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Digital questionnaire platform in the Danish Blood Donor Study

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ABSTRACT

Objectives: The Danish Blood Donor Study (DBDS) is a prospective, population-based study and biobank. Since 2010, 100,000 Danish blood donors have been included in the study. Prior to July 2015 all participating donors had to complete a paper-based questionnaire. Here we describe the establishment of a digital tablet-based questionnaire platform implemented in blood bank sites across Denmark.

Methods: The digital questionnaire was developed using the open source survey software tool LimeSurvey. The participants accesses the questionnaire online with a standard SSL encrypted HTTP connection using their personal civil registration numbers. The questionnaire is placed at a front-end web server and a collection server retrieves the completed questionnaires. Data from blood samples, register data, genetic data and verification of signed informed consent are then transferred to and merged with the questionnaire data in the DBDS database.

Results: The digital platform enables personalized questionnaires, presenting only questions relevant to the specific donor by hiding unneeded follow-up questions on screening question results. New versions of questionnaires are immediately available at all blood collection facilities when new projects are initiated.

Conclusion: The digital platform is a faster, cost-effective and more flexible solution to collect valid data from participating donors compared to paper-based questionnaires. The overall system can be used around the world by the use of Internet connection, but the level of security depends on the sensitivity of the data to be collected.

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1. Introduction

The Danish Blood Donor Study (DBDS) is a prospective, population-based study as well as a biobank (www.DBDS.dk). DBDS was established in 2010 [1]. By the fall of 2015, 100,000 Danish blood donors had been included. The eligible participants are adults aged 18–67 years, who are donors at the Danish blood banks. The donor population in Denmark consists of more than 230,000 donors (5.4% of the Danish population aged 18–67 years), who give around 300,000 blood donations annually (www.bloddonor.dk). The nationwide Danish blood bank is an integrated part of the Danish healthcare system financed by local and state taxes. The Danish healthcare system is administered by democratically elected assemblies from national state institutions, regions and municipalities. The Danish blood banks are non-profit organizations owned and operated by each of the five regions in Denmark. The blood banks have a national board to structure collaboration across regions on recruiting donors, processing and distributing the blood for the Danish population. DBDS is building upon the structured Danish blood bank system in the regions responsible for administrating donation sites at 27 hospitals in addition to five mobile donation units using 180 selected sites nationally (e.g., large companies and universities). Of the 100,000 blood donors who agreed to participate in DBDS, 40,000 were included from mobile sites and 60,000 were included at the hospitals.

At the blood donation centers and attached laboratories, the entire necessary infrastructure needed for the collection of structured data and biological samples is in place. Both blood plasma and DNA are available from all donors. The blood bank infrastructure already has laboratory facilities with educated staff (nurses, technicians, IT specialists and physicians). In addition, the blood bank has staff for the subsequent testing of the blood for a variety of biomarkers and expertise in large scale storage of biological material.

Access to participants at the blood banks is fundamental in our study. Blood donors are asked to participate and sign an informed consent when they visit the blood bank. This consent allows us to use the blood samples from their donations to study the impact of genetic and immunological factors on current and future health and disease. Information on outcome and demographic factors is merged with the Danish health registers [2].

From March 2010 until July 2015, all participating donors had to complete a four-page paper-based questionnaire with questions of self-experienced physical and mental health including the 12-item short form (SF-12®) standardized health survey [3], smoking habits, alcohol intake, exercise, food intake, supplemental iron intake, height, weight, and waist circumference.

As a follow-up to the initial paper-based questionnaire, we have developed and implemented a digital and flexible tablet-based questionnaire platform, using the open source survey software tool LimeSurvey [4]. This enables a rapid, easy, and cost-effective procedure to collect valid data on health traits from the participating donors prospectively at the donor sites. The digital questionnaire is more focused on research including the following questionnaire domains: allergy, ADHD, migraine, hidradenitis, depression, Restless Legs Syndrome. It also contains questions from the paper-based questionnaire; SF-12, smoking habits, alcohol intake, height and weight.

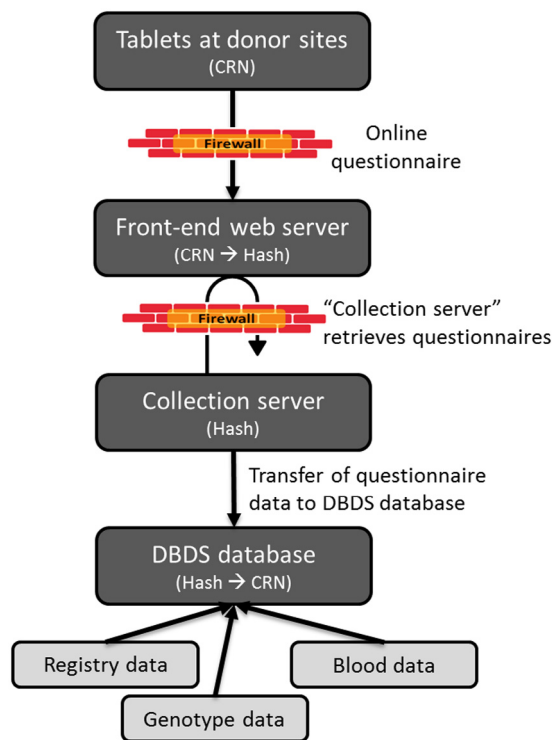


Fig. 1 – Description of dataflow.

The electronically based platform can facilitate personalized questionnaires, presenting only questions relevant to the specific blood donor by hiding unneeded follow-up questions on screening question results. At the same time, such flexibility also makes it possible to implement subgroup-targeted questionnaires, personalized from previous answers to questionnaires or biological measurements.

2. Methods

All participating blood donors complete a digital questionnaire on tablets during their visit to a blood bank (Fig. 1). The questionnaire is accessed online using a homepage at the front-end web server and will be saved following completion by the blood donor. The collection server retrieves the completed questionnaires and subsequently deletes them from the front-end web server every hour as an additional safety precaution to protect the person-identifiable data. The questionnaire data are frequently transferred from the collection server to the central DBDS database. Data from blood samples and verification of signed informed consent are then transferred to and merged with the questionnaire data in the DBDS database.

3. Systems

We chose a platform consisting of free and open source software that can be acquired at little or no cost. The questionnaire is built in LimeSurvey [4] (<https://www.limesurvey.org/> Version 2.06±), which is run on a Red Hat Enterprise Linux Server (ver.6.7)

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