

Chapter 11

Methods for Descriptive Studies

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11.1 Introduction

Descriptive studies in eHealth evaluations aim to assess the success of eHealth systems in terms of the system planning, design, implementation, use and impact. Descriptive studies focus on describing the process and impact of eHealth system development and implementation, which often are contextualized within the implementation environment (e.g., a healthcare organization). The descriptive nature of the evaluation design distinguishes descriptive studies from comparative studies such as a before/after study or a randomized controlled trial. In a 2003 literature review on evaluations of inpatient clinical information systems by van der Meijden and colleagues, four types of study design were identified: correlational, comparative, descriptive, and case study (van der Meijden, Tange, Troost, & Hasman, 2003). This review inherited the distinction between objectivist and subjectivist studies described by Friedman and Wyatt (1997); in the review, van der Meijden and colleagues defined descriptive study as an objectivist study to measure outcome variable(s) against predefined requirements, and case study as a subjectivist study of a phenomenon in its natural context using data from multiple sources — quantitatively or qualitatively (van der Meijden et al., 2003). For simplicity, we include case study under the descriptive study category in this chapter, and promote methodological components of qualitative, quantitative, and mixed methods for designing eHealth evaluations in this category. Adopting this wider scope, the following sections introduce the types of descriptive studies in eHealth evaluations, address methodological considerations, and provide examples of such studies.

11.2 Types of Descriptive Studies

There are five main types of descriptive studies undertaken in eHealth evaluations. These are separated by the overall study design and the methods of data collection and analysis, as well as by the objectives and assumptions of the evaluation. The five types can be termed: qualitative studies, case studies, usability studies, mixed methods studies, and other methods studies (including ethnography, action research, and grounded theory studies).

11.2.1 Qualitative Studies

The methodological approach of qualitative studies for eHealth evaluations is particularly appropriate when “we are interested in the ‘how’ or ‘why’ of processes and people using technology” (McKibbon, 2015). Qualitative study design can be used in both formative and summative evaluations of eHealth interventions. The qualitative methods of data collection and analysis include observation, documentation, interview, focus group, and open-ended questionnaire. These methods help understand the experiences of people using or planning on using eHealth solutions.

In qualitative studies, an interpretivist view is often adopted. This means qualitative researchers start from the position that their knowledge of reality is a social construction by human actors; their theories concerning reality are ways of making sense of the world, and shared meanings are a form of intersubjectivity rather than objectivity (Walsham, 2006). There is also increasing uptake of critical theory and critical realism in qualitative health evaluation research (McEvoy & Richards, 2003). The assumption for this paradigm is that reality exists independent of the human mind regardless of whether it can be comprehended or directly experienced (Levers, 2013). Irrespective of the different epistemological assumptions, qualitative evaluations of eHealth interventions apply similar data collection tools and analysis techniques to describe, interpret, and challenge people’s perceptions and experiences with the environment where the intervention has been implemented or is being planned for implementation.

11.2.2 Case Studies

A case study investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident (Yin, 2011). Case study methods are commonly used in social sciences, and increasingly in information systems (IS) research since the 1980s, to produce meaningful results from a holistic investigation into the complex and ubiquitous interactions among organizations, technologies, and people (Dubé & Paré, 2003). The key decisions in designing a case study involve: (a) how to define the case being studied; (b) how to determine the relevant data to be collected; and (c) what should be done with the data once collected (Yin, 2011). These decisions remain the crucial questions to ask when designing an eHealth evaluation case study. In eHealth evaluations, the fundamental question regarding the case definition is often answered based on consultation with a

range of eHealth project stakeholders. Investigations should also be undertaken at an early stage in the case study design into the availability of qualitative data sources — whether informants or documents — as well as the feasibility of collecting quantitative data. For instance, eHealth systems often leave digital footprints in the form of system usage patterns and user profiles which may help in assessing system uptake and potentially in understanding system impact.

Case study design is versatile and flexible; it can be used with any philosophical perspective (e.g., positivist, interpretivist, or critical); it can also combine qualitative and quantitative data collection methods (Dubé & Paré, 2003). Case study research can involve a single case study or multiple case studies; and can take the strategy of an explanatory, exploratory or descriptive approach (Yin, 2011). The quality of eHealth evaluation case studies relies on choosing appropriate study modes according to the purpose and context of the evaluation. This context should also be described in detail in the study reporting; this will assist with demonstrating the credibility and generalizability of the research results (Benbasat, Goldstein, & Mead, 1987; Yin, 2011).

11.2.3 Usability Studies

Usability of an information system refers to the capacity of the system to allow users to carry out their tasks safely, effectively, efficiently and enjoyably (Kushniruk & Patel, 2004; Preece, Rogers, & Sharp, 2002; Preece et al., 1994). Kushniruk and Patel (2004) categorized the usability studies that involve user representatives as usability testing studies and the expert-based studies as usability inspection studies. They highlighted heuristic evaluation (Nielsen & Molich, 1990) and cognitive walkthrough (Polson, Lewis, Rieman, & Wharton, 1992) as two useful expert-based usability inspection approaches. Usability studies can evaluate an eHealth system in terms of both the design and its implementation. The goals of usability evaluations include assessing the extent of system functionality, the effect of interface on users, and identifying specific problems. Usability testing should be considered in all stages of the system design life cycle. The idea of testing early and often is a valuable principle for having a good usable system (e.g., to get usability evaluation results from early-stage prototypes including paper prototypes). Another principle, although challenging for eHealth innovations, is to involve users early and often — that is, to keep real users close to the design process. The interaction design model (Cooper, 2004) recommends having at least one user as part of the design team from the beginning, so that right from the formulation of the product its concept actually makes sense to the type of users it's aimed for; and the users themselves should participate in the usability testing.

A classic usability study is done through user participation, either in a laboratory setting or in the natural environment. There is also a suite of techniques that are sometimes called “discount” usability testing or expert-based evaluation (as they are applied by usability experts rather than end users). The most prominent expert-based approach is heuristic evaluation (Nielsen & Molich, 1990).

Whichever approach is taken for usability studies, the target measures for usability are similar:

- How long is it taking users to do the task?
- How accurate are users in doing the task?
- How long does it take users to learn to do the task with the system?
- How well do users remember how to use the system from earlier sessions?
- And, in general, how happy are users about having worked the task with the tool?

A usability specification can combine these five measures into requirements, such as: at least 90% of users can perform a given task correctly within no more than five minutes one week after completing a 30-minute tutorial.

11.2.4 Mixed Methods Studies

Increasing uptake and recognition of mixed methods studies, which combines qualitative and quantitative components in one research study, have been observed in health sciences and health services research (Creswell, Klassen, Plano, & Smith, 2011; Wisdom, Cavaleri, Onwuegbuzie, & Green, 2012). Mixed methods studies draw on the strength of utilizing multiple methods, but have challenges inherent to the approach as well, such as how to justify diverse philosophical positions and multiple theoretical frameworks, and how to integrate multiple forms of data. A key element in reporting mixed methods studies is to describe the study procedures in detail to inform readers about the study quality.

Given the nature of eHealth innovations — often new, complex and hard to measure — a mixed methods design is particularly suitable for their evaluations to collect robust evidence on not only their effectiveness, but also the real-life contextual understandings of their implementation. For instance, the system transactional data may indicate the technology uptake and usage pattern; and end user interviews collect people's insights into why they think certain events have happened and how to do things better.

11.2.5 Other Methods (ethnography, action research, grounded theory)

In addition to the above four main categories of designs used in eHealth evaluation studies, this section introduces a few other relevant and powerful approaches, including ethnography, action research, and grounded theory methods.

- With origins in anthropology, an ethnographic approach to information systems research aims to provide rich insights into the human, social and organizational aspects of systems development and application (Harvey & Myers, 1995). A distinguishing feature of ethnographic research is participant observation, that is, the researcher must have been there and “lived” there for reasonable length of time (Myers, 1997a). Interviews, surveys, and field notes can also be used in ethnography studies to collect data.
- Similarly, multiple data collection methods can be used in an action research study. The key feature of action research design is its “participatory, democratic process concerned with developing practical knowing” (Reason & Bradbury, 2001, p. 1). Action research studies naturally mix the problem-solving activities with research activities to produce knowledge (Chiasson, Germonprez, & Mathiassen, 2009), and often take an iterative process of planning, acting, observing, and reflecting (McNiff & Whitehead, 2002).
- Grounded theory is defined as an inductive methodology to generate theories through a rigorous research process leading to the emergence of conceptual categories; and these concepts as categories are related to each other as a theoretical explanation of the actions that continually resolve the main concern of the participants in a substantive area (Glaser & Strauss, 1967; Rhine, 2008). In the field of information systems research, grounded theory methodology is useful for developing context-based, process-oriented descriptions and explanations of the phenomena (Myers, 1997b). A 2013 review found that the most common use of grounded theory in Information Systems studies is the application of grounded theory techniques, typically for data analysis purposes (Matavire & Brown, 2013).

It is worth noting that the use of the above methods does not exclude other designs. For instance, ethnographic observations can be undertaken as one element in a mixed methods case study (Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010).

11.3 Methodological Considerations

There are a range of methodological issues that need to be considered when designing, undertaking and reporting a descriptive eHealth evaluation. These issues may emerge throughout the study procedures, from defining study objectives to presenting data interpretation. This section provides a quick guide

for addressing the most critical issues in order to choose and describe an appropriate approach in your study.

11.3.1 Study Objectives and Questions

The high-level goals of an eHealth evaluation study are often planned in the initial phase of the study. The goals define what the study is meant to reveal and what is to be learned. These may be documented as a multilevel statement of high-level intentions or questions. This statement is then expanded in the methodology section of the final study report with specific aspects of the purpose of the evaluation: that is, things you want to find out. For instance, if the innovation were an electronic referral (e-referral) system:

- The acceptance of e-referrals by all impacted healthcare workers.
- The impact of e-referrals on safety, efficiency and timeliness of healthcare delivery.
- The key problems and issues emerging from a technical and management perspective in implementation of e-referrals.

Some of the above specific statements may be expressed as testable hypotheses; for example, “Use of e-referrals is widely accepted by General Practitioners (GPs).” A good use of expanded objectives is to state specific research questions; for example, we might ask, “Do GPs prefer e-referrals to hard copy referrals?” as part of the “acceptance” assessment objective above.

11.3.2 Observable and Contextual Variables

In many cases, eHealth evaluation will be linked to (as part of, or coming after) a health IS implementation project that had a business case based on specific expected benefits of the technology, and specific functional and non-functional requirements as critical success factors of the project. These should be part of the evaluation’s benefits framework. International literature (e.g., the benefits found with similar technology when evaluated overseas) may also inform the framework. The establishment of benefits framework in an eHealth evaluation will dictate the study design and variables selection, as well as the methods of data collection and analysis. For instance, observable variables to measure system outcome may include: mortality, morbidity, readmission, length of stay, patient functional status or quality of health/life.

One of the strengths of descriptive studies is that the study findings are contextualized within the system implementation environment. Hence, it is a good practice to explain in the methodology what system(s) is evaluated, including the technologies introduced, years and geography of implementation and use, as well as the healthcare delivery organizations and user groups involved in their use. Contextual variables also include those detailing the evaluation parameters

such as research study period and those contextual conditions that are relevant to the system implementation success or failure, for example, organizational structure and funding model.

11.3.3 Credibility, Authenticity and Contextualization

The philosophy of evaluation that is taken along with the detailed research procedures should be described to demonstrate the study rigour, reliability, validity and credibility. The methods used should also be detailed (e.g., interviews of particular user or management groups, analysis of particular data files, statistical procedures, etc.). Data triangulation (examining the consistency of different data sources) is a common technique to enhance the research quality. Where any particularly novel methods are used, they should be explained with reference to academic literature and/or particular projects from which they have arisen; ideally, they should be justified with comparison to other methods that suit similar purposes.

Authenticity is regarded as a feature particular to naturalistic inquiry (and ethnographic naturalism), an approach to inquiry that aims to generate a genuine or true understanding of people's experiences (Schwandt, 2007). In a wider sense of descriptive eHealth evaluation studies, it is important to maintain research authenticity — to convey a genuine understanding of the project stakeholders' experiences from their own point of view.

Related to the above discussion on credibility and authenticity, the goal of contextualizing study findings is to support the final theory by seeing whether “the meaning system and rules of behaviour make sense to those being studied” (Neuman, 2003). For example, to draw a “rich picture” of the impact of the evaluated eHealth implementation, the study may inquire and report on “How has it impacted the social context (e.g., communications, perceived roles and responsibilities, and how the users feel about themselves and others)?”

11.3.4 Theoretical Sampling and Saturation

Theoretical sampling is an important tool in grounded theory studies. It is to decide, on analytic grounds, what data to collect next and where to find them (Glaser & Strauss, 1967). This requires calculation and imagination from the analyst in order to move the theory along quickly and efficiently. The basic criterion is to govern the selection of comparison groups for discovering theory based on their theoretical relevance for furthering the development of emerging categories (Glaser & Strauss, 1967).

In studies that collect data via interviews, ideally the interviewing should continue, extending with further theoretical sampling, until the evaluators have reached “saturation” — the point where all the relevant contributions from new interviewees neatly fit categories identified from earlier interviews. Often time and budget do not allow full saturation, in which cases the key topics of interest and major data themes need to be confirmed, for example, by repeating emphasis from individuals in similar roles.

11.3.5 Data Collection and Analysis

Descriptive studies may use a range of diverse and flexible methods in data collection and analysis. Detailed description of the data collection methods used will help readers understand exactly how the study achieves the measurements that are relevant to your approach and measurement criteria. This includes how interviewees are identified, and sources of documents and electronic data, as well as pre-planned interview questions and questionnaires.

In terms of describing quantitative data analysis methods, all statistical procedures associated with the production of quantitative results need to be stated. Similarly, all analysis protocols for qualitative data should be clarified (e.g., the data coding methods used).

11.3.6 Interpretation and Dissemination

Key findings from descriptive studies should provide answers to the research objectives/questions. In general, these findings can be tabulated against the benefits framework you introduced as part of the methodology. Interpretation of the findings may characterize how the eHealth intervention enabled a transformation in healthcare practices. Moreover, when explaining the interpretation and implications drawn from the evaluation results, the key implications can be organized into formal recommendations.

In terms of evaluation dissemination, the study findings should reach all stakeholders considering uptake of similar technology. Evaluation and dissemination as iterative cycles should be considered. Feedback from dissemination of interim findings is a valuable component of the evaluation *per se*. A dissemination strategy should be planned, specifying the dissemination time frame and pathways (e.g., conventional written reporting, face-to-face reporting, Web 2.0, commercial media and academic publications).

11.4 Exemplary Cases

This section illustrates two descriptive eHealth evaluation studies, one case study as part of the commissioned evaluation on the implementation and impact of the summary care record (SCR) and HealthSpace programmes in the United Kingdom, and the other study from Canada as a usability evaluation to inform Alberta's personal health record (PHR) design. These two examples demonstrate how to design a descriptive study applying a range of data collection and analysis methods to achieve the evaluation objectives.

11.4.1 United Kingdom HealthSpace Case Study

Between 2007 and 2010, an independent evaluation was commissioned by the U.K. Department of Health to evaluate the implementation and impact of the summary care record (SCR) and HealthSpace programmes (Greenhalgh, Stramer et al., 2010; Greenhalgh, Hinder et al., 2010). SCR was an electronic summary of key health data drawn from a patient's GP-held electronic record

and accessible over a secure Internet connection by authorized healthcare staff. HealthSpace was an Internet-accessible personal organizer onto which people may enter health data and plan health appointments. Through an advanced HealthSpace account, they could gain secure access to their SCR and e-mail their GP using a function called Communicator.

This evaluation undertook a mixed methods approach using a range of data sources and collection methods to “capture as rich a picture of the programme as possible from as many angles as possible” (Greenhalgh, Hinder et al., 2010). The evaluation fieldwork involved seven interrelated empirical studies, including a multilevel case study of HealthSpace covering the policy-making process, implementation by the English National Health Service (NHS) organizations, and experiences of patients and carers. In the case study, evaluators reviewed the national registration statistics on the HealthSpace uptake rate (using the number of basic and advanced HealthSpace accounts created). They also studied the adoption and non-adoption of HealthSpace by 56 patients and carers using observation and interview methods. In addition, they interviewed 160 staff in national and local organizations, and collected 3,000 pages of documents to build a picture of the programme in context. As part of the patient study, ethnographic observation was undertaken by a researcher who shadowed 20 participants for two or three periods of two to five hours each at home and work, and noted information needs as they arose and how these were tackled by the participant. An in-depth picture of HealthSpace conception, design, implementation, utilization (or non-use and abandonment, in most cases) and impact was constructed from this mixed methods approach that included both quantitative uptake statistics and qualitative analysis of the field notes, interview transcripts, documents and communication records.

The case study showed that the HealthSpace personal electronic health record was poorly taken up by people in England, and it was perceived as neither useful nor easy to use. The study also made several recommendations for future development of similar technologies, including the suggestion to conceptualize them as components of a sociotechnical network and to apply user-centred design principles more explicitly. The overall evaluation of the SCR and HealthSpace recognized the scale and complexity of both programmes and observed that “greatest progress appeared to be made when key stakeholders came together in uneasy dialogue, speaking each other’s languages imperfectly and trying to understand where others were coming from, even when the hoped-for consensus never materialised” (Greenhalgh, Hinder et al., 2010).

11.4.2 Usability Evaluation to Inform Alberta’s PHR Design

The Alberta PHR was a key component in the online consumer health application, the Personal Health Portal (PHP), deployed in the Province of Alberta, Canada. The PHR usability evaluation (Price, Bellwood, & Davies, 2015) was part of the overall PHP benefit evaluation that was embedded into the life cycle of the PHP program throughout the predesign, design and adoption phases. Al-

though using a commercial PHR product, its usability evaluation aimed to assess the early design of the PHR software and to provide constructive feedback and recommendations to the PHR project team in a timely way so as to improve the PHR software prior to its launch.

Between June 2012 and April 2013, a combination of usability inspection (applying heuristic inspection and persona-based inspection methods) and usability testing (with 21 representative end users) was used in Alberta's PHR evaluation. For the persona-based inspection, two patient personas were developed; for each persona, scenarios were developed to illustrate expected use of the PHR. Then in the user testing protocol, participants were asked to "think aloud" while performing two sets of actions: (a) to explore the PHR freely, and (b) to follow specific scenarios matching the expected activities of the targeted end users that covered all key PHR tasks. Findings from the usability inspection and testing were largely consistent and were used to generate several recommendations regarding the PHR information architecture, content and presentation. For instance, the usability inspection identified that the PHR had a deep navigation hierarchy with several layers of screens before patient health data became available. This was also confirmed in usability testing when users sometimes found the module segmentation confusing. Accordingly, the evaluation researchers have recommended revising the structure and organization of the modules with clearer top-level navigation, a combination of content-oriented tabs and user-specific tabs, and a "home" tab providing a clear clinical summary.

Usability evaluation can be conducted at several stages in the development life cycle of eHealth systems to improve the design — from the earliest mock-ups (ideally starting with paper prototypes), on partially completed systems, or once the system is installed and undergoing maintenance. The Alberta PHR study represents an exemplary case of usability evaluations to inform the development of a government-sponsored PHR project. It demonstrates the feasibility and value of early usability evaluation in eHealth projects for having a good usable system, in this case avoiding usability problems prior to rollout.

11.5 Summary

Descriptive evaluation studies describe the process and impact of the development and implementation of a system. The findings are often contextualized within the implementation environment, such as — for our purposes — the specific healthcare organization. Descriptive evaluations utilize a variety of qualitative and quantitative data collection and analysis methods; and the study design can apply a range of assumptions, from positivist or interpretivist perspectives, to critical theory and critical realism. These studies are used in both formative evaluations and summative evaluations.

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