WORK-PACKAGE 4

Taking stock of emerging and new data collection technologies and their potential impact on the development of future cohort studies and the need to optimise the integration of data.

D4.2

Repository of European/international communication technologies (including social media) used in population-based cohorts, patients' cohorts, clinical trials, and exposure cohorts ordered by region

SYNergies for Cohorts in Health: integrating the Role of all Stakeholders

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The SYNCHROS project (www.synchros.eu) has received funding from the
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EXECUTIVE SUMMARY

This report contains a concise description of the online repository of European/international technologies used in population cohorts, patients' cohorts and clinical trials oriented by region (Deliverable 4.2).

The document contains the following information:

1. Description of methodology of mapping population cohorts, patients' cohorts and clinical trials using social media and new communication technologies as well as overall structure and content of the repository.
2. An overview of the public repository of European/international technologies used in population cohorts, patients' cohorts and clinical trials.
3. Conclusion drawn from the search of the repository including analysis by region, type of study and type of new communication technologies.

Most of the studies that use new communication technologies were conducted in US (69 studies) and in Europe (47 studies). Mobile data collection was the technology most frequently used in the studies (in 119 studies) of which smartphones and/or smart apps were used in 112 studies and mobile phones in 42 studies. Nineteen studies used social media for data collection and among them Facebook and/or Twitter was the most popular. Geospatial technology was used in 30 studies (with GPS and remote sensing used in most of the studies) and smart sensors in 9 studies (including 5 studies using ingestible sensors). There were no studies using artificial intelligence, crowdsourcing and crowd seeding techniques or passive data collection.

The information collected under WP4 (task 4.2) will be presented during the 32nd Annual Conference of the International Society for Environmental Epidemiology (August 24-27, 2020) – the presentation title: "New communication and data collection technologies used in population and patient cohorts".

Texts to be complemented by inforgraphics, e.g.spider-diagramm (use of technologies, …)

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1. INTRODUCTION

The project aims to establish a sustainable European strategy for the development of the next generation of integrated population, patient and clinical trial cohorts, thereby contributing to an international strategic agenda for enhanced coordination of cohorts globally. To support the delivery of the overall objective, WP4 is centered on taking stock of the emergence of the use of digital technology for real time data collection – such as social media, wearables and smart phone sensors that will be particularly relevant for the design of future cohort studies involving patients, including clinical trials, and populations. The emergence of new communication technologies brings different new possibilities for data collection for cohorts and clinical trials. Work package 4 conducted a mapping of the different new communication technologies relevant to digital data collection (Deliverable 4.1). Task 4.2 builds on the findings of D4.1 to map existing population cohorts, patient cohorts and clinical trials, in Europe and beyond, using new and emerging data and communication technologies with the ultimate project goal to evaluate if and how they could play a role in the optimization of cohort studies.

2. METHODOLOGY

To ascertain the types of technologies that have been used and the type of studies in which they have been implemented, the following approach was taken:

I. Conduct a mapping using the ascendant (e.g., electronic records, repositories, initiatives/studies provided by WP1 and partners within the project) and descendant (e.g., review of scientific papers) search approaches to map the main cohorts and clinical trials conducted in Europe as well as internationally.
II. Request technical data for the data collection from the identified studies on: a) the study type; b) the study main objective; c) region, country; d) the design of the study/ population included in the study/number of participants; e) wave number and years in which they were carried out; f) data collection source; g) institution responsible for the study/principal investigator/contact person; h) type of data collection technology.

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To achieve the aim of mapping of existing population cohorts, patients' cohorts and clinical trials using social media and new communication technologies two approaches for searching strategies have been selected:

I. WP1 identified initiatives of harmonization and integration studies through MEDLINE search. The results from WP 1 were evaluated to determine population cohorts, patient cohorts and clinical trials using new and emerging data communication technologies for data collection.
II. A separate search strategy has been developed which involved the review of the manuscripts obtained in the search in MEDLINE/PUBMED/COCHRANE/EBSCO databases or reference list of selected papers or review papers.

2.1Inclusion/exclusion criteria for mapping new and emerging data and communication technologies – developed under task 4.1.

Table 1 Inclusion and exclusión criteria for mapping new and emerging data and communication technologies

Inclusion	Exclusion
Existing data collection technologies	Publications/articles/reports with a publication date before 2012
Innovative data collection technologies	Blogs
Data collection technologies from unrelated fields	Articles not in English
Active & passive data collection technologies	New communication technologies not used for data collection
Mobile and smart devices	
Personal monitoring devices	
Disease/public health surveillance technology	
Social media	
Crowdsourcing/crowd seeding	
Geospatial technology	

Inclusion	Exclusion
Technologies that enable storing, managing, and querying data and sharing data among devices and databases	

The following keywords were used:

Table 2 Keywords used for search in MEDLINE, PUBMED, COCHRANE and EBSCO databases

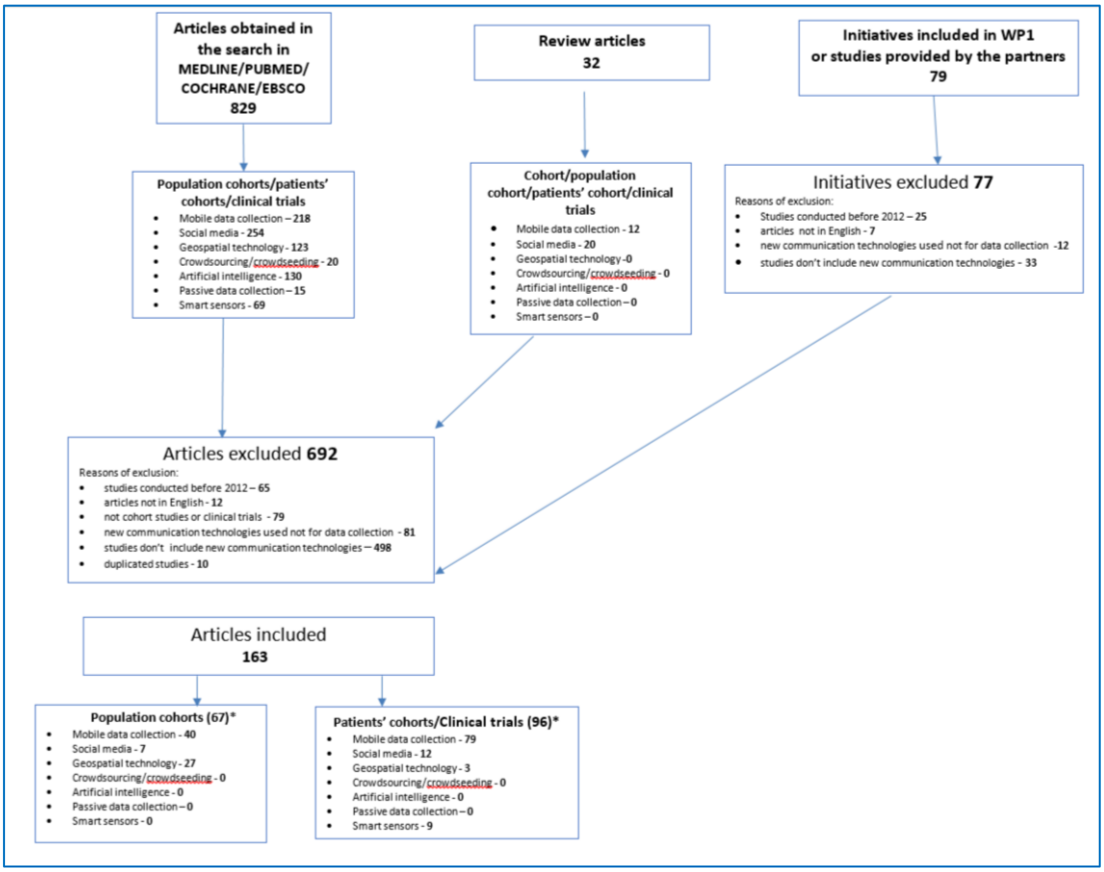
Related to study design	(AND) Related to new and emerging data and communication technologies
Cohort	Mobile data collection
Population based cohort	Smartphone
Birth cohort	Cellular phone
Patient cohort	Mobile phone
Clinical trial	Mobile apps
	Tablet
	Laptop
	Wearable device
	Smartwatch
	Digital watch
	Social media
	Social network sites
	Social platforms
	Twitter
	Facebook
	Google
	Geospatial technology
	Global navigation satellite systems
	Geographical Information System
	Remote sensing
	Smart sensors
	Ingestible electronic devices
	Bio-sensors

Related to study design	(AND) Related to new and emerging data and communication technologies
	Crowdsourcing
	Crowd seeding
	Artificial intelligence
	Passive data collection

The result of the search process is presented in the diagram below. As a first step, the initiatives of harmonization and integration of health studies identified by WP1 partners and MEDLINE search under WP1 or provided by WP4 partners were evaluated for the identification of those that use new communication technologies. However, using this methodology only resulted in the identification of two studies: The Nord-Trøndelag Health Study (HUNT4) and Avon Longitudinal Study of Parents and Children (ALSPAC). Therefore, we decided to develop a separate search strategy which involved the review of the manuscripts obtained in the search in MEDLINE/PUBMED/COCHRANE/EBSCO databases or reference list of selected papers or review papers. All the studies listed according to the established keywords were evaluated by two researchers (based on the title/abstract and if needed full text of the paper). Finally, 163 studies met the inclusion criteria for that search strategy. The most important reasons for exclusion of the studies were as follows: 1) studies were conducted before 2012, 2) articles were not in English language, 3) there were no cohort studies or clinical trials, 4) new communication technologies were not used for data collection or communication, 5) studies have not included selected new communication technologies and 6) some of them were published in several papers (i.e. duplicated studies).

2.2 Results of the searching process – studies included in the public repository https://repository.synchros.eu

Figure 1 PRISMA diagram of mapping search results



*In one study more than one new communication technologies can be used.

3. REPOSITORY OF THE STUDIES USING NEW COMMUNICATION TECHNOLOGIES

The repository itself (https://repository.synchros.eu/) has been developed under the WP 1 (D1.2). It offers a public collection of information about the main European and international efforts to harmonize and integrate cohort data including details about harmonization and integration methodology, communication technologies used in cohorts and exposure and health risk cohorts. It represents the digital platform of compiled European and international initiatives and cohorts mapped by WP1, WP2 and WP4 of the SYNCHROS project accessible for the public. The SYNCHROS repository has been developed with the objective of having a long-term solution that can continuously be enriched, even after the project has ended. The final studies identified from

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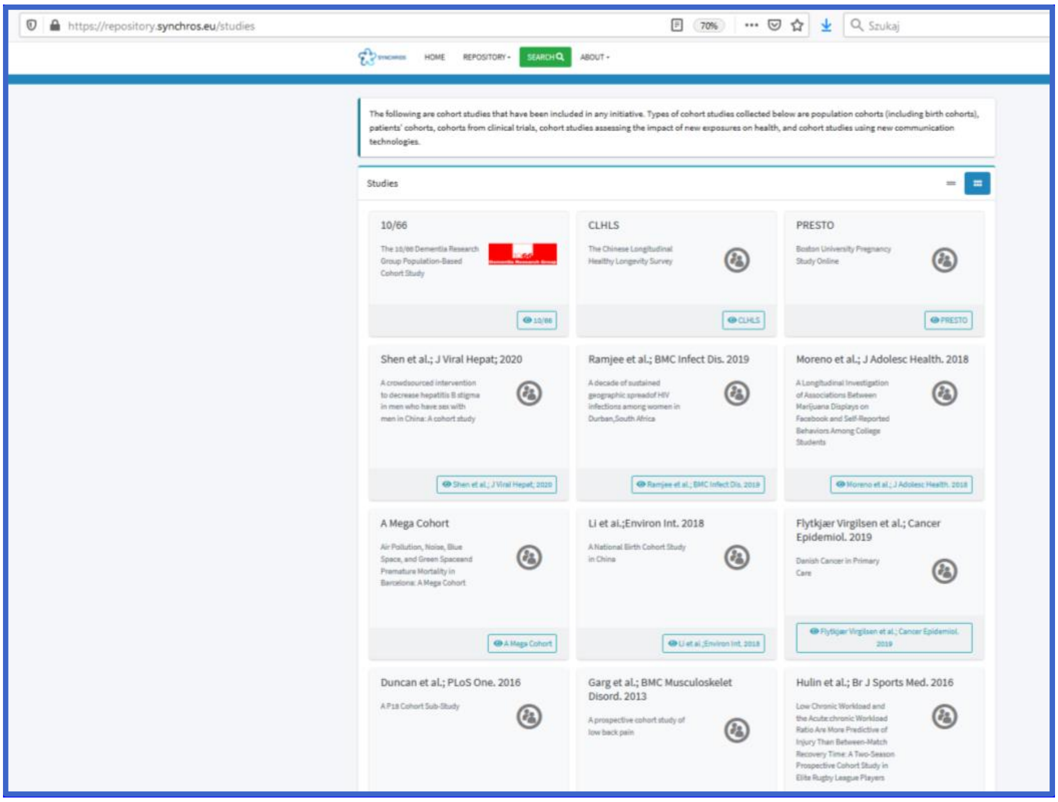
the search conducted, have been mapped in the repository. The repository contains 163 studies (population cohorts, patients' cohorts and clinical trials) that use new communication technologies.

Figure 2 SYNCHROS Repository – overview of cohort studies



The following are cohort studies that have been included in any initiative. Types of cohort studies collected below are population cohorts (including birth cohorts), patients' cohorts, cohorts from clinical trials, cohort studies assessing the impact of new exposures on health, and cohort studies using new communication technologies.

Studies

10/66
The 10/66 Dementia Research Group Population-Based Cohort Study

CLHLS
The Chinese Longitudinal Healthy Longevity Survey

PRESTO
Boston University Pregnancy Study Online

Shen et al.; J Viral Hepat; 2020
A crowdsourced intervention to decrease hepatitis B stigma in men who have sex with men in China: A cohort study

Ramjee et al.; BMC Infect Dis. 2019
A decade of sustained geographic spreadof HIV infections among women in Durban,South Africa

Moreno et al.; J Adolesc Health. 2018
A Longitudinal Investigation of Associations Between Marijuana Displays on Facebook and Self-Reported Behaviors Among College Students

A Mega Cohort
Air Pollution, Noise, Blue Space, and Green Spaceand Premature Mortality in Barcelona: A Mega Cohort

Li et ai.;Environ Int. 2018
A National Birth Cohort Study in China

Flytkjær Virgilsen et al.; Cancer Epidemiol. 2019
Danish Cancer in Primary Care

Duncan et al.; PLoS One. 2016
A P18 Cohort Sub-Study

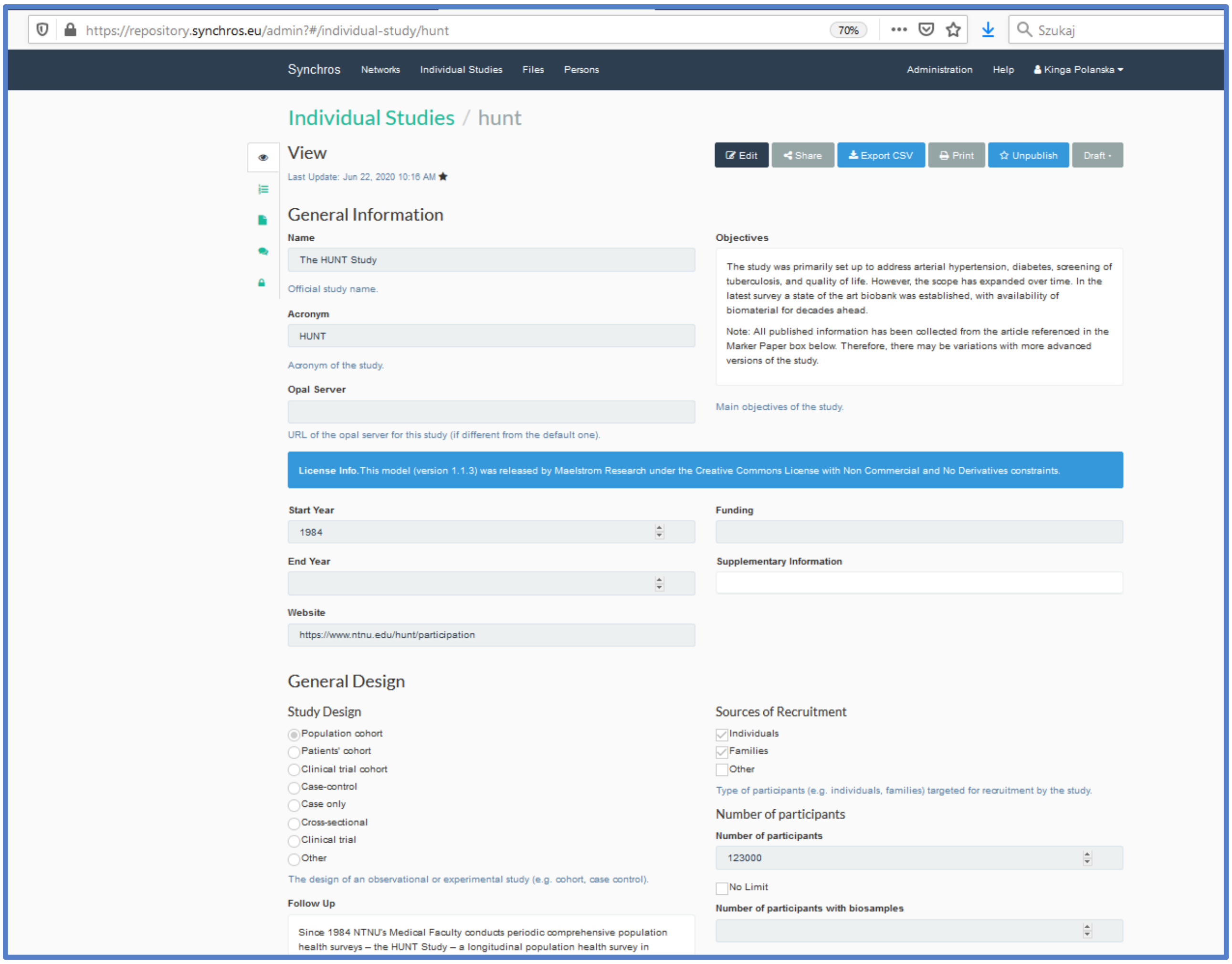
Garg et al.; BMC Musculoskelet Disord. 2013
A prospective cohort study of low back pain

Hulin et al.; Br J Sports Med. 2016
Low Chronic Workload and the Acute:chronic Workload Ratio Are More Predictive of Injury Than Between-Match Recovery Time: A Two-Season Prospective Cohort Study in Elite Rugby League Players

For each study included in the repository the following information has been added:

1) General information: study name and acronym (if available), study objectives, study design and funding sources.

Figure 3 – SYNCHROS repository – data of individual study



Individual Studies / hunt

View

Last Update: Jun 22, 2020 10:16 AM ★

General Information

Name
The HUNT Study
Official study name.

Acronym
HUNT
Acronym of the study.

Opal Server
URL of the opal server for this study (if different from the default one).

Objectives

The study was primarily set up to address arterial hypertension, diabetes, screening of tuberculosis, and quality of life. However, the scope has expanded over time. In the latest survey a state of the art biobank was established, with availability of biomaterial for decades ahead.

Note: All published information has been collected from the article referenced in the Marker Paper box below. Therefore, there may be variations with more advanced versions of the study.

Main objectives of the study.

License Info. This model (version 1.1.3) was released by Maelstrom Research under the Creative Commons License with Non Commercial and No Derivatives constraints.

Start Year
1984

End Year

Website
https://www.ntnu.edu/hunt/participation

Funding

Supplementary Information

General Design

Study Design

● Population cohort
○ Patients' cohort
○ Clinical trial cohort
○ Case-control
○ Case only
○ Cross-sectional
○ Clinical trial
○ Other

The design of an observational or experimental study (e.g. cohort, case control).

Follow Up
Since 1984 NTNU's Medical Faculty conducts periodic comprehensive population health surveys – the HUNT Study – a longitudinal population health survey in

Sources of Recruitment

☑ Individuals
☑ Families
☐ Other

Type of participants (e.g. individuals, families) targeted for recruitment by the study.

Number of participants

Number of participants
123000

☐ No Limit

Number of participants with biosamples

2) Population description including type of population and number of participants.

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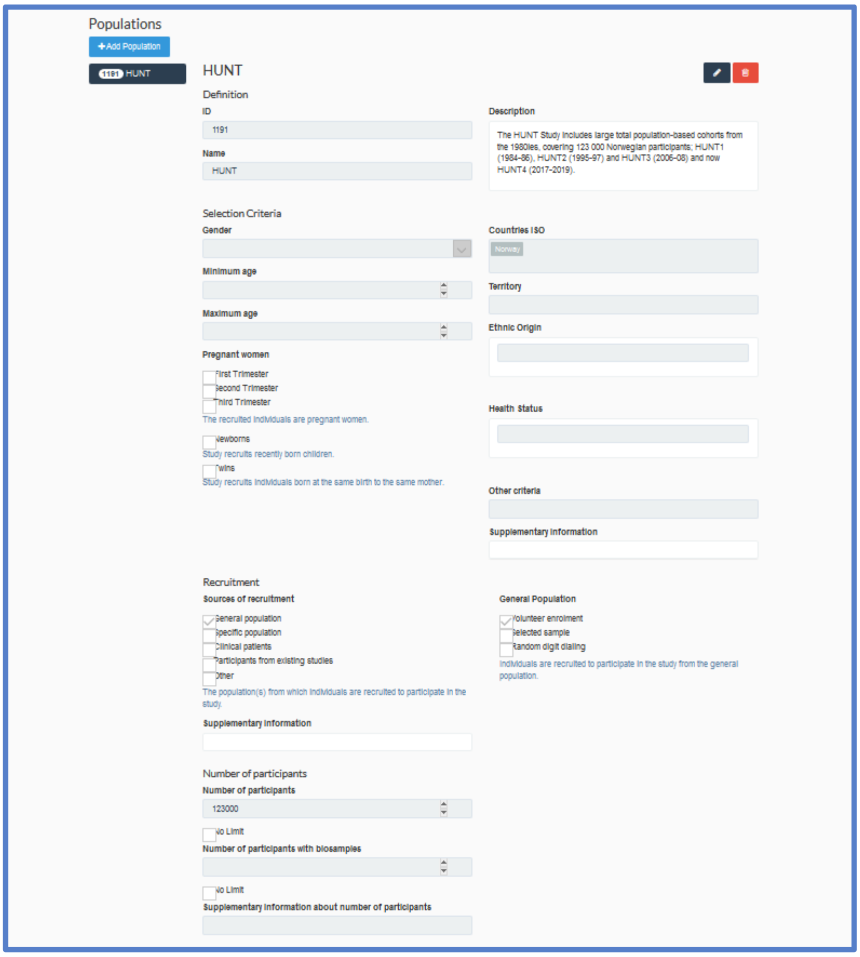
Figure 4 SYNCHROS repository - Population description including type of population and number of participants



Populations

HUNT

Definition

ID: 1191

Name: HUNT

Description: The HUNT Study includes large total population-based cohorts from the 1980ies, covering 123 000 Norwegian participants; HUNT1 (1984-86), HUNT2 (1995-97) and HUNT3 (2006-08) and now HUNT4 (2017-2019).

Selection Criteria

Gender

Countries ISO: Norway

Minimum age

Territory

Maximum age

Ethnic Origin

Pregnant women

☐ First Trimester
☐ Second Trimester
☐ Third Trimester

The recruited individuals are pregnant women.

☐ Newborns

Study recruits recently born children.

☐ Twins

Study recruits individuals born at the same birth to the same mother.

Health Status

Other criteria

Supplementary information

Recruitment

Sources of recruitment

☑ General population
☐ Specific population
☐ Clinical patients
☐ Participants from existing studies
☐ Other

The population(s) from which individuals are recruited to participate in the study.

General Population

☑ Volunteer enrolment
☐ Selected sample
☐ Random digit dialing

Individuals are recruited to participate in the study from the general population.

Supplementary information

Number of participants

Number of participants: 123000

☐ No Limit

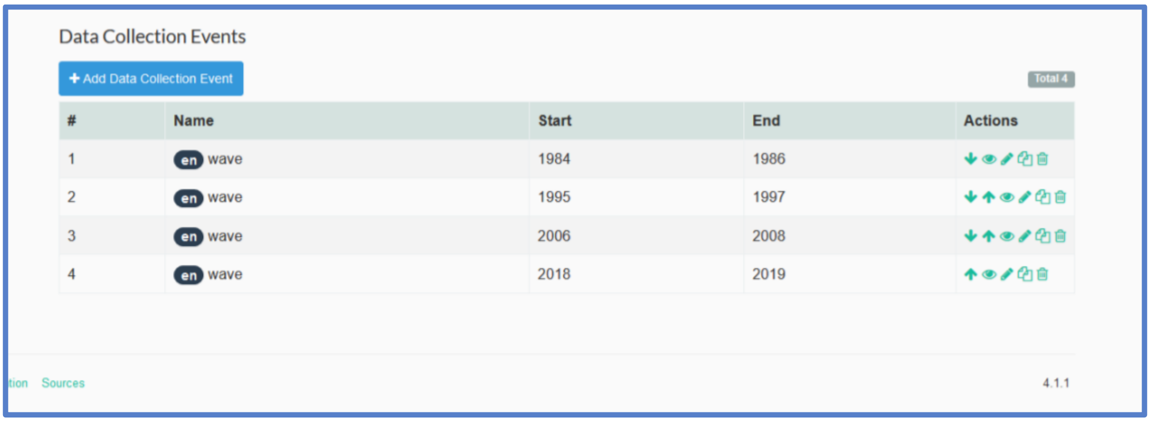
Number of participants with biosamples

☐ No Limit

Supplementary information about number of participants

3) Data collection event describing each wave of the study and new communication technologies used in the study.

Figure 5 SYNCHROS repository – description of data collection event



Data Collection Events

#	Name	Start	End	Actions
1	en wave	1984	1986	
2	en wave	1995	1997	
3	en wave	2006	2008	
4	en wave	2018	2019	

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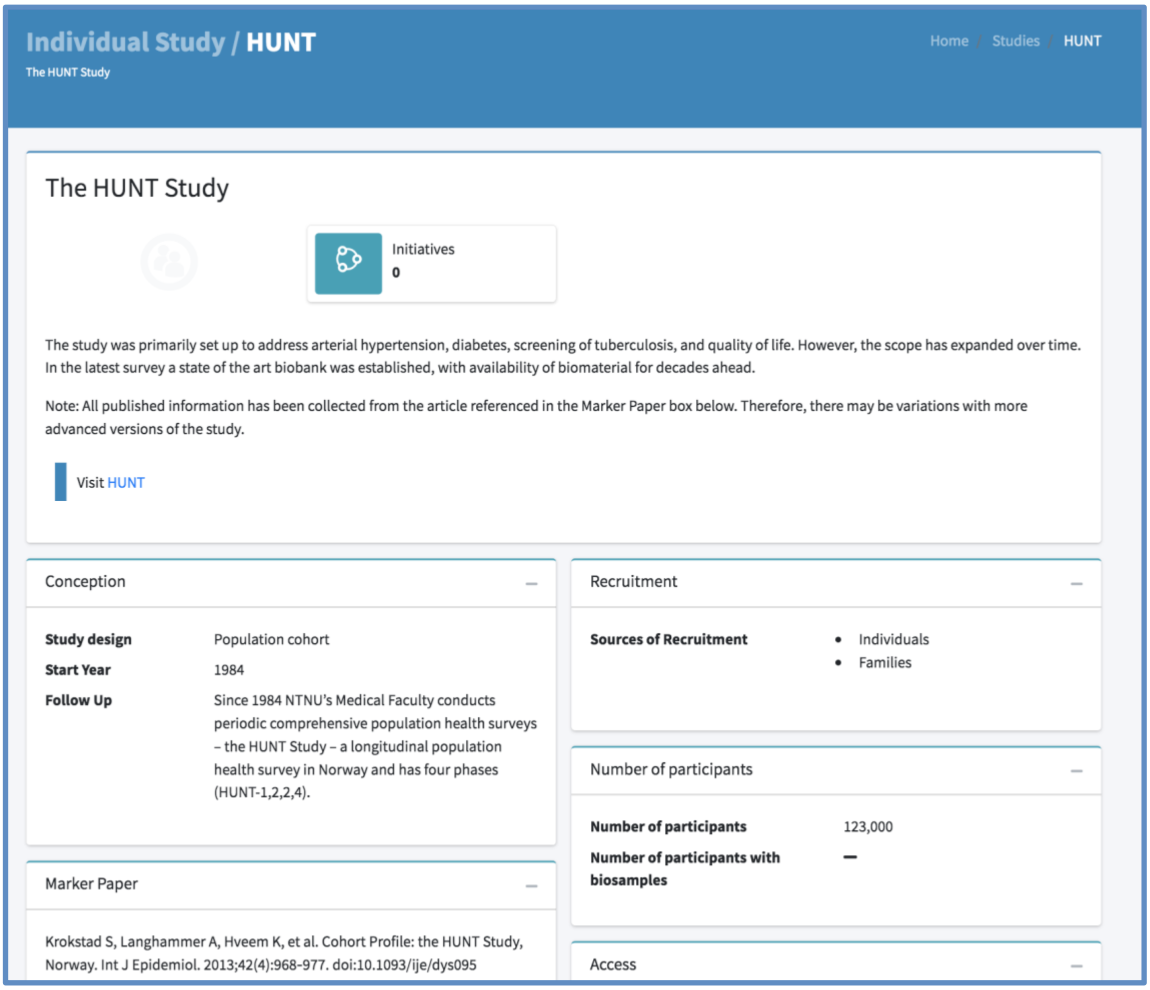
All entered studies (163 studies using new communication technologies) are available to the public (https://repository.synchros.eu) in the searchable repository. The detailed information for each individual study can be generated as seen in the example presented below:

Figure 6 SYNCHROS Repository – detailed information of individual studies



The HUNT Study

The study was primarily set up to address arterial hypertension, diabetes, screening of tuberculosis, and quality of life. However, the scope has expanded over time. In the latest survey a state of the art biobank was established, with availability of biomaterial for decades ahead.

Note: All published information has been collected from the article referenced in the Marker Paper box below. Therefore, there may be variations with more advanced versions of the study.

Visit HUNT

Conception

Study design Population cohort

Start Year 1984

Follow Up Since 1984 NTNU's Medical Faculty conducts periodic comprehensive population health surveys – the HUNT Study – a longitudinal population health survey in Norway and has four phases (HUNT-1,2,2,4).

Marker Paper

Krokstad S, Langhammer A, Hveem K, et al. Cohort Profile: the HUNT Study, Norway. Int J Epidemiol. 2013;42(4):968-977. doi:10.1093/ije/dys095

Recruitment

Sources of Recruitment
- Individuals
- Families

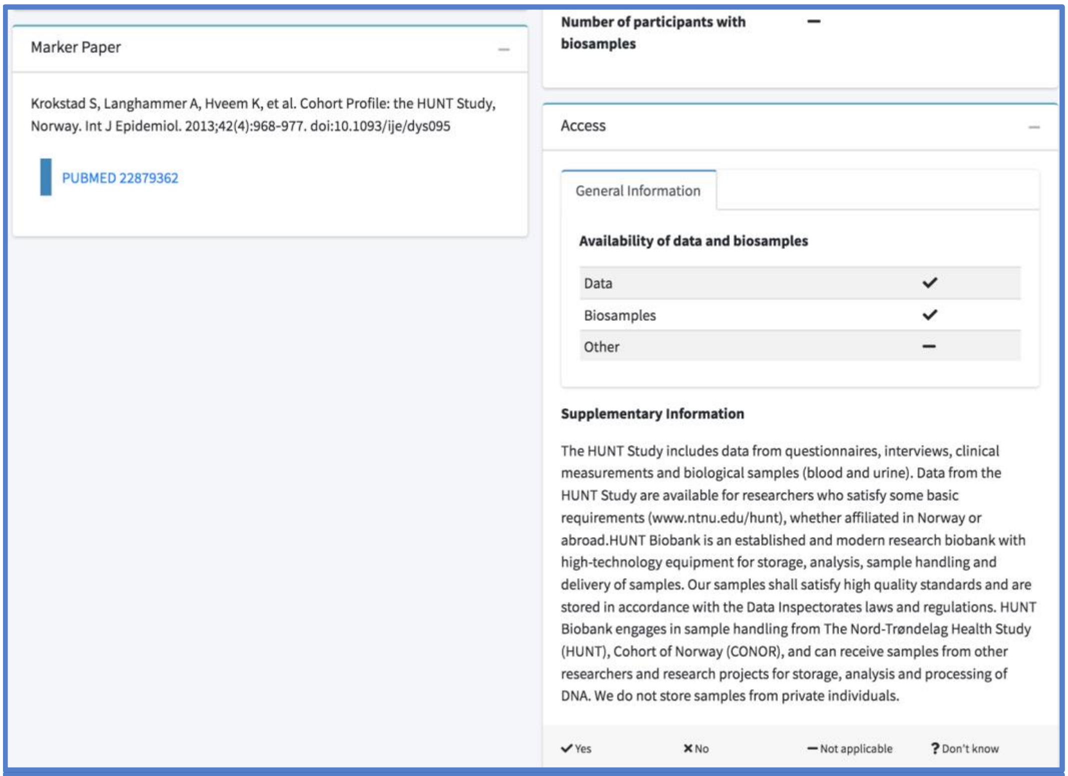
Number of participants

Number of participants 123,000

Number of participants with biosamples —

Access

*Image continues in below



Marker Paper

Krokstad S, Langhammer A, Hveem K, et al. Cohort Profile: the HUNT Study, Norway. Int J Epidemiol. 2013;42(4):968-977. doi:10.1093/ije/dys095

PUBMED 22879362

Number of participants with biosamples	—

Access

General Information

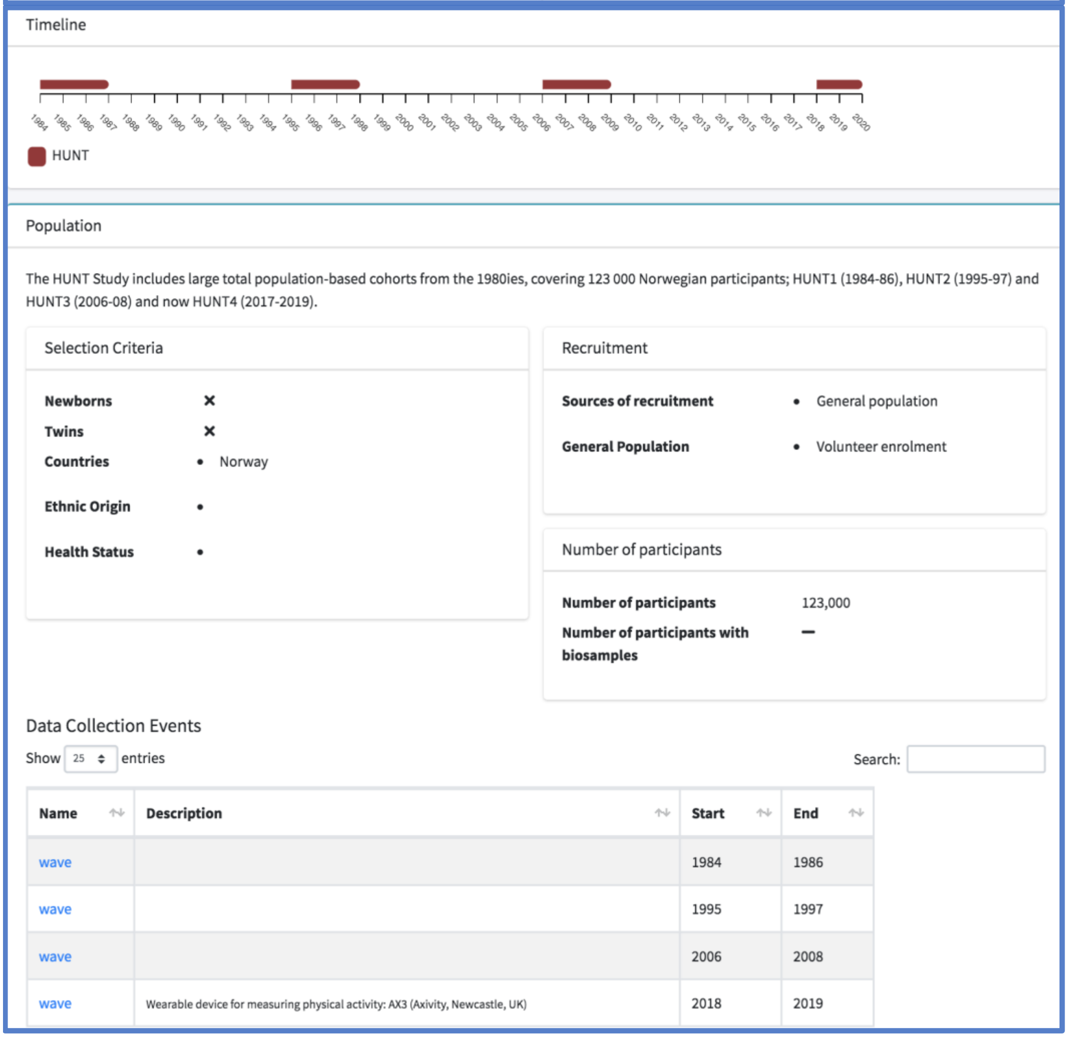
Availability of data and biosamples

Data	✓
Biosamples	✓
Other	—

Supplementary Information

The HUNT Study includes data from questionnaires, interviews, clinical measurements and biological samples (blood and urine). Data from the HUNT Study are available for researchers who satisfy some basic requirements (www.ntnu.edu/hunt), whether affiliated in Norway or abroad.HUNT Biobank is an established and modern research biobank with high-technology equipment for storage, analysis, sample handling and delivery of samples. Our samples shall satisfy high quality standards and are stored in accordance with the Data Inspectorates laws and regulations. HUNT Biobank engages in sample handling from The Nord-Trøndelag Health Study (HUNT), Cohort of Norway (CONOR), and can receive samples from other researchers and research projects for storage, analysis and processing of DNA. We do not store samples from private individuals.

✓ Yes ✕ No — Not applicable ? Don't know



Timeline

Population

The HUNT Study includes large total population-based cohorts from the 1980ies, covering 123 000 Norwegian participants; HUNT1 (1984-86), HUNT2 (1995-97) and HUNT3 (2006-08) and now HUNT4 (2017-2019).

Selection Criteria

Newborns	✕
Twins	✕
Countries	• Norway
Ethnic Origin	•
Health Status	•

Recruitment

Sources of recruitment	• General population
General Population	• Volunteer enrolment

Number of participants

Number of participants	123,000
Number of participants with biosamples	—

Data Collection Events

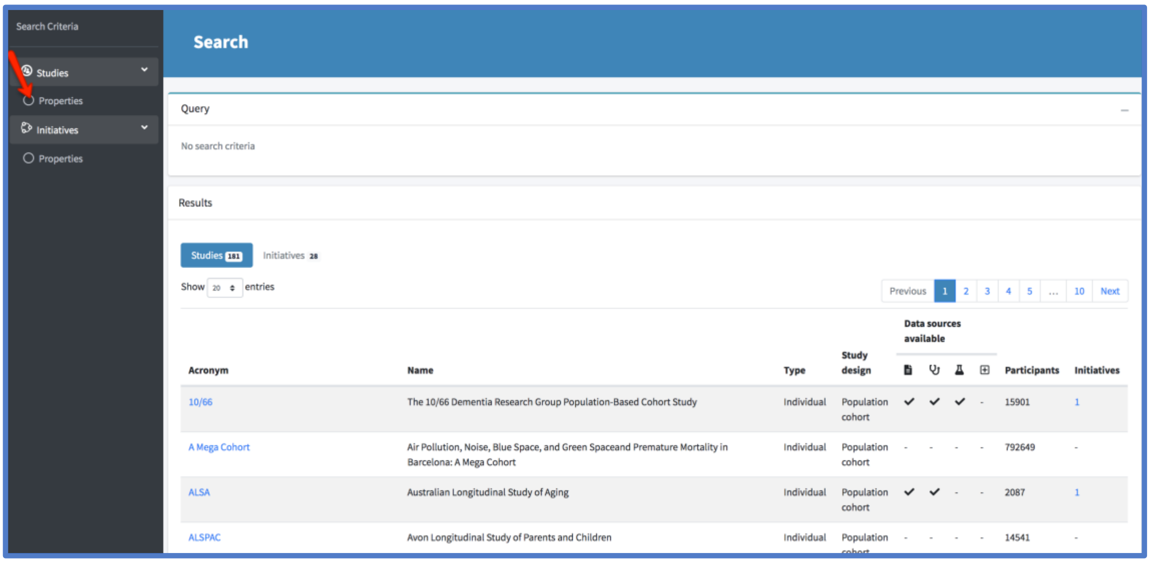
Show 25 entries

Search:

Name	Description	Start	End
wave		1984	1986
wave		1995	1997
wave		2006	2008
wave	Wearable device for measuring physical activity: AX3 (Axivity, Newcastle, UK)	2018	2019

In addition, the search can be carried out by selecting or writing the desired initiative/study properties through the left menu of the general search page. This can be done by country/region, population, type of study and type of new communication technologies used in the studies.

Figure 7 SYNCHROS Repository – Search engine



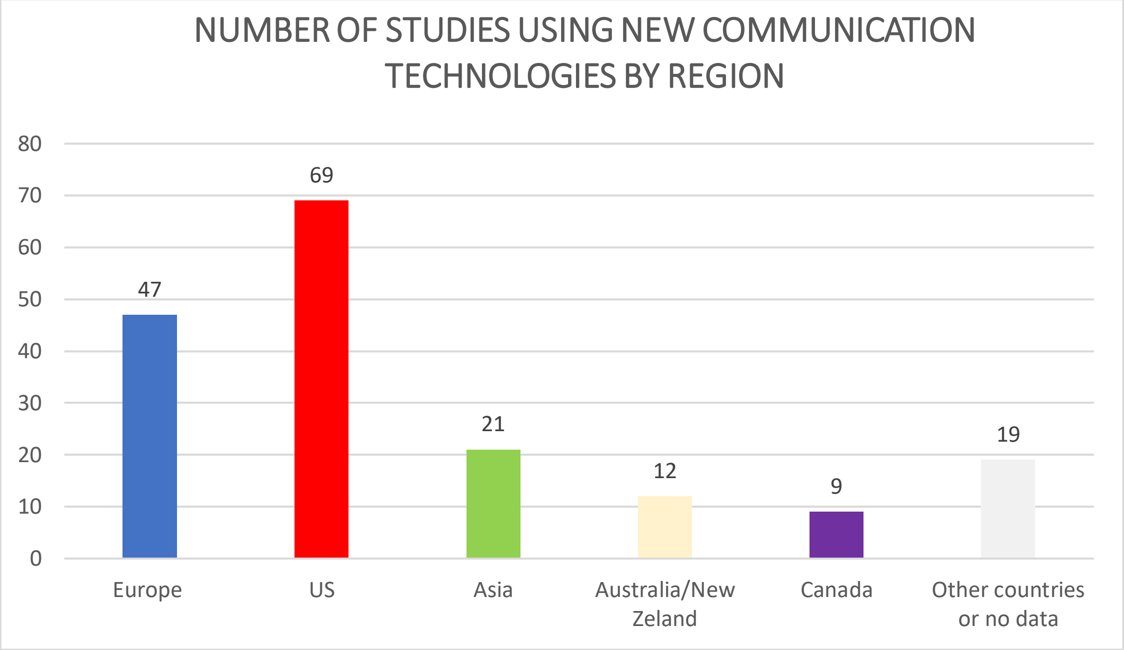
No search criteria

Acronym	Name	Type	Study design	Data sources available				Participants	Initiatives
				🗎	⚕	⚗	⊞		
10/66	The 10/66 Dementia Research Group Population-Based Cohort Study	Individual	Population cohort	✓	✓	✓	-	15901	1
A Mega Cohort	Air Pollution, Noise, Blue Space, and Green Spaceand Premature Mortality in Barcelona: A Mega Cohort	Individual	Population cohort	-	-	-	-	792649	-
ALSA	Australian Longitudinal Study of Aging	Individual	Population cohort	✓	✓	-	-	2087	1
ALSPAC	Avon Longitudinal Study of Parents and Children	Individual	Population	-	-	-	-	14541	-

4. EUROPEAN/INTERNATIONAL POPULATION COHORTS, PATIENTS' COHORTS AND CLINICAL TRIALS USING NEW COMMUNICATION TECHNOLOGIES

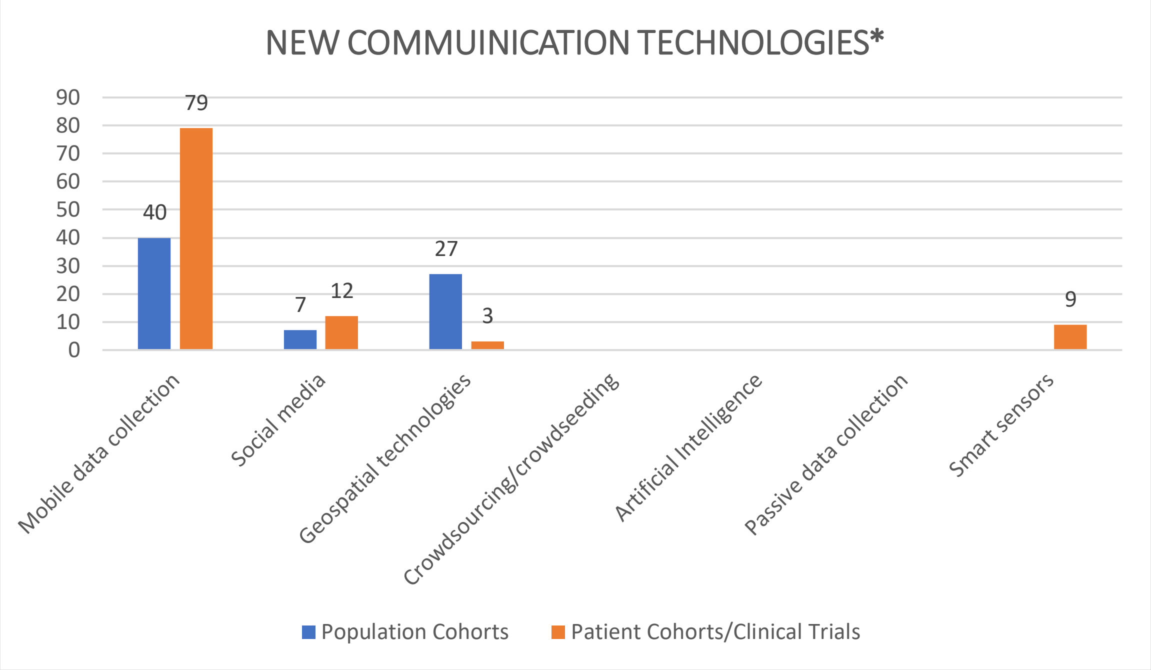
Our findings show that most of the studies that use new communication technologies were conducted in the US (69 studies) and in Europe (47 studies). Looking at the studies conducted in Europe most of them used mobile data collection, geospatial technology and smart sensors. Some of the studies are based on international collaboration.

Figure 8 – Number of identified studies using new communication technologies by region



Mobile data collection was the technology that was most frequently used in the studies (in 119 studies) and among this type of technology smartphones and/or smart apps were used in 112 studies and mobile phones in 42 studies (the other studies collect the data using smartwatches and wearables or tablets/laptops). Nineteen studies used social media for data collection and among them Facebook (15 studies) or Twitter (8 studies) were the most popular. Geospatial technology was used in 30 studies (with GPS and remote sensing used in most of the studies) and smart sensors in 9 studies (including 5 studies using ingestible sensors). There were no studies using artificial intelligence, crowdsourcing and crowd seeding techniques or passive data collection.

Figure 9 Number of identified studies that use new communication technologies by type of technology



*Number of studies in which new communication technologies were used are presented (in one study more than one new communication technologies can be used).

5. LIMITATIONS

While the methodology we employed for the search adopted was comprehensive, we are aware that our finding is not exhaustive. There may be other cohorts/ clinical trials conducted that may have used different new communication technologies that are yet to be published.

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