

1 Using Electronic Health Record Systems in Nursing Research: Exploring the Challenges

2

3 Background: Electronic Health Records (EHR) provide an interesting potential data set for nursing
4 research but can present challenges for data collection and data quality, as health care IT systems are
5 often not designed with research in mind.

6 Aim: To present an example of data collection using Electronic Health Records (EHR), conducted as part
7 of a research study into the role of the school nurse in child protection.

8 Methods: Descriptive analysis of quantitative, secondary data.

9 Discussion: Data were successfully obtained from Electronic Health Records (EHR) to understand school
10 nursing caseloads and interventions with vulnerable children and young people. Major limitations
11 included variances in record systems, such as different 'labels' used for interventions. These limitations
12 were addressed during data collection by reviewing organisational record keeping guidance and a
13 working knowledge of the different EHR systems.

14 Conclusion: Conducting research using Electronic Health Records (EHR) has provided important
15 learning about the potential of this type of data and the promise it holds for future research.

16 Implications for Practice: Organisations who wish to engage in research using existing data might
17 consider embedding pathways for data collection that are easy for potential researchers to navigate.
18 Electronic Clinical Record (EHR) systems need to be sensitive for research, but not at the expense of
19 efficiency in clinical practice.

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21 Keywords: Health Records, Clinical Records, Nursing Records, Administrative Data, Secondary Analysis.

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23 Introduction:

24 Electronic Health Records (EHR) are systems designed to electronically store and organise data on
25 patient care. Documented components can include diagnoses, patient notes, nursing care plans, test
26 results and clinician diaries (Hayrinen *et al.* 2008). A number of EHR systems are used within health

27 services in the UK and internationally, and in the UK the NHS hope to move towards paperless patient
28 records by 2020 (National Information Board, 2014). Using EHR in research has gained increased
29 interest in recent years because it allows for the collection of broad health information across a large
30 population (Cowie *et al.* 2017; Zhang *et al.* 2018). The collection of this data is often performed by
31 running system reports on administrative data from pre-set templates or analysing electronic patient
32 notes (Castillo *et al.* 2015; Connelly *et al.* 2016). Patients are informed about how their confidential
33 health data may be used in research or service improvement, and since May 2018 NHS patients in
34 England have been able to 'opt-out' of this arrangement (NHS England, 2018). All health and care
35 organisations in England must introduce similar opt-out processes by 2020. Using results from EHR in
36 research is defined as secondary analysis of existing data, which is differentiated from primary data
37 analysis. Secondary analysis of existing data encompasses data collected for other purposes (such as
38 birth and death registries) and data originally collected as part of a different research study (Cheng and
39 Phillips, 2014). This article presents an example of using EHR for research, as part of a research study
40 into the role of the school nurse in child protection. An overview of the advantages and disadvantages
41 of using EHR for research is given, followed by a description of data collection, limitations and
42 recommendations for future practice.

43

44 Introduction to the Study

45 Data collection for a PhD study into the role of the school nurse in child protection took place between
46 June 2016-January 2018 and was conducted in three school nursing services (from different health
47 organisations) across England. Ethical approval was obtained from the affiliated university and the
48 Health Research Authority (HRA) for England. The study was designed in two stages; stage one involved
49 the analysis of data from EHR, and stage two involved semi-structured interviews with a sample of 25
50 school nurses. Data from EHR were collated from school nurses' electronic diaries to understand their
51 patient caseload, and the type and frequency of appointments offered to vulnerable children and young
52 people. Electronic diaries were a routine part of clinical practice for school nurses, who used them to

53 record times/dates of appointments with children, the interventions offered to them and the outcome
54 of these appointments. These records, as with hand-written nursing notes, are evidence of nursing care
55 and can be used as a legal document (Stevens and Pickering, 2010). EHR in this study were 'owned' by
56 the NHS rather than individual schools, who had no access to them. Therefore, one data set (per study
57 site) represented school nursing activity to support all schools covered by the NHS school nursing
58 service in that county. Schools and school nursing services had different policies around information
59 sharing and confidentiality, thus maintained different record-keeping systems. To maintain
60 confidentiality in this study, data was collected and anonymised by a designated professional within
61 each health organisation.

62

63 Data Collection

64 A data request sheet was developed according to the research team's knowledge of EHR and the
65 information that might best address the research objectives. The data request items were linked to the
66 aims and objectives of the research study and a systematic review of school nursing literature (Author
67 *et al.* 2019). One of the research objectives was to understand the type and scope of school nursing
68 interventions offered to vulnerable children and young people. The data request sheet contained a list
69 of information to be obtained by running reports on school nursing activity from EHR (Table 1), and this
70 was securely emailed to an identified contact within the service management team for each
71 organisation, for feedback and initial advice. In addition, one member of the research team was a
72 practising school nurse with a working knowledge of EHR.

73

74 Data was requested for the previous two academic years, 2015/6 and 2016/7, although most items of
75 data could only be provided for the 2016/7 academic year. Reasons given for this were in relation to
76 time constraints of the parties involved in collating the data, a recent changeover of health provider in
77 one organisation (meaning they could not access data owned by the previous provider) and the persons
78 collating the data only having permission to view the latest information for the last reporting year.

79 Although these were not direct issues with the EHR systems themselves, they were part of the wider
80 complexities of conducting research in a large, dynamic health organisation. A member of the service
81 management team returned the final data set on Microsoft Excel spreadsheets or the completed data
82 request sheet, and by means of a secure, encrypted email. To comply with ethical approval of the study,
83 all names of school nursing staff, patients and any other identifiable information were removed by this
84 nominated person. A telephone call or face-to-face visit was offered to a member of the service
85 management team in each organisation, to talk through the data request sheet and raise any issues or
86 concerns. Each study site accepted an initial visit to discuss data collection and the data request sheet.
87 This was to promote trust and good communication, which can be central to positive collaboration
88 between and within agencies (Williams, 2011).

89

90 Table 1: Data Request Sheet, School Nursing Activity Data

91

Research Question <i>(derived from systematic review)</i>	Data Request
How many children on school nursing caseloads?	1. What is the total school nursing caseload size? 2. What is the total child protection caseload size? 3. What is the total child in need caseload size? 4. What is the total team around the child/family caseload size?
How do school nurses identify children at risk of child abuse?	5. What is the total number of referrals made to social care by school nurses in the last academic year? 6. What is the range of risk assessment tools used by school nurses to safeguard children and young people?
What interventions are offered to children at risk of child abuse?	7. What is the total number of contacts/interventions with all children by the school nursing team in the last academic year? 8. What is the total number of contacts/interventions with children with a safeguarding or child protection alert (on their clinical records) by the school nursing team in the last academic year? 9. What is the average total time spent on interventions relating to all children by the school nursing team in the last academic year? 10. What is the average total time spent on interventions relating to

	children with a safeguarding or child protection alert (on their clinical records) by the school nursing team in the last academic year?
How do school nurses work with children at risk of child abuse?	11. What is the range and type of interventions provided by school nurses relating to all children in the last academic year? 12. What is the range and type of interventions provided by school nurses relating to children with a safeguarding or child protection alert in the last academic year?

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93

94 Data Management

95 Data were managed on Microsoft Excel, to produce descriptive statistics on school nursing caseloads
96 and school nursing interventions. Microsoft Excel was deemed sufficient by the research team to
97 produce descriptive statistics and was a familiar programme to the organisations providing the data.

98 The researcher attended a university course on using Microsoft Excel for data management, in June
99 2016. Data were aggregated within each organisation and focused on the activity of the school nursing
100 service, rather than individual school nurses. Organisational data were transferred onto one single
101 master spreadsheet, as this aided comparisons between each service across the three organisations.

102 Additionally, each organisation sent two to three spreadsheets or templates each in response to the
103 data request, and one used a pivot table (an interactive table that generates specific data from the
104 spreadsheet), so it was necessary to extract the required information and combine these into a more
105 manageable format. The master spreadsheet contained tabs for each school nursing service, and a tab
106 to present comparable data between the services.

107

108 Discussion

109 Despite acknowledging the challenges of using data from EHR in research, in this study it provided an
110 insight into annual school nursing activity across multiple study sites. It allowed the research team to
111 begin to understand and compare the size of school nurses' patient caseloads and the frequency and

112 type of interventions offered to vulnerable children and young people. It was a method that did not
113 require school nurses to complete additional data collection tools in order to inform the research.

114

115 It is known that data from EHR systems has potential in research, as it allows for the collection of large
116 amounts of information on a population and does not rely on participant responses to other methods
117 of primary data collection (Castillo *et al.* 2015; Connelly *et al.* 2016; Cowie *et al.* 2017). Collecting data
118 from readily available electronic databases can be more cost-effective than attempting to collect similar
119 data through primary data collection methods and reduces the burden on potential participants
120 (Administrative Data Liaison Service, 2010; Zhang *et al.* 2018). Additionally, the recording of data usually
121 follows consistent pro-forma and is subject to audit, as was true of the school nursing data in this study
122 (Administrative Data Liaison Service, 2010; Nursing and Midwifery Council, NMC, 2015). Audit is defined
123 as a process of comparing current practice against a specified organisational standard (such as
124 contemporaneous record keeping) and is not for the purposes of testing or answering a research
125 question (The Regulation and Quality Improvement Authority, 2018). Data can therefore be presumed
126 to be unbiased in relation to any future research use as it is collected for clinical purposes only
127 (Appleton and Cowley, 1997). However, the use of clinical records by health providers and researchers
128 for evidence of care provision may be in conflict with the perspective of some nurses, who find the
129 amount of record keeping activities increasingly overwhelming and distracting from direct time with
130 patients (Cunningham *et al.* 2012).

131

132 In this study, it was essential to have the co-operation of a designated professional within each
133 organisation to collect and anonymise the data from the different systems, and investment by the
134 primary researcher in maintaining communication, support and gratitude to this person was valuable.
135 It is known that working at the boundaries between organisations, such as health and academia, can
136 have challenges and it can be important to communicate well, build trust and set out a common vision
137 for the outcome of the project (Williams, 2011). In research, investment in support and liaison with key

138 stakeholders at regularly points throughout the lifetime of a research study can improve engagement,
139 as stakeholders feel included in the decision-making processes (Phillipson, Lowe and Ruto, 2012).

140

141 Obtaining data from EHR had several anticipated limitations and despite attempting to control for
142 these, some of the results highlighted the complications of using a system not designed for research
143 purposes. The major limitations involved the difference in the size and definition of the term '*school*
144 *nurse caseload*' and the presence of possible recording discrepancies, such as 1 recording of a '*new*
145 *birth visit*', despite school nurses working solely with children 5-19 years. It has been acknowledged in
146 critical analyses of research using large sets of administrative data that recording discrepancies are
147 unavoidable as part of everyday 'human error' (Sivarajah *et al.* 2017; Zhang *et al.* 2018).

148

149 In administrative data such as EHR, clinicians may mis-classify interventions at the point of selecting
150 pre-set options and distractions in the clinical environment may impact on the time and concentration
151 required for record keeping (Brouwer, Policastri and Moga, 2015; Castillo *et al.* 2015). Comparing data
152 across different services and organisations may be a challenge if they use different EHR systems, and
153 different labels for interventions (Castillo *et al.* 2015; Connelly *et al.* 2016). These limitations exist
154 because most EHR systems were not designed with research in mind and are primarily for supporting
155 clinical care and providing evidence for commissioners about the performance of a service against
156 financial targets (Brouwer, Policastri and Moga, 2015; Cowie *et al.* 2017). EHR systems are usually
157 designed and supported by a sub-contractor who bids to provide such services to a health provider
158 through a tendering process. Although EHR systems are considered efficient, timely and cost effective
159 (Ozair *et al.* 2015), the tendering process means systems used across the country and between local
160 health services are often different and information held about a patient can be fragmented.

161

162 In this study, the EHR data itself used many non-descript labels to define interventions, and it was not
163 always clear the type of nursing care that had been delivered e.g. '*school nurse clinic appointment*'. In

164 addition, attempting to combine data from three different EHR systems with differing formats and
165 which used different labels was complex. Not all organisations could provide the full data set on the
166 original request as the EHR system did not have the required sensitivities. The system either did not
167 record the level of accuracy needed to answer the specific item in the data request, or it was not
168 possible to run a report on the system to collate the information required. In addition to lack of
169 sensitivity of the EHR system, one organisation felt it was too time consuming to investigate how they
170 may alter the EHR system to run these reports, due to long-term staff sickness.

171

172 Obtaining the data from each school nursing service was a lengthy process (approximately ten months)
173 and involved negotiation with multiple parties within the organisations, particularly due to the need for
174 a third party to collect and anonymise the data to be sent to the research team. The local record keeping
175 guide for each service was obtained from the lead for school nursing, and this helped to understand
176 how school nurses might categorise their interventions and to compare similar interventions across the
177 different services. This proved particularly important as each school nursing service defined types of
178 interventions differently.

179

180 A reflection on the process of working with EHR deemed it to be an important learning activity,
181 especially as there is increasing interest in this type of research. Health research using existing data
182 sets, sometimes referred to as 'Big Data Research', is thought to provide the potential to understand
183 research questions on a population level (Bates *et al.* 2014; Zhang *et al.* 2018). This interest is driven in
184 part by the increasing implementation of EHR internationally and the general improvements in
185 computing technology (Bates *et al.* 2014, Jin *et al.* 2015).

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187 Conclusion

188 Data from EHR allowed for an overview of school nursing practice across a large area to be formed,
189 using data that was expected to be recorded contemporaneously and in real-time. Challenges of this

190 approach included liaising with multiple stakeholders and the lack of sensitivity of EHR systems to
191 answer detailed research questions. Improved liaison between research institutions and health
192 organisations internationally could clarify pathways for researchers to access health data, and
193 potentially improve EHR systems in the future.

194

195 Recommendations for Practice

196 If school nursing services (and indeed other health and social care organisations) are going to be
197 examined and compared nationally and want to be used as evidence of the impact of school nursing
198 care, consistent and comparable EHR systems are important. Organisations who wish to engage in
199 future EHR research might consider pathways that are easy to navigate for researchers to obtain data,
200 considering systems that are amenable to research as well as service audits and key performance
201 indicators. Systems should of course be efficient for practice, as nurses can find the amount of record
202 keeping activities increasingly overwhelming and distracting from direct time with patients
203 (Cunningham *et al.* 2012, Royal College of Nursing, 2018). Organisations who do not already involve
204 front-line practitioners and staff with research expertise in the design and implementation of record-
205 keeping systems might consider this as a way of promoting systems that are fit for the future of health
206 research.

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