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The necessity of a resuscitation registry in Estonia: qualitative approach based on expert interviews and document analysis

Master's thesis

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Taaselustamise registri vajadus Eestis: kvalitatiivne uuring ekspertintervjuude ja dokumendianalüüsi põhjal

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Author’s declaration of originality

I hereby certify that I am the sole author of this thesis. All literature, other materials and works by others used in producing this thesis have been cited. This thesis has not been presented for examination anywhere else.

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Abstract

Background: Sudden cardiac arrest is the third leading cause of death in Europe. Out-of-hospital cardiac arrest (OHCA) is a time-sensitive medical emergency, and a favourable neurological outcome for the patient determines whether resuscitation was successful. A national resuscitation registry would contribute to continuous monitoring and regular assessment of pre-hospital and post-resuscitation outcomes, and facilitate data comparison with other countries, but Estonia does not have one and is not collecting resuscitation data at national level. **The aim** of the study is to examine the benefits and challenges of current resuscitation data collection and analysis in Estonia, building a resuscitation registry and joining EuReCa. **Methods:** A qualitative approach was followed, including semi-structured expert interviews (n = 3), document analysis, and a written structured interview. All data was subjected to qualitative content analysis. **Results** reveal that Estonian ambulance units collect all necessary pre-hospital resuscitation data, mostly in a standardized form, based on the internationally recognised Utstein-style format. However, post-resuscitation data fields are not included in the Estonian resuscitation card, nor can ambulance staff access their patients' in-hospital post-resuscitation outcomes. While all Estonian ambulance units collect resuscitation data based on the same resuscitation card in the national e-ambulance system, data collection and analysis are conducted by each individual unit and not exchanged with others. However, pre-hospital resuscitation data are collected in a systematic and standardized way, thus reflecting preparedness for a nationwide data gathering. Data collection and analysis at national level would also require a dataset owner and a designated information system. **Conclusions:** The benefit of a national resuscitation registry is that it combines pre-hospital and post-resuscitation data. Assessing the whole resuscitation process would contribute to improved healthcare planning, emergency services provision, and treatment. An approval and funding from the Ministry of Social Affairs (MoSA) are also needed.

This thesis is written in English and is 51 pages long, including 6 chapters, 1 figure and 4 tables.

Annotatsioon

Taaselustamise registri loomine Eestis: kvalitatiivne uuring ekspertintervjuude ja dokumendianalüüsi põhjal

Taust: Äkiline südameseiskus on Euroopas kolmas peamine surmapõhjus. Haiglaväline äkksurm on ajatundlik meditsiiniline hädaolukord ja eduka taaselustamise tulemuse määrab patsiendi neuroloogiline seisund. Riiklik elustamisregister aitaks kaasa haiglaeelsete ja elustamisjärgsete tulemuste pidevale jälgimisele ja regulaarsele hindamisele, ning hõlbustaks andmete võrdlemist teiste riikidega, kuid Eestis seda veel pole. Samuti puudub üleriigiline elustamisandmete kogumine ja analüüs. **Uurimistöö eesmärk** on uurida praeguse elustamisandmete kogumise ja analüüsi, elustamisregistri loomise, ja EuReCa-ga liitumise eeliseid ja väljakutseid. **Meetodid:** viidi läbi kvalitatiivne uurimus, mis hõlmas poolstruktureeritud ekspertintervjuusid (n = 3), dokumendianalüüsi ja kirjalikku struktureeritud intervjuud. Kõikide andmete puhul rakendati kvalitatiivset sisuanalüüsi. **Tulemused** näitasid, et Eesti kiirabiüksused koguvad Utstein-põhise elektroonilise elustamiskaardiga kõiki vajalikke, ja põhiliselt standartseid, haiglaeelseid elustamisandmeid. Kiirabitöötajatel ei ole ligipääsu patsientide elustamisjärgsetele andmetele ja neid andmevälju pole ka elustamiskaardil. Kuigi kõik Eesti kiirabiüksused koguvad elustamisandmeid sama elustamiskaardi alusel riiklikus e-kiirabi süsteemis, siis andmeid kogutakse ja analüüsitakse üksusepõhiselt ja teistega neid ei jagata. Kuna haiglaeelseid elustamisandmeid kogutakse süstemaatiliselt ja standardiseeritud viisil, näitab see valmidust üleriigiliseks andmete kogumiseks. **Järeldused:** Riiklik elustamisregister võimaldaks kokku koguda haiglaeelsed ja elustamisjärgsed andmed. Tervikliku elustamisprotsessi hindamine aitaks parendada tervishoiuteenuste planeerimist, hädaabiteenuste osutamist ja ravi. Elustamisregistri loomiseks on vaja luba ja rahastust Sotsiaalministeeriumilt.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 51 leheküljel, 6 peatükki, 1 joonist ja 4 tabelit.

List of abbreviations and terms

AED	Automated external defibrillator
A&E	Accident & Emergency
ASYS	Asystole
bCPR	Bystander cardiopulmonary resuscitation
Brady	Bradycardia
CC	Chest compression
CNS	Central nervous system
CPC	Cerebral Performance Category
CPR	Cardiopulmonary resuscitation
DA-CPR	Dispatch-assisted cardiopulmonary resuscitation
DC	Discharge
Defib.	Defibrillation
DNAR	Do not attempt resuscitation
Educ	Educational institution
EMC	Emergency medical care
EMS	Emergency medical services
ERC	Estonian resuscitation card
ETAIS	Estonian Scientific Computing Infrastructure
EuReCa	European Registry of Cardiac Arrest
Fav	Favourable
HCP	Health care provider
HoHIS	Hospital Health Information System
ICD-11 MMS	International Classification of Diseases for Mortality and Morbidity Statistics
IHCA	In-hospital cardiac arrest
MoSA	Ministry of Social Affairs
mRS	Modified Rankin Scale
NorCar	Norwegian Cardiac Arrest Registry
OHCA	Out-of-hospital cardiac arrest
PEA	Pulseless electrical activity
Rec	Sports/recreation event
ROSC	Return of spontaneous circulation
SCA	Sudden cardiac arrest

SCD	Sudden cardiac death
SCRR	Swedish Cardiopulmonary Resuscitation Registry
SNC	Central nervous system
TCPR	Telephone CPR
ToC	Theory of Change
VF	Ventricular fibrillation
VT	Ventricular tachycardia

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1 Introduction

Sudden cardiac arrest (SCA) is the third leading cause of death in Europe [1]. SCA occurs in 0.4 % of the general population and around 6% of those with elevated risk factors [2]. SCA (or simply cardiac arrest) occurs when the heart abruptly and unexpectedly stops pumping blood to the brain and other vital organs [3]. Broadly, there are two categories of cardiac arrest: in-hospital (IHCA) and out-of-hospital (OHCA). The advantage of IHCA is that medical assistance and equipment such as defibrillators are usually quickly at hand which is not the case with out-of-hospital cardiac arrest. OHCA is a time-sensitive and challenging medical emergency and generally around nine out of 10 people who have it will die within minutes [3]. The survival rate for OHCA can be improved through better knowledge of cardiopulmonary resuscitation (CPR) techniques, early defibrillation, and shorter ambulance arrival times, among other things [4]. In addition to survival, successful resuscitation entails the patient regaining a favourable neurological state and the ability to have a normal life [4].

Numerous European countries, including Estonia, have adopted an Utstein-style OHCA resuscitation template, which has been internationally recognised as the standard for collecting and reporting OHCA data [1]. Reporting the same data points and using the same definitions enables the comparison and assessment of resuscitation outcomes within and between countries, enabling better understanding of epidemiology and improved treatment and public health [5]. Completing the Utstein template also permits emergency medical services (EMS) to assess and make their services more transparent. However, the quality and completeness of data are key for data comparison, quality benchmarking and health system planning [1].

The European Registry of Cardiac Arrest (EuReCa) was created in 2008 with the aim of collecting and analysing standardized OHCA data in Europe, providing quality benchmarks for OHCA measurement and helping to build and improve European resuscitation registries [6]. Between 2014 and 2022, EuReCa conducted three studies which analysed resuscitation data from 30 European countries, not including Estonia [6].

The results highlighted considerable variability between countries regarding incidence rates, patient characteristics, outcomes, and the significant health burden of OHCA in Europe [7].

Estonia started to document and analyse nationwide pre-hospital resuscitation attempts in 1999 [8]. Between 2008 and 2018, all Estonian ambulance units moved to the national e-ambulance system [9] and started to use the electronic resuscitation card (see Appendix 2). With the launch of the e-ambulance system, national resuscitation data collection on ambulance cards was discontinued. Sipria et al. (2016) have argued that Estonia needs a cardiac arrest (resuscitation) registry[1] to continuously monitor and regularly assess pre- and in-hospital resuscitation outcomes, compare data with the other countries and join EuReCa [4].

The aim of the study is to examine the benefits and challenges of current resuscitation data collection and analysis in Estonia, building a resuscitation registry and joining EuReCa.

The thesis consists of six chapters. Chapter one introduces the topic of the thesis. Chapter two gives an overview of sudden cardiac arrest and survival, resuscitation data collection and registries. The third chapter describes the methodology and methods and the fourth one the results. Chapter five includes the discussion of the study results and chapter six the summary of the thesis.

[1] In this study, the terms resuscitation registry and cardiac arrest registry are used interchangeably. Resuscitation data is collected by out-of-hospital (OHCA) and in-hospital (IHCA) cardiac arrest registries, depending on where cardiac arrest occurred.

2 Background

2.1 Sudden cardiac arrest, resuscitation, and survival

This sub-section will outline cardiac arrest of cardiac origin and the corresponding ICD codes for mortality and morbidity statistics, what is considered a positive resuscitation outcome and what are the core components in the chain of survival that a positive outcome depends on.

Sudden cardiac arrest is the leading cause of death in the world and about 25 % of cases occur without any prior cardiac history [10]. SCA is linked to issues in the heart's electrical system that make the heart quiver instead of pumping blood to the rest of the body (ventricular fibrillation) [11]. Heart-beats are controlled by the heart's electrical system but if there is a problem with the electrical activity in the lower chamber of the heart, the heart rhythm becomes abnormal [12]. The most common cause of SCA is arrythmia (heart beating too quickly, too slowly or irregularly) [11]. SCA is a life-threatening emergency that needs to be addressed immediately by calling ambulance services, performing CPR, or using a portable defibrillator, if one is at hand [13]. The defibrillator will measure the person's heart rhythms and indicate whether a shock is needed and if so, how many are needed [11]. Notably, about 69 % of OHCAs occur at home [10], so public awareness and early recognition of cardiac arrest, correct CPR techniques, quick EMS arrival and early defibrillation can all help reduce mortality and improve neurological recovery from OHCA [10].

The International Statistical Classification of Diseases for Mortality and Morbidity Statistics (ICD-11 MMS) lists cardiac arrest involving symptoms or signs as part of the circulatory system under the code MC82 [14]. It also includes the option to select out-of-hospital or in-hospital cardiac arrest [14]. The sub-types of cardiac arrest that fall under this category are: *MC82.0 Ventricular tachycardia and fibrillation cardiac arrest, MC82.1 Bradycardic cardiac arrest, MC82.2 Asystolic cardiac arrest, MC82.3 Cardiac arrest with pulseless electrical activity, MC82.4 Cardiopulmonary arrest* and *MC82.Z Cardiac arrest, unspecified* [14] . The latter option reflects that not all causes of cardiac

arrest can be identified, especially without enough background information, complete data, or sometimes even after a post-mortem examination [15]. The other cardiac arrest types, those of non-cardiac origin, are not classified under MC82. For example, cardiac arrests can also be linked to complications from anaesthesia, the nervous system, labour or delivery, traumas etc [15].

Whereas the initial goal of OHCA is the return of spontaneous circulation and the consequent survival, it is patient's favourable neurological outcome that defines the overall positive outcome of survival [4] and reflects good quality EMS. Therefore, the revised Utstein template (see section 2.2 for more details) also includes Patient Outcomes data fields for Cerebral Performance Category (CPC), modified Rankin Scale (mRS) or a paediatric equivalent [5]. CPC is calculated on a 5-point scale where 1 refers to good and 5 means dead. The mRS has 7 points ranging from 0 (no symptoms) to 6 (dead) [5]. These scales also comprise patient-reported outcomes and health-related quality of life. A favourable neurological outcome after cardiac arrest at discharge is considered as CPC $\leq$ 2 or mRS $\leq$ 3 [5]. For example, CPC 1 means that the patient has made full or near-full recovery and is able to lead a normal life and return to work [4]. CPC 2 means that patient's central nervous system was considered satisfactory, and they could still live independently and work with certain limitations [4].

A strong chain of survival is key to a successful OHCA outcome. The core elements in the chain of survival comprise early recognition of cardiac arrest, emergency call, bystander CPR (and automated external defibrillator (AED) if available), early ambulance arrival and defibrillation [16]. After the return of spontaneous circulation (ROSC) the links in the chain of survival include advanced life support including medication, airway and post-resuscitation care comprising transport to hospital and in-hospital care [17]. As a single weak link in the chain of survival can negatively influence the overall resuscitation outcome, collaboration between the community, emergency call centre, ambulance and hospital are paramount [17].

2.2 The Utstein template and reporting

There are two types of Utstein-style resuscitation data collection and reporting: one for IHCA and the other for OHCA. This thesis focuses on OHCA.

The first Utstein recommendations for OHCA were published in early 1990 with the aim of standardizing definitions and data points [1]. The Utstein resuscitation guidelines and the structured, uniform data collection template permit EMS, practitioners, and researchers to monitor, compare and improve resuscitation outcomes and ultimately enhance public health nationally and internationally [5]. The Utstein template from 2004 was revised in 2014 to include four levels of patient outcomes [5].

The Utstein template for OHCA focuses on cardiac arrest of cardiac origin [4]. The core Utstein factors include: dispatcher ID, dispatcher CPR, response times, resuscitation attempted, location and time of cardiac arrest, patient age and sex, witness status (bystander, EMS personnel), bystander CPR and AED, aetiology (cause of arrest), EMS process (first defibrillation time, targeted temperature control, drugs given), hospital process (reperfusion, targeted temperature control, organ donation), patient outcomes (any ROSC, survived event, survival to discharge or 30 days survival, favourable neurological outcome at discharge CPC $\leq$ 2 or MRS $\leq$ 3) [5].

Utstein-style reporting has revealed that additional factors contributing to a successful resuscitation outcome include public access to AEDs, dispatcher-assisted CPR and correct resuscitation techniques and understanding of whether resuscitation is required at all [5]. Also, a world-wide meta-analysis found that OHCA patients whose cardiac arrest was witnessed by EMS or a bystander who performed CPR had higher survival to discharge, 1-month and 1-year survival [18].

In addition to standardized and structured data collection, data quality and data completeness are paramount for data transparency, comparability, uniform analysis, and reporting. About 70 % of the European countries have OHCA registries but their completeness of data differs greatly [1]. While Utstein-style reporting encourages uniform data collection and comparison between EMSs, regions, and countries, there is still variability in the data collection process [5] which influences data transparency and reporting outcomes. For this reason, correct, and reliable data are needed to understand the type and cause of cardiac arrest and how to improve treatment outcomes [1] and identify and address weaker links in the OHCA chain of survival. Collecting and monitoring data will also help identify gaps and mistakes in the data, especially when comparing with standardized data from other countries, and thus improving the quality of reporting.

2.3 Sudden cardiac arrest registries

There are several sudden cardiac arrest registries that collect and provide pre-hospital and post resuscitation data nationally and at the European level. This chapters gives an overview of the European, Norwegian, and Swedish registries, their aims, outcomes, challenges, and benefits.

2.3.1 European Registry of Cardiac Arrest

The European Registry of Cardiac Arrest (EuReCa) contributes to the most comprehensive resuscitation data collection and outcome overview in Europe [1]. EuReCa focuses on providing high quality evidence of OHCA epidemiology by helping to build and support cardiac arrest registries and resuscitation studies throughout Europe [6]. Since its establishment in 2008, EuReCa has conducted three Europe-wide prospective cohort studies on the epidemiology of OHCA, EuReCa One (2014), EurReCa Two (2017) and EuReCa Three (2022), with each successive study building on previous research [6].

EuReCa One included data from 27 countries and was the first study to research the epidemiology of OHCA at the European level [7]. EuReCa Two comprised 28 countries and focused on the performance of bystander CPR in Europe [7]. Both studies highlighted the variability in OHCA incidence rate, patient characteristics, and outcomes in European countries [7]. For example, whereas CPR before EMS arrival increased by 8% between EuReCa One and Two, from 48% to 58% of cases, there was no corresponding increase in survival to hospital discharge and the studies revealed variations in defining bystander CPR [7]. In response, EuReCa Three focused on Europe-wide quality data collection for OHCA [19] with the additional aim of enhancing knowledge of longitudinal OHCA epidemiology [6]. The study included cardiac arrest registries from around 30 European countries on condition they could provide at least the core Utstein-style data set [6] (this source includes the full list of core questions). Data analysis for EuReCa Three is ongoing [6].

2.3.2 National cardiac arrest registries

Building national OHCA registries and collecting, analysing, and comparing resuscitation data are crucial for improving OHCA outcomes [19]. For this purpose, all registries must

adhere to Utstein-style data collection recommendations and use Utstein templates [19]. So far, only six European countries have established national resuscitation registries covering the whole country: Denmark, Ireland, Norway, Portugal, Sweden, and Switzerland [1], [20]. The other countries have either national registries with partial coverage, local registries, or no registries at all [1], [20]. Norway and Sweden stand out with their high-quality registries, continuous data collection and analysis [21], [22].

The Norwegian Cardiac Arrest Registry (NorCar) was created in 2013. Norway is the only country in the world to have introduced cardiac arrest as a reportable condition. Between 2013 and 2018, the number of registered resuscitation cases rose from 1101 to 3400 [21], strongly suggesting that mandatory cardiac arrest reporting contributed to obtaining a more truthful and comprehensive overview of the number of incidents and resuscitation attempts. Furthermore, the population-based registry has permitted a systematic assessment of the chain of survival such as early identification of cardiac arrest, bystander CPR, timely defibrillation, handling of emergency calls, dispatch assisted CPR (DA-CPR), ambulance arrival time and care, transport, and hospital treatment [21]. It revealed that the reported bystander-assisted CPR in Norway is 80%, which is the highest rate ever published [21]. In Norway, survival to 30 days after successful resuscitation has stayed steady at 7.4 per 100 000 inhabitants [21] and these statistics help to plan healthcare.

The Swedish Cardiopulmonary Resuscitation Registry (SCRR) was established in 1990. In addition to OHCA data it also includes in-hospital cardiac arrest (IHCA) data [22], which is rare as most registries around the world record OHCA cases only. Combining OHCA and IHCA enables an even more comprehensive overview of epidemiology of cardiac arrest and resuscitation attempts. SCRR is one of the oldest resuscitation registries in Europe. A Swedish nationwide study (2022) researched trends in survival after cardiac arrest over a 30-year period (1990-2020) [22]. The results revealed that while survival in OHCA increased 2.2 times, the neurological outcome did not improve [22].

2.4 Resuscitation data collection in Estonia

In 1999, Estonia started to collect and analyse nationwide OHCA resuscitation data by using ambulance cards corresponding to Utstein-style reporting [4]. A study from 2008 on bystander-witnessed out-of- hospital cardiac arrests of cardiac origin assessed

resuscitation attempts and patient survival after hospital discharge [4]. The research covered the resuscitation period from 1999 to 2002. Patients' quality of life was also assessed, and long-term survival data were retrieved from the Estonian Population registry in 2004 [4]. The results revealed that out of 854 bystander resuscitation attempts, 91 people (10.7%) survived to hospital discharge and most of them survived one and even more than three years after the resuscitation. However, their quality of life was reported to be worse than that of the general population [4]. In 2016, further research was conducted on nationwide bystander resuscitation outcomes for the period 1999-2013 [8]. Out of 8586 resuscitation attempts, 3335 (38.8%) were most likely linked to sudden cardiac arrest. Resuscitation ended with ROSC in 10.2% (341/3335) of cases. The results showed that the survival rate for sudden cardiac arrest was the highest during the last five years of the research: 13.8 % for the period 2009-2013, 7.9 % for 2004-2008 and 9.4% for 1999-2003 [8]. The survival rate was improved thanks to shorter ambulance arrival times, early defibrillation, and better knowledge of CPR techniques [8].

The Ambulance Information System project was launched in 1995 between the Union of Estonian Medical Emergency and the Ministry of Social Affairs (MoSA), with the aim of bringing all Estonian ambulance units online [23]. In 2006 development of the nationwide e-ambulance system was launched [24] and between 2008 and 2018 all Estonian ambulance units gradually moved from paper records to the new software [9]. As a result, the nationwide resuscitation data collection and analysis based on ambulance cards ended but the new e-ambulance system did not permit it either. Currently, Estonia has 10 ambulance units covering the whole country [25].

2.5 Theoretical approaches

Theory of Change and Systems thinking are widely used in complex public health interventions with the goal of strengthening and improving health systems, treatments, and health outcomes [26], [27].

Theory of Change (ToC) was coined by Weiss (1995) as a comprehensive and systematic approach to thinking and documenting on how a program or intervention is expected to work, who will benefit and how, and what the preconditions are for the expected change [28]. A good Theory of Change includes defining the situation and the expected outcomes, identifying the program or intervention boundaries, investigating potential

solutions, and communicating assumptions [29]. The present study builds on Theory of Change with the objective of establishing how resuscitation data are being collected and analysed in the e-ambulance system, and assessing whether Estonia needs to reinstate nationwide resuscitation data collection, build a resuscitation registry and join EuReCa.

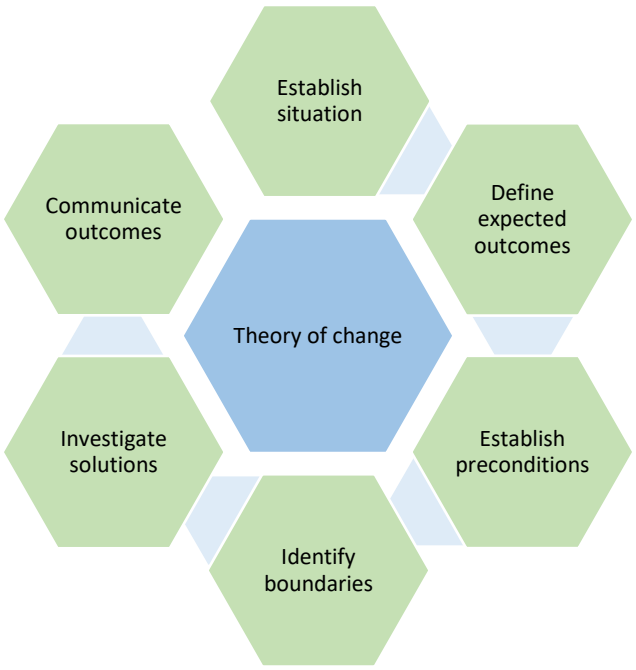

Figure 1. Theory of Change

The ToC diagram in Figure 1 helps to visualize the key elements of ToC, formulate and structure the research questions without omitting anything important, and thus obtain a comprehensive overview of the current resuscitation data collection, including opportunities, challenges, and the readiness to build a resuscitation registry.

Systems thinking is an approach to problem-solving and decision-making that considers the interconnections and interdependencies among various components or parts of a system [27]. It involves analysing how different elements of a system, such as people, processes, structures, and technology, interact and influence each other to create a larger, more complex whole [27]. Systems thinking is goal oriented [30], and so is the chain of survival. In this study, systems thinking was considered from the perspective of resuscitation data collection and the interconnectedness of the data flow, data overview and data analysis in the chain of survival, with the goal of identifying whether any improvement is needed. Initially, this study considered linking the results to systems thinking and the chain of survival. However, as this study focuses on resuscitation data

collection and analysis, without extending it to the other elements such as people, systems, structures, and technology, it was decided not to apply this approach.

2.6 Problem statement and study aim

Problem statement: whereas a resuscitation registry would enable continuous monitoring and regular assessment of pre- and in-hospital resuscitation outcomes and comparison with data from other countries [4], Estonia is currently not collecting and analysing nationwide resuscitation data.

The aim of the study is to examine the benefits and challenges of current resuscitation data collection and analysis in Estonia, building a resuscitation registry and joining EuReCa.

Research questions:

1. How have resuscitation data collection and analysis been organised in Estonia?
2. What are the main advantages and challenges for the e-ambulance system in systematically collecting and analysing resuscitation data?
3. What are the benefits and prerequisites for reinstating nationwide data collection and analysis?
4. What are the main benefits and challenges for establishing a resuscitation registry in Estonia?
5. What are the main benefits and challenges for Estonia in joining EuReCa?

3 Methodology

This section of the thesis introduces the research methodology, and it gives a detailed overview of the study design, participants and materials, data collection, data analysis, ethical considerations, and reliability of the study.

3.1 Overview of study design

This is a qualitative study based on semi-structured expert interviews, a structured interview and document analysis. The main features of qualitative research are its exploratory nature and text-based unstructured data [31]. A positive feature of qualitative research is that it is text-based and enables acquisition of in-depth insight into a specific topic or experience [32]. On the other hand, qualitative research is considered subjective as it is analysed by interpreting, categorizing, and summarizing the text [32]. However, a qualitative approach enables exploration of rich data on a topic and their meanings, as opposed to quantitative analysis where numbers can show trends but not the meanings [31], [33].

Semi-structured interviews fall between structured and unstructured interviews [34]. In structured interviews, all interview questions to the participants are the same and are asked in the same order [31]. Unstructured interviews are conducted in a free format and interview questions are not strictly pre-defined [34]. For semi-structured interviews, an interview plan is prepared in advance including the interview questions and supportive questions with the goal of finding answers to the research questions [34]. The questions are asked in a flexible order depending on each interviewee's answers, and supporting questions or new complementary questions are asked if necessary [31].

In expert interviews, the emphasis is on the knowledge and expertise, not on the person [35]. Expert interviews are considered an effective way to quickly obtain good quality results and deep insight into a topic [36]. In this study, the purpose of expert interviews was to collect rich text-based data via semi-structured interviews and obtain answers to all five research questions: RQ1, RQ2, RQ3, RQ4 and RQ5.

For a qualitative structured interview, the interview questions are carefully planned and pre-determined in advance [31]. The open-ended questions are designed to enable the

interviewee to provide elaborated and detailed answers [37]. See Appendix 5 for the structured interview plan. The individual interview was conducted in writing with one employee from the Health System Development department of the Ministry of Social Affairs of Estonia and the answers were obtained by email. This interview is similar to an expert interview in that the focus is on the information, not on the person. The response from MoSA contributes to answering RQ4 by providing the State's position on the creation of and the need for a resuscitation registry.

Document analysis is qualitative research involving a systematic procedure for evaluating or reviewing digital or printed documents [38]. In this study, document analysis compared the data fields in three Utstein-based resuscitation documents, with a focus on identifying which data fields were overlapping, different or missing from the Estonian resuscitation card (ERC) (see Appendix 2) compared with the Utstein template (2014) [5] and the EuReCa study inclusion questions [6]. Document analysis contributes to answering RQ1, RQ2, RQ4 and RQ5.

3.2 Participants and materials

The participants for expert interviews were selected through targeted sampling (improbability category). Targeted sampling means that the interviewees are chosen by the researcher based on the research aim and the convenience of obtaining answers to the research questions [39]. Expert interviews were carried out with three ambulance experts and the following inclusion criteria:

- Extensive knowledge and experience in the field of Estonian EMS (operational, managerial and research).
- Current or recent board member of the Union of Estonian Medical Emergency.
- Head of an Estonian ambulance service or critical emergency medicine (anaesthesiology and intensive care).

Other important aspects which were taken into consideration when selecting ambulance experts for the interviews were their continuous effort to raise public awareness and improve emergency medical services including resuscitation. The selected experts have participated in debates regarding EMS and resuscitation at national level, and given interviews or contributed to articles on national news channels and newspapers and on

the websites of the Ministry of Social Affairs, EHIF, hospitals and ambulance units. They have also actively participated in annual ambulance conferences.

The website of the Union of Estonian Medical Emergency listed all its board members [40] and 10 ambulance units in Estonia [25]. Further details for ambulance experts (position, contact details) were searched on specific ambulance and hospital webpages. For a more comprehensive overview, and to establish whether there were any important differences in the service provision and data collection between Estonian ambulance units, experts were contacted from units that differed in terms of size (number of brigades) and service area (city, county, continent, islands). Before the interviews, the experts were sent an informed consent form explaining the aim of the study and the ethical considerations (see Appendix 3 and section 3.5 of the present study).

For the structured interview, the head of the Health System Development department of the Ministry of Social Affairs was contacted by email. This department was selected to participate in the present study as they are involved in the management of this area. Thus, targeted sampling (improbability category) was applied, meaning that the department was chosen by the researcher based on the research aim and the convenience of obtaining answers to the research questions. The email explained the purpose of the interview, set out the interview questions, and enquired whether theirs would be the appropriate department to answer these questions. See Appendix 5 for the structured interview plan including the interview questions. The head of the department forwarded the query to the most appropriate employee of the department to answer the interview questions. No informed consent was sent but the Health System Development department confirmed by email that they would provide the answers in writing and would send the reply to the author of the study by email.

Document analysis compared the data fields between the Estonian resuscitation card (Appendix 2), the Utstein template [5] and the EuReCa inclusion questions for the Europe-wide studies [6]. These resuscitation documents were selected to find out whether the ERC included all the compulsory data fields listed in the two internationally recognised forms which are the basis for national and Europe-wide data comparison and studies. The Estonian resuscitation card and the guidelines on how to fill it in, were received from an Estonian ambulance staff member by email. These guidelines are also available online [41]. To avoid confusion, it is important to note that the resuscitation

card listed on Riigiteataja [42] is an old version, and not the one which is used on the ambulance mobile workstation (see Appendix 2 for current version). The present study ignored the old version. The Utstein template [5] and the EuReCa study inclusion questions [6], with the corresponding guidelines on how to fill each of them in, were included in two separate research articles.

3.3 Data collection

For data collection, three methods were applied: expert interviews, a structured interview and document analysis.

3.3.1 Expert interviews

The individual semi-structured expert interviews with Estonian ambulance experts were carried out by the author of this thesis. The interviews were conducted via Microsoft Teams in February and March 2023. They comprised four themes and 12 questions with prompts (see the expert interview plan in Appendix 4).

- Theme 1: Resuscitation data collection and analysis with Q1, Q2, Q3, and Q4 from theme 2 aims to answer RQ1 and RQ2.
- Theme 2: Nationwide resuscitation data collection and analysis in Estonia with Q4, Q5 and Q6 aims to answer RQ3.
- Theme 3: Building a resuscitation registry in Estonia with Q7, Q8 and Q9 aims to answer RQ4.
- Theme 4: Joining the European Registry of Cardiac Arrest (EuReCa) with Q10 and Q11 aims to answer RQ5.
- Q12 was a general question in case experts had anything important to add on the topic.

In total, three expert interviews were conducted with the duration varying between 30 and 41 minutes. Although the sample size was small, data saturation was reached. Data saturation means that new data did not provide additional information to answer the research questions [43]. The interviews were recorded in Teams. After the interviews, the recordings were automatically saved on the Taltech's OneDrive, protected by a safe password and only accessible by the author of the study. Additionally, the interviews were recorded on the Voice-Memos app on the author's mobile phone, also protected by a safe password and only accessible by the author. After the interview ended, the recording on

Voice-Memo was emailed to the Estonian Speech Recognition and Transcribing Editing Service [44] for transcription (see ethical considerations in section 3.5). The transcribed text was sent to the author by the software within an hour and was also saved on Taltech's OneDrive. The transcribed text was corrected by listening to the Teams recording. The interviews were all in Estonian and only the relevant passages for the present thesis were translated into English.

3.3.2 Structured interview

The individual structured interview was conducted with one employee of the Health System Development department of the Ministry of Social Affairs by the author of the study. It was conducted after the expert interviews. The interview included five questions with the aim of answering RQ4 from the State's point of view (see Appendix 5 for the structured interview plan). The interview was answered in writing and received by email. The full written answer is only accessible by the author of the study. The relevant excerpts were translated from Estonian into English and used in this study.

3.3.3 Document analysis

Qualitative document analysis compared and analysed the three selected resuscitation documents – the Estonian resuscitation card (Appendix 2), the Utstein template (2014) [5] and the EuReCa core questions for resuscitation studies [6]. Document analysis is conducted in a systematic way with the aim of answering the research questions [45]. As the resuscitation documents do not reflect all the data fields and dropdown menus, the corresponding guidelines on how to fill in each document were consulted in parallel [5], [6], [41]. Document analysis built on the expert interview themes (see section 3.3.1 and Appendix 4) to complement and corroborate expert opinions and contribute to answering the research questions. Document analysis was therefore conducted after the data from expert interviews was collected and consulted. The selected passages were translated from Estonian into English and used in the present study.

3.4 Data analysis

Data analyses for the expert interviews, structured interview and document analysis were conducted manually.

Qualitative content analysis enables a focus on the main meanings of the text, to see the integrity of the content [46]. Qualitative content analysis is not rigidly focused on the coding system, allowing the researcher to review and add codes and categories during the analysis process if needed [46]. In this study, the aim is to find and match meaningful codes and categories which permit the researcher to summarize the main points and ideas from the perspective of the research questions. Inductive coding means that the codes are not determined in advance but are generated from the data with the aim of answering the research questions [47]. Deductive coding means that codes are deducted from existing literature [47].

3.4.1 Expert interviews

To analyse the data, a code tree with themes, categories and codes was created (see Table 1 below). The four themes were taken from the interview plan (Appendix 4):

- Theme 1: Resuscitation data collection and analysis
- Theme 2: Nationwide resuscitation data collection and analysis in Estonia
- Theme 3: Building a resuscitation registry in Estonia
- Theme 4: Joining the European Registry of Cardiac Arrest (EuReCa)

To create categories and codes, the expert interview transcripts were read repeatedly. Similar themes and keywords in the text were colour-coded and grouped into a logical system. In total, seven categories based on codes/keywords, were identified. Qualitative content analysis combined with inductive and deductive coding was applied. While most codes were deductive, two inductive codes were also detected.

Table 1. Coding and categorization schema

Theme	Category	Code/keyword	Coding	RQ
Theme 1: Resuscitation data collection and analysis	1. Data collection on ambulance cards	Data on paper	deductive	1
		Nationwide data collection	deductive	1
		Pre-hospital data	deductive	1
	2. Data collection and analysis in e-ambulance	Nationwide system	deductive	2
		Transition issues	deductive	1&2
		Resuscitation card	deductive	1&2
		Standardized data	deductive	2
		Data analysis module	deductive	2
		Pros and cons of the system	deductive	2
		Automatic data insertion	deductive	2
		No nationwide data collection	deductive	2
		Decommissioning	inductive	2
	3. Data quality	Data accuracy vs errors	deductive	2
		Data completion	deductive	2
		Personalised vs non-personal data	deductive	2
		Data recall	deductive	2
		Blank or incompl. data fields	deductive	2
		Data verif. & correction	deductive	2
	4. Data access	Post-resuscitation data	deductive	1&2
		Data Protection Act	deductive	1&2
		Data request from hospitals	deductive	1&2
Theme 2: Nationwide resuscitation data collection and analysis in Estonia	5. Reinstatement of nationwide resuscitation data	Collection & analysis silos	deductive	3
		Data collection owner	deductive	3
		Appropriate system	deductive	3
		Need for reinstatement	deductive	3
		Quality indicators	inductive	3
Theme 3: Building a resuscitation registry in Estonia	6. Resuscitation registry	Pre-hospital registry	deductive	4
		Combined data	deductive	4
		Nationwide data analysis	deductive	4
		International participation	deductive	4
		Request to Ministry	deductive	4
		Preconditions	deductive	4
		Preparedness	deductive	4
Theme 4: Joining the European Registry of Cardiac Arrest	7. EuReCa	Utstein template	deductive	5
		Too small dataset	deductive	5
		International comparison	deductive	5
		Service & treatment improvement	deductive	5

Table 1 reflects the groupings in the code tree. It shows each theme including the corresponding categories, keywords, codes (inductive or deductive) and the research questions that will be answered. While Theme 1. included four categories, the other themes had only one category per each.

3.4.2 Structured interview

The structured written interview with the representative of the Health System Development department of the Ministry of Social Affairs was read repeatedly and passages that helped to answer RQ4 were highlighted and selected for this study (marked with S-1). The structured interview contributed to the expert interview Theme 3. *Building a resuscitation registry in Estonia*. It was conducted after the expert interviews were completed and their relevant passages were already selected (marked with E-1, E-2, and E-3). The purpose of involving MoSA in the study was to complement and balance expert opinions with the State's view on the need to establish a resuscitation registry. Therefore, no separate coding was carried out.

3.4.3 Document analysis

For the present study, the Estonian resuscitation card (see Appendix 2), the Utstein template from 2014 [5] and the EuReCa core questions for acceptance in the European-wide resuscitation studies [6] - all based on Utstein-style reporting and guidelines - were compared and analysed. The goal of the document analysis was to identify which data fields between these three sources (cards/templates/questions) overlapped, differed, or were missing from the ERC. As Estonia does not currently have a nationwide data collection and analysis in place and is not participating in the EuReCa studies, the focus of the document comparison was to identify which fields compared to the two international forms were missing from the ERC. To compare the data fields, the three resuscitation forms were printed on paper and the guidelines accompanying each resuscitation form were consulted in parallel online [5], [6], [41]. Not all data fields are visible on the resuscitation forms, but they are included in the dropdown menus or in the corresponding guidelines and consulting the guidelines also enabled the researcher to distinguish between compulsory and optional data fields and standardized and free text. The similarities and differences between the data fields were highlighted in three separate Excel sheets (see Tables 2, 3 and 4 in section 4.1). For additional details, see the description before and under each table.

3.5 Ethical considerations and the reliability of the study

Ethics. Experts were contacted by email and asked whether they would like to participate in the expert interviews. They confirmed their participation by email. Before the interview, each expert was sent an informed consent form (see Appendix 3) by email with the option of signing it digitally. The informed consent form explained the purpose and approximate length of the interview and included the following ethical aspects: free will to participate, confidentiality, right to withdraw at any time, how the interview data would be stored and when it would be deleted. Conducting expert interviews did not require approval from the ethics committee. The interview recordings and transcriptions were saved on the author's Taltech OneDrive, protected by a safe password and only accessible by the author of the study. All names (expert names, locations) that could have enabled to identify the experts, and any names mentioned in the interviews, were pseudonymized: E-1, E-2 and E-3 for experts, S-1 for the representative of MoSA and Doctor X for a name mentioned in the responses. The audio files of the interviews were transcribed with the help of the Estonian Speech Recognition and Transcribing Editing Service [48], a fully automated service run on the server belonging to the Estonian Scientific Computing Infrastructure (ETAIS) [44]. A potential ethical concern could be that the audio files were emailed to an external server and the data could be linked to the specific experts. Hence, the informed consent form notified all the experts that the Taltech transcribing service (see Appendix 3) would be used. Moreover, the audio-files included experts' professional opinions without any sensitive or personal details about them.

No informed consent form was sent to the interviewee who participated in the structured interview, but all ethical considerations were followed.

Reliability. As opposed to quantitative research which deals with numbers, qualitative research is considered subjective as it relies on personal assessments, attitudes, and opinions [31]. However, this qualitative research did not aim to collect any personal opinions and attitudes per se. Instead, the expert interviews focused on gathering ambulance experts' in-depth knowledge and experience of EMS, with a focus on resuscitation data collection and analysis. The reliability of their answers was strengthened when the experts gave similar or "exactly the same" answers to the same questions or their answers were corroborated with findings from the document analysis. To balance expert opinions, a structured interview on the State's position on the

resuscitation registry was also conducted. Additionally, document analysis allowed verification of information regarding resuscitation-related data fields.

The author used reflexivity n the analytical approach. Reflexivity means reflecting on one's own experience and how this may have influenced the research analysis and findings [49]. This technique helps to reduce bias and the influence of personal expectations and opinions on study findings, and increase reliability.

4 Results

This chapter gives an overview of the results from document analysis of Utstein-style resuscitation forms, expert interviews with ambulance experts, and a structured interview with a representative of MoSA. It includes sections on document analysis, resuscitation data collection and analysis in general and at national level, building a resuscitation registry and joining EuReCa.

4.1 Document analysis

This section describes the results of the data comparison and analysis between three resuscitation cards. Although all three documents are based on Utstein-style, document analysis revealed that whereas the Estonian resuscitation card is per patient, the Utstein template and the EuReCa questions include data fields for total numbers per country or region. The ERC also includes more data fields than the two other forms. The results of the document analysis are reflected in Tables 2-4 below.

Table 2 reflects all the data fields listed in the Utstein template (2014). These data fields were compared to those on the ERC and the EuReCa questions.

Table 2. Document analysis based on data fields from the Utstein template (2014).

Data fields from Utstein	**Utstein**	**ERC**	**EuReCa**
Total Population Served by EMS	yes	yes	yes
Cardiac Arrests Attended	yes	yes	yes
Resuscitation Attempted (VF, VT, PEA, ASYS, Brady, AED Non-shockable, AED shockable, Not Recorded, Unknown)	yes	yes	yes
Resuscitation not attempted (All Cases, DNAR, Obviously dead, Signs of Life)	yes	yes	yes
EMS description (Text)	yes	yes	no
Dispatcher ID CA (Yes, No, Unknown)	yes	yes	yes
Dispatcher CPR (Yes, No, Unknown)	yes	yes	yes
Response times (MM:SS 90 % Fractile)	yes	yes	yes
Location (Home, Work, Rec, Public, Educ, Nursing, Other, Unknown)	yes	yes	yes
Patient (Age, Sex)	yes	yes	yes
Witnessed (Bystander, EMS, Unwitnessed, Unknown)	yes	yes	yes
Bystander CPR (No bCPR, bCPR, CC Only, CC/Vent, Unknown)	yes	yes	yes
Bystander AED (Analyse, Shock, Unknown)	yes	yes	yes
Etiology (Medical, Trauma, Overdose, Drowning, Electrocution, Asphyxial, Not recorded)	yes	yes	yes
EMS Process: First Defib Time (mm:ss)	yes	yes	yes
EMS Process: Targeted Temp Control (Indicated - Not Done, Not Indicated, Unknown)	yes	yes	no
EMS Process: Drugs Given	yes	yes	no
Hospital Process: Reperfusion (Attempted)	yes	hospital	no
Hospital Process: Targeted Temp Control (Indicated/Done, Indicated/Not Done, Not Indicated, Unknown)	yes	hospital	no
Hospital Process: Organ Donation	yes	HoIS	no
Patient outcomes:			
EMS Witnessed Included: All EMS Treated Arrests:			
Any ROSC (Yes/Unknown)	yes	yes	yes
Survived Event (Yes/Unknown)	yes	yes	yes
Survival$_{DC}$ or Survival 30d (Yes/Unknown)	yes	hospital	yes
Fav neurological$_{DC}$ CPC ≤2 or MRS≤3 (Yes/Unknown)	yes	hospital	no
EMS Witnessed Excluded: Shockable bystander witnessed*, Shockable bystander CPR, Non-shockable witnessed, User Defined Subgroup:			
Any ROSC (Yes/Unknown)	yes	yes	yes
Survived Event (Yes/Unknown)	yes	yes	yes
Survival$_{DC}$ or Survival 30d (Yes/Unknown)	yes	hospital	yes
Fav neurological$_{DC}$ CPC ≤2 or MRS≤3 (Yes/Unknown)	yes	hospital	no

Document analysis revealed that apart from the missing post-resuscitation data fields, which need to be filled in by hospitals (marked with light grey), the ERC includes all compulsory data fields listed in the Utstein template and the EuReCa questions (see Tables 2 and 3). Although EuReCa includes post-resuscitation data fields, those for *favourable neurological* outcome are missing.

Table 3 below includes all the additional data fields from the EuReCa inclusion questions. These were compared to the Utstein and ERC data fields.

Table 3. Document analysis based on additional data fields from the EuReCa questions.

Additional data fields from EuReCa	**Utstein**	**ERC**	**EuReCa**
Country of cardiac arrest	yes	yes	yes
Region of cardiac arrest	yes	yes	yes
Who started CPR	optional	yes	yes (optional)
Time CPR by EMS	optional	yes	yes (optional)
Patient ID	yes	yes	yes
Time of cardiac arrest (Year, Month, Day, Time)	yes	yes	yes
Time of call received at dispatch centre	For response time	yes	yes
Time on scene		yes	yes
Time started TCPR	optional	yes	yes (optional)
Bystander (Age, Gender)	optional	name, phone	yes (optional)
Time CPR started by bystander	optional	yes	yes (optional)
Person sent to help CPR	optional	yes	yes (optional)
If person sent to help, who?	optional	yes	yes (optional)
Time CPR started by person sent to help	optional	yes	yes (optional)
First recorded rhythm	yes	yes	yes
First shock from AED or EMS	yes	yes	yes
Time of first ROSC	yes	yes	yes
Time of CPR ended	optional	yes	yes (optional)
Died on scene	yes	yes	yes
Time left scene	optional	yes	yes (optional)
Time hospital arrival	optional	yes	yes (optional)
Status of arrival at hospital	yes	yes	yes
Month of hospital discharge (Month)	yes	hospital	yes
Date of hospital discharge (Day)	yes	hospital	yes

As Table 3 shows, about half of the residual questions listed in EuReCa, but not visible in the Utstein template are marked as optional. Also, the additional post-resuscitation data fields to be filled in by hospitals (marked with light grey) are missing from the ERC. One

notable difference is that the Utstein template and EuReCa include the *Bystander Age and Gender data* field, but the ERC collects *Bystander name and phone number* instead.

Table 4 below includes all the residual data fields listed in the ERC which are not available or visible in the Utstein template or EuReCa.

Table 4.: Document analysis based on additional data fields from the ERC.

Additional data fields from the ERC	**Utstein**	**ERC**	**EuReCa**
Ambulance medical brigade	no	yes	no
Author of the card	no	yes	no
Case type	no	yes	no
Priority	no	yes	no
Caller	no	yes	no
Notified order	no	yes	no
EMS Departure (to the scene)	no	yes	no
EMS Free	no	yes	no
Anamnesis and summary of brigade's activities	no	yes	no
Diagnosis	no	yes	no
State of CNS before clinical death	yes	yes	no
Evaluation of the implementation of pre-ambulance ABC techniques	no	yes	no
Condition before qualified resuscitation techniques	no	yes	no
Skin colour	no	yes	no
Pupil size	no	yes	no
Consciousness	no	yes	no
Light reflex	no	yes	no
Self-breathing	no	yes	no
Respiratory reflex	no	yes	no
Palpable pulse	no	yes	no
Respiratory measures	no	yes	no
Primary diagnosed form of circulatory arrest	no	yes	no
Phasing (defib.)	no	yes	no
Energy (defib.)	no	yes	no
Number of times until first defibrillation	no	yes	no
Electrocardiostimulation	no	yes	no
Frequency (Electrocardiostimulation)	no	yes	no
Amperage (Electrocardiostimulation)	no	yes	no
Mode (Electrocardiostimulation)	no	yes	no
Duration of clinical death	no; can be calculated	yes	no; can be calculated
ROSC trigger	yes	yes	no
Result of the visit	no	yes	no

Document analysis revealed that one of those data fields *State of CNS before clinical death* is available in the Utstein template but not in EuReCa. Additionally, both international documents include data fields based on which *Duration of clinical death* can be calculated. One reason why the ERC has more data fields than the other two documents may be that the ERC is per patient whereas the other two collect total numbers per region or country.

An important difference identified by document analysis is that the Utstein template includes all, EuReCa includes most, and the ERC excludes all post-resuscitation data fields.

4.2 Resuscitation data collection and analysis

This section gives an overview of resuscitation data collection and analysis before and in the e-ambulance system, data quality, and data access.

4.2.1 Data collection and analysis based on ambulance cards

Expert interviews revealed that before the implementation of the e-ambulance system, *"all resuscitation cards were filled in on a two-sided paper of which one half-copy was sent to Tartu to doctor X who gathered all the resuscitation cards. /.../ did the statistics and kept the database over the years." (E-1)*

The above quote demonstrates that it was possible for a single dedicated person to gather and analyse nationwide resuscitation data.

The resuscitation data that was collected before implementation of the e-ambulance system included *"the whole resuscitation process: pre-resuscitation state, what happened, when it was detected, who detected it, who started the CPR or whether it was attempted at all, what was done for the resuscitation and whether the resuscitation attempt was adequate or not. /.../ first form of cardiac arrest, defibrillation, ensuring the respiratory system, the type of heart massage, time and quantity of medication intake and the results, a brief description of the resuscitation process, hospitalization, and condition upon hospital arrival." (E-1).* Document analysis revealed that the previously collected pre-hospital data points are still present in the current ERC (see Tables 2-4 in section 4.1).

This sub-section has shown that the paper-based nationwide data collection and statistics were well organized, and that all necessary pre-resuscitation data was collected.

4.2.2 Data collection and analysis in the e-ambulance system

Since 2008, when Estonian ambulance units started to adopt the national e-ambulance system, the transition from the paper-based resuscitation card to the digital one was complex because "*at the very beginning, the resuscitation part and the ambulance card continually needed to be filled in, but it wasn't possible to extract the resuscitation part separately /.../." (E-2)* Issues with the digital resuscitation card led to the discontinuation of the nationwide data collection as *"he [doctor X] wasn't granted access to all the resuscitation cards, and this is why he stopped gathering the data." (E-1)* There was lack of cross-functional co-operation between IT developers and the authorities funding the development of the e-ambulance system:

> *"The current e-ambulance in Estonia has been an exceptionally long and convoluted process and has been very unsuccessful in terms of its solution. /.../ the funding came from different places and three different layers were created /.../. Thus, a very clumsy portal was created /.../." (E-3)*

The above quote reflects the complexity of the system and explains why certain issues with the e-ambulance system have yet to be solved.

In the e-ambulance system, the resuscitation card is part of the ambulance card (see Appendix 2) and during the interviews, the experts sometimes used the terms resuscitation card and ambulance card interchangeably. Additionally, document analysis revealed that the emergency services only need to fill in the resuscitation part when a patient requires resuscitation. In case of resuscitation, certain data fields from the ambulance card (see Appendix 2) are automatically filled in by the emergency response centre. An expert also noted that *"the data which is already available in the ambulance card does not get duplicated in the resuscitation part." (E-3).*

Regarding the data type in the resuscitation card, the experts agreed that *"most are multiple-choice, meaning standardized or numerical fields" (E-2)* and that *"it is done intentionally so that it would be analysable." (E-2)* Document analysis also confirmed that the ERC includes mostly standardized data and dropdown menus, facilitating data analysis and secondary data usage.

Comparing the e-ambulance system to the previous paper-based data collection process, one expert noted:

> *"I cannot say that anything is significantly better. Perhaps the fact that the new system calculates the times itself. At the same time, it is easy to get the times wrong because /.../ the system automatically fills in the start time when you begin inserting the data. /.../. Therefore, if you don't fill in the resuscitation card extremely carefully then mistakes occur very easily." (E-1)*

The comment illustrates how the e-ambulance system facilitates and complicates data entry. Initially, the issues with start times had a big impact on the resuscitation statistics, and to some extent this problem persists:

> *"This is also one of the reasons why all the statistics went out of hand. People were not used to the e-ambulance system and many mistakes were made. Even now, mistakes are made because when you want to change anything later /.../ then the system records it, let's say with a delay of two hours or two days." (E-1)*

As the above quote shows, initially many mistakes occurred due to the peculiarities of the software and the issues with start times have still not been solved. Getting used to the new e-ambulance system was also challenging.

The advantage of the e-ambulance system is that it includes the data analysis module for statistics. Although this helps to generate reports, the experts also highlighted that the data analysis module *"is very difficult to use"* (E-1) as *"a lot of manual adjustments are needed /.../." (E-1)* meaning that preparing data for reports can be slow and time-consuming. One expert also pointed out that a further drawback of the analysis module is that *"mistakes are currently not identifiable by artificial intelligence /.../ and when there are unrealistic times or the CPR box has been left unticked, the system does not notify that the data field is incorrect or empty."* (E-3). Without verification of the data, unrealistic data or mandatory empty data fields may remain unnoticed.

One ambulance expert also noted that due to concerns with data quality and the expiry of defibrillators' digital data, units print off defibrillators' protocols. Consequently, for their annual resuscitation report, they duplicate activities:

> *"It is carried out like a study, where paper-based resuscitation cards and digital data in the e-ambulance system are being compared. /.../ As the defibrillator's*

memory disappears after a while, we also keep the data in paper-form. But often, resuscitation data also needs to get analysed and compared later." (E-3)

The above quote illustrates that the current resuscitation data collection and analysis process is not fully digital; a parallel paper-based solution is required to strengthen data quality, store documents and generate reports.

The experts highlighted that in 2025, the e-ambulance system will be replaced by a new commercial software already in use in Sweden which will be adapted to the Estonian context:

"We hope that it will be much better than the current one as with this one there are lots of problems. Especially in terms of functioning, it is no longer developed further /…/." (E-1)

This quote reflects that the e-ambulance system is no longer viable and instead of fixing the recurring issues, a new and hopefully a more user-friendly solution will replace it.

As this sub-section has shown, while adoption of the e-ambulance system triggered important issues in the resuscitation data collection and analysis process, it also automated certain data entry and increased data standardization.

4.2.3 Data quality

Regarding the quality of the data, one expert stated that *"it is constantly improving, as it depends how consistently and often the data entry of the cards is being verified." (E-1)* The expert also added that *"in terms of content, the quality of the data is very good"* and *"the difference is that the times can be a bit incorrect." (E-1)* Another expert agreed that *"as concerns the resuscitation itself /.../ I presume there are relatively accurate data /.../"* but found that the "*quality of the data is poor*" (E-2) especially regarding reaction times:

"What is very important in terms of resuscitation is the reaction time, how quickly was the patient reached and when did the clinical death occur. I don't think that it is very well defined. /…/." (E-2)

As resuscitation is a time-critical and highly stressful medical emergency *"naturally, you are not filling in the card during resuscitation." (E-1)* which indicates that resuscitation data are filled in with a delay. Therefore, data needs to be recollected later which can increase inaccuracies. However, the positive aspect of data entry is that the e-ambulance system gives an approximate timeframe for events:

> "/…/ *the electronic ambulance card sets the timeframe to some extent /.../. Plus, there is the emergency call time. /.../ it is the exact time when the emergency call was made, and it is available on the resuscitation card." (E-2)*

The above quote reflects that the e-ambulance system facilitates data entry thanks to its automatic solutions, leading to more accurate data. Yet there can also be problems with this: *"sometimes e-ambulance freezes and doesn't let you choose the correct unit /.../. Finally, when you insert 0,00 and add milligrams, then it would let you insert." (E-1)*

As the above quote shows, occasionally the e-ambulance system even impedes correct data entry and ambulance staff needs to find work-arounds to be able to insert correct data.

Additionally, one expert pointed out that when data analysis is only machine-based then without looking into the data, it can be inaccurate or remain undetected:

> *"The classical example is that the analysis module or the ambulance database generates statistics based on the diagnosis code. But without opening, in case of non-personalised data, there is often more than one ambulance visit allocated /.../ to one resuscitation patient." (E-3).*

The above extract indicates that errors linked to non-personalized data can be more difficult to detect than those linked to personalized data. Incomplete data fields can also be problematic and create confusion. For example, experts noted that in the e-ambulance system, it is not compulsory to fill in all the data fields, which can result in incomplete resuscitation cards. Document analysis also confirmed that not all data fields are mandatory. One expert said that in case of empty data fields "*maybe it's possible to read it from the text, because well, we also write the legend next to it." (E-2).* Nonetheless, the expert admitted that *"if it's not possible to read it, well then I can say that it's pretty hopeless." (E-2)*

These quotes reflect that whereas legends help to guess data, as time goes by, it is more difficult or even impossible to remember what was going on with a specific resuscitation.

To improve data quality, some ambulance units verify all their resuscitation cards. There are also ambulance units that have introduced random quality controls on all ambulance cards, not just the resuscitation ones:

"/.../ I think that about 20 % of the ambulance cards need to get verified. And the resuscitation card may not be included in that check. The verifications can vary in different institutions." (E-2)

This quote shows that there is no uniform quality check in place and ambulance units decide themselves how to conduct these, leading to variation in data quality between ambulance units.

The experts also noted that the *"ambulance card can only be modified by the creator of the card"* (E-3) and the *"changes can be introduced within 30 days"* (E-1). During this time frame *"it is the easy way"* (E-3) to modify the cards but afterwards *"the cards need to be overwritten"* (E-3). One expert stated: *"we have tried to verify all the cards the next working day /.../ week-end cards sometimes get checked after a week /.../. In fact, we check them all /.../."* (E-1) However, *"the worry is with part-time employees."* (E-1)

The above excerpts demonstrate that whereas it is not complicated to correct mistakes by opening the card and inserting the correct details, it becomes tricky when employees have been away from work for several days or weeks and no longer remember details of their resuscitation cases on their return.

"Then there are two options: one is leaving the data field blank and the other one is guessing /.../ Especially when the times are missing then it is almost impossible to remember these afterwards." (E-2)

Whereas no data means a blank field, guessing may result in the wrong data entry.

This sub-section has shown that while ambulance units do aim to maintain or increase data quality, certain mistakes emerge due to limitations in the e-ambulance system.

4.2.4 Data access

Expert interviews and document analysis both revealed that whereas the Utstein template includes data fields for pre-hospital and post-resuscitation data, the ERC, although Utstein-based, only has pre-hospital data fields (see Table 2 in section 4.1 above). Two experts agreed that data protection is the main reason why ambulance units cannot see post-resuscitation data filled in by hospital staff:

"/.../ it is mostly because of the data protection that you cannot see personalized data. For this you need a confidentiality agreement and a reason to look at the data." (E-2)

However, one expert confirmed that ambulance units can later check into which hospital they transported their patients and request post-resuscitation data:

> *"/.../ at the end of each study period, we will send a request to the corresponding hospital."/.../ through a head of department or a designated doctor who deals with it at the hospital. And as these patients have been transported to the hospital by us, our request is totally legitimate." (E-3)*

Another expert corroborated this, stating: *"you must be entitled to request the data, it's not that each ambulance staff would like to know what happened to their patient. It doesn't work like that." (E-2)*

The above quote reflects that whereas ambulance staff may want to know much sooner, whether their patient died or survived and what was their neurological outcome, they are not able to request the data.

In fact, ambulance staff are not just interested in whether the patient is alive per se, but *how* they are living – their quality of life:

> *"Have they gone back to their normal life, are they working /.../ or are they somewhere in a care home, let's say bedridden and with dementia. This is in fact considered as a negative resuscitation outcome." (E-2)*

When data for resuscitation patients cannot be combined or accessed by ambulance staff, they may mistakenly get the impression that the statistics are great:

> *"Yet when knowing that a person is alive but not knowing the other part may give surprisingly good resuscitation outcomes, which are not comparable with the other countries as they do not consider these as positive outcomes." (E-2)*

Accessing both pre-hospital and in-hospital resuscitation data would therefore help ambulance staff to get a more comprehensive overview of their patients and assess their performance. When post-resuscitation data are received once a year for the EMS annual report, too much time has passed to remember specific resuscitation circumstances and the emergency care provided.

The above sub-section has identified that the ERC includes pre-hospital but not post-resuscitation data, hindering ambulance staff from obtaining a comprehensive overview of their patients.

4.3 Nationwide resuscitation data collection and analysis in Estonia

When Estonian Ambulance units moved from paper-based ambulance cards to the e-ambulance system, it was not anticipated that the nationwide resuscitation data collection would no longer be possible:

> *"It came as a surprise. In fact, we did not expect that it will disappear for a while or that no one will deal with it. Somehow the ambulance card was created, and first, the resuscitation part was forgotten and then it was caught up, but the connection was already broken /.../." (E-2)*

The above quote indicates that the change process was not smooth and included important gaps which disrupted data collection and analysis. The expert interviews also confirmed that nationwide data collection and analysis has still not been restored:

> *"At present, when you log into the e-ambulance, you can only see the cards of your own institution, when you are an analyst. Therefore, everyone can conduct analysis only based on their own cards /.../ but these are no longer sent somewhere centrally." (E-1)*

The above excerpt identifies a lack of systematic and structured approach in the e-ambulance system to permit data collection and analysis beyond one's own unit or at the national level. When asked whether Estonia should reinstate the nationwide resuscitation data collection and analysis, the experts unanimously agreed that it should:

> *"It is elementary! A country that tries not to be a developing country in medicine owns statistics about its work and can participate in international studies and collaboration programmes." (E-1)*

The above quote indicates that it is a problem that Estonia does not have resuscitation statistics at the national level, which in turn impedes international collaboration.

Moreover, reinstating nationwide data collection and analysis would be relatively easy as data is already being collected by all the ambulance units separately:

> *"In fact, the data are available, these just need to move from one database to the other." (E-2)*

The experts also agreed that the preconditions for the reinstatement of the national resuscitation data collection and analysis include motivation and funding from the Ministry of Social Affairs and a dedicated data collector who owns the resuscitation dataset:

"*To reinstate the national resuscitation data collection, the system should enable it, and someone should be interested in being the owner of the dataset." (E-1)*

Although the nationwide resuscitation data collection based on Utstein was discontinued, since 2022 the Estonian Health Insurance Fund (EHIF) has collected and analysed nationwide resuscitation quality indicators for Service Quality Analysis, though these quality indicators form a small fraction of the data fields listed in the Utstein template.

"The last two periods we had the obligation to provide the Estonian Health Insurance Fund with general data, which are quality indicators. These have been generalized based on a slightly different principle than requested by Utstein." (E-3)

The collection and analysis of quality indicators suggests that when the key parties are sufficiently motivated, nationwide data collection and analysis is feasible.

The above section identified drawbacks of discontinuing nationwide resuscitation data collection and analysis and the preconditions for restoring it.

4.4 Building a resuscitation registry in Estonia

As noted in section 4.2.4, the Estonian resuscitation card only includes pre-hospital data fields (see Table 2 in section 4.1). However, the experts highlighted that *"the purpose of the resuscitation registry is that pre- and in-hospital resuscitation data will be combined." (E-2)* In addition to the other important aspects, the registry would also enable to assess whether *"people have been trained for first aid, are there AEDs available in public spaces? How has the emergency care been organised; does the emergency response centre have enough knowledge to assist with CPR until ambulance arrival? /.../ the number of ROSCs and how many have left hospital in good neurological condition /…/." (E-3)*

Moreover, the experts agreed that a systematic, uniform, nationwide data collection such as *"a resuscitation registry also enables to participate in international projects. /…/ So far, as Estonia does not have one, it* [Estonia] *has been left out" (E-1).*

The requirement for systematic data collection also resonated in the structured interview on the State's position for creating a resuscitation registry. The interviewee explained that to create a resuscitation registry, "*it is necessary to collect resuscitation data in a*

systematic way, also enabling secondary data usage."/.../ "One option is to create a registry, where specifically resuscitation data will be collected, and where data analysis, data processing, and later also the aggregated and non-personalized data output takes place." (S-1) Additionally, the representative of MoSA stressed that *"the maintenance of registries also includes administrative burden"* such as */.../ the establishment and maintenance of a separate information system for the registry." (S-1)* and possibly *"/.../extra work for healthcare providers." (S-1)* and that *"in terms of sustainability there are doubts here." (S-1)*

As the above quotes demonstrate, creating a resuscitation registry requires additional financial resources and workforce, and streamlining, including secondary data usage, is paramount.

Additionally, the representative of MoSA highlighted that *"data analysis in the registries is possible after three base requirements have been completed"* which include *"data collectors", "an information system"* and *"data quality." (S-1)* These criteria for creating a registry demonstrate the requirement for a thorough procedure and means before the registry can be launched. Despite this, the expert interviews pointed out that Estonia is well placed for establishing a resuscitation registry due to "*the previous experience of conducting research, plus the old database" (E-3)* and *"a kind of theoretical readiness to send structured data." (E-3)* Moreover *"most ambulance units are already collecting and storing the data and when a dataset owner is ready to collect the data, ambulance units are ready to forward it." (E-3)*

These quotes indicate that the ambulance experts have a strong willingness to build a resuscitation registry, and the ambulance units have a certain degree of readiness to build it. Nevertheless, the creation of a resuscitation registry requires approval from MoSA.

An expert revealed that *"the Union of Estonian Medical Emergency wrote an official letter to the Ministry of Social Affairs for building this [resuscitation] registry. We also gave reasons. But we haven't received any reply." (E-3)*

This may indicate that MoSA has other priorities than the resuscitation registry. However, in the structured interview, the representative of MoSA highlighted that *"in the past, registries have been created primarily based on the most pressing problems of public health /.../. Now we have initiated a portfolio management system for development works,*

where ideas taken into development are assessed and prioritized based on specific criteria." (S-1)

There is thus a formal procedure in place based on which MoSA prioritizes the creation of the registries. To find out whether a resuscitation registry can or should be created, it is therefore necessary to check the criteria based on which TEHIK assesses the new developments.

On the other hand, the structured interview also revealed that instead of a registry *"as an alternative future perspective we see a solution in the upTIS program"* by *"enabling the reusage of the already collected data through upTIS"* and that *"here plays a big role the Health Sense project which aims to enhance anonymized and pseudonymized health data output with the created tools for research and other development." (S-1)*

Moreover, based on the example of the cancer registry, the representative of MoSA also highlighted the potential risk of *"duplication of data" (S-1) in a registry.* Therefore, the interviewee suggested that *"the solution which could be suitable for both the health care providers (HCPs) and the other data users consists of pooling and enabling the reusage of already existing data. As part of the upTIS program, we are creating a framework on how to enable secondary data usage via the health information system." (S-1)*

The above excerpts emphasize that in fact a registry may not be the optimal solution for gathering the resuscitation data into one place, and that avoiding data duplication and enabling data reusage should be the key elements of data pooling. Notably, the representative of MoSA stressed that *"today, it is important to systematically document and enable secondary usage of the collected healthcare data".* (S-1)

The keywords that resonated in the State's position on collecting data in a systematic way were secondary data usage, sustainability of a system and an alternative solution to the resuscitation registry via upTIS.

The above section has examined the perceived need for, benefits and drawbacks of a resuscitation registry, as well as the preconditions and the necessary steps that need to be considered before creating it.

4.5 Joining the European Registry of Cardiac Arrest (EuReCa)

Estonia is potentially well placed to join EuReCa in that it already collects resuscitation data based on the Utstein template:

> *"/.../ in fact, in Europe resuscitation data are being collected according to a very clear format. The content of this format is available in our ambulance card." (E-3)*

A precondition for joining EuReCa is that Estonia has a resuscitation registry or at least nation-wide resuscitation data collection. As Estonia is a small country, regional data collection is not an option:

> *"Estonia has 10 ambulance units. As none of them has a big enough sample, they cannot scientifically prove anything. Therefore, the different units will not be able to participate in the EuReCa projects." (E-1)*

Additionally, the expert interviews revealed that Estonia is currently not able to join EuReCa as *"we are not collecting the data, there is nothing to send. There isn't even an authority that would be able to send it or keeps the data." (E-3)*

Nevertheless, all experts agreed that Estonia needs to join EuReCa as it enables the Estonian emergency services to compare their resuscitation data with the rest of the world and to find out whether they are doing well or not:

> *"Ambulance care is the greatest and the most important work, but we are not able to compare and do not have data about how we are doing /.../." (E-1)*

However, another expert argued that Estonia is in fact successful: *"it would be great to show the data, as we are doing really well." (E-2)* Furthermore, comparing data with other countries would permit Estonia to improve its emergency medical care and treatment:

> *"The reason why the data are being collected is to find out the best methods of treatment and methods of action. And if we would send our data, we could be part of it." (E-2)*

The above quotes indicate that Estonian ambulance units want to join EuReCa and compare Estonian resuscitation outcomes with those of other countries, to position themselves at the European level, and to find out what they are doing well and what needs improvement.

5 Discussion

This chapter includes a thorough discussion of the study results. It builds on Theory of Change, compares the present study results to previous research and provides answers to the research questions.

5.1 Document analysis

The present study results revealed that when compared to the internationally recognised Utstein template (2014) and the EuReCa inclusion questions, the Utstein based Estonian resuscitation card includes all relevant pre-hospital resuscitation data fields. However, the study also found that in case of ROSC and patient's handover to hospital, the in-hospital Patient Outcomes fields comprising Survival discharge or Survival 30 days and Favourable neurological discharge are not included in the ERC. Yet previous research has highlighted the importance of patient outcomes when assessing resusctation outcomes and for that reason, after the revision of the Utstein template in 2014, the Favourable neurological discharge data field and patient reported outcome measures reflecting patient's health-related quality of life, were also added to the form [5]. For example, on the Cerebral Performance Category, CPC 1 and CPC 2 are considered as favourable neurological outcomes but CPC 3 refers to a severe cerebral disability, CPC 4 to coma/vegetative state and CPC 5 to brain death [50]. For this reason, post-resuscitation data are needed to assess whether, in fact, a resuscitation was successful and what may have influenced the outcome.

Furthermore, the present study findings demonstrated that ambulance staff can only see data that they have filled in, that is pre-hospital resuscitation data, without being allowed to consult the in-hospital data. Still, to assess their performance and decisions, ambulance staff wants to know what happened to their patient in the hospital, did the patient die or survive and what was their neurological outcome. Conversely, hospital personnel dealing with a resuscitated patient must access their pre-hospital resuscitation data as otherwise they would not know why a patient was brought to the hospital and how to treat them further. Based on § 2. Healthcare and § 4^1. Personal data processing of the Health Services Organisation Act1, hospital personnel is permitted to access health data of their patient [51]. This indicates that access to combined resuscitation data is possible for hospitals but

not for ambulance units. For instance, previous research has shown that a strong chain of survival, including pre-hospital and post-resuscitation process, is key for a successful resuscitation outcome [16], [17]. Currently, ambulance staff does not get a comprehensive overview of their patient and does not know whether a resuscitation was successful.

Besides, document analysis established that whereas the EuReCa questions include Survival discharge and Survival 30 days, the Favourable neurological discharge field is missing. This was unexpected as based on previous research, patients' favourable neurological outcome and whether they can live a normal or near-normal life is one of the most important aspects defining whether a resuscitation was successful [4]. In fact, the main study aims of EuReCa One, Two and Three were OHCA epidemiology the European level, bystander CPR performance and European-wide quality data collection for OHCA, respectively [7]. These aims do not specifically focus on patients' neurological outcome but on why cardiac arrest occurred, did bystanders provide good quality CPR and how is data quality across countries. Therefore, it appears that favourable neurological outcome has not yet been the focus of the EuReCa studies.

Another difference identified during the document analysis of the present study is that while the Utstein template and EuReCa collect information on bystander age and gender, the ERC collects their name and phone number with this data field. As this field is optional, it is probably not relevant whether Estonia collects bystander information or not when deciding to apply to join EuReCa. On the other hand, if Estonia wants to assess bystander CPR performance at regional or national level, then age and gender would help to identify which bystander age groups are more likely to perform CPR and who have the best CPR techniques. As name and phone number cannot help to identify CPR performance per age group, these seem to be informative details in case a bystander needs to be contacted again. As bystander age and gender on the Utstein template are optional, it may be the reason why there is not much research on which gender or age groups are more likely to attempt CPR. In contrast, there are several studies on patients' CPR outcomes and their chances and condition of survival based on their gender [52], [53]. Notably, previous research has revealed that women are less likely to receive CPR than men [52]. When explaining the possible reasons behind it, then men suggested potential fears of accusations of sexual assault/harassment and women were more worried about causing physical harm or injury to the person requiring CPR [52]. Still, the participants were selected based on their ability to correctly define CPR and had not necessarily

attempted one. So, in a real-life emergency, they may judge based on other criteria whether to attempt CPR. Conversely, another study found that gender did not influence bystander's decision to attempt CPR [53].

To conclude, document analysis confirmed that the Estonian resuscitation card includes all pre-resuscitation data fields listed in the Utstein template and EuReCa but excludes all in-hospital data fields.

5.2 Resuscitation data collection and analysis

The present study results have shown that when Estonian ambulance units moved from paper-based resuscitation data collection process to the national e-ambulance system, the transition was complex. Compared to the previous process, the new digital system offered advantages, but it also included elements which complicated data entry, created confusion and contributed to mistakes. Based on the numerous challenges, the study results also gave insight into why it took 10 years for all ambulance units to adopt the e-ambulance system [9]. Therefore, this study relates to Weiss's (1995) Theory of Change [28] to understand what contributed to the complex usage of the e-ambulance system and what could have been done differently. It appears that when the e-ambulance system was developed, systematic thinking and documenting on how a program is expected to work, was not applied. Notably, the study results revealed that the e-ambulance system was funded by three different stakeholders, each having a different vison and approach on how to develop the software. Consequently, the e-ambulance system did initially not enable the extraction of the resuscitation parts from the ambulance cards which in turn contributed to the discontinuation of the previous systematic nationwide data collection and analysis. Besides, it is also possible that the end users automatically expected that certain functions or aspects will be continuously available and did not communicate these to developers. For this reason, applying the two key elements of ToC, namely defining the situation and how the new program is expected to work [29], could have helped to avoid the missing functions in the new system.

Next, the study results revealed that certain reoccurring mistakes and issues in the system have still not been solved. This explains why the end-product was not a success and reflects a lack of cross functional co-operation between developers, funding agencies and end-users. Additionally, the e-ambulance system was not user-friendly, it took long-time

to get used to it and as a result many mistakes occurred. This may indicate a lack of training for how to use the e-ambulance system. When reflecting on the issues in the e-ambulance system, it appears that end user perspective was not fully considered either. This relates to ToC's key elements of how a program is expected to work and who and how will they benefit [28]. To illustrate, this means that ambulance staff knows how to use the system smoothly, thus saving time, avoiding confusion, and reducing mistakes. Also, as certain mistakes keep reoccurring due to the peculiarities of the system, it reflects the lack of control mechanisms such as not blocking unrealistic data entry or not allowing the system to record wrong start times. Here, ToC's key element of identifying potential solutions [29] could have helped to avoid these mistakes occurring again.

Moreover, the study findings highlighted that the e-ambulance system includes a statistical data analysis module with the aim to facilitate data analysis. Yet manual adjustments are needed to prepare or generate reports which is time-consuming. For example, to increase data quality, one ambulance unit compares digital resuscitation data with paper-based defibrillators' protocols. These study findings resonate with the key elements of ToC, notably how a system is expected to work and what are the potential solutions [28], [29]. Hence, when offering a digital solution, it's important to avoid manual adjustments and paper-based duplication. To improve system's usability, it is necessary to explore ways for storing defibrillators' data permanently and digitally.

Nevertheless, the present study results confirmed that the e-ambulance system is not developed further and in 2025 it will be replaced by a new commercial software. This reflects that the system is no longer viable, and a new solution has been offered. Despite the downside, ambulance units will have to continue using the old system for another two years without getting any improvements such as new functions or corrections. Applying Theory of Change and considering preconditions for the expected change [28] may have avoided a two-year long waiting period with existing issues and no improvement to the current system.

Additionally, the study findings indicated that resuscitation data quality depends on different aspects. As resuscitation is a highly stressful and time-sensitive emergency, data are entered into the e-ambulance system with a delay and data accuracy also depends on data recollection. Besides, not all data fields are compulsory to fill in, and there is no reminder when mandatory data fields have been left blank. To address the issues with

blank data fields and data inaccuracy, the key aspects of ToC, specifically how a program is expected to work, and who, and how will they benefit [28], could be applied. For example, an alert notifying ambulance staff each time when a mandatory data field has been left blank, could be added. When certain resuscitation details have been forgotten, there should be an option to mark it, instead of filling in a data field for the sake of it. The study results also outlined that ambulance units do not have a uniform data verification process in place which contributes to fluctuations in data quality across the units. For instance, previous research has identified that data completeness between the European OHCA registries, differs greatly [1]. Since Estonia does not collect nationwide resuscitation data and is not participating in the EuReCa studies, it is difficult to determine the extent of data completeness on national and international level.

Nonetheless, the study findings revealed that resuscitation data quality is constantly improving. One important quality issue is the difficulty in recording reaction times accurately, which can arise from a variety of factors. Notably, after automatically recording the ambulance arrival time at the patient's address, it also takes time to reach the patient and start resuscitation. The last two datapoints require manual data entry after resuscitation and depend on whether ambulance staff checked the time and how well they recalled it later. Thus, the recorded reaction time can fluctuate between ambulance staff and depend on the emergency. Whereas the Utstein template encourages the standardization of definitions and the collection of the same datapoints, the EuReCa studies revealed that the definition of datapoints varies between countries [1], [5]. It also indicates that participating in European-wide studies helps identify differences in data definitions, update recommendations on data collection, and find solutions to improve data quality.

The study results indicated that data protection is the main reason why ambulance staff cannot access post-resuscitation data. At the managerial level, the ambulance units have a legal right to request and obtain post-resuscitation data but when ambulance staff receives the resusctation outcomes with a delay, it is more difficult or impossible to recall a specific case. Previous research on resuscitation outcomes has emphasised that out-of-hospital survival rate can be improved by better CPR techniques, early defibrillation, and shorter ambulance times and in addition to survival, patient's favourable neurological outcome defines whether resuscitation was successful [4]. In order to assess and improve their services, and knowing much sooner whether their patient had a positive neurological

outcome, would facilitate resuscitation assessment. A delay in obtaining the data means that, in the meantime, there will be several other resusctation attemps without knowing how the previous ones ended.

Importantly, based on the Personal Data Protection Act, § 20. Specifics of the processing of special categories of personal data, health care data processing is only permitted when it is necessary to protect the vital interests of the data subject [54]. Hence, when ambulance staff has arrived at an emergency location, they are entitled to look at the patient data. In contrast, when the patient has been transferred to the hospital, the contract of the health care service provision between ambulance services and patient expires. However, the Health Services Organisation Act1, § 17^2 Emergency Medical Services Funding Agreement specifies that the contract for the financing of ambulance services must include, among other things, indicators of the quality and efficiency of the ambulance service [51]. As ambulance staff needs to assess their services and the whole resuscitation process, obtaining the post-resuscitation data from the corresponding hospitals is paramount. If there is no information about patients' survival or neurological outcome, it would be difficult to determine whether the resuscitation attempts were successful or if there is anything that could have been done differently.

Hence, the study results highlighted that when ambulance staff do not know what happened to their resuscitated patient after hospital delivery, they may get the impression that patient outcome was positive. However, for a full assessment of the chain of survival, and with the goal to improve services and treatment, it is important to combine pre-hospital and post-resuscitation data. Notably, previous research has stated that one weak link in the chain of survival can negatively influence the overall resuscitation outcome [17]. Thus, collaboration between the different stakeholders such as community, emergency call centre, emergency medical services and hospital are needed [17]. Previous research has also revealed that the revised Utstein-style reporting with the sub-sections of outcome groups, aims to map the patient journey through different systems, gain knowledge and contribute to improvement in resuscitation outcomes [5]. So, accessing the whole resuscitation process may indicate that certain actions or aspects have a higher likelihood to influence specific outcomes. Without identifying these, certain negative actions may be unknowingly repeated.

In conclusion, while the national e-ambulance system can be complex, it offers a statistical data analysis module that facilitates reporting. However, the system will soon be replaced and will not be developed further. Despite recurring mistakes, resuscitation data quality is improving. While the Personal Data Protection Act [54] prohibits ambulance staff from accessing the data of their former patients, post-resuscitation data from hospitals can be obtained at the managerial level. An overview of the entire resuscitation process can help assess and improve patient outcomes.

5.3 Nationwide resuscitation data collection and analysis in Estonia

To begin with, the study results revealed that it came as a surprise when the national resuscitation data collection and analysis was not possible on the e-ambulance system. When applying ToC, it reflects that the expected outcomes [29] of the e-ambulance system were not discussed or considered. Although the data analysts of ambulance units can access and analyse their own resuscitation data, there is no data exchange across units. However, ambulance units are interested in obtaining nationwide statistics on resuscitation data to assess the quality of resuscitation services and patient outcomes. Also, nationwide data collection would enable participation and collaboration in international programs and research. Initially, it was the e-ambulance system that hindered nationwide resuscitation data collection, but now the law imposes limits on data collection. As pointed out in section 5.2 of the present study, the Personal Data Protection Act [54] and the Health Services Organisation Act1 [51], set limitations on who can access patient data. Thus, based on these Acts, without a specific permission, it is not possible to collect pre-hospital and post-resuscitation into one place. Whereas the purpose of the national data collection and analysis is to combine pre-resuscitation and post resuscitation data, and to enable data exchange between different ambulance units, neither is currently possible.

Apart from the restrictions in the law, the study results demonstrated that as all ambulance units already collect resuscitation data based on the same electronic resuscitation cards, Estonia is well placed for reinstating a nationwide data collection. The drawback is that as there is no uniform data verification in place, there could be fluctuations in data quality. For this reason, the elements of ToC, such as defining the situation and identifying the expected outcomes [29], could enable the identification of an optimal data verification

process with the goal of systematically applying it in all ambulance units. Previous research has demonstrated that whereas the Utstein template enables uniform data collection, the process of collecting data varies between countries [5]. Still, coordinating variations between countries with different customs, laws, and healthcare organizations is likely more challenging than implementing a uniform data verification process in a small country like Estonia. The present study results emphasized that for the nationwide resuscitation data collection and analysis, a data collector who owns the dataset, a system which enables it, and the funding and motivation from MoSA are also needed. While based on a different concept than Utstein, EHIF already collects Service Quality Indicators on resuscitation data. This demonstrates that a nationwide data collection and analysis can be justified based on well-grounded needs.

To conclude, this section showed that ambulance units are collecting and analysing resuscitation data in silos. Notably, data exchange between ambulance units, as well as the collection and analysis of pre-hospital and post-resuscitation data on a national level, are strictly regulated by law.

5.4 Building a resuscitation registry in Estonia

First, the current study results highlighted that the purpose of a resuscitation registry is that pre-hospital and post-resuscitation data are in one place. A resuscitation registry facilitates the monitoring and assessment of the whole resuscitation process such as the knowledge of emergency response centres to assist with CPR, CPR training, the availability of AED-s in public spaces and the favourable neurological outcome. Importantly, previous research has shown that public CPR techniques and early defibrillation can contribute to the improvement of neurological recovery of OHCA [10]. Moreover, another research revealed that ca 69% of OHCA occur at home [10]. This highlights the necessity for public CPR training, including the recognition of early cardiac arrest and the preparedness to attempt CPR. To illustrate, the population-based Norwegian Cardiac Arrest Registry (NorCar) has facilitated a systematic assessment of the whole chain of survival, by providing information on bystander CPR readiness and trends of survival [21].

Next, research based on the OHCA data in the Swedish Cardiopulmonary Resuscitation Registry (SCRR) revealed that while during a 30-year period OHCA survival increased

more than two-fold, the favourable neurological outcome did not improve [22]. The Swedish example reflects that while one quality indicator improved, the other did not. This highlights the benefits of a systematic and comprehensive data collection for displaying trends and the aspects which need further investigation. Another research pointed out that people who survived hospital discharge or lived more than 1-3 years after ROSC, reported a quality of life which was worse than that of the general population [4]. This indicates that survival from resuscitation is complex. Therefore, it is important to collect and analyse resuscitation data in a comprehensive way to understand what should be avoided, what could be done differently or improved.

Furthermore, the present study results emphasised that a systematic resuscitation data collection enabling secondary data usage is paramount. Notably, the base requirements for a registry are a data collector, information system and data quality. Though, a standalone resuscitation registry requires additional costs, extra work for HCPs and an increased administrative burden which could put the sustainability of a registry in doubt. On the other hand, the aspects facilitating the creation of a resuscitation registry in Estonia include the previous experience of the nationwide data collection, conducting research, the existence of the old resuscitation database, and readiness to send data. Whereas the Union of Estonian Medical Emergency has already justified the need for a resuscitation registry by the Ministry of Social Affairs, the representative of MoSA confirmed that TEHIK now has a portfolio management system in place with specific assessment criteria to prioritise the need for development work [55]. Consequently, to establish whether Estonia can build a resuscitation registry, it is necessary to follow the process in the portfolio management system. If the creation of a resuscitation registry gets approved, the next steps towards it could be taken. If not, then the other avenues such as upTIS should be explored.

In fact, the study results revealed that a resuscitation registry may not be the optimal solution for resuscitation data collection and analysis. For example, the representative of MoSA referred to upTIS as an alternative future perspective to a resuscitation registry, with the benefit of reusing already existing data, a new health information system and reduction or avoidance of data duplication. Applying ToC's elements [28], [29] of documenting how a resuscitation registry and upTIS are expected to work, what are the preconditions for the expected change, the establishment of system boundaries and potential solutions, plus comparing the results, could facilitate the identification of the

best possible solution. The possibilities to link additional patient health data to resuscitation details, should also be considered. For example, previous research has shown that to establish patients' long-term survival, the data was retrieved from the Population Registry [4]. A further option is to combine resuscitation data with long-term survival and long-term quality of life by retrieving the corresponding data from EHIF or HoHIS, which could contribute to a comprehensive overview of patient outcomes and OHCA epidemiology. Notably, previous research has identified that about 25 % of sudden cardiac arrest cases occur without any prior cardiac history [10]. Therefore, linking various health data and conducting comprehensive research could increase the understanding of epidemiology and contribute to the prevention of cardiac arrest.

In conclusion, this section highlighted the pros and cons of a resuscitation registry. The benefits included having the whole resuscitation data are in one place, contributing to a comprehensive overview of patient outcomes and cardiac arrest epidemiology. The drawbacks comprised additional workload and cost for a standalone registry. A potential alternative to a resuscitation registry, upTIS, was also offered.

5.5 Joining the European Registry of Cardiac Arrest (EuReCa)

First, the present study results revealed that the advantage of Estonia joining EuReCa is that all Estonian ambulance units are already collecting the resuscitation data based on the same Utstein-style electronic resuscitation cards. As Estonia is a small country, and there is no nationwide data collection in place, due to the small data even the biggest Estonian ambulance units cannot participate in the EuReCa studies. Namely, the precondition of joining EuReCa is a nationwide resuscitation registry or at least an alternative nation-wide data collection. In contrast, the other countries with a much bigger population than Estonia, such as France, Germany, Poland, and the UK, have participated in the EuReCa studies based on the resuscitation registries with partial coverage [20].

Second, the study results emphasized the importance of participating in the EuReCa studies to identify the best treatments and methods of action. As EuReCa has the most comprehensive OHCA data collection and patient outcome overview in Europe [1], it helps to contribute to a better understanding of epidemiology, and how the different elements in the chain of survival influence patient outcomes. Notably, EuReCa's focus is on the provision of high-quality evidence of OHCA epidemiology and an improved

understanding of the cause of cardiac arrest of cardiac origin [6]. For instance, previous research has demonstrated that not all causes of cardiac arrests can be identified due to incomplete data, insufficient background information, and sometimes even a post-mortem examination does not permit the identification of the cause [15]. However, the bigger the resuscitation data pool, the more comprehensive overview it enables on OHCA epidemiology, contributing to better treatments and prevention. Besides, the EuReCa Two study has pointed out an important variability between the incidence rate, patient characteristics, and resuscitation outcomes between the different countries, as well as a big health burden of OHCA in Europe [7]. Therefore, when joining EuReCa, Estonia could benefit from finding out where the country stands in terms of its bystander CPR, EMS services and patient outcomes, what are the important similarities and differences in patient characteristics when compared to the other countries, how to improve treatment and contribute to the prevention of SCA.

In conclusion, this section discussed the benefits and preconditions of Estonia joining EuReCa. Likewise, EuReCa's comprehensive pool of resuscitation data, and research, contributes to the understanding of cardiac arrest epidemiology and patient outcomes, and facilitates the identification of trends and best practices in the field.

5.6 Main contribution

The present study has contributed to the understanding of how resuscitation data collection and analysis is currently organized in Estonia. It has established the main reasons why Estonia does not collect and analyse resuscitation data at national level. Additionally, the study has identified the main challenges and benefits of collecting and analysing resuscitation data in the e-ambulance system and highlighted the preconditions for, and the benefits of creating a national resuscitation registry and joining EuReCa. Finally, document analysis has indicated which data fields of the Estonian resuscitation card are missing or different when compared to the Utstein template and the EuReCa study inclusion questions. To the knowledge of the author of this study, this is the first ever document analysis to compare these three Utstein-based resuscitation forms.

5.7 Limitations

Although this study provides a valuable insight into the resuscitation data collection and analysis from the perspective of Estonian ambulance services, it has some limitations. Specifically, the study did not examine how post-resuscitation data are filled in by hospital staff or whether it is carried out systematically, digitally or on paper. Therefore, the scale of work needed to combine pre-hospital and post-resuscitation data are currently unknown.

Additionally, interviewing more than three ambulance experts and a different representative of MoSA may have given slightly different answers. Still, as the expert interviews reached data saturation, the core points would have remained the same or similar.

Finally, while this study has identified the data fields which are missing from the Estonian resuscitation card when compared to the Utstein template and the EuReCa study inclusion questions, it did not conduct an analysis from the legal perspective on how the data could be combined for the purpose of a national data collection and analysis. Nevertheless, it identified the main reasons why the data cannot be currently combined.

5.8 Future research

As Estonian ambulance units will soon transition from the current e-ambulance system to a new digital solution MobiMed [56], future research could explore the features offered in the new software, and how the resuscitation data collection and analysis will be organized.

Additionally, future research could investigate whether based on the portfolio management system, Estonia would qualify for a resuscitation registry. Also, it could study the benefits and challenges of the existing Estonian registries and identify the negative aspects, such as data duplication, that must be avoided.

Finally, a further study could examine the advantages and disadvantages of utilizing upTIS and a resuscitation registry as a comprehensive database for the nationwide resuscitation data collection and analysis.

5.9 Final conclusions

Based on the study findings, the following conclusions can be drawn in response to the research questions:

All Estonian ambulance units collect resuscitation data based on the same Utstein-style electronic resuscitation card. The Estonian resuscitation card includes all necessary pre-hospital resuscitation data fields but excludes all post-resuscitation data fields.

The main advantages of the current e-ambulance system comprise predominantly standardized pre-hospital resuscitation data, and the data analysis module for statistics. The main challenges are that the e-ambulance system is not user-friendly, and there is need for manual adjustments and data duplication on paper. Also, while the quality of data is improving, certain mistakes keep recurring.

The benefits of nationwide data collection and analysis include making resuscitation statistics available at the national level and enabling Estonia's participation in international studies and collaboration programs. While pre-hospital resuscitation data are already available, they need to be gathered. Further prerequisites include a designated information system and a data set owner.

The main benefits of a resuscitation registry include holding all resuscitation data (pre-hospital and post-resuscitation data) in one place, facilitating secondary data usage, improving healthcare information and planning, and enabling participation in international projects. The main challenges include the need to secure approval and funding from MoSA, a designated information system and a dataset owner.

The main benefits to Estonia of joining EuReCa are that it would enable data comparison with other countries, giving more information about resuscitation outcomes and thereby potentially improving treatment. Estonian ambulance units already collect resuscitation data based on Utstein style. The main challenges include the need for a nationwide data collection (e.g., a resuscitation registry) and combining pre-hospital and post-resuscitation data.

6 Summary

The aim of the thesis was to examine the benefits and challenges of current resuscitation data collection and analysis in Estonia, building a resuscitation registry and joining EuReCa. The author of the thesis conducted three semi-structured expert interviews, a structured written interview, and document analysis based on three Utstein-style resuscitation forms.

The expert interviews revealed that while ambulance units collect all necessary pre-hospital data, they cannot access post-resuscitation data. Document analysis confirmed that while the Utstein-style template includes pre-hospital and post-resuscitation data fields, the Estonian resuscitation card includes all pre-hospital data fields but no post-resuscitation ones. Patient outcomes are needed to assess whether a resuscitation was successful, so the omission of post-resuscitation data significantly limits the usefulness of current resuscitation data collection through the e-ambulance system.

Currently there is no nationwide resuscitation data collection and analysis, but all ambulance units collect pre-hospital data using standardized Utstein-style resuscitation cards. This systematic and standardized data collection offers is a potential advantage for gathering data at national level.

In a resuscitation registry, pre-hospital and post-resuscitation data would be combined, enabling a comprehensive overview of the whole resuscitation process and patient outcomes. However, the new heath information system, upTIS, may offer an alternative to a resuscitation registry and contribute to secondary data usage.

In conclusion, nationwide resuscitation data collection and analysis, or a resuscitation registry, in Estonia would permit nationwide statistics and participation in EuReCa studies. Comparison of nationwide and international resuscitation data would allow more informed assessment of Estonian resuscitation outcomes and enable positive elements and areas for improvement to be identified. Having a comprehensive overview of the whole resuscitation process helps in planning health care, and could contribute to cardiac arrest epidemiology and better treatment methods.

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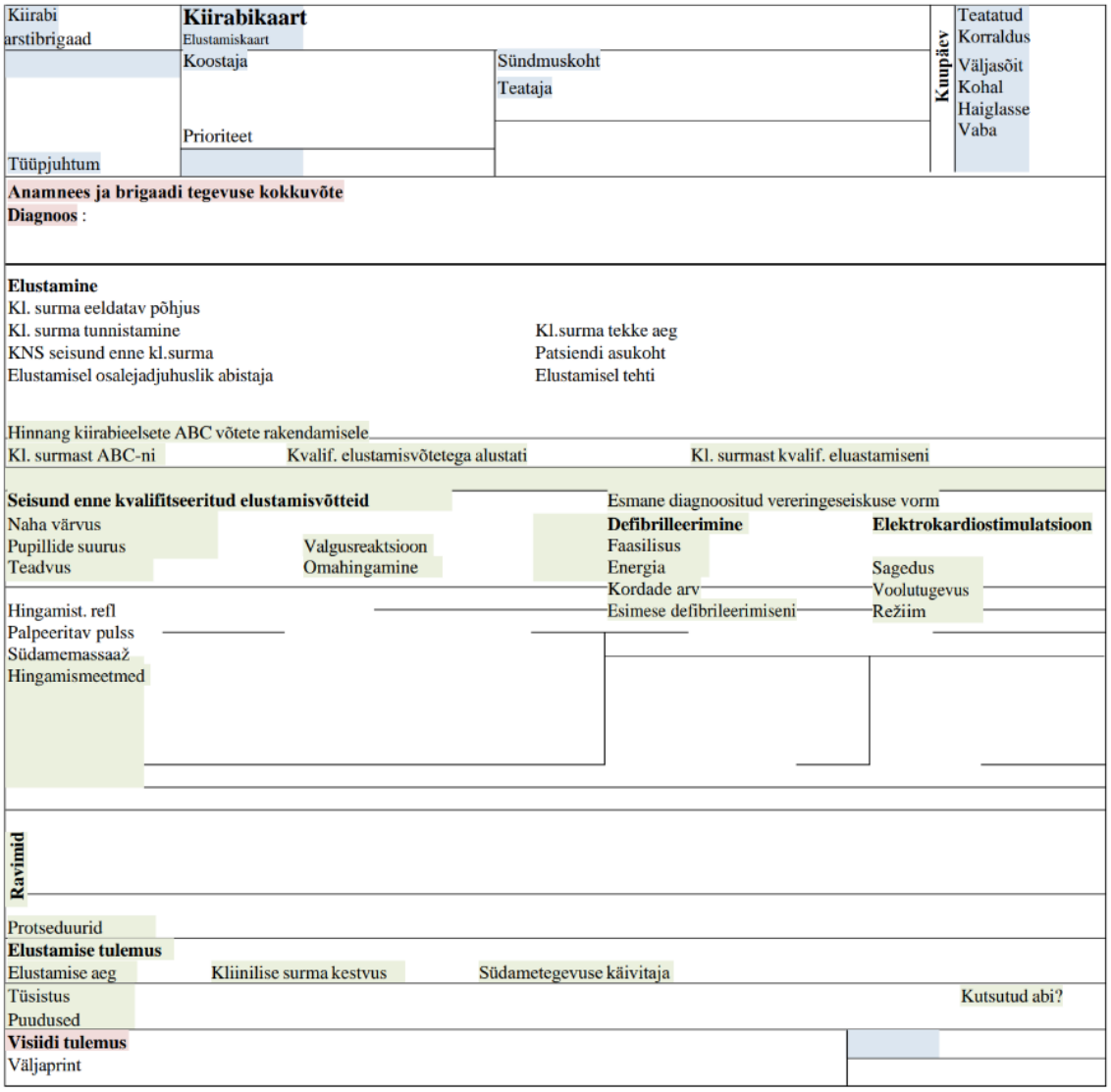
Appendix 2 – Estonian resuscitation card (view from the ambulance mobile workplace)



Kiirabi arstibrigaad

Kiirabikaart
Elustamiskaart

Koostaja

Sündmuskoht
Teataja

Prioriteet

Tüüpjuhtum

Kuupäev

Teatatud
Korraldus
Väljasõit
Kohal
Haiglasse
Vaba

Anamnees ja brigaadi tegevuse kokkuvõte
Diagnoos :

Elustamine
Kl. surma eeldatav põhjus
Kl. surma tunnistamine
KNS seisund enne kl.surma
Elustamisel osalejadjuhuslik abistaja

Kl.surma tekke aeg
Patsiendi asukoht
Elustamisel tehti

Hinnang kiirabieelsete ABC võtete rakendamisele
Kl. surmast ABC-ni
Kvalif. elustamisvõtetega alustati
Kl. surmast kvalif. eluastamiseni

Seisund enne kvalifitseeritud elustamisvõtteid
Naha värvus
Pupillide suurus
Teadvus
Valgusreaktsioon
Omahingamine

Esmane diagnoositud vereringeseiskuse vorm

Defibrilleerimine
Faasilisus
Energia
Kordade arv
Esimese defibrileerimiseni

Elektrokardiostimulatsioon
Sagedus
Voolutugevus
Režiim

Hingamist. refl
Palpeeritav pulss
Südamemassaaž
Hingamismeetmed

Ravimid

Protseduurid

Elustamise tulemus
Elustamise aeg
Kliinilise surma kestvus
Südametegevuse käivitaja

Tüsistus
Puudused
Kutsutud abi?

Visiidi tulemus
Väljaprint

Estonian resuscitation card: translation	
Kiirabikaart elustamiskaart	**Ambulance card** resuscitation card
Kiirabi arstibrigaad	Ambulance medical brigade
Tüüpjuhtum	Case type
Koostaja	Author of the card
Prioriteet	Priority
Sündmuskoht	Event location
Teataja	Caller
Kuupäev	**Date**
Teatatud Korraldus	Notified order
Väljasõit	Ambulance departure to scene
Kohal	Ambulance arrival
Haiglasse	Hospital arrival
Vaba	Ambulance free
Anamnees ja brigaadi tegevuse kokkuvõte:	**Anamnesis and summary of brigade's activities:**
Diagnoos	**Diagnosis**
Elustamine	**Resuscitation**
Kl. surma eeldatav põhjus	Presumed cause of clinical death
Kl. Surma tunnistamine	Recognition of clinical death
KNS seisund enne kl. surma	State of central nervous system (CNS) before clinical death
Elustamisel osalejad juhuslik abistaja	Resuscitation participants random helper
Kl. Surma tekke aeg	Time of clinical death
Patsiendi asukoht	Arrest location
Elustamisel tehti	Performed during resuscitation
Hinnang kiirabieelsete ABC võtete rakendamisele	Evaluation of the implementation of pre-ambulance ABC techniques
Kl. surmast ABC-ni	From clinical death to ABC
Kvalif. elustamisvõtetega alsutati	Qualified resuscitation was started at
Kl. surmast kvalif. elustamiseni	From clinical death to resuscitation
Seisund enne kvalifitseeritud elustamisvõtteid	**Condition before qualified resuscitation techniques**
Naha värvus	Skin colour
Pupillide suurus	Pupil size
Teadvus	Consciousness
Valgusreaktsioon	Light reflex

Omahingamine	Self-breathing
Hingamist. refl	Respiratory reflex
Palpeeritav pulss	Palpable pulse
Südamemassaaž	Heart massage
Hingamismeetmed	Respiratory measures
Esmane diagnoositud vereringeseiskuse vorm	Primary diagnosed form of circulatory arrest
Defibrilleerimine	**Defibrillation**
Faasilisus	Phasing
Energia	Energy
Kordade arv esimese defibrileerimiseni	Number of times until first defibrillation
Elektrokardiostimulatsioon	**Electrocardiostimulation**
Sagedus	Frequency
Voolutugevus	Amperage
Režiim	Mode
Medications	**Drugs given**
Protseduurid	Procedures
Elustamise tulemus	**Resuscitation outcome**
Elustamise aeg	Resuscitation time
Kliinilise surma kestvus	Clinical death duration
Südametegevuse käivitaja	Heartbeat trigger
Tüsistus	Complication
Puudused	Problems/limitations during resuscitation
Kutsutud abi?	Sent for help?
Visiidi tulemus	**Result of the visit**
Väljaprint	Printout

Appendix 3 – Informed consent form

Informed consent form

Dear participant,

Thank you for accepting the participation in the expert interview of the study which aims to to analyze how the resucitation data collection has been organized in Estonia, and whether there is a need to build a resuscitation registry and join the European Registry of Cardiac Arrest. Your opinion and experience as ambulance expert are of great value. This study is also part of the Digital Health Master thesis of Tallinn University of Technology, with the defence taking place in May 2023.

As part of the study, an individual expert interview will be conducted in a location or environment that is convenient for you (e.g. Microsoft Teams) at a suitable time in February-March 2023. The duration of the interview is approximately 45 minutes, depending on the amount of answers you provide. Any personal data that could be identified and linked to your person will not be collected.

Participation in this research is voluntary and if you wish, you can withdraw from it at any time. However, the data which has been collected up to the point of withdrawal will still be used in pseudonymised form for analisys. Interviews will be recorded and transcribed as soon as possible. For transcription, the web-based speech recognition software of Tallinn University of Technology will be used. After the transcription, all audio and video files will be deleted.

The data collected for the study will be stored on the OneDrive server of Tallinn University of Technology. It is protected by a password and accessible only by the researcher of the study and her supervisor Kadi Lubi.

The study results will be published in a generalized form and the confidentiality of the participants will be guaranteed. After a successful defense of the Master thesis, the collected pseudonymized data and the raw analysis file will be permanently deleted.

I, ... have been informed about the aim of the above-mentioned study and the study method. I confirm with the digital signature my willingness to participate in the study and give the permission to process the data and answers I have provided.

I am aware that if any questions arise during the study, I can obtain any additional information from the researcher:

Mirjam Sepp, mirsep@ttu.ee

Appendix 4 – Expert interview plan

Theme	Question	Prompt	Time
1. Resuscitation data collection and analysis	1. Please describe how has the resuscitation data collection and analysis been organized in Estonia?	When you think of the time before the implementation of the e-ambulance system, then how was the resuscitation data collection and analysis organized? What data was being collected? When you compare the data collection process before the e-ambulance system and now, then what is currently much better, and is there anything important missing from the past? In what form is the resuscitation data being inserted into, and collected in the e-ambulance system (e.g., standardized, free text)? What type of data is dominant?	14 min.

		At what point is the data being collected after the resuscitation (e.g., directly before and after resuscitation, 30 days survival, 5-year survival)?	
	2. How is the data quality?	What kind of mistakes tend to occur when inserting the resuscitation data? When data has been inserted incorrectly or important data fields have been left blank, then who, when and how can correct or complete it? How regularly is the data being verified and, if necessary, corrected and completed? In terms of time and content, how is the data correction and data completion process for the ambulance staff correcting and completing the data? Do you think that all relevant resuscitation data are being collected or is there anything important missing? If you think that there is something missing, then what exactly?	
	3. What are the pros and cons of the e-ambulance data analysis module?	Do you think that the data analysis module works as it should, or is there anything important missing (if yes, then what exactly)?	

		How could the potential shortcomings of the current system be solved (development, investment, new software)?	
2. Nationwide resuscitation data collection and analysis in Estonia	4. Why was the nationwide resuscitation data collection discontinued?	Was it known in advance when joining the e-ambulance system? What factors have contributed to the limitations of the e-ambulance system in terms of nationwide data collection and analysis?	8 min.
	5. In your opinion, why should or shouldn't nationwide resuscitation data collection and analysis be restored?	What are the pros and cons for restoring the nationwide data collection and analysis and what are the challenges?	
	6. *If the respondent thinks that it is important to restore the data collection and analysis, then ask:* How could the state-wide data collection be restored?	What is available (e.g., relevant standardized data)? What is missing (e.g., human resources, funding, development, data collector)? Do the data fields on the resuscitation card permit Utstein-style reporting? If yes, how?	

		Since 2022, the Estonian Health Insurance Fund (EHIF) collects ambulance quality indicators for Service Quality Analysis. Would it possible to collect nationwide resuscitation data (Utstein-style) through EHIF? If yes, what are the preconditions? If not, what are the obstacles?	
3. Building a resuscitation registry in Estonia	7. Does Estonia need a resuscitation registry?	Could you please justify your opinion? Has anyone already tried to initiate the creation of the resuscitation registry? If yes, how far did they get and what was the obstacle?	10 min.
	8. What does the establishment of the registry depend on?	Who are the main target groups which should initiate and lead the creation of the registry (e.g., specialists)? What additional resources may be needed (funding, motivation, change of law, time)? To what extent should specialists be involved and what is their exact role in the process of building the registry?	
	9. What are the first necessary steps for building the resuscitation registry?	Whose permission is needed and by whom should the need be justified (The Ministry of Social Affairs, National Institute for Health Development)	

		Who would fund it? Is there any additional resuscitation data that should be collected compared to the current data collection in the e-ambulance system? If yes, then what data should be added?	
4. Joining the European Registry of Cardiac Arrest (EuReCa)	10. In your opinion, what is the need for Estonia to join EuReCa?	Please justify your opinion. What are the pros and cons of this affiliation and the potential challenges? How to address the potential challenges?	8 min.
	11. What type of data collection is necessary?	What data should be included in the data set? What type of data should be collected? Which form would be suitable for the data collection?	
Summary	12. Is there anything that you would like to add to this topic?		5 min

Appendix 5 – Structured interview plan

Questions to the representative of the Health System Development department of the Ministry of Social Affairs of Estonia:

1. Is a resuscitation registry necessary from the State's point of view and could you please justify your position?

2. When creating a resuscitation registry in Estonia, then what is needed for it (briefly, what is the process and which resources are necessary)?

3. On what basis does the State prioritize the creation of registries (e.g., whether to create a registry or not)?

4. Does the State have an alternative to offer instead of a resuscitation registry (this question is being asked by taking into consideration that upTIS will soon be created and in 2025 the e-ambulance system will be replaced by a new software; from the State's perspective, should the resuscitation registry be combined with another registry)?

5. Do you have anything important to add on the topic of resuscitation registry that should be taken into consideration?