

Success Factors of an Early EHR System for Child and Adolescent Mental Health: Lessons Learned for Future Practice Data-Driven Decision Aids

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Abstract

This paper recounts the successful BUPdata, a discontinued electronic health record (EHR) system for Child and Adolescent Mental Health Services (CAMHS) in Norway. It was developed and owned by the national association for CAMHS and fulfilled needs for collaborative care, practice insight, and service management. It aimed to unify the requirements of government, administration, clinicians, patients, and researchers alike, with the goal of providing uniform quality of care nationally. When CAMHS became integrated with specialist healthcare, BUPdata was replaced with more a general EHR system offering far less functionality and insight into CAMHS practice. We have studied BUPdata, and interviewed stakeholders in order to develop decision aids based on practice data analysis and give clinicians and patients insight into successful local practice, collaboration patterns, and overview of local resources.

Keywords:

Electronic Health Record, Clinical Decision Support Systems, Child and Adolescent Mental Health Services.

Introduction

Child and Adolescent Mental Health Services (CAMHS) in Norway are organized as separate clinical units, with a high degree of autonomy, and independent from both primary and other specialist health services. A long and strong tradition of multidisciplinary collaboration with social services, educational psychological services, schools, patient organizations, and both patients and parents was changed after a major reform of public health services in 2004 when CAMHS and other mental health services were integrated into regional health trusts. Electronic Health Record (EHR) systems have been in use in Norwegian healthcare for more than 35 years. First gaining widespread acceptance in general practice and CAMHS, some years later in hospitals and remaining municipal health services. Even with public healthcare funding, IT in healthcare was not centrally organized, and a multitude of EHR systems are still operational. CAMHS had to adopt hospital EHRs in order to streamline diagnosis-related payment models, quality control, and production reporting.

This paper presents the history of the EHR, BUPdata, that served CAMHS in place around Norway until 2019. We recount the features and functions that made this EHR a success in order to lay the foundation for the development of a novel, and domain-specific, knowledge aid and clinical decision support system (DSS). The findings are based on both, the study of software artifacts, as well as interviews held with system designers, managers, secretaries, data users, and other stakeholders. The objective of this study is to develop guidelines and requirements for the IDDEAS [9] project, which aims to develop CAMHS-specific decision aids integrated in general EHR systems [8,10].

Background

In 1984, the Norwegian Association for Child and Adolescent Psychiatric Institutions (NFBUI) decided on having a common information system to support clinical work and foster quality in clinical practice. At that time, EHR systems were replacing paper records in Norway, and NFBUI prescient leaders decided that they needed a tool to support the multi-faceted and uniquely collaborative work environment in CAMHS. The first such systems were deployed in 1986. One point of discussion was whether the system should support data collection for research and management, or for day-to-day clinical work. As a result, developers concluded that information models should include details required for research needs, while user interfaces would be designed primarily to support clinicians. By 1990 NFBUI would become both the owner and the developer of a full-fledged EHR system, BUPdata, including its deployment and provision of support, as well as its user-training for almost all CAMHS across the country. One main reason for the successful adoption of BUPdata was that local administrative personnel and secretaries were active in NFBUI and responsible for introduction of the system training and user-training. Other early design decisions were to record and code family history, as well as collaborative care, and to use a multidimensional classification, allowing clinicians to represent the state, condition, and progress of patient care. BUPdata started as a tool for outpatient clinics, and only later became important for inpatient logistics. A company, HIADATA AS, was funded by early developers to provide EHRs for collaborating services and to commercialize BUPdata [1].

Before the healthcare reform, CAMHS clinics in Norway were funded by counties. Clinics had a high degree of autonomy, yet still collaborated closely with other primary and specialist healthcare services, as well as schools, families, and social services. For more than 20 years, BUPdata was under continuous development, and in some regions, it was used 10 years after end of development. Some clinics have 30 years of complete CAMHS EHR. Ultimately, the reform of specialist services, including CAMHS, into health trusts, reduced autonomy. As the market for specialty-specific EHR systems evaporated, NFBUI was dissolved into a more general professional association, the Norwegian Association of Child and Adolescent Psychiatry (NBUP), and HIADATA was merged into a multinational software company.

During the transition, CAMHS clinics became more tightly integrated into general hospitals, and by 2010, all regions, except central Norway, adopted the hospital EHR system, DIPS. The remaining association funds were directed to implement diagnostics and CAMHS-specific support for DIPS [2].

BUPdata was a product of initial close cooperation between users, stakeholders, and developers. Commercialization, buyout, a stagnant market, and ideas about potential cost savings with IT simplification, ultimately brought its downfall. Remarkably, CAMHS using BUPdata was the first Norwegian health service to be able to provide, collect and compare quality and outcome data on an individual patient level. Even now, after the last BUPdata system was put to rest in 2019, national CAMHS reports to the national patient registry still retain important parts of the original detailed and coded view of collaborative clinical roles, interventions and activities, in addition to the multiaxial representation based on ICD-10, that accommodates a more long-term view of patient trajectories, capturing main psychiatric diagnoses, comorbidities, function level and somatic conditions [3,5].

Methods

The aim of this study was to present and discuss relevant features and functions of BUPdata acquired from the following sources:

1. System and design documentation. This includes database design schemas, user documentation, government requirements, actual data reports and coding/classification systems, and national standards for CAMHS reporting/coding [4].
2. NFBUI and NBUP reports and minutes to understand organizational priorities and BUPdata objectives [2].
3. Interviews.

Semi-structured interviews are used as the main method for this study. The interviews were done digitally, and held by «first author» and «second author», in English or Norwegian, at times both in the same interview. Notes were taken throughout in order to capture and remember issues which required further elaboration or questions. The reviews were recorded using Zoom application. Automatic captioning/transcription was done in Panopto, with moderate success. Using notes, autotranscription and recording review, the interviews were transcribed into English.

Interview objectives

Interview subjects were selected according to their role or exposure to systems usage, functionality, and development. We collected statements about functions and features, likes and dis-

likes, ambitions, and requirements of BUPdata. The main objective of interviewing designers and developers was to identify the original decision making behind the architecture and model design, as well as their subjective reasoning for both the functionality advantages and shortcomings of BUPdata, compared to other EHR systems designed for services related to CAMHS. The main purpose behind interviewing clinicians was to uncover usage and requirements related to patient treatment and clinical use. Secretaries, and to a lesser extent, their managers were particularly important, because they effectively introduced BUPdata to the clinics, were responsible for training and implementation, and thus became important agents for change – such as translating clinicians and managerial needs into developer requests. This important set of users organized annual meetings and workshops for driving and developing BUPdata requirements. Researchers on BUPdata were initially regarded as important stakeholders, but ambitions did not translate into necessary funding and attention, so actual research on the use of BUPdata was less than expected.

Interviewees

System designers and users are categorized into the following groups:

1. **Initial designers and developers** of the BUPdata system, the early NFBUI stakeholders.
2. **Analysts and managers** responsible for reports and epidemiology studies.
3. **Office users and secretaries** who were pioneer BUPdata users; they were previously responsible for typing the notes/journals dictated by the doctors and allied professionals. They were given, and took, the responsibility for introducing BUPdata, played a key role in training clinicians and developing requirements.
4. **Clinicians**, the main users of the EHR.

Two sets of questions were prepared, and used as structured interview guides. One for clinicians, and one for other BUPdata stakeholders. The interviewees often took provided further elaboration beyond our prepared structured interview guide.

Table 1 - Interview questions for non-clinicians (group 1,2 and 3)

1	Please tell us about your role, if any related to BUP, before developing/using BUPdata?
2	What challenges particular to CAMHS motivated the development of an EHR system in Norway?
3	How did BUPdata serve BUP patients, clinicians, and healthcare organizations?
4	Based on your experience, what would you have done differently?
5	What were the biggest challenges of developing BUPdata for CAMHS?
6	What were the most important clinical requirements in designing BUPdata for CAMHS?
7	What were the parts that were designed, but never implemented?
8	Explain about data analysis using BUPdata.
9	Please feel free to explain more about data, analysis and data usage

Table 2 – Interview questions for clinicians (group 4)

1	Please tell us about your role, if any related to BUP, before using BUPdata?
2	In what purpose/areas did you use BUP data? What was your experience?

- 3 Please explain about your usage of BUPdata in daily clinical work, administration, and research.
 - 4 What challenges did you face?
 - 5 What specific achievements did BUPdata bring for the mental health and medical services?
 - 6 What research was conducted using BUPdata? Did you take part in improving BUPdata functionality or usage?
 - 7 What were positive and negative aspects or properties of BUPdata?
 - 8 Which specific features made BUPdata unique?
 - 9 Which limitations and shortcomings did you experience using BUPdata? Did you ever use BUPdata for providing analytical reports?
 - 10
 - 11 What do you think about using BUPdata for supporting clinical decision making?
 - 12 What do you think about the role of clinical decision support systems in improving mental health services?
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Findings and results

Strong motives for development of EHR for CAMHS

In Norway, there had been little central coordination of EHR and clinical information system development, apart from required activity reporting. Hospitals, regional health authorities, and local managers were in control of IT use and implementation, resulting in many solutions and actors. It was natural that a tight-knit CAMHS community with responsibility for long-term collaborative care of young patients needed proper information systems. CAMHS motivation was very different from that of the early hospitals, which essentially handled patient and employee logistics, and used General Practitioners (GPs) EHRs requiring structured notes for their returning patients, as well as nursing homes and municipal services that needed continuity of care records for the elderly. BUPdata became a tool exclusively catering to professional and organizational needs, quite independent from the EHR development for general hospital, municipality, and GPs.

The initial idea behind BUPdata was to improve and compare practices of more than 70 decentralized CAMHS clinics in the country. Norway has an inconvenient topography, and so the proximity to patients and families is very important. NFBUI took a leading role in developing an EHR system and ensuring national implementation and the provision of user-training. Two other motivating factors contributed to the rapid implementation and expanded coverage of BUPdata: CAMHS clinics were small with secretaries and managers very close in proximity to the daily clinic operations. Furthermore, clinicians regarded themselves as guardians and documenters, rather than providers of quick and limited interventions.

Deployment, education, and development mediated by administration and mercantile staff

One of the main reasons for developing and deploying BUPdata was to allow for the comparison of clinical services provided by each of the local CAMHS clinics. NFBUI established a committee to enable ownership and development; secretaries saw the potential utility and developed system requirements. After a short while, the initial project led to the funding of a separate company.

The responsibility of educating clinicians about the transition from paper health records to an EHR system was led by the secretaries, who were already using computers for other registration purposes. Introduction, instruction, and motivation were in the hands of the data users directly benefitting from improved data quality. The clinicians were willingly trained to provide high-quality data, for both patient care, activity

reporting, and clinic management. *"It was a very well functioning system which was stable and gave us the opportunity to register things that we rarely ever had registered in with pen and paper".*

Domain-specific data model for clinical, research, and administrative use

BUPdata was an EHR designed specifically for serving CAMHS. Over time, it came to provide utilities and services for many purposes: It was the first EHR in Norway to offer a secure patient portal. It was also the first EHR to fulfill national requirements for reporting activity on the level of individual care episodes to the National Patient Register. Most importantly, CAMHS were early adopters of comprehensive and rich coding of the current patient status, condition, and progress. In addition to free-text encounter notes, activity, intervention, and diagnosis were also carefully coded. In contrast to many other EHRs, demographics, family, and care collaborator roles were also modeled in the record. CAMHS enabled multiaxial, multi-diagnosis, state-based encoding of diseases as well as absence of such, thus enabling a rich view of patient state, condition, and progress. This approach enabled representation of long treatment processes, where episodes of care may span many years and encounters, with long series of condition and function codings.

Usability for clinicians, administration, and managers

BUPdata strived for simplicity of use. Easy-to-navigate layout, simple interface organization, transparent functionality, clinically motivated data structure and workflow support were perceived as important success factors [6]. *"The registration and writing of the notes had one screen, they were integrated in one, so one place to do with the same operation which made it more effective and easier to use for the clinicians".* This contrasts with the currently used EHR system that most clinics use, which are more general and requires more navigation: *"...While for instance in [EHR name], you had to register in one window and to write in another place...".* During the interviews we learned that BUPdata was successful and satisfying for clinicians, as they preferred typing the notes themselves, because they felt they had more control of the note content, even if this took some more time. *"That is an example of how BUPdata tried [...] all the time to make it easier for the clinicians as much as possible".*

The administrative functionality for reporting and assessment was present in BUPdata from the beginning. This was a huge incentive for adoption. Statistics and local quality control are often absent from more general EHR systems.

Direct support for collaboration and process documentation

CAMHS collaborated with other services, and it was natural that such collaboration was prioritized in the design of BUPdata. Collaborators, their roles, their efforts, and interventions were coded explicitly; It offered a platform for information sharing and communication between CAMHS, health centers, schools, and families. *"... who was present, but also if we had meetings with the school or parents or other persons in the patient's life. So you'll find not only the sessions with the patient, but you'll also find collaborators With all their services or school or ..., so you can get a picture of how, how much we did work with other ...".*

The healthcare reform gradually integrated CAMHS into hospital IT infrastructure and their EHR systems. Even if BUPdata integrated well with other hospital IT systems, the vendor saw

no future business opportunities; maintenance and development thus came to an end. In some regions, BUPdata installations were in daily use for almost 10 years after the last version was released.

BUPdata was successfully used as an EHR system, as a patient administration system, and as a source of research data and statistics. It was a huge step forward from the traditional pen and paper approach. NBUP (succeeding NFBUI in 1998 [2]) hoped that investment of time and funds into the general hospital EHR would enable the same level of service, ease of use and analysis functions. One of our informants shared that *"[The company] did nothing to accommodate our needs, apart from implementing the six-axis diagnosis system to support mandated national reporting, and psychosocial demographics"*. IT-strategies actively discouraged domain-specific diversity and EHR functionality. Reorganization of care and a steady influx of new clinicians gave less focus on CAMHS-specific objectives and uniqueness. In many hospitals, BUPdata was still kept for quality control, patient administration, research, and continuity of care. The generalized hospital EHR did not support importing vital and structured data about collaborators and procedures. *"None of our specialised [clinic-specific] reports [analyses] are available any longer. Nothing about collaboration and roles remain in the record. So we were stuck with meaningless letter templates and whatever. Standardized forms are of little value"*. Although BUPdata was not maintainable, the replacement EHR systems have lacked desired functionality.

Discussion

The main purpose of this study was to identify how a fine-tuned clinical information system was designed and implemented in order to fulfill important needs in the Norwegian CAMHS. We plan to use this experience to develop practice-data driven decision aids that uncover local patterns of assessment, treatment and collaboration. In particular, we are interested in how such aids can be realized by adding "domain-intelligence" about context, patient and practice-awareness to general EHR systems.

The main findings of the study can be summarized as follows:

- Insight into own and local clinical practice is important and should be available to clinicians.
- Practice reports and quality assessment should always be available and based on live clinical data.
- Clinically meaningful, stable, and well-founded domain information models for structuring and validated coding information are very important if used by and for clinicians.
- Implementation and training should be tightly integrated with the service, and managed by individuals directly gaining from system development and deployment.
- EHRs should support patients with decades of history and complex collaborative care.

The findings also reflect explicit challenges related to BUPdata and EHR use:

- CAMHS has a domain-specific model. In particular, it allows representation of gradients and processes of disease and function.
- EHRs are vulnerable to health service reorganization.

- Data analysis functionality was underutilized because of limited resources.
- BUPdata architecture, and EHR architecture in general, were not ready for service integration.
- Management failed to understand that collaboration and planning support was crucial to CAMHS.

The main learnings for future CAMHS decision aids:

1. Integrate services and interfaces, not systems;
2. Retain the simplest working domain model;
3. Clinical and patients needs should direct information modeling;
4. Make information available to those making it;
5. Accept that the clinic is an information and knowledge-intensive workplace;
6. Traditional diagnostic coding are event-based, but should accommodate long-term processes and change.

Conclusions

BUPdata was an innovation with complete coverage, fast implementation, and successful use. It would have been interesting to try and measure outcome with respect to quality or effect with CAMHS based on BUPdata versus CAMHS with other EHR systems. However, population prevalence, service organization, change of diagnostics, and treatment practices are major confounders to such an undertaking. The overall impression has been that efficiency in information use and management, and the degree of insight, have all been reduced after switching from BUPdata. The positive effect has been better integration with other specialist care services and sharing the same EHR system, but this has come with the loss of substantial utility for CAMHS.

In Norway, the healthcare strategy is directed towards "One citizen – One record". Perhaps this has been erroneously interpreted as "Every citizen – One record system" [7]. Developing systems that amplify input information by outputting analyses and practice knowledge useful for clinicians and patients alike will be a good way to preserve the experience and heritage of BUPdata. One final insight is that future EHRs must be designed to accommodate for future domain-specific, data-driven add-on decision aids.

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