Citizens' Summits on COVID-19:

'Suddenly the borders played a role again'

Interreg Euregio Meuse-Rhine European Regional Development Fund

EUROPEAN UNION

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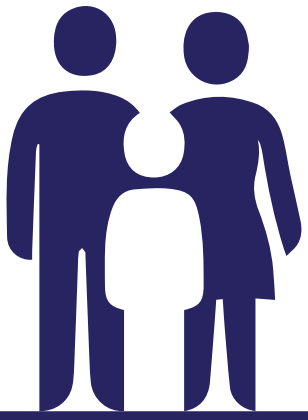
euPREVENT | COVID infectious diseases



Lost, involved, lonely, anxious, enthusiastic, committed, traumatic, quiet, back to basics, heart-breaking, heart-warming, united, misunderstood, unrecognized, tired, longing, hope, complicated by the borders in the Meuse Rhine Euregion.

Astrid van der Zanden, EPECS
Jo Maes, EPECS

Maastricht 9 November 2021

Preface

Preface

Thank you for reading this report. Thank you for listening to us, for being interested in our experiences. Some outcomes will surprise you. Some outcomes will prove to be antagonistic to boundaries, some stories are encouraging and some are profoundly sad.

The volunteers hope to give you a glimpse into their lives with COVID-19, their fears and negative and positive experiences. Hopefully you will process all this in your daily life and benefit from it.

This report was written by EPECS (European Patients Empowerment for Customised Solutions) on behalf of the euPrevent COVID-19 project, a project that EPECS enjoyed working on with its network and volunteers. EPECS used its expertise to get in touch with citizens in border regions and to collect their experiences regarding COVID-19. We have all seen the brief interviews with citizens on television, but if we give them the floor… what do they really think about certain issues? What did COVID-19 and the various measures for containing it mean to them? Posting something on social media is easier for a lot of citizens, but what is behind a post? As with many things, it is about continuing the conversation with your constituents, the people you're doing it for: the citizens. EPECS welcomes an initiative to ask citizens once again for their opinion. This makes abstract decisions and rules 'real', gives them a name, a smile, or a tear because you and I are affected by those decisions and rules.

We strongly invite you to read the outcome of the summits. A very diverse picture is presented: lost, involved, lonely, anxious, enthusiastic, committed, traumatic, quiet, back to basics, heart-breaking, heart-warming, united, misunderstood, unrecognized, tired, longing and hope.

EPECS would like to thank euPrevent for this opportunity to organise the summits. We were very happy to do so. All discussion leaders would like to thank the participants: for their openness and interest in one another and especially for their compassion. As everyone noticed during the summits: we are not alone. Sorrow is shared, a smile is passed on. Thank you. These were very special days.

Jo Maes
Chairman EPECS

1. Introduction

This first chapter focusses on the background to the project and the importance of involving citizens in the COVID-19 topics and in Euroregional cooperation. In this chapter we introduce ourselves, EPECS. The chapter also addresses the role of EPECS and our expertise.

1.1 Background

In March 2020 the World Health Organization (WHO) declared Europe the epicentre of the new coronavirus (SARS-CoV-2) pandemic. Within six weeks after the first reported and confirmed COVID-19 patient in Europe, all 27 EU member states were affected. The Meuse-Rhine Euroregion (EMR) was affected: the Netherlands, Belgium and Germany all implemented different national policies to deal with COVID-19, causing complex situations for citizens living in cross-border regions. How should these citizens deal with these differences considering the fact that their daily life, their work and their social contacts have always been based on a borderless concept?

The challenge can be even a matter of life or death when it comes to medical care. Take for example the ambulance service in Maastricht, the Netherlands: due to border restrictions a COVID-19 patient was not allowed to be transferred to the hospital of Aachen in Germany (which is just half an hour away by car) and had to be transferred by helicopter to Rotterdam (the Netherlands), which is much further away. It turned out that the hospital in Rotterdam was fully occupied and the patient had to be transferred to yet another hospital.

This example stresses the importance of cross-border collaboration between governments and health services, especially in times of crisis. The COVID-19 pandemic and the different measures that were adopted on either side of the border to cope with the same issues suddenly changed the way citizens made use of health care and how they travelled across the border for family visits, to shop, or to work. Therefore, COVID-19 had a comprehensive and intense impact on border regions like the EMR.

Research that can contribute to coordinated and harmonised Euroregional and European policy in times of a health crisis is essential. What exactly were the effects of COVID-19 on the EMR and its citizens, and how could they be measured and evaluated? These are the research questions explored via the project “The impact of COVID-19 on the EMR”, referred to as project “euPrevent COVID-19”. Citizens’ summits were organised in all three countries to gain insight into citizens’ perspective regarding COVID-19.

1. Introduction

1.2 Project framework

The project euPrevent COVID-19 was funded by Interreg EMR which is a cooperation among several partners from the EMR: GGD Zuid Limburg (Public Health Authority South Limburg, the Netherlands), euPrevent Foundation, MUMC (Maastricht University Medical Centre, the Netherlands), Sciensano (Belgium), Gesundheitsamt Düren (Health Department of Düren District), Gesundheitsamt StädteRegion Aachen (Health Department of Aachen Municipality), Gesundheitsamt Heinsberg (Health Department of Heinsberg District) and Deutschsprachige Gemeinschaft Belgiens (the German- speaking Community of Belgium).

The whole project was designed to collect data on the prevalence of antibodies in a large population of the EMR citizens, and this data is related to several possible determinants, such as compliance with infection prevention measures in the EMR, the social network of the participants, their willingness to be vaccinated and their demographics. It is particularly important to generate knowledge about the epidemiology of immunity, including acquired immunity (through vaccination intention, vaccination behaviour) and natural immunity, and its determinants. The results of the study will be used to gain insight into the extent to which people living in the Meuse-Rhine Euroregion built up antibodies, what similarities and differences there are in the various countries and what effects national infection prevention measures had. This data constitutes a solid basis for monitoring the disease and for imposing or lifting measures on a national or a regional level. In addition to the collection of quantitative data on the impact of COVID-19 in the EMR, the project also investigated lived experiences by giving EMR citizens a voice.

1.3 Importance of citizens' involvement

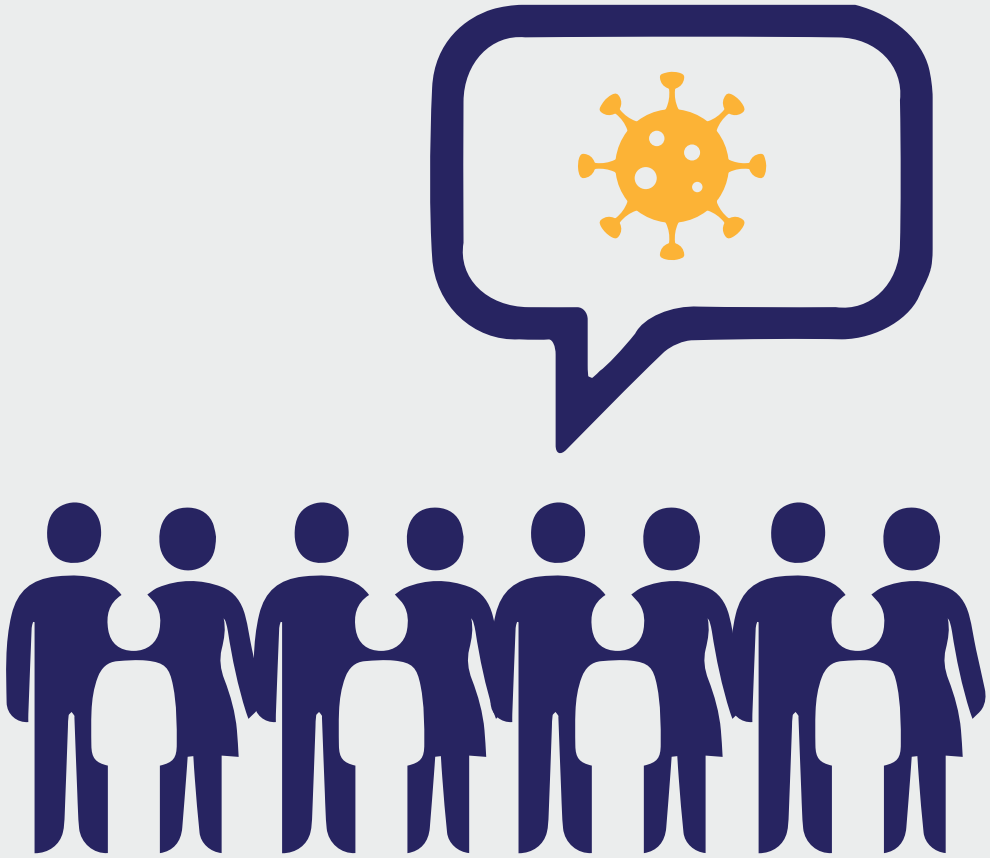
The goal of the project was to investigate and assess the impact of COVID-19 on citizens of the EMR, and the final target group is EMR citizens. Engaging citizens in the study and learning directly from citizens' experiences during the pandemic has given the research deeper insight. The knowledge we have gained from the citizens is first-hand information and constitutes an important empirical part of the project. Therefore, eight regional citizens' summits were organised so that citizens from various regions in the EMR were invited to share with us their experience during the corona period, with a particular focus on the cross-border element. These mainly include seven selected cities: Aachen (Germany), Maastricht (the Netherlands), Liège (Belgium), Hasselt (Belgium), Düren (Germany), Heinsberg (Germany), and Eupen (Belgium). In Maastricht, the citizens' summits were organised twice in different periods (June and September 2021) to see how the pandemic evolved.

1. Introduction

1.4 EPECS

The EPECS (European Patients Empowerment for Customised Solutions) foundation is committed to the health and well-being of European citizens by promoting civic participation. Since its establishment in 2007, it has gained a lot of experience in organising citizens' events and building up exchange platforms between citizens and professionals. EPECS was therefore invited to support the project group in organising the citizens' summits and drawing up the reports.

Between May and September 2021, eight citizens' summits were organised by EPECS within the framework of project "euPrevent COVID-19": 8 May in Aachen (DE), 5 June in Maastricht (NL), 12 June in Liège (BE), 19 June in Hasselt (BE), 4 September in Düren (DE), 11 September in Heinsberg (DE), 18 September in Eupen (BE) and 25 September in Maastricht (NL). This report provides an overview of the input of these citizens regarding their personal experience during the COVID-19 pandemic.



2. Methodology

In this chapter we describe the methodology and the way in which the citizens' summits were conducted. We examine the selection of themes, the recruitment of citizens and the role of the moderators. The chapter ends by discussing the possibilities and limitations of the method used.

2.1 Comparative analysis

Different national infection prevention measures affect citizens differently. In the EMR, the cross-border element plays an important role. The citizens' summits were designed to gather qualitative data on relevant topics for EMR citizens during the health crisis. By collecting life experiences across the EMR, we aimed to identify similarities and differences in the impact of COVID-19 and of infection prevention measures. This comparative approach was employed to analyse how citizens from different border regions experienced the COVID-19 pandemic, and how citizens from the same region (using Maastricht as an illustration) experienced different periods during the pandemic.

2.2 Identification of topics

With the advice of external experts, the project group and EPECS jointly determined three topics for discussion. Each topic involved several open-ended questions. These open-ended questions were used to stimulate discussion between participating citizens. Moreover, this type of question enabled moderators to identify what it is that participants value most when they introduce other topics into the discussion.

The key topics identified in the first stage include:

1. How did COVID-19 influence the citizens: in their physical and mental health, daily life, work and social contacts, travel;

2. How did the citizens find information on national response measures related to COVID-19 in their own country and in neighbouring countries, and how did they experience this information;

3. How did citizens experience health care during the pandemic and what are their opinions on health care.

2. Methodology

During the course of the project we decided to incorporate a fourth topic regarding vaccination, as a growing number of people had been vaccinated in European countries and participants spontaneously discussed vaccination against COVID-19. This was done after the first two citizens' summits, in Maastricht and Aachen. The fourth topic is:
4. What thoughts did the citizens have regarding the different vaccination strategies and to what extent were they willing to be vaccinated against COVID-19.

2.3 Participation of citizens

The invitations to citizens were mainly disseminated via the partners of the euPrevent COVID-19 project and EPECS. Sometimes other partners of euPrevent, who were not involved in this project but worked with other target groups, also made a great contribution in inviting citizens. For instance, the Suchthilfe Aachen (Addiction Treatment Centre), the Arbeitsgemeinschaft für Suchtvorbeugung und Lebensbewältigung (ASL, Working Group for Addiction Prevention and Life Coping) (BE), and the University of Liège (BE) also helped to invite citizens in Aachen, Eupen and Liège. The idea of this method was to acquire access to a diverse range of citizens, with different ages, genders, ethnicity, education and social background, so that participants in the summit would constitute a good representation of citizens from the region where the summit was organised.

Each citizens' summit aimed at reaching about 24 citizens per event. After a general presentation on the euPrevent COVID-19 project, citizens were divided into 6 focus groups. A focus group helped to gather thoughts and experiences by means of group interaction. The baseline for discussion was Theme-Centred Interaction (TCI). The citizens were informed about the topics that were to be discussed at the summit and each participant was given the opportunity to talk about his/her own experience. Under the guidance of a specially trained moderator, each group explored the topics in a roundtable discussion setting. In this setting participants were on an equal footing which encourages the exchange of information. Moreover, each citizens' summit was organised in the native language spoken by the participating region. This ensured that citizens felt at ease about sharing their life experience in an open-minded and participant-friendly atmosphere.

The citizens who participated were given a guarantee regarding transparency and the protection of privacy. To protect the privacy of the citizens, the report was made anonymous. All citizens were informed that the anonymized report would consist of the participant's contributions and would be presented on euPrevent's website and during the final conference organised as part of the project euPrevent COVID-19. All participating citizens were informed of this guarantee regarding transparency. Moreover, all citizens present at the summits expressed their willingness to receive the report by e-mail.

[1] Experience shows that TCI is an effective approach to a group discussion. This approach was also adopted at the WHO citizens' summits in 2019. See report Citizens' Summits held at Eupen (BE) and Aachen (DE) in February 2019.

2. Methodology

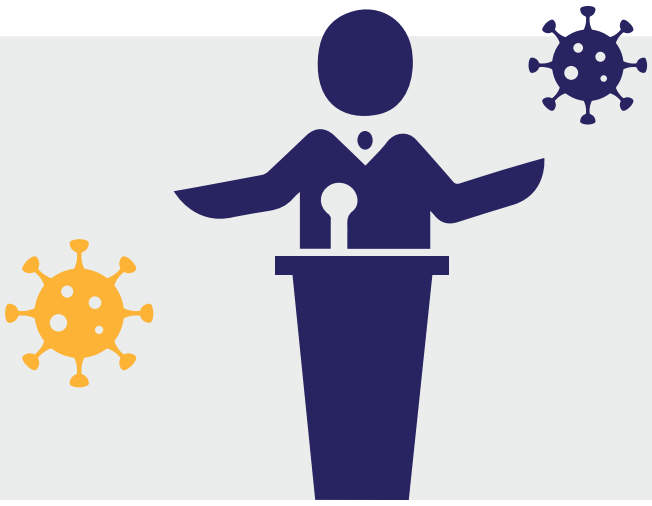
2.4 Role of moderators

At least 6 moderators were available to chair the roundtables at each citizens' summit. EPECS made sure that each summit had at least one standby moderator who could intervene if needed. The role of the moderator was to chair the discussion in such a way that every participant had an equal opportunity to give his or her own feedback on each question. The moderator remained non-judgmental towards the participating citizens, thereby creating an open-minded and friendly atmosphere during small group discussions to encourage active participation.

As each citizens' summit was organised in the local language where the summit took place, the moderators for each session were either native speakers or multilinguals. The selection of moderators was based not only on their language skills, as they were also expected to have a good understanding of the goal and structure of the project, their role as moderator and the methodology of the citizens' summit. The moderators were mostly health care professionals, academics from related disciplines (e.g. sociology, psychology), volunteers and members of EPECS.

If the moderators had not already received prior training or were experienced in moderating group discussions, they received specific training on the techniques of moderation in relation to the topics of the summits (either in English or in German). This training was given by an external bureau specialised in the training of trainers. During this training, the moderators learned how to moderate a roundtable discussion and how to deal with all kinds of situations: what if somebody was not saying anything or if someone was too loquacious, aggressive or sad and so on. The project organisers provided the moderators with background information on the project, the structure of the citizens' summit, supportive questions, and instructions on how to keep a discussion going in a positive and constructive way.

The moderators took substantial notes during each small group discussion, and the reporters drew up this final report based on those notes.



2. Methodology

2.5 Citizens' summit as a method

A citizens' summit is a valuable instrument for facilitating in-depth discussion with citizens. It provides the latter with an opportunity to voice their stories and enables professionals and policymakers to extract relevant information. Taking time to listen to citizens and take their in-depth stories seriously is an expression of the wish of policymakers and researchers to see citizens as equal stakeholders and not merely as a group of people that 'undergo' something. This makes the impact of policy and institutional functioning more visible and real. Furthermore, the outcome makes this impact recognisable and more suited to informing the professionals who design and implement policies, as things are heard that may never have been considered. However, there are also limitations that need to be taken in consideration, both in this project and for the future:

- Though a cross-sectional representation of society is wished for, realising this is not always possible. Citizens participate on a voluntary basis, so we depend on their willingness to participate. As a result, there is no guarantee that this representation was actually reached.

- COVID-19 made it impossible in this project to organise physical citizens' summits. That meant it was not always easy for everybody to participate, since it required access to a digital communication platform like Zoom.

- Digital meetings have some challenges. We noticed that it was easy for citizens to simply not turn up, so even though they actively registered for a citizens' summit, the 'no show' rate at the end of the series of citizens' summits was rather high.

- Taking into consideration the number of citizens who participated, the question was raised whether this participatory approach could be further refined or adapted in order to acquire more input from citizens.

- Moreover, an overall feeling of 'COVID-19-tiredness' was experienced by both the organisers and the moderators. It is not clear whether this feeling was warranted, but participation rates clearly dropped with each subsequent citizens' summit.

3. Outcome

It needs no further explanation when we say that COVID-19 has had an impact on everyone's life. Not only on everyone's private life but also on everyone's working life. In this chapter we explore this in more detail. We asked participants whether COVID-19 had an impact on their physical and mental health, their daily life, their social life, and their work, especially in a border region.

The results of each topic are presented separately and where possible direct quotes from participants have been placed, anonymously, in boxes.

As stated earlier, this is about citizens' opinions and experiences: there is no right or wrong. The main aims were to provide a listening ear and to be able to retrieve this valuable information. It is about how they see and experience things, not about finding the truth. It is about retrieving their daily life truths.

3.1 COVID-19 and my life

As indicated, we first wanted to know what impact COVID-19 had on everyone's life. As this is a broad open-ended question, we created sub-questions that, if needed, could be used in the small groups. These sub-questions were:

1. Has COVID-19 affected your physical and mental health? Did you receive sufficient medical treatment and care?
2. Has COVID-19 affected your social life? Have you changed or cancelled your appointments with others? Have your personal contacts changed?
3. Have you started to shop and exercise differently?
4. Have you travelled abroad in the past year? For what reason? Has COVID-19 changed how often and for what reason you travel abroad?

The following sub-paragraphs reflect on these questions from the perspective of citizens.

3. Outcome

3.1.1 Physical and mental health

Has COVID-19 affected your physical and mental health?
Did you receive sufficient medical treatment and care?

A majority indicated that they had experienced a lot of stress due to COVID-19. Participants felt stress regarding their chance of getting infected and of receiving appropriate treatment. Furthermore, the participants suffered a lot of stress about whether they had COVID-19 or not. That stress increased if the participant's health was already diminished or if they were older: suppose I get COVID-19, will I survive? Should I start living a healthier life so I don't get COVID-19 or to increase my chances of beating COVID-19?

And If I do get COVID-19, will a younger person with COVID-19 get precedence? Will they think I am too old to be given treatment?

There were also concerns about obtaining regular treatment that they normally received or for illnesses that cropped up other than COVID-19. Will I get the treatment I need or will someone with COVID-19 take precedence? Regular care was scaled down, so for many participants their medical treatment was put on the back burner so that COVID-19 patients could be dealt with. This caused a lot of uncertainty about their own long-term health. Does delay mean the participant will get treatment too late? However, participants mentioned that in cases where they needed care urgently, they got the treatment and care they needed. Those who had to go to work faced a lot of stress, both regarding the chance of getting infected at work and the possibility of not having sufficient protective supplies at work to keep them healthy.

Some participants also indicated that the duration of the COVID-19 pandemic influenced their mental well-being. In the beginning it was okay because they thought it would soon be over. It was new and there was a sense of togetherness. But the longer the pandemic lasted and the more that participants regarded measures as unclear or incomprehensible, the less their mental well-being became.

Several participants called it a kind of despondency. Going to a hospital or a general practitioner was no longer so matter-of-fact. All kinds of conditions were attached. And once in hospital or at the doctor's, you could easily get the feeling that you were being treated - as one participant put it - as if you had Ebola. It is not about a lack of friendliness, but about literally being pigeonholed and kept at a distance.

3. Outcome

The most heart-breaking was the fact that you cannot be with your loved one during the last moments of their life. Many of them found this traumatic.

The uncertainty is killing you. Because you can't say: do this because then you won't get it.

My work revolved around COVID-19 anyway, so I could not escape it, either at work or privately. That made it very tough.

Many students experienced feelings of depression. Students need a change of scenery to be able to study effectively but learning in groups was not allowed.

I can't cope with it anymore and there is little solidarity because nobody is coping.

Having just faced one horror, we could see the next life-threatening condition coming.

You think you are invulnerable and can handle anything, until you discover that invulnerability is an illusion.

In the next paragraph we discuss social life during COVID-19. Mental wellbeing and social life were often mentioned as being closely linked to each other.

3.1.2 Social life

Has COVID-19 affected your social life? Have you changed or cancelled your appointments with others? Have your personal contacts changed?

The common denominator was that social life changed a lot: social life was reduced for most people, but more for some than for others. You hardly saw your family and friends anymore. In addition, it was impossible to visit sick family members and friends, which was very stressful. Many found not being able to see their children, brothers and sisters, or grandchildren very difficult. Some citizens even spoke of having become alienated from their grandchildren because it was lasting so long. This caused a lot of stress and even more feelings of loneliness.

Contact was maintained via Whatsapp, facetime and Skype, but that is different from being together. Participants missed hugging one another a lot. A Dutch-speaking citizen called it 'huidhonger' which could be translated as 'skin craving' or 'touch deprivation'.

3. Outcome

One participant said that conversations had also changed: there was a lot of discussion about COVID-19 and whether it was there or not, and who was to 'blame'. Some discovered new layers in their friendships as a result, but others were forced to say goodbye to friends because of different views. In some families, it became a subject to be avoided in order to prevent separation into 'camps'. Juggling work, entertaining and home-schooling for their children was not always easy for participants, especially if they lived in a small house or apartment or were already responsible for taking care of another adult.

Despite the negative aspects, some good features emerged as well. One participant said that she found she had more contact by phone and computer, including from strangers who helped her. She experienced this as positive. Suddenly your neighbours were helping you or even strangers. People got notes in their mailbox offering their help if needed, to do the shopping for instance. Furthermore, a participant from Belgian Limburg indicated that many wonderful projects started, such as a project involving painting by small children for the elderly, or scouts who went shopping for elderly people.

Some participants mentioned that it had a positive effect on their relationship: couples saw one another differently and spent more time together.

Having to say goodbye via a screen or telephone: the distance couldn't be more noticeable. Someone dies alone. The loss you feel at not being able to… traumatising to this date.

It affects everyone, everyone is more careful, much lonelier.

Not being able to hold your children and grandchildren in your arms anymore.... It does something to you.

My Belgian family could not come to the funeral: that was very confronting and had a massive impact.

Many friendships shifted or disappeared.

Fortunately, people who irritate you were not able to visit you.

You suddenly get to know your neighbours.

Digitization and having to obtain supplies have increased my knowledge about many new things. Beautiful networks have been created.

3. Outcome

I don't miss my former life: I like the peace and quiet of the city, although it was a bit unsettling in the beginning.

You become more aware of nature.

You have to change your behaviour and your social life because of the risks, not because of the rules.

Being together all the time under the same roof. No time to relax, no time for yourself.

In the next paragraph we discuss whether the participants changed their shopping and exercise behaviour.

3.1.3 Shopping and exercising

Have you started to shop and exercise differently?

Shopping had fallen away for most participants, especially 'fun shopping'; and they developed new ways of obtaining groceries: either online or shopping as quickly as possible and also less frequently (from several times a week to once a week) and early in the morning to avoid busy hours. In their own words, the participants did not really hoard. They did think about the amount of food and drink in their house in case they were suddenly confronted with COVID-19. If they suddenly needed to go into quarantine, then many felt they should have enough food in their house, so that they did not have to depend on other ways of obtaining food.

The majority indicated that they exercised less as a result of COVID-19, although some started to exercise more purposefully (walking or cycling to the supermarket). Prior to COVID-19, hardly anyone thought about what one could or could not do. Because of COVID-19, people no longer take for granted many of the things they used to take for granted. This includes, for example, going to a neighbouring country and going out for meals. Sports schools were suddenly closed, and alternatives had to be found for swimming, fitness and football. Things that they did more frequently included taking a walk or going out for a bike ride.

It also made participants more creative. One of the participants, for example, started a vegetable garden.

3. Outcome

Because I can only do my shopping with a social worker and with a face shield on, I am now limited to the one supermarket that accepts this.

I have spent much less money. I also plan my shopping now: once a week and I no longer make impulsive purchases.

I no longer feel the need to go shopping.

In the next paragraph we discuss whether people still travelled abroad.

3.1.4 Traveling abroad

Have you travelled abroad in the past year? For what reason?
Has COVID-19 changed how often and for what reason you go abroad?

Most did not go abroad while others reduced the amount of traveling they did. A distinction was made between traveling for the purpose of a holiday and traveling for day-to-day purposes. A few travelled abroad because of products they needed which could be bought just over the border; this also included things as gas and groceries. One participant indicated that she felt like a smuggler because she was not allowed to go from Belgium to Germany to do her shopping. But as groceries are much cheaper there, she did her shopping there anyway. She would cross the border on foot with the children. After arriving back at their car, they put everything under their seats.

In addition to this, participants visited relatives and friends, not just for socialising but also out of necessity. Participants did not regard helping their parents who live in the neighbouring country as traveling but as providing informal care. Not being able to do this due to the borders being closed was seen as stressful for both parties involved. However, even though this kind of day-to-day travel was not regarded as real ‘traveling’, the participants did reduce it as much as possible. Most of them refrained from traveling for the purpose of going on holiday. Many participants cancelled their holidays or interrupted their vacations. It was difficult to get home: some managed via detours. The few who did go on holiday, followed the rules strictly.

3. Outcome

I miss vacations very much. Doing nothing at home feels different from doing nothing abroad.

The worst thing was the closing of the borders: because of that commuting was hampered, visiting relatives was not possible, nor shopping, it affected everything.

Searching your car when you had crossed the border between the Netherlands and Belgium was an extreme form of control.

Suddenly the borders played a role again.

In one country you still had to wear a mouth mask and in another country you didn't. It was a very strange situation. You were checked if you travelled from the Netherlands to Germany, but if you travelled from Germany to the Netherlands you weren't checked.

3.2 COVID-19 related information and national measures

How the participants perceived COVID-19 depended a lot on the content of the information presented and how it was presented. The general question asked was:
How did they find information on national response measures relating to COVID-19 in their own country and in neighbouring countries, and how did they experience this information.

The questions which guided the discussion of this topic were the following:

1. Did you receive enough information about COVID-19? Were you able to apply and follow the COVID-19 measures? (easy/difficult? Problems?)

2. Did the national policy lead you to change or cancel your membership of associations? What influence has this had?

3. Are you aware of COVID-19 measures in neighbouring countries and do you know where to get this information? Do you take it into account when travelling to another country? Personal experience, e.g. being refused entry to another country?

The participants' views on this topic are described in the next sub-paragraph.

3. Outcome

3.2.1 Information

Did you receive enough information about COVID-19? Were you able to apply and follow the COVID-19 measures? (easy/difficult? Problems?)

The majority indicated that they experienced an overload of information, some of which was contradictory. However, some German participants felt that they were not sufficiently informed by their national government. Others found that the information given by the country was very good.

Participants saw contradictions especially between government sources and the press. They regarded the media as exaggerating and sensation-seeking. Others said that the requirements were unclear: why do you have to wash your hands, etc? Some participants indicated that there should be more reliance on COVID-19 specialists: they should know how things will go. And some noticed that a decision was taken on a national level but was changed again on a Flemish level. Furthermore, it was very confusing that each European country had different rules: this caused uncertainty and reduced confidence in their own internal policy.

It was particularly difficult for people who were not used to looking things up on the internet and reading texts issued by their government.

The government should have used influencers earlier, so that those who only get their information from social networks find good reasons to get vaccinated.

Since the rules were constantly being changed, almost on a weekly basis, even professionals were sometimes unclear. The participants noticed this, because when they inquired somewhere, they got even more unclear answers or just the answer “I don’t know any more either!”.

However, there was a slight difference in how the Dutch, Germans and Belgians felt about the provision of information: the Belgians were overall quite satisfied, whereas the Dutch were a lot more critical.

Communication took place via two GGDs (Brabant and Zuid-Limburg) and that was confusing. It seemed as if the two processes ran alongside each other.

The measures were not always communicated properly, which often led to despair. It became clear to me that health is not an EU subject.

3. Outcome

Europe should have opened the umbrella from the beginning and said: we are going to regulate this on a European level, and this is the basic structure for everyone from which we will start.

I felt let down by the lack of leadership.

Reports about COVID-19 automatically appeared on one couple's screen via news apps. After a while they distanced themselves from the many notifications. Too much is too much....

3.2.2 Membership of associations

Did the national policy lead you to change or cancel your membership of associations? What influence has this had?

The answers were very diverse: some cancelled memberships, while others - for reasons of piety - did not cancel anything. Some participants started to do more voluntary work. Others were more consciously occupied with avoidance and their own health, and yet others who just let go. A lot was done online or outdoors where they felt there was more space.

One participant mentioned that some of the associations of which she was a member suffered due to COVID-19: the largest one even had to shut down.

I am a member of the carnival and the home club and I would never unsubscribe because they depend on contributions.

3. Outcome

3.2.3 COVID-19 and travelling

Are you aware of COVID-19 measures in neighbouring countries and do you know where to get this information? Do you take it into account when travelling to another country? Personal experience, e.g. being refused entry to another country?

Traveling abroad was also mentioned in a previous paragraph. This question, however, specifically addressed whether the participants who did go abroad were able to obtain information about COVID-19 measures in the neighbouring countries.

Most of them indicated that they either did not go to neighbouring countries or they knew where to find information. A few had problems because a zone suddenly changed colour: what to do when you are already there or when you plan to leave on that very day. They felt that this information could have been communicated better. A smaller group found it difficult to find country-specific information that was up to date.

Many participants found it difficult to keep up with the ever-changing rules in their own country, let alone in neighbouring countries.

Long live Facebook: that's where I got a lot of information today.

3. Outcome

3.3 COVID-19 and health care

One of the main topics that kept resurfacing, irrespective of the stage of the pandemic, was the burden on the health care system and the effects this had on individual participants who needed to make use of the health care system. This was thus the topic of the third part of the discussions with the participants:

How did participants experience health care during the pandemic and what are their opinions on health care.

To get insight into what this meant for the participants, the following sub-questions were discussed with them:

1. Were you hesitant about contacting a doctor? Do you normally visit your family doctor or the hospital? Has this changed? Do you seek health care more or less frequently? Why?
2. What is your relationship with and/or your opinion of medical care?
3. How do you see health care providers, what they deliver and how they are valued? What do you think the future holds for health care?
4. What do you see and experience regarding equal access to care?
5. How do you feel about being transferred to a hospital in a neighbouring country? Would you rather stay in your own country, even if it is much further away?

The views of the participants are described in the next sub-paragraphs.

3.3.1 Using the health care system

Were you hesitant about contacting a doctor? Do you normally visit your family doctor or the hospital? Has this changed? Do you seek health care more or less frequently? Why?

The majority indicated that normal care was postponed: annual gynaecological check-ups, dental appointments, etc; but for some, this care continued as usual.

3. Outcome

Some did not approach their GP because the GP was already so busy or because the GP was difficult to reach. One participant said that an ordinary patient had to shuffle off for the benefit of a COVID-19 patient. It seemed as if cancer suddenly no longer “existed”. Another comment was that little information was given about the consequences of postponing surgery and care. People were afraid of the possible consequences. Some did not want to go to hospital for fear of contracting COVID-19. They had heard stories from acquaintances who had been affected. One of the participants, who is a GP, saw as much as a 90% decrease in appointments in his practice. On the other hand, the number of questions via the telephone, Whatsapp etc. exploded. Uncertainty was a major issue here, and it changed during the COVID-19 period. When it came to not being able to go to hospital or if care was delayed, citizens were much more understanding at the beginning of the pandemic than a year later.

Avoid those places if not really necessary.

I have never refused to go or to see a patient, but many of my colleagues refused patients and abandoned their posts. They were afraid.

3.3.2 Experiencing medical care

What is your relationship with and/or your opinion of medical care?

The participants were divided on the topic of medical care. Some were very positive and trust the staff. Others felt abandoned: they received little help and had to find out many things for themselves. The distance from one another and from the staff was experienced as problematic. One participant said that the term “corona victim” is misplaced. We don’t talk about cancer victims, do we? Other diseases are just as bad. Another participant said that she had to pay a lot herself, but while at first her mouth masks were reimbursed because of her mental condition, now it is the other way around: she can now buy 100 mouth masks per month while in the past there were not enough even in hospitals.

3. Outcome

3.3.3 Value and future of health care

How do you see health care providers, what they deliver and how they are valued? What do you think the future holds for health care?

All participants said the same thing, namely that in the beginning there was a lot of attention for care-workers, but that this quickly faded away. Many participants felt the praise for the health care system and its employees was excessive. They do deserve recognition and appreciation, but their glorification was an exaggeration. They need more appreciation from the government: in terms of workload and financial appreciation.

Care-workers have to work for too long, they are overtired and underpaid. This is considered very bad. It is asking for a burnout.

The financial compensation that was promised to care-workers has either not been paid out yet or it is a gross sum, so it is very insignificant. One participant called it a “shut up and be quiet” gift.

The profession was already unattractive to school children, but people are afraid that this has made matters worse. Also, the initiative of showing appreciation for care-workers was initially seen as positive, but what use is it if nobody sticks to the rules?

A big challenge in the future will be mental health care. During the COVID-19 period this was inaccessible for many people and COVID-19 itself also had a huge impact on some people’s mental health: there were a lot of dismissals, people were unable to say goodbye to loved ones, children are growing up with mouth masks, etc.

The profession of health care provider needs to become attractive again.

Friends who work in health care worry about how things will be when they are old themselves, there will not be enough staff.

I feel respect and pity for health care providers.

3. Outcome

3.3.4 Equal access to care

What do you see and experience regarding equal access to care?

Some participants indicated that before COVID-19 occurred, there was certainly equal access to care. Looking from a broader perspective and not only at COVID-19, some also indicated that people with physical disabilities found it difficult to access care. This was partly due to waiting lists, but also because COVID-19 showed no signs of going away. Operations were therefore being cancelled.

One participant said that in Belgium there was a difference in access to health care: those who can afford it take out good hospitalisation insurance and get good specialists; others can only pay for basic care.

Another participant indicated that equal access exists for people who know how to find it. “We have to deal with rapid changes, many adjustments, new rules. You have to be able to cope with rapid changes and these must be accompanied by clear instructions”.

Yet another indicated that equal access to care does not exist: few doctors make house calls these days, which is a problem for the elderly; and many doctors no longer have sufficient time for their patients, so they are more likely to prescribe medication than, for example, physiotherapy.

Equal access to care is strongly influenced by the way insurance is regulated in a country. Self-employed people sometimes fall through the cracks, and the same applies to homeless people and asylum-seekers.

Some German participants said that inequality will always exist because health care is decked by government insurance and private insurance. In the Netherlands, however, everyone is treated the same when they are in hospital.

A Dutch participant said that a low socio-economic status is linked to poor health. People on welfare do not go to the dentist because it is too expensive, so this is something that relates not only to COVID-19. They are aware of this even in ‘normal’ times.

3. Outcome

3.3.5 Transfer to a neighbouring country

How do you feel about being transferred to a hospital in a neighbouring country? Would you rather stay in your own country, even if it is much further away?

Almost all participants indicated that if it is necessary for their health, it does not matter whether they are treated in their own country or in a neighbouring country or even further away. If you are very ill, the doctor decides what is best. It is important to consider the language and the distance. Being able to communicate with the medical staff is essential, so one person indicated that they would rather be treated in Maastricht than Liège because of the language barrier. Another indicated that Düsseldorf is doable, but that there are countries to which the participant would rather not go. A few indicated that such transfers should be arranged by the hospitals themselves, which should also take the language issue into account. Another indicated that “language and empathy” go together, so that it is sometimes difficult if you are not treated in your country of residence.

People sometimes said that distance could be a problem. A location closest to home is always preferred. That way you are close to home, and it is easier for your family to come and visit you. For example, one participant indicated that it would be a problem where their own children are concerned, because then the distance would be too great. Another participant said that when she was injured abroad, she insisted on being brought back to her country of residence.

One participant remarked that in the countries surrounding the Netherlands, the risk of MRSA infection (hospital infection) is greater and that you must go into quarantine for post-operative care in the Netherlands. That’s something to think about.

It is about choosing between life or death: very simple. Everything that needs to be done should be done, even if it means I have to travel to the other side of the world.

I voluntarily went to a hospital in Malta after too many postponements of care in Belgium.

Never thought about it. But if I must, I would do it and my family would accept it.

3. Outcome

3.4 Vaccination issue

During the sequel of the citizens' summits, vaccination was increasingly becoming an issue. The decision was therefore made, after two citizens' summits, to incorporate this topic in the remaining citizens' summits. Especially because the countries were putting a lot of effort into getting as many people as possible vaccinated. The question we asked was therefore:
What are your thoughts on the different vaccination strategies and to what extent are you willing to be vaccinated against COVID-19?

The sub-questions that guided this topic are:

1. Do you want to be vaccinated, have you been vaccinated, or do you know when you will be vaccinated? If you have been vaccinated, how was your experience with the whole vaccination process, from the moment you received the invitation until the end of vaccination?

2. What about side effects of the vaccination?

3. Do you think that vaccination should be made compulsory for certain professions, for example in health, hospitality and education? Would you accept it yourself?

These individual questions are addressed in the following paragraphs.

3.4.1 Vaccination or not

Do you want to be vaccinated, have you been vaccinated, or do you know when you will be vaccinated? If you have been vaccinated, how was your experience with the whole vaccination process, from the moment you received the invitation until the end of vaccination?

Most people said they had been (partly) vaccinated. The reason often given for agreeing to vaccination was not to get sick, not to make others sick, and also to regain one's freedom.

The whole process of vaccination at the vaccination centre was experienced as very pleasant, and very well organised. However, one participant, who is a GP, indicated that he had been inundated with questions about the vaccines and the procedure. He regretted that he could not participate in the decision-making on these practical issues.

3. Outcome

The comment was also made that the government should have intervened earlier and more adequately in relation to fake news. They should have called in influencers who are active on social media sooner, as opponents are also active on social media. As a result, dissemination of the right information shrank, while dissemination of the wrong information increased. Making an appointment for vaccination was sometimes difficult, often as a result of poor communication.

For some participants, vaccination or non-vaccination also created an undesirable us/them culture. One participant said that her friendship with her best friend ended because he was against vaccination, and she was in favour.

Some participants who were undecided about whether to agree to vaccination. Several things eventually persuaded them to do so: realising that you often accept travel vaccination without even thinking about it; someone close to you may have died of COVID-19 or experienced COVID-19; you may have experienced COVID-19 yourself; the impact of having COVID-19 or not being vaccinated on your social life.

Vaccination gives peace of mind.

Vaccination is the way out of the crisis.

3.4.2 Side effects of vaccination

What about side effects of the vaccination?

Some participants experienced post-vaccination side effects such as fatigue, nausea or pain in the arm. One spent two days in bed.

Some participants said that they should have been better informed about the side effects and others said that they should not have been mentioned.

Communication about AstraZeneca was very poor and automatically led to bad associations even though the vaccine is actually safe.

The few people who were not vaccinated said they would not do so because there was no clarity yet about the short-term and long-term effects.

3. Outcome

I had a fever for 1.5 days and headaches, and I felt good about it as it meant my immune system was responding.

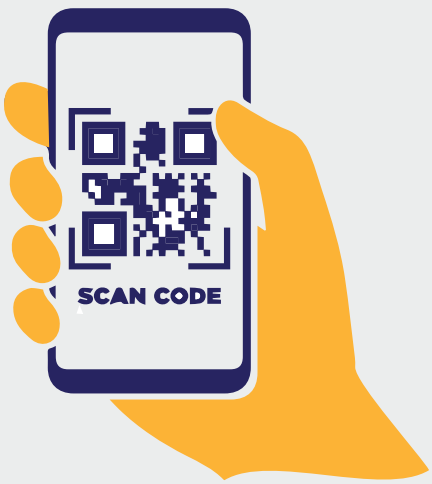
I worried a lot about my son: he was sick for 3 days.

3.4.3 Mandatory

Do you think that vaccination should be made compulsory for certain professions, for example in health, hospitality, and education? Would you accept it yourself?

The participants found the question of whether vaccination should be mandatory for certain professions a difficult one. A German participant indicated that the nursing staff had been vaccinated far too late, and that legislation needs to be developed further in a responsible way. Another participant believed that vaccination should not be mandatory, but people should be persuaded that being vaccinated is right.

If vaccination becomes mandatory, what will happen to those who cannot be vaccinated?



4. Conclusions and recommendations

The following questions were leading in the citizens' summits:

1. **How did COVID-19 affect the participants: their physical and mental health, daily life, work and social contacts, travels;**

2. **How did the participants find information on national response measures relating to COVID-19 in his/her own country and neighbouring countries, and how they had dealt with implementation;**

3. **How did the participants experience health care during the pandemic and what are their opinions on health care.**

4. **What thoughts do they have on the different vaccination strategies and to what extent are participants willing to be vaccinated against COVID-19.**

The main conclusions based on these questions are presented in this chapter. Recommendations are presented in the second paragraph. This includes consideration of differences that may or may not exist between the countries.

4.1 Conclusions

The main conclusions of the citizens' summits are:

1. Living in a border region and crossing borders in daily life in a Euroregion was not really addressed by the authorities when planning their infection prevention measures. It left the impression that people in the border regions were 'ignored'. A border is often not perceived as a border in the minds and daily habits of citizens living in border regions. When border connections were suddenly cut off, people living in a border region felt extra restricted compared to those living in other parts of the countries.

2. The participants expressed their surprise and even irritation about the fact that national governments made their own decisions independently, without taking into account the cross-border element. The participants appeal for solidarity among the EU countries instead of relying on the unilateral, uncoordinated actions of individual countries.

3. The experiences of the inhabitants of border regions reflect numerous similarities in the bordering countries of the Netherlands, Germany and Belgium.

4. Conclusions and recommendations

4. Perception of the impact of living in a border region improved over time as restrictions within the border regions diminished. For other elements of the pandemic, perceptions did not change during the time-frame in which the citizens' summits were held (before and after the summer holidays of 2021). This is irrespective of whether only a few participants attended or more. So, from this point of view the results were consistent.

5. Participants missed face-to-face contact, being near one another. Most experienced a sense of loneliness in one way or the other. And this was enhanced due to living in a border region.

6. In a time of crisis like that presented by COVID-19, people need effective leadership, a comprehensible and timely (COVID) strategy, which in turn requires transparent and clear communication with people in general and relevant stakeholders in particular. An effective COVID policy that people want is not limited to national borders, but must also take into account the cross-border element.

4. Conclusions and recommendations

4.2 Recommendations

Some recommendations that EPECS would like to make, having heard the citizens and their experience during this pandemic, are:

1. The subsidiarity principle, which ensures that - even during pandemics - health policies within the EU are a national responsibility, and should be accompanied by new coordination mechanisms and rulings that, given the fact that 30% of the EU population live in border regions, EU member states take into account the impact of their national policies on border regions of their country.

2. Apart from the experienced and expressed desire for more clear and coherent information on the national policy of a country in dealing with the COVID pandemic, additional clear information is needed from the national governments to explain why and how the national policy fits border regions of the country.

3. Special attention should be paid to citizens in border regions who want to be able to be with loved ones in their final days: irrespective of COVID-19 risks.

4. A point of attention that EPECS wants to express: the health care system in each country is tested during a pandemic. As the pandemic is long, working in health care is harsh and challenging. EU policies should address this issue, promote working in health care and invite young people in the EU to study and engage in health care jobs.

5. People also expect a flexible and effective health care system whereby the needs of other patients than COVID-19 patients are also taken care of, rather than ignored. This could be realised by e.g. Euroregional collaboration within the health care system to scale up the existing health care capacity.

6. As 30% of the population of the EU live in a border region, this pandemic - this virus - which pays no heed to borders again makes it clear that border regions offer a unique opportunity for the EU to enhance its cohesion, by developing policies that specifically bring and keep populations together in border regions, even in times of crisis.