroepen vertelden dat het gebruik van Iuvenelis hun gevoel van 'wederzijdse afhankelijkheid' en 'gemeenschappelijk eigenaarschap van doelen' versterkte en dat het bijdroeg aan 'nieuw ontwikkelde professionele activiteiten'. Deze uitkomsten suggereren dat het gebruik van Iuvenelis interdisciplinaire samenwerking kan bevorderen. Bij aanvang verschilde de mate van interdisciplinaire samenwerking tussen professionals van verschillende organisaties. Deelnemers aan de focusgroepen herkenden deze verschillen en schreven ze toe aan verschillen in randvoorwaarden voor interdisciplinaire samenwerking, wat benadrukt dat een gedeelde visie tussen organisaties en goede randvoorwaarden vanuit organisaties nodig zijn om interdisciplinair samenwerken verder te versterken.

In **hoofdstuk 7** is gekozen voor een kwalitatieve methode om te onderzoeken hoe ouders en jongeren de invloed van Iuvenelis op de kwaliteit van zorg ervoeren. Er werden diepte-interviews gehouden met in totaal dertien ouders en zeven jongeren, met een variatie aan verschillende achtergrondkenmerken. Deelnemers vertelden dat zij door het gebruik van Iuvenelis meer kwaliteit van zorg ervoeren doordat zij beter geïnformeerd en meer betrokken waren, zij meer grip op hun gezondheidsgegevens hadden en gemakkelijker afspraken konden beheren of vragen konden stellen. Ouders met een migratie achtergrond die nog niet bekend waren met Iuvenelis, verwachtten dat ze door toegang tot het dossier meer inzicht in en grip op hun zorg zouden krijgen. Wel werden er zorgen geuit over ongelijke toegang en was er behoefte aan betere communicatie over Iuvenelis voor, met name, mensen in kwetsbare omstandigheden. Zowel ouders als jongeren zagen nog kansen tot verbetering, zoals breder interdisciplinair gebruik van Iuvenelis en verbetering van de kwaliteit van rapportages. Samenvattend concludeerden we dat het gebruik van Iuvenelis mogelijk de persoonsgerichtheid, tijdigheid, veiligheid, efficiëntie en integratie van zorg verbetert. Maar gelijke toegankelijkheid vereist aandacht en een persoonsgerichte bejegening door professionals is cruciaal.

Conclusie

Met dit onderzoek leveren we een eerste onderbouwing voor de hypothese dat interdisciplinair gebruik van een open dossier in zorg voor jeugd bijdraagt aan geïntegreerde persoonsgerichte zorg. Hoewel er geen definitieve causale verbanden kunnen worden gelegd in dit proefschrift, lijken onze resultaten erop te wijzen dat het gebruik van een open dossier bijdraagt aan eigen regie bij ouders en jongeren, en dat het positief bijdraagt aan hoe ouders en jongeren de kwaliteitsaspecten persoonsgerichtheid, veiligheid, efficiëntie en tijdigheid ervaren. De bevindingen in dit proefschrift duiden er ook op dat interdisciplinair gebruik van een open dossier de samenwerking tussen professionals van verschillende organisaties kan bevorderen. Het ontwikkelen en implementeren van Iuvenelis werd echter enigszins gehinderd door de complexiteit van co-creatie tussen drie organisaties en door de COVID-19 epidemie. Als gevolg daarvan waren niet alle ouders en jongeren op de hoogte van het bestaan van Iuvenelis en waren professionals niet volledig ingevoerd in het systeem, wat de evaluatieresultaten mogelijk heeft gematigd. Dit benadrukt het belang van een adequate implementatie om de beoogde resultaten op middellange en lange termijn te bereiken.

Bij het ontwikkelen, implementeren en gebruiken van open dossiers als hulpmiddel bij geïntegreerde persoonsgerichte zorg zijn drie zaken van belang. Ten eerste: mensen in kwetsbare omstandigheden lijken meer dan gemiddeld te profiteren van het gebruik van open dossiers. Om een digitale kloof te voorkomen, dienen zij altijd te worden betrokken bij de ontwikkeling van zulke dossiers. Ten tweede: professionals spelen een belangrijke rol in het bevorderen van klantportaalgebruik, maar ook in het bevorderen van ervaren eigen regie. Daarom dienen houding en gedrag van professionals altijd aandacht te krijgen tijdens implementatie van open dossiers. Ten derde: organisaties in de gezondheidszorg dienen een visie over en randvoorwaarden voor geïntegreerde persoonsgerichte zorg op te nemen in hun organisatiebeleid.

Tot nu toe ontbrak grotendeels onderzoek naar het gebruik van open dossiers met ouders en jongeren. Met deze eerste evaluatie van de ontwikkeling, implementatie en het gebruik van een interdisciplinair open dossier in de Nederlandse zorg voor jeugd, hopen we drempels te verlagen voor het implementeren elders van open dossiers voor en met kinderen, jongeren en hun ouders. Daarnaast draagt dit proefschrift bij aan de kennis over mogelijke voordelen van het gebruik van open dossiers onder deze doelgroepen.

Peek into the Client Portal

A peek into the client portal of EPR-Youth.

To illustrate some of the accounts provided in our research, the following pages offer a brief overview of what the client portal looks like. Screenshots and short explanatory texts provide a general idea of the aspect parents and adolescents valued most: secure and easy access, clear summaries of important information, insight in who has access to their health record and why, explanations when topics are not easily understood, and the ability to ask questions and collaborate with professionals in a care plan.

Starting page

Parents and adolescents gain access using a Digital ID (DigiD). In all displayed examples, only fictional names are utilized.

Client portal overview, displaying a left-side menu, scheduled appointments in the centre and upcoming appointments on the right. The portal distinguishes between appointments that parents can schedule within the portal (upper right) and appointments planned by the organisation (lower right). Appointments are collectively presented here for all children: Suzanne, Fons, and Marijn.

Insight in access and in permissions granted

logs inzage dossier

View log, enabling parents or adolescents to track which professional has accessed their health record over the past month, the past 3 months or a specified period. The view log is individually displayed for each child. In this instance, it pertains to Marijn. On June 17th, an unauthorized professional accessed Marijn's health record, leaving an explanation which is visible under 'toelichting'.

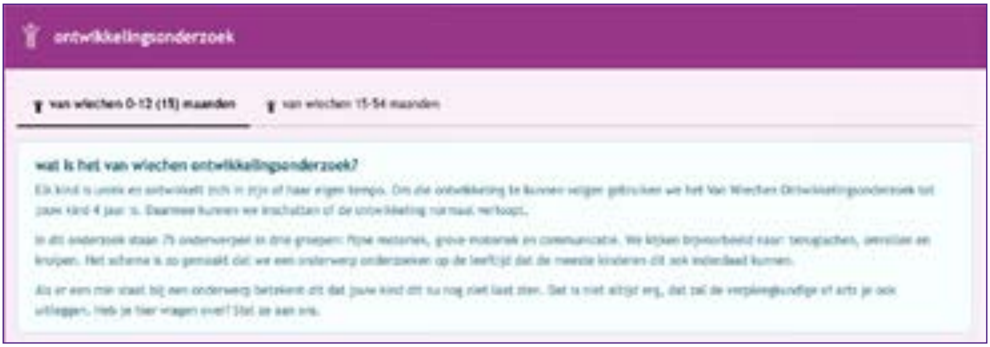
autorisaties

toestemming uitwisselen vaccinatiegegevens met RIVM

gezin

On the same page as the view log, an overview of their family and permissions granted to share vaccination data with the national institute of public health (RIVM) can be found.

Usability: aiming for understandable language, simple screens, and explanation of difficult topics.



wat is het van wiechen ontwikkelingsonderzoek?

During the development of EPR-Youth, the parental and adolescent consultation group identified topics that needed clarification. For these topics, blue text boxes providing explanations have been included. The text box above explains the tool used for monitoring a child's development.

Growth charts: on the right is the standard display of the growth chart. Clicking the purple 'i' button on the left side brings up the screen shown on the left, featuring a legend for the various components of the growth chart and the option to hide items. In the upper right, users can switch to a different reference population. Specific growth charts are accessible for children of Turkish, Moroccan, or Hindustani origin, for children with Down syndrome, and for prematurely born children.

Vaccination schedules are provided for each child in the family. A green checkmark indicates administered vaccinations. Similar summaries present completed and upcoming consultations, growth, and development.

Interactivity of the client portal: asking questions and making shared plans.

overzicht › vaccinatie marijn

gesprek: "vaccinatie marijn"

Marijn

Wanneer moet Marijn weer een vaccinatie hebben? De vorige is uitgesteld vanwege dat hij ziek was.
Pamela van Thiel
17-06-2023 23:13:47

Waarom hoor ik niets van u?
Pamela van Thiel
18-06-2023 10:44:45

He, dat is gek, ik dacht dat ik had gereageerd. Maar bij deze alsnog: het klopt dat Marijn een vaccinatie nog moet hebben die niet ingepland staat. Schikt het jou om volgende week woensdag of vrijdag tussen 13 en 14.30 langs te komen? Dan hebben we inloopspreekuur namelijk. (of een andere woensdag/vrijdag). Als dit niet lukt, laat het even weten, dan bel ik je om een andere afspraak te plannen.
18-06-2023 10:46:49

Parents and adolescents have the option to pose questions within the portal, which are then addressed by a professional. The conversation is accessible to both the client and the professional. Above, the portal perspective is depicted, while below showcases the professional's viewpoint within EPR-Youth.

Klantvragen

▾ Vaccinatie Marijn
Pamela van Thiel, 17-06-2023 23:13:47

Pamela van Thiel: Wanneer moet Marijn weer een vaccinatie hebben? De vorige is uitgesteld vanwege dat hij ziek was.
17-06-2023 23:13:47

Pamela van Thiel: Waarom hoor ik niets van u?
18-06-2023 10:44:45

Hayzel Lohuizen: He, dat is gek, ik dacht dat ik had gereageerd. Maar bij deze alsnog: het klopt dat Marijn een vaccinatie nog moet hebben die niet ingepland staat. Schikt het jou om volgende week woensdag of vrijdag tussen 13 en 14.30 langs te komen? Dan hebben we inloopspreekuur namelijk. (of een andere woensdag/vrijdag). Als dit niet lukt, laat het even weten, dan bel ik je om een andere afspraak te plannen.
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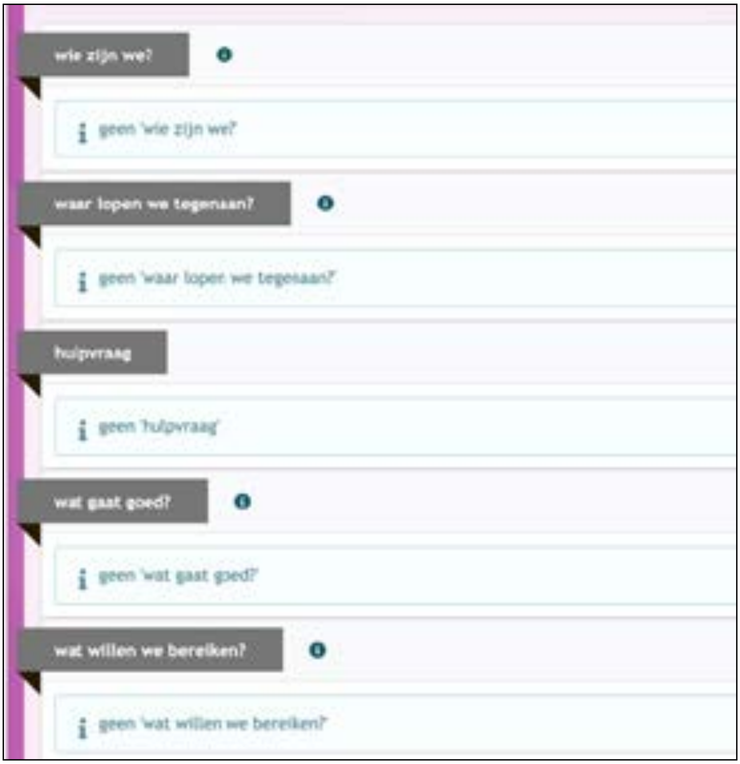

geen 'wie zijn we?'

geen 'waar lopen we tegenaan?'

geen 'hulpvraag'

geen 'wat gaat goed?'

geen 'wat willen we bereiken?'

Facilitating collaborative care plans: each parent or adolescent seeking assistance from youth care is entitled to formulate a plan involving their family and close contacts. This is referred to as a 'familiegroepsplan'. Through the client portal, they can initiate their own plan by responding to specific questions. Their responses are subsequently integrated with information documented by the professional, culminating in a unified shared care plan.

Dankwoord

Dankwoord

Het is zover, mijn proefschrift is af! Daarmee sluit ik een intensieve, maar ook mooie en leerzame periode af. Dat wil ik niet doen zonder alle mensen te bedanken die een bijdrage hebben geleverd aan dit proces: zonder jullie was dit proefschrift er niet gekomen. Het schrijven van een dankwoord is een leuke klus. Niet alleen omdat dit het meest gelezen gedeelte van het proefschrift schijnt te zijn, maar ook omdat het je als schrijver terugbrengt naar de afgelopen tijd en stil doet staan bij alle mooie momenten gedurende het proces en bij alle prachtige mensen die daarin meegedacht en meegedaan hebben. En als laatste, niet onbelangrijk detail: omdat je vorm en inhoud van het dankwoord helemaal zelf mag bepalen!

Dus begin ik enigszins tegendraads met het bedanken van de mensen die het dichtst bij mij staan. Waar geen promovendus kan zonder een steunend netwerk, geldt dat voor een ‘single working mom’ dubbel en dwars. Lieve **Naomi, Jonathan en Damaris**, we hebben het er vooraf over gehad wat het zou betekenen als ik promotieonderzoek ging doen. Dat ik dan misschien minder tijd zou hebben voor jullie, en dat dat volgens jullie (duh) geen probleem was. Maar wie had verwacht dat jullie zo betrokken zouden zijn op verschillende momenten en manieren? Sparren over stukjes onderzoek, meelezen in Engelse teksten, een terug-vertaling maken van een vertaalde vragenlijst, het hele proefschrift nog eens met elkaar doorlezen op punten en komma’s, super bedankt! En Ik ben blij, Naomi en Damaris, dat jullie mijn paranimfen willen zijn. Lieve **Iris**, je zult het weten dat je Jonathans vriendin bent: je hoort erbij dus je mag meedoen, ook hierbij. Superlief dat ook jij wilde meelezen in de eindversie.

Jan-Walter, lief broertje, heb ik je nu stiekem toch nog ingehaald voor de eindstreep? Dat was oprecht niet de bedoeling, maar ik wilde het nu toch wel eens af hebben. Het was bijzonder om min of meer gelijk op te lopen in dit PhD traject, jij in Groningen en ik in Wageningen, en om ervaringen , frustraties en inspiratie uit te wisselen. Succes met de laatste loodjes, ook jij bent er gelukkig bijna. En dan een feestje!

Lieve buuffies **Melissa, Joyce en Anke**, ik heb zoveel aan jullie gehad de afgelopen paar jaar. Zeker tijdens corona, maar ook daarna was het heerlijk om af en toe even bij een wijntje stoom af te kunnen blazen of te vieren als er een artikel gepubliceerd was. Die wijntjes houden we er in, want er blijft altijd wel iets om stoom over af te blazen of iets om te vieren: proost!

Lieve **Dynant**, ik ben blij dat jij mijn neef bent en dat we zo’n goed contact hebben. Het afgelopen anderhalf jaar heeft in het teken gestaan van jouw ziek-zijn. In februari 2022 hadden we niet verwacht dat jij dit moment mee zou maken. En toch had je ook toen altijd nog aandacht voor de dingen waar ik mee bezig was. Dank voor alle goede gesprekken en de gezelligheid bij een hapje en een drankje, vaak tot diep in de nacht.

Lieve **papa, mamma, oma en Frits**, wat fijn dat jullie dit ook mee kunnen maken, live of op afstand. Er is zoveel veranderd sinds jullie jong waren. Oma, in jouw tijd was er van ‘doorleren’ geen sprake: na de lagere school ging jij meteen aan het werk, hoewel je volgens jouw onderwijzer meer in je mars had. Ondernemend als je was heb je het alsnog ver geschopt, maar voor de volgende generatie hoopte je op meer opleidingskansen. En nu studeren jouw achterkleinkinderen aan de universiteit en ronden twee van jouw kleinkinderen een promotie-onderzoek af. Ik zeg: missie geslaagd.

Maar dan natuurlijk ook dank aan mijn promotie-team. **Emely**, ik kwam een beetje bijzonder binnenrollen, via het lijntje met de academische werkplaats AGORA. Ik had al subsidie van ZonMw en een bijbehorend onderzoeksvoorstel, maar dat was nog niet genoeg voor een PhD-traject. Toch zag jij er wel potentie in en je heette me van harte welkom, toen we eenmaal hadden vastgesteld dat mijn onderzoek bij jouw chairgroup paste en jij als promotor bij mijn onderzoek. Ik heb veel van je geleerd, vooral als het gaat om even een stapje terug doen en objectief kijken naar het onderzoek waar ik soms zo vanuit inhoudelijke kennis ingezogen werd. Maar ook leerde ik onder jouw supervisie de omslag te maken van wollige beleidstaal naar meer concrete wetenschappelijke verslaglegging, en dan ook nog in beknopt Engels. Dat was een hele klus in het begin en hoeveel gemakkelijker gaat dit nu. Hartelijk dank voor alles. **Annemien**, dank dat jij mijn co-promotor wilde zijn. In de periode dat Emely deels uitgevallen was ben jij in het gat gesprongen en ik kon in de afgelopen paar jaar eigenlijk altijd bij jou terecht. Dank voor je onverstoorbare geduld, voor regelmatig een luisterend oor, en voor al die keren meelezen, meepuzzelen, meedenken!

Wie hier ook niet ongenoemd mag blijven, ook al is hij helaas niet meer onder ons, is **Henk van Stel**. Beste Henk, zonder jouw aanmoedigingen was ik er nooit aan begonnen. Hoe ironisch: uiteindelijk pakte ik de handschoen op, juist omdat jij er niet meer was. Je besloot ons laatste gesprek voor de zomer van 2018 met de woorden: 'Geniet van de vakantie, ik spreek je daarna en dan gaan we het hebben over promoveren.' Helaas kwam jij die zomer om het leven. Jouw oproep bleef overeind, en ik was het met je eens dat dit onderwerp een promotieonderzoek verdiende, en mijn onverdeelde aandacht. Graag had ik dit traject deels onder jouw begeleiding doorlopen. Het heeft niet zo mogen zijn. Voor alle voorwerk, en voor de liefde voor onderzoek die je mij hebt bijgebracht: heel veel dank!

Anja, wat was ik blij met jouw hulp bij de statistische analyses. Het lukte jou om de meest complexe analyses begrijpelijk aan mij uit te leggen zodat ik het niet alleen op dat moment snapte, maar ook later nog weer terug kon halen. **Gerrit**, dank je wel dat jij het stokje kon overnemen toen Anja tijdelijk niet beschikbaar was. Dank voor je immer snelle reacties en je geduld met mijn vragen als ik het naadje van de kous nog niet gevonden dacht te hebben.

Dear **CHL-colleagues**, I did not meet all of you regularly, only being present in Wageningen on Mondays. But the ones of you that I did meet, were always very welcoming. Although my research topic was a bit of an outlier, I never felt isolated in our chairgroup. We always managed to find connections, overlap and common ground to discuss. I have enjoyed our lunch conversations very much! **Sanne en Merije**, dank voor het delen van tips over trainingen, analyses en de afronding van dit traject. Sanne, dank dat je op het eind wilde meedenken met mijn paranymfen! Dank **Vera, Evy en Alexandra** voor jullie hulp met al die praktische dingetjes die van de onderzoekswereld een jungle maken.

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Dank ook aan collega's van het management van Icare JGZ en leden van de Raad van Bestuur van Espria, voor het in mij gestelde vertrouwen. Dank jullie wel **Chantel, Maurice, Jeroen, Bernice** en natuurlijk **John**, dat jullie mij de kans gaven van dit onderzoek een promotietraject te maken en bereid waren om als organisatie en concern twee jaar lang mijn onderzoeksuren te financieren. Maurice, ik heb genoten van al onze gesprekken, waarin we het steeds eens waren over het doel, maar zelden over de route daarnaartoe. Heel stellig eigenwijs zei jij: 'Het kan me niet schelen wat er uit het onderzoek komt, we gaan dit gewoon doen, want ouders en jongeren hebben hier recht op!' In het laatste gaf ik je gelijk, en over het eerste worden we het niet eens, en dat is prima. Van de mensen die betrokken waren bij het onderzoek was jij altijd het meest kritisch, maar juist dat heeft mij geholpen mijn denken aan te scherpen. **Wim, Ingrid, Cor**, onze gesprekken over visie in relatie tot dit onderwerp waren inspirerend. Jullie 'rabiate' vasthoudendheid aan de bedoeling was uitermate helpend voor het proces. Wel ben ik blij dat we de term 'organisch veranderen' inmiddels uit ons vocabulaire geschrapt hebben.

Collega's in de projectgroep (en daarna de CIA): **Marjolein, Marjo, Marjolein, Carin, Hanneke, Jos, Erik, Marian, Frederike, Annemieke, Suzan, Tessa, Laura, Cornelis, Hettie, Iris** (en dan vergeet ik vast nog iemand): dank dat ik deel uit mocht maken van de projectgroep, en dat ik de informatie uit die bijeenkomsten mocht gebruiken voor de procesevaluatie. Het was een mooi maar ook dikwijls stekelig proces. We maakten pijnlijke momenten mee, zijn mensen kwijtgeraakt onderweg, irriteerden ons soms mateloos aan elkaar en toch vonden we elkaar steeds beter en dat bracht ons op een uitkomst om trots op te zijn. **Jarno, Robbert-Jan, Meindert-Jan, Maarten**: soms was ik zo nieuwsgierig wat jullie erover dachten en zeiden als jullie na afloop van een bijeenkomst terug reisden naar jullie thuisbasis. Meindert-Jan en Robbert-Jan, dank voor het meedenken over de vertaling van mijn onderzoeksvragen naar uit het systeem aggregeerbare bruikbare data!

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About the author

Curriculum Vitae

Janine Benjamins was born on the 16th of October 1971 in Hoogeveen, the Netherlands. After completing her secondary education in Emmen, Janine studied medicine at the University of Amsterdam. She obtained her medical degree in 1997 and has been working in preventive child healthcare since 1998 first in Amsterdam and since 2003 in the North Veluwe region. Contributing to excellent 'care for youth' has become her passion.

Specializing in Public Health, between 2009 and 2012, Janine developed an interest in health system development and research. She started working as a policy advisor in the North Veluwe region, actively involved in the development of doctor-nurse task delegation in preventive child health care. Since then, she has been contributing to innovations in 'care for youth' in her region, such as the transformation of 'care for youth' towards integrated and client-centered care and the development of an interdisciplinary client-accessible electronic patient record, EPR-Youth (Jeugddossier Noord-Veluwe).

After securing funding from ZonMw for the development of EPR-Youth in 2018, she commenced the work described in this thesis. Janine conducted her research at the Consumption and Healthy Lifestyles chairgroup at Wageningen University, under the supervision of prof. dr. Emely de Vet and dr. Annemien Haveman-Nies. Her PhD project focused on the implementation and evaluation of EPR-Youth, investigating how using this EPR contributed to client autonomy, to interdisciplinary collaboration and to perceived quality of care. In November 2021, she was awarded the Flora van Laar prize by the Dutch Association of Youth Physicians (AJN) for her paper ' 'Implementation of a client-accessible and multidisciplinary youth health record in the Netherlands; a mixed-methods process evaluation’.

As an external PhD-candidate, Janine has always combined her PhD study with her job as a policy advisor in the North-Veluwe Centres for Youth and Family. After completing her PhD she aspires to continue further developing EPR-Youth, solidifying her commitment to excellent 'care for youth'.

Janine lives in Amersfoort and is the proud mother of Naomi (2000), Jonathan (2002) and Damaris (2005).

List of Publications

Publications in peer-reviewed journals

Sloot F, Sami A, Karaman H, **Benjamins J**, Loudon SE, Raat H, Sjoerdsma T, Simonsz HJ (2015). Effect of omission of population-based eye screening at age 6-9 months in the Netherlands. Acta Ophthalmologica, 93 (4), 318-321. https://doi.org/10.1111/aos.12556

Benjamins SJ, Damen MLW, van Stel HF (2015). Feasibility and Impact of Doctor-Nurse Task Delegation in Preventive Child Health Care in the Netherlands, a Controlled Before-After Study. PLoS ONE 10(10): e0139187. https://doi.org/10.1371/journal.pone.0139187

Frea Sloot, Aya Sami, Hatice Karaman, Mari Gutter, **Janine Benjamins**, Trijntje Sjoerdsma, Huibert Jan Simonsz (2017). Semistructured Observation of Population-based Eye Screening in The Netherlands, Strabismus, 25:4, 214-221, https://doi.org/10.1080/09273972.2017.1395596

Telleman, M.A.J., Sloot, F., **Benjamins, S.J.**, Simonsz, H.J. (2019). High rate of failed visual-acuity measurements with the Amsterdam Picture Chart in screening at the age of 36 months. Acta ophthalmologica, 97(1), 24-28. https://doi.org/10.1111/aos.13898

van ‘t Hoff, E.J., **Benjamins, S.J**. & Haveman-Nies, A. (2020). Een instrument om interdisciplinaire samenwerking te onderzoeken binnen de Nederlandse zorg voor jeugd. Tijdschrift Jeugdgezondheidszorg 52, 14-19. https://doi.org/10.1007/s12452-019-00204-4

Benjamins J, Haveman-Nies A, Gunnink M, Goudkuil A, de Vet E (2021). How the Use of a Patient-Accessible Health Record Contributes to Patient-Centered Care: Scoping Review. J Med Internet Res 2021;23(1):e17655. htpps://doi.org/10.2196/17655

Benjamins J, de Vet E, Jordaan G, Haveman-Nies A. Effect of using client-accessible youth health records on experienced autonomy among parents and adolescents in preventive child healthcare and youth care: A mixed methods intervention study. Journal of Child Health Care. 2023;0(0). doi:10.1177/13674935231177782

Benjamins J, Duinkerken J-G, den Hamer-Jordaan G, Canfijn R, Koster R, de Vet E, Haveman-Nies A. Implementation of EPR-Youth, a Client-Accessible and Multidisciplinary Health Record; A Mixed-Methods Process Evaluation. International Journal of Integrated Care, 2023; 23(2): 26, 1–16. DOI: https://doi.org/10.5334/ijic.6905

Datasets, published in DANS Easy repository

Benjamins, S.J. (Icare JGZ; Consumption and Healthy Lifestyles, Wageningen University & Research); Haveman-Nies, A. (GGD NOG; Consumption and Healthy Lifestyles, Wageningen University & Research); Vet, E.W.M.L. de (Consumption and Healthy Lifestyles, Wageningen University & Research) (2021): Data underlying the project 'Jeugddossier Noord Veluwe'. DANS. https://doi.org/10.17026/dans-267-zj9d

Benjamins, S.J. (Icare JGZ; Consumption and Healthy Lifestyles, Wageningen University & Research); Haveman-Nies, A. (GGD NOG; Consumption and Healthy Lifestyles, Wageningen University & Research); Gunnink, M. (Icare JGZ); Goudkuil, A. (Icare JGZ); Vet, E.W.M.L. de (Consumption and Healthy Lifestyles, Wageningen University & Research) (2021): Data underlying the publication: How the Use of a Patient-Accessible Health Record Contributes to Patient-Centered Care: Scoping Review. DANS. https://doi.org/10.17026/dans-xyk-d85b

Hoff, E. van 't (GGD NOG; Consumption and Healthy Lifestyles, Wageningen University & Research); **Benjamins, S.J.** (Icare JGZ; Consumption and Healthy Lifestyles, Wageningen University & Research); Haveman-Nies, A. (GGD NOG; Consumption and Healthy Lifestyles, Wageningen University & Research) (2021): Data underlying the publication: 'Een instrument om interdisciplinaire samenwerking te onderzoeken binnen de Nederlandse zorg voor jeugd'. DANS. https://doi.org/10.17026/dans-xaz-upcw

Benjamins, S.J. (Icare JGZ; Consumption and Healthy Lifestyles, Wageningen University & Research); Haveman-Nies, A. (GGD NOG; Consumption and Healthy Lifestyles, Wageningen University & Research); Vet, E.W.M.L. de (Consumption and Healthy Lifestyles, Wageningen University & Research); Jordaan, G. (Consumption and Healthy Lifestyles, Wageningen University & Research; Christelijke Hogeschool Ede); Canfijn, R. (Antonius Ziekenhuis Nieuwegein); Koster, R. (Icare JGZ) (2021): Data underlying the paper 'Implementation of a client-accessible and multidisciplinary youth health record in the Netherlands; a mixed-methods process evaluation'. DANS. https://doi.org/10.17026/dans-znd-cgwm

Benjamins, S.J. (Wageningen University & Research, Icare JGZ); Vet, E.W.M.L. de (Wageningen University & Research); Jordaan, G. (Wageningen University & Research); Haveman-Nies, A. (Wageningen University & Research) (2022): Data underlying the paper 'Effect of the use of a client-accessible youth health record on experienced autonomy among parents and adolescents in preventive child healthcare and youth care; a mixed methods intervention study.'. DANS. https://doi.org/10.17026/dans-zxq-c63v

Benjamins, J. (Wageningen University & Research); Vet, E. de (Wageningen University & Research); Laarman, C. (Wageningen University & Research); Haveman-Nies, A. (Wageningen University & Research) (2022): Data underlying the paper 'Effect of an electronic health record on interdicisplinary collaboration between professionals in care for youth: a mixed methods intervention study.'. DANS. https://doi.org/10.17026/dans-x8k-hmab

Non-scientific publications

blog website NCJ 'Eigen regie, samen verantwoordelijk', 25 september 2020. https://www.ncj.nl/inspiratie/blog-eigen-regie-samen-verantwoordelijk-van-janine-benjamins/

blog website NCJ 'Samen met ouders bouwen aan een dossier', 6 mei 2021. https://www.ncj.nl/inspiratie/samen-met-ouders-bouwen-aan-een-dossier/

Award

The paper 'Implementation of a client-accessible and multidisciplinary youth health record in the Netherlands; a mixed-methods process evaluation’ was awarded the Flora van Laar prize in November 2021. This prize is awarded every other year by the Dutch Association of Youth Physicians (AJN). Its purpose is to stimulate research and innovation in the field of preventive child healthcare and related disciplines. The prize is awarded to a professional working in preventive child healthcare (JGZ), for outstanding and/or innovative research, or for a pioneering innovative activity in the field of preventive child healthcare.

Janine Benjamins
Wageningen School of Social Sciences (WASS)
Completed Training and Supervision Plan

Name of the learning activity	Department/Institute	Year	ECTS*
A) Project related competencesA1 Managing a research project			
WASS Introduction Course	WASS	2019	1.0
Writing PhD proposal	WUR	2019	6.0
Presenting work in CHL Seminar: 'Patient-accessible electronic health records'	WUR	2019	0.5
Scientific Writing	Wageningen in'to Languages	2019	1.8
'How does a patient-accessible health record contribute to patient centered care? A scoping review.'	ICIC '20 (virtual conference)	2020	1.0
'Jeugddossier Noord Veluwe, Ervaringen met een multidisciplinair en client-toegankelijk dossier.'	'Jeugd in Onderzoek' (virtual)	2021	1.0
'Ouders en jongeren in hun eigen dossier, hoe dan?!'	Webinar 'Open House Actiz Jeugd'	2021	1.0
'Open dossiers en inclusieve zorg, (g)een contradictio in terminis.'	AJN congress, Utrecht	2021	1.0
A2 Integrating research in the corresponding discipline			
'Prior learning' in research methodology, qualitative and quantitative research	NSPOH	2015-2019	4.0
Writing reviews	NVMO,Utrecht	2018	0.2
Facilitating interactive processes, COM60306	WUR	2021	6.0
Participative Action Research	School for Participation, Amsterdam	2023	3.0
B) General research related competences			
B1 Placing research in a broader scientific context			
E-health online module	University of Twente	2021	0.65
B2 Placing research in a societal context			
Organize consultative group for managers in preventive child health care, discussing dilemma's encountered when developing and implementing a client-accessible child health record	NCJ/Icare JGZ	2018-2021	2.0
Participate in Regional Academic Workplace for Youth (RKJ)	Regio Noord Veluwe	2019-2022	1.0
Participate in Participative Action Research	PAO Oldebroek	2019-2022	1.0

Blog 'eigen regie, samen verantwoordelijk'	NCJ	2020	0.1
Blog 'samen met ouders bouwen aan een dossier'	NCJ	2021	0.1
C) Career related competences/personal development			
C1 Employing transferable skills in different domains/careers			
Searching and organizing Literature for PhD	Library	2019	0.6
Referee at research mini symposium for medical doctors in Public Health	NSPOH	2020	0.5
Reviewing research proposals on behalf of ZonMw	ZonMw	2020-2021	0.5
Development and teaching online training module 'Training dossiervoering'	Centres for Youth and Family Noord-Veluwe	2021	2.0
Supervision BSc and MSc thesis students	WUR, University of Utrecht, Viaa	2021-2022	2.0
Total			**36.95**

*One credit according to ECTS is on average equivalent to 28 hours of study load

Abbreviations:
AJN = Artsen Jeugdgezondheidszorg Nederland
CHL = Consumption and Healthy Lifestyles
EUPHA = European Public Health Association
ICIC = International Conference for Integrated Care
JGZ = Jeugdgezondheidszorg
NCJ = Nederlands Centrum Jeugdgezondheidszorg
NSPOH = Netherlands School for Public and Occupational Health
NVMO = Nederlandse Vereniging voor Medisch Onderwijs
PAO = Participatief Actie Onderzoek
WASS = Wageningen Social Sciences
WGS = Wageningen Graduate Schools
WUR = Wageningen University and Research
ZonMw = Zorgonderzoek Nederland Medische Wetenschappen

Colophon

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