

Short Report

The EpiCom Survey—Registries Across Europe, Epidemiological Research and Beyond

Hannah Gordon,^a Ebbe Langholz^b

^aDepartment of Gastroenterology, Royal London Hospital, London ^bGastroenterology Section Dept. C, Gentofte and Herlev Hospital, Copenhagen

Corresponding author: Dr Hannah Gordon, BA Hons, MBBS, MRCP, Department of Gastroenterology, Royal London Hospital, Whitechapel Rd, London E1 1BB, UK. Email: hannahgordon@doctors.org.uk.

Abstract

The 2015 EpiCom survey evaluated population, patient, and research registries across Europe. Information was collected from 38 countries. The registries included those falling within the remit of national statistics, hospital databases, twin and multiplex registries, inflammatory bowel disease [IBD] registries and biobanks, and cancer and surgical registries. The scale and nature of registries were investigated, and where possible a contact detail for each registry was obtained.

The survey demonstrated 33 birth and death registers across Europe. It also highlighted ethical and legal challenges in linking information from health and social registries: 30 delegates reported that their home country has a hospital database; 21 have adverse events registers, although the majority only mandate reporting of events that occur during drug trials; 17 countries have twin registries; And IBD registries have been established in 19 countries, with 15 countries having a biobank with IBD samples. The cancer registries were the most complete and consistent.

Despite heterogeneity between countries, the registries represent an invaluable source of information for future IBD research. Supplementary material [available at *ECCO-JCC* online] depicts active registries in each of the participating countries.

1. Introduction

EpiCom is the epidemiological committee for ECCO, the world's largest IBD organisation. The EpiCom mission is to support epidemiological research across Europe, while developing robust datasets to support patient cohort trials. The EpiCom vision extends to the evaluation of quality of care, in order to enhance our understanding of how differing practices influence patient outcomes, including quality of life, surgery, neoplasia, and mortality.

The collaborative work ethic of ECCO has facilitated the success of EpiCom to date; this has not only provided an array of clinical and scientific expertise, but also a vast patient population. EpiCom has supported the EpiCom Study Group, which has published 13 original research articles. These projects include the evaluation of a large multinational inception cohort,^{1–5} pregnancy outcomes,^{6,7} the financial burden of IBD across Europe,⁸ treatment and hospitalisation,^{1,4} environmental factors,^{4,5} and evaluation of the East-West gradient.⁹

To strive further towards the EpiCom goals, it is essential to make the best use of established resources. These include resources

outside ECCO and sometimes outside the typical remit of gastroenterology. Thus the EpiCom Survey was designed to answer the question of what research registries and datasets are already available across Europe, and how best these can be accessed.

2. Method

The EpiCom Survey was undertaken from June 2015 to June 2016. ECCO national representatives and DG Sante contact points from each of the 36 ECCO member countries, plus Luxembourg and Iceland, were asked to complete a questionnaire requesting information about registries within their country. The survey was devised by EpiCom members.

The survey enquired about population registers, birth and death registers, disability benefits registers, hospital registers, adverse events and prescription registers, surgery registers, cancer registers, twin and multiplex registers, and IBD patient registers and biobanks. When possible, respondents were asked to provide a contact for each



register, and to comment on whether it is a national or local facility and if it is a public organisation.

Respondents from each country were sent reminders about the survey. Thereafter information was researched by EpiCom members using standard search engines. Several respondents contributed insightful comments with their survey responses; when possible, these have been included. The full questionnaire is available as Supplementary material at *ECCO-JCC* online.

3. Results

3.1. Response

National representatives and/or contacts from 33 countries responded to the survey. EpiCom members completed the survey for the five countries that did not respond. The results for each country are represented visually in a series of maps [[available as Supplementary Figure 1 at *ECCO-JCC* online] demonstrating the countries for which information was obtained.

3.2. National statistics

3.2.1. Population registries

In all, 27 countries have population registries [Supplementary Figure 2, available at *ECCO-JCC* online]; 23 of these are national and 20 are public. One is private, for-profit. Contact details are available for 17. Many of the state population registries provide statistical reports, but are not otherwise available for public access.

3.2.2. Birth and death registries

Perhaps surprisingly, only 33 out of 38 countries reported birth and death registries [see Supplementary Figure 3, available at *ECCO-JCC* online]; 28 are national, 22 public, and one private for-profit. Contact details were provided for 17.

3.2.3. Disability pension registries

A total of 21 countries reported a disability pension registry [see Supplementary Figure 4, available at *ECCO-JCC* online]; 10 are national and 15 are public. Contact details were provided for 10.

However, the extent to which these facilities can be used for IBD research is questionable. The UK registry does not have readily available how many IBD patients made a successful claim. Poland and Moldova reported that their registries were not for public access, and Romania mentioned that participation was insurance dependent. The linking of information to health records is prohibited in many areas; Ireland reported national information governance laws prohibitive of linking health and social security systems.

3.3. Hospitalisation databases, medication databases, and patient registers

3.3.1. Hospital databases

Of the 38 countries, 30 have a hospitalisation database [see Supplementary Figure 5, available at *ECCO-JCC* online]; 22 are public and national, Nine are local, and one is a private for-profit organisation. Contact details were provided for 15 of the databases.

The level of detail provided within national hospital registries is often limited; frequently they lack specifics of treatment. However, broad diagnostic categories are usually coded. Further detail is often only available within local health records.

3.3.2. National patient registry with diagnosis and treatment

Respondents from 18 countries reported a national patient registry [see Supplementary Figure 6, available at *ECCO-JCC* online] containing information about diagnosis and treatment. Nine provided contact details, 15 registries are public, and one is private for-profit.

3.3.3. Prescription registry

Respondents from 14 countries confirmed that they have prescription registries [see Supplementary Figure 7, available at *ECCO-JCC* online]; nine are national and 10 are public. Contact details were provided for nine.

3.3.4. Adverse events registries

A total of 21 of the responding countries have an adverse events registry [see Supplementary Figure 8, available at *ECCO-JCC* online]. Contact details were provided for 11: 20 are national, 12 are public, one is listed as a private for-profit organisation. However, the majority only mandated reporting of adverse events from clinical trials.

3.3.5. Birth defect registries

In all, 14 countries have registries of birth defects [see Supplementary Figure 9, available at *ECCO-JCC* online]. All of these are national and public. Contact details were provided by eight countries.

3.4. Twin and multiplex registries

3.4.1. Twin registries

Furthermore, 17 countries reported some form of twin registry [see Supplementary Figure 10, available at *ECCO-JCC* online]; 11 are national registries, 11 are defined as public, and contact details are available for seven. It is worth noting that even among twin registries deemed public and national there is considerable variation in recruitment and participation. The Scandinavian twin cohorts are fully inclusive population registries with links to health records. However, the majority of European twin cohorts are made up from twins who have responded to advertisements, thus introducing bias and limiting links with health care.

3.4.2. IBD multiplex family registry

Six countries reported an IBD multiplex registry [see Supplementary Figure 11, available at *ECCO-JCC* online]; four are national, five are public, and contact details were provided for five.

3.5. IBD registries and biobanks

3.5.1. IBD registries

Nineteen countries confirmed active IBD registries [see Supplementary Figure 12, available at *ECCO-JCC* online]; 11 are national, 10 are public. Contact details were provided for 11. IBD registries are a new entity for many; even in countries with a national registry, not all centres or patients participate, and completeness of data varies.

3.5.2. Registry of specific treatments

Sixteen respondents reported a registry of specific IBD treatments such as biologics [see Supplementary Figure 13, available at *ECCO-JCC* online]. Ten are national, six are local, and 13 are public. Contact details were provided for 11.

3.5.3. IBD biobanks

In all, 15 countries report biobanks containing samples from IBD patients [see Supplementary Figure 14, available at *ECCO-JCC*

online]; 12 are national, 10 are public, and four are private for-profit [one unknown]. Contact details were provided for biobanks within 10 countries.

The International IBD Genetics Consortium have undertaken meta-analysis of genotyped IBD patients from across the world. Within the UK, the IBD Bioresource has been launched as a subset of the established UK NIHR Bioresource. The UK IBD Twin Registry is currently creating an IBD twin biobank, and the Danish Twin Registry has already stored DNA, RNA, plasma, serum, blood, and stool from all monozygotic IBD twins willing to participate.

3.6. Surgery and cancer registries

3.6.1. Registry of surgery

A total of 15 respondents confirmed that their country had a surgical register [see Supplementary Figure 15, available at *ECCO-JCC* online].;11 are national registries, 13 are public. The contact details of eight registries were provided.

3.6.2. Registry of histopathology

Twelve respondents reported a registry for histopathology [see Supplementary Figure 16, available at *ECCO-JCC* online]. The majority are local. Contact details for six have been provided.

3.6.3. Cancer registries

The most complete registers across Europe are the cancer registers. All responding countries reported a cancer registry [see Supplementary Figure 17, available at *ECCO-JCC* online]; 31 are national. Of these, one is private for-profit and 24 are public; the remainder are unknown. The contact details of 18 were provided.

4. Discussion

The EpiCom Survey has demonstrated that a wealth of epidemiological data is already assimilated across Europe. This has huge potential for IBD research. The immediate challenge is how best to utilise this information.

This study also demonstrates considerable heterogeneity between the registries across Europe. National data collection varies profoundly, as do legal and cultural attitudes towards confidentiality, consent, and central records. This can seem overwhelming when planning our next steps. However, the success of the European cancer registries is inspirational; it provides assurance that with the correct infrastructure the EpiCom aims are achievable throughout Europe.

The survey comments confirmed that IBD databases, registries, and biobanks are relatively novel to many countries and are rapidly growing across Europe. As these resources develop, ECCO wishes to foster early collaboration. The success of the International IBD Genetics Consortium is testament to the importance of pooling expertise, resources, and samples.¹⁰

At present, ECCO is reaching out to the contacts provided for each registry. The aim is to develop a portfolio of registries happy to participate in ECCO research. ECCO members will be encouraged to use the network, in order to maximise project potential and collaborate with like-minded researchers. This will be particularly useful when studies encompass niche areas such as rare disease phenotypes, twin and family studies, or inception cohorts.

In addition to epidemiological research, a network of registries will also facilitate translational science and trial recruitment. All are required for us to best serve our current and future IBD patients.

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Supplementary Data

Supplementary data are available at *ECCO-JCC* online.

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