

Citizen Summits

held at Eupen (BE) and Aachen (DE) in February 2019

“Do you see me as a human being when helping me?”

“Do you think of me when planning health care?”

“I would love to share my story and my experiences; will you give me that opportunity?”





ABBREVIATIONS

Conference	Conference “Keeping People at the Centre of Health and Sustainable Development Policies”.
CoR	European Committee of the Regions
EGTC	European Grouping of Territorial Cooperation
EHIC	European Health Insurance Card
EMR	Euregio Meuse-Rhine
EPECS	European Patients Empowerment for Customised Solutions
RHN	Region for Health Network
SDG	Sustainable Development Goals
Summits	Citizen summits held at Eupen (BE) and Aachen (DE) in February 2019
TCI	Theme-Centred Interaction
UN	United Nations
WHO	World Health Organisation

EPECS

European Patient Empowerment for Customised Solutions

Authors:

Astrid van der Zanden, Jo Maes

CONTENT

4	Foreword
5	Acknowledgements
6	Executive Summary
8	1. Introduction
10	2. Framework
10	2.1 Sustainable development (goals)
12	2.2 Equity
13	2.3 Participatory Approach
14	2.4 Human resources in health
15	3. Methodology
15	3.1 Round table
16	3.2 Moderators
17	3.3 Participants
18	3.4 Topics
19	3.5 Recommendations for using round tables
20	4. Equity
21	4.1 Actions to be taken to reach equity
28	4.2 Conclusion
29	5. Participatory approach
29	5.1 Participation in discussions
30	5.2 Role of citizens in health care and policies
32	5.3 Developing the relationship between professionals and citizens
34	5.4 Cross border
34	5.5 Points to ponder
35	5.6 Conclusion
36	6. Human resources
36	6.1 Professionals' attitude and work ethics
38	6.2 Where to locate health care professionals
38	6.3 Career in health care
39	6.4 Task of health care professionals
42	6.5 Conclusion
43	7. Conclusion and recommendations
43	7.1 Equity
44	7.2 Participatory approach
46	7.3 Human resources in health
46	7.4 Closing remarks
47	8. Reference list

FOREWORD: EUREGIO MEUSE-RHINE

The conference on “Keeping People at the Centre of Health and Sustainable Development Policies” will be held In June 2019. In the report the word “conference” is used for referring to the conference on “Keeping people at the centre of health and sustainable development policies”. The conference is formally hosted by ¹:

- the Euregio Meuse-Rhine (EMR)
- the European Committee of Regions (CoR)
- euPrevent | EMR
- the World Health Organisation, Region for Health Network (WHO RHN)

The EMR focuses on the contribution of our citizens. After all, they are the ones who matter to us: they are our *raison d'être*. That is why we are convinced that the work of the Euregio must also involve its citizens, in a citizen-friendly way, especially when it comes to health and well-being.

That is also the reason why we have chosen to give citizens living in the Euregio Meuse-Rhine a role in the conference. In order to do this properly, we called in the EPECS Foundation. EPECS focuses on the interest of citizens and patients in cross-border areas.

We have experience with EPECS when it comes to providing knowledge and experience in the field of cross-border citizens' interests. We feel they are the ideal partner to support the organisation of citizen summits in a Euregio such as ours. And in our view, this has paid off once again. We have great pleasure in supporting this publication and we are convinced that this report will lead to good insights and be used for sustainable development policies.

We would like to thank EPECS and we are working closely with our regions and euPrevent to discover the best ways of putting the recommendations of this report into practice.

FOREWORD: EPECS

The EPECS foundation was invited by one of the hosts of the conference, euPrevent, as a citizens' expertise centre on cross-border cooperation, to contribute to an active new way of engaging citizens in topics that are important to the WHO, CoR and the EMR.

EPECS was honoured to receive the request and gratefully accepted the invitation to organise two bilingual citizen summits in the EMR in order to engage citizens. It was a unique opportunity to hold citizen summits where citizens are able to speak their mind on topics that will be discussed with professionals during the conference.

This report gives insight into the outcome of those citizen summits which show, surprisingly (or not), irrespective of your EU country of residence or in which EU country you receive health care, we all want and need the same thing: involvement.

On behalf of all participants and on behalf of EPECS, the authors want to thank the EMR, euPrevent, the CoR and the WHO RHN for the opportunity given to citizens by asking about their experiences regarding the topics that will be discussed during the conference. EPECS expresses the sincere hope that the idea of a citizen summit will be given a prominent place when organising conferences in the future and that these summits will precede conferences more frequently. May this be a sustainable development.

EPECS would also like to express the sincere hope that the WHO RHN, CoR, EMR, euPrevent and all regions participating in the conference will actively take into account what was said by all participating citizens and use those thoughts and ideas in their policies.



Gisela Walsken

Cologne Government Regional Office President,
Chairwoman of the Euregio Meuse-Rhine,
President of the Region Aachen Zweckverband



EPECS board

Mr Jo Maes (chairman), The Netherlands
Mr Nicolas Decker (treasurer), Luxemburg
Mr Martien Overkemping, The Netherlands
Ms Merete Menze, Germany
Ms Silke Tamm-Kanj, Germany

ACKNOWLEDGEMENTS

This report is the first of hopefully many to come on the involvement of people and keeping them at the centre of health and sustainable development policies.

First of all, we would like to say a big thank you to all citizens who participated in the summits!! You made the citizen summits into a huge success. Thank you for your enthusiasm, your personal stories, and your willingness to share your expertise and contribute your time. Without you, the summits would have never been so successful. We were honoured that you were willing to spend your free Saturday with us.

EPECS is grateful that the regions of the EMR and euPrevent gave us the opportunity to organise the citizen summits with their support. EPECS is also a firm believer in including citizens in matters like public health and cross-border cooperation. Without the support of these organisations, organising the summits would not have been possible.

A special word of thanks goes to the WHO RHN Regions for Health Network of the World Health Organisation for their theoretical input. That input was vital for us in order to make the citizen summits and this report a success. Based on their input, we were able to train our moderators and create the guidelines and topics for the citizen summits.

We would also like to express our appreciation not only for the content-related input but also for the political support that we received from the CoR. By providing this, they affirm that they regard citizen participation as being of great value.

Without the organisational support of the EMR-office and the partner regions – the citizen summits would not have taken place.

We would like to thank the partner regions of the EMR for their help in finding citizens. Thank you!

To the trainer and the moderators: a big thank you for your dedication! Without your help, guidance and support, the summits would not have been such a success.

EXECUTIVE SUMMARY

This report was prepared by EPECS, at the request of the EMR. EPECS was requested to organise two bilingual citizen summits in the EMR in order to engage citizens and to give input and feedback for the conference. The goal of the conference is to establish how to keep people at the centre of health and sustainable development policies.

This report focuses on what we can and may expect from our citizens. It is an overview of their stories and on how their stories and opinions will further sustainable development, thereby keeping them at the centre of health and at the centre of sustainable development policies.

The three main topics at the citizen summits were the same as the topics to be discussed by the professionals during the conference: equity, participatory approach and human resources in health. The overall goal was to ask the participants how these three topics could enhance and aid sustainable development.

The citizen summits took the form of round table settings with at each table a maximum of seven citizens and a specially trained moderator. The citizens came from all regions of the EMR. In total over 120 citizens participated.

The participants claim that they had hardly heard of the word equity in relation to health care. When asked what equity meant for them, they said: equity is “person-oriented”, “tailor-made”, or “adjusted equality”. Participants were very clear on how to achieve equity. For the majority of the citizens, “accessibility for all” is fundamental to achieve equity. Furthermore, they feel that there must be affordable care and nutrition, methods of communication must change, innovations should be established and community initiatives and cross-border care should be encouraged and nourished.

Participants suggested that for receiving appropriate health care, whether in their country of residence or in a neighbouring country, they needed “a one-stop shop”, or one person to guide them through the system(s). According to the participants, equity should go hand-in-hand with tailor-made approaches focusing more on individuals.

In order to determine whether a participatory approach was known to the participants, they were asked if they had ever been asked to participate in discussions on (the future of) health in general and health care in particular. Participants had scarcely been involved in discussions on health and health policies in the past. Participants said they were glad to have the opportunity to do so at the summits. Organisations and policy-makers should actively ask citizens for their know-how via citizens’ conferences or other means. The goal must be to have a good cross-section of society, i.e. not limited to citizens who are able to express themselves more eloquently or are more financially sound. There should be more counselling, not just for citizens but also for professionals. They should be taught early during their training how to communicate with their future patients, thereby promoting the idea that patients should involve their network more actively in the whole process.

On the topic of human resources in health, in general, the participants want professionals to be nearby and to be very accessible, regardless of whether they live in a city or in the suburbs. The participants said that they are willing to travel for specialised care, but this should mean allowing them to visit the nearest specialist even if the latter does happen to practice in a neighbouring country.

The majority felt that professionals do not treat patients as individuals, but rather as their illness. The cause for this behaviour should mainly be sought in the lack of time professionals have to really listen to patients. The employment of volunteers, families or informal caretakers could provide professionals with the time they need. A volunteer could help by performing supporting tasks. Other participants strongly denounce the idea that volunteers should be involved in health care. Others suggested solutions deploying pensioners or migrants or even robotics/home automation. According to the participants The only way the above-mentioned solutions could work is with proper regulation, e.g. of volunteers.

The comments made and the stories told by citizens confirmed that the sustainable development and WHO goals are indeed a mirror of the wishes of people in their role as citizens.

The questions that capture the essence of what participants wondered and wish for are those that appear on the title page:

Do you see me as a human being when helping me?

Do you think of me when planning health care?

I would love to share my story and my experiences; will you give me that opportunity?



CHAPTER 1 INTRODUCTION

Do you see me as a human being when helping me?

Do you think of me when planning health care?

I would love to share my story and my experiences; will you give me that opportunity?

Health is all about people. Without people there is no health, no perception of health, no demand for health care, no struggles in obtaining health care, no discussions on health care policies, no feelings of happiness or sadness regarding the ability to obtain health care.

EPECS believes without doubt that in the next two decades citizens will play – and are challenged to play – a crucial role, not only in their own health, but also in health care in general and health care policies. After all, why not? Why shouldn't citizens also be a deciding factor?

From a monetary perspective, every single European citizen is paying for the health care system and industry, whether directly or indirectly via taxes for example. In wealthier countries like the Netherlands, this probably amounts to more than €6,000 per year per person. There is no reason why citizens should be excluded from the right to raise their voice and exert their influence on how their money is spent.

From a political perspective, every single European citizen can vote. But being able to vote and elect politicians in order to steer health care policies in the direction that citizens want, is no longer enough.

People want to be heard on a local level and away from the political arena.

“Hear me, see me and let me be part of the development group. Use my knowledge and use my experience. Let me be your conversation partner as a patient and as a citizen. Not as CEO, manager, voter or investigator.”

The concept of *Positive Health* ² is buzzing around in the Euregio Meuse-Rhine. For EPECS the new definition of Health, *Positive Health* – meaning the ability to adapt and self-manage in light of the physical, emotional and social challenges of life – also hugely implies the fortified role of citizens. As one participant said: “the patient has to become a professional, the doctor has to become more human”. But is that even possible? Are we expecting and demanding too much of patients by giving them responsibility for their own health and by adopting their perspective on what is and is not healthy for them? Doesn't the ability to determine what you want and need differ in every stage of life and even in every situation you find yourself in? What if you cannot determine your *Positive Health*?

From EPECS point of view, it *is* possible and it is actually common sense. On a legal level, health care systems in the EU already have at their fundament the right of self-determination which is effected e.g. via the protection by law of everyone's right to life ³ and the right to respect for private and family life ⁴. Obtaining health care is each citizen's legal right, as stipulated in the EU Directive 2011/24 of the European Parliament and the Council of 9 March 2011 on the application of patients' rights on cross-border health care.

In the event that a person cannot determine their own *Positive Health*, logic dictates that the health care system and informal care-givers around patients provide as much as possible to realise an optimal situation.

Negative emotions always accompany change, for instance when people change towards a healthier lifestyle. Citizens have to be actively involved, to emphasize and express their interests, steering them towards a new way of thinking, that being healthy is important and the key to (economic) success and thus to sustainable development.

It goes without saying that citizens want to – and shall – play a crucial role in developing health care policies, but to (permanently) engage them on all levels is still, by and large, a road yet to be taken.

This report focusses on what we can and may expect from our citizens. It is an overview of their stories and on how their stories and opinions will further sustainable development, thereby keeping them at the centre of health and at the centre of sustainable development policies.

Chapter two focusses on the framework of sustainable development and the three topics discussed during the citizen summits. It gives an overview of the three topics: equity, participatory approach and human resources in health. Chapter three explains the methodology of the citizen summits, the questions presented to the participants and provides a general overview of the participants.

The results of the citizen summits are described in the following three chapters: equity (chapter four), participatory approach (chapter five) and human resources (chapter six). Every chapter provides a summary of the stories and opinions of the citizens. The chapters all end with the conclusion EPECS formulated based on the outcome. However, EPECS encourages everybody to read the stories and opinions of the citizens in depth in order to draw their own conclusions. It is our hope that the discussions will continue during the conference in June.

Chapter seven contains our main conclusions and recommendations.

CHAPTER 2 FRAMEWORK

The goal of the conference is to establish how to keep people at the centre of health and sustainable development policies. In relation to that goal, the first questions to be answered are:

What are sustainable development policies?
How can you keep people at the centre of health?

In order to answer the first question, we have to explain what sustainable development is. This is clarified in paragraph 2.1 and the policies are set out for achieving it.

The second question is a more challenging one, which we hope will be answered – in part – via the outcome of the citizen summits on *equity*, *participatory approach* and *human resources in health*. These key words are explained in paragraphs 2.2, 2.3 and 2.4.

2.1 SUSTAINABLE DEVELOPMENT (GOALS)

In order to understand the sustainable development goals, it is vital to understand what is meant by sustainable development.

Sustainable development is defined by the United Nations as “[a] development that meets the needs of the present without compromising the ability of future generations to meet their own needs. It calls for concerted efforts towards building an inclusive, sustainable and resilient future for people and planet”.⁵

In order to achieve sustainable development, three core elements should be harmonized: economic growth, social inclusion and environmental protection.⁶ In 2015 the United Nations adopted the 2030 Agenda, setting out a vision and principles for sustainable development in the coming decade. A total of seventeen *Sustainable Development Goals*⁷ were set in order to achieve sustainable development. The seventeen goals are: “no poverty, zero hunger, good health and well-being, quality education, gender equality, clean water and sanitation, affordable and clean energy, decent work and economic growth, industry/innovation and infrastructure, reduced inequalities, sustainable cities and communities, responsible production and consumption, climate action, submarine life, life on land, peace/justice and strong institutions, partnerships for the goals”.

These SDGs were put together with the help of citizens, making that the embodiment of the participatory approach. In total almost 7.8 million people voted for their favourite theme. A United Nations working group of seventy countries merged those themes into a list of seventeen goals. These goals, which surpass the notion of helping poorer countries, have been set for all countries.

The seventeen SDGs can be considered as ‘the blueprint to achieve a better and more sustainable future for all. They address the global challenges we face, including those related to poverty, inequality, climate, environmental degradation, prosperity, and peace and justice. The goals interconnect and in order to leave no one behind, it is important that we achieve each goal and target by 2030.’⁸

It is the responsibility of the Member States to implement the SDGs. The WHO Regional Office for Europe works in partnership with governments, the private sector, civil society organisations and citizens, as well as with United Nations agencies to facilitate and promote implementation of the SDGs.

As stated earlier, one of the SDGs is good health and well-being: “Ensuring healthy lives and promoting the well-being of all, at all ages, is essential to sustainable development”.⁹ All the organising partners of the summits have health goals related to that SDG.

To contribute to this, the goal of the WHO RHN is to “create synergy between regions and stakeholders in the field of health issues (mutual learning); strengthen cooperation/collaboration between regional and local actors and international institutions in health; promote the contribution of regions and local authorities, and particularly health authorities, to the international policy-making process; and increase the understanding of regional and local health systems (exchange of experiences)”.¹⁰

The goal of the “Health Group of the Committee of Regions” is to reinforce the work of local and regional health networks with special attention to “health workforce, patient mobility, nutrition and obesity and health inequality indicators’ and ‘to discuss the use of structural funds”.¹¹

The EMR and euPrevent have the mutual goal to improve the quality of life of citizens in the EMR, especially from a public health perspective.

Based on this SDG, they established three main topics: *equity, participatory approach* and *human resources* in the area of health.

These three topics are vital in order to answer the second question: “How to keep people at the centre of health.”

2.2 EQUITY

Equity is defined by the WHO as “the absence of systematic differences in health or health outcomes where everyone has a fair opportunity to attain their full health potential and no one is disadvantaged from achieving this potential. Resources, policies and programmes are distributed and designed in ways most likely to lead to equitable health outcomes of the entire population.” ¹²

For the benefit of participants, the concept of equity was explained via fig 1. It first explains equality as the concept that everyone is equipped with a bicycle, regardless of personal needs. This means equality has been reached: everyone received the same, with no exceptions. This resulted in some citizens not being able to use the bicycle due to personal circumstances. In order to ensure that everyone can use the bicycle, the bicycle must be adapted to the personal needs of the individual. By doing so equity is reached.

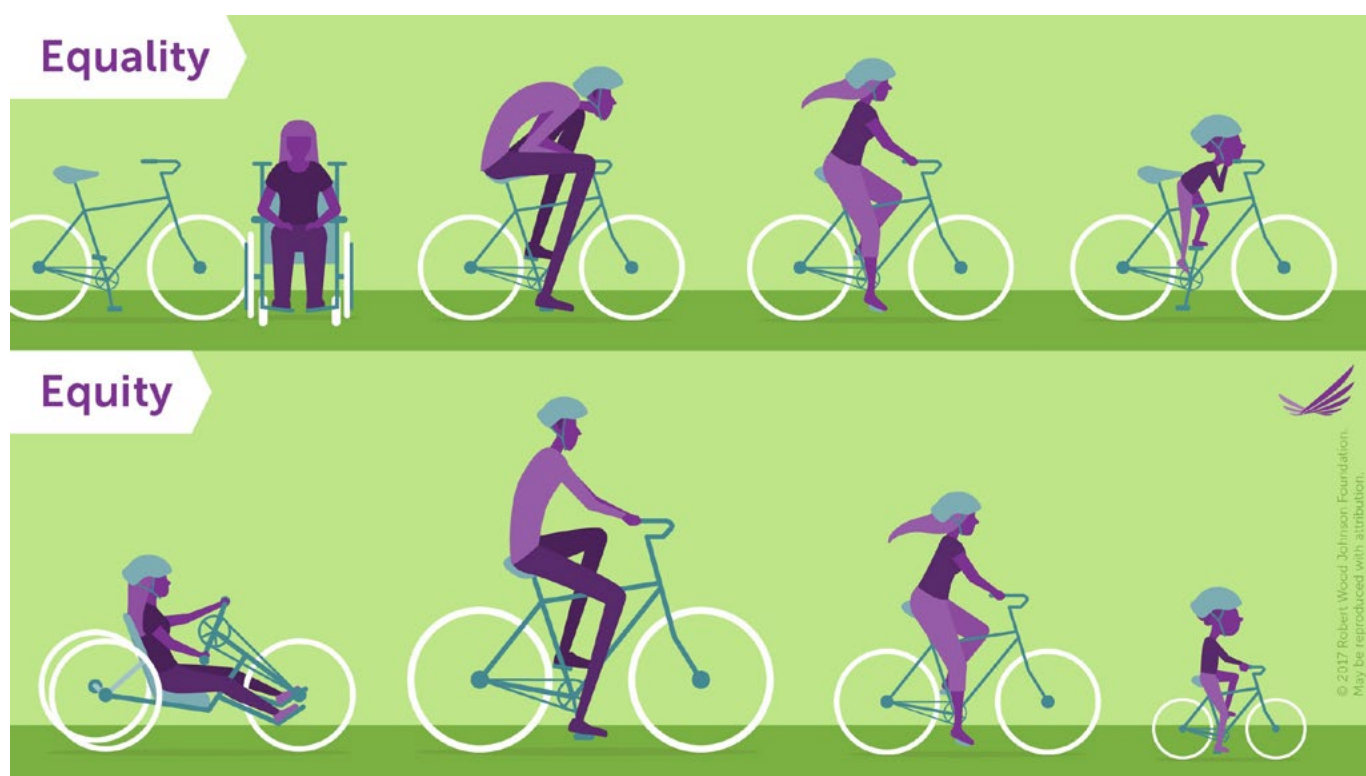


Figure 1: equality vs equity

2.3 PARTICIPATORY APPROACH

According to the Institute of Development Studies the Participatory Approach “includes a range of activities with a common thread: enabling ordinary people to play an active and influential part in decisions that affect their lives. This means that people are not just listened to, but also heard; and that their voices shape outcomes”. ¹³

The UN used a participatory approach to set the SDGs by asking people to vote. This is precisely what needs to be done in order to be able to achieve the SDGs on a regional level: include citizens in creating sustainable development policies, make them co-owner of the change and their own well-being and health. This fits in with a remark made by the Institute of Development Studies: “It is often people who have the least say in decisions about their lives who are most affected by using the methods”.

Keeping people at the centre means involving citizens in the process, as their contribution represents value for all. Professionals should not only talk about citizens, but they should talk with them, defining what would be the best choice for them. Listen to them! Really listen to them! But how can this be realised?

Pursuing the advice of the President of the European Commission, Jean-Claude Juncker, dialogue should be sought with citizens at a local, regional and euregional level. It is important to engage in conversation with them on a political and strategic level and regard them as equal, able partners.

However, little research has been done on finding an innovative way to effectively, actively and structurally involve (people in their role as) citizens.

In Europe there are initiatives and examples of involving citizens more in policy-making outside the traditional way of elections and referenda. For example:

- The European Union launched a programme *Europe for Citizens* ¹⁴. This programme is about democratic engagement and civic participation.
- The European Union launched a consultation so citizens can tell them how they see the future of Europe ¹⁵.
- As an active member of the WHO Regions for Health Network, Trentino (IT) launched a website to ask for the input of citizens for their regional health plan ¹⁶.
- In Belgium a well-known though relatively new initiative is the top 1000 citizen summit in which 1000 randomly chosen citizens were invited by the municipal council to participate in a summit to consult with them about topics in their city or village ¹⁷.
- An experiment in Maastricht, the Netherlands, showed a large bias in actual participation. Highly educated people were over-represented. Poorer citizens and those battling with (health) illiteracy did not attend, though the municipality did ask them to participate several times. In order to get 200 people together, they were finally obliged to send a personal invitation, from the Mayor of the municipality of Maastricht, to more than 5,000 people. The bias remained however, and still no more than 200 attended ¹⁸.

Nevertheless, there are few examples of the involvement of citizens in sustainable development policies in the area of health. Especially not about health-related topics on a regional, euregional and European level.

Chapter three describes how citizens were involved in these citizen summits.

2.4 HUMAN RESOURCES IN HEALTH

“Human resources for health or health workers comprise all people engaged in actions whose primary intent is to enhance health, and who play a central and critical role in improving access and quality health care for the population. They include physicians, nursing professionals, midwives, dentists, allied health professions, community health workers, social health workers and other health care providers, as well as health management and support personnel; others may not deliver services directly but are essential to effective health system functioning, including health services managers, medical records and health information technicians, health economists, health supply chain managers, medical secretaries and others. They provide essential services that promote health, prevent diseases and deliver health care services to individuals, families and communities based on the primary health care approach”. ¹⁹

It is common knowledge that by 2050 the demographics in Europe will have changed: the working population is expected to decline, and the number of older people is rising, especially the population over 75 years of age. This is having a huge impact on society. According to the World Population Data Sheet 2018 ²⁰, by 2050 the number of people worldwide will have increased by 29%, the older population (65+) will have doubled and the number of children (0-4) will have decreased to 20%.

Changes are also visible in the EMR. The number of senior citizens is increasing, and they are getting older, while the number of young citizens is decreasing as well as the size of the working population.

In the EMR we are tackling the question of how to take care of our future senior citizens and what to expect from our future younger generation. Can we provide our citizens with sufficient guidance and help?

It has long been claimed that ‘Health systems can only operate if there is a health workforce’ (WHO/GHWA, 2013) ²¹ and we believe that a well-educated, well-trained and highly skilled health and social care workforce in the right geographical location is vital to provide high-quality services.

CHAPTER 3 METHODOLOGY

Whilst preparing for the citizen summits, a lot of thought went into the form these should take. EPECS opted for round tables to further discussion among participants in order to acquire as much information as possible, giving participants every opportunity to join in the thinking process.

This chapter describes the use of the round tables as well as the method used during the summit and the work that it entailed to achieve the outcome we wanted: obtaining as much information as possible.

3.1 ROUND TABLE

According to EPECS, more than everything else, equivalence is an essential component of future health policies in Europe. This equivalence is best symbolised by organising round tables as they provide an academic discussion forum and promote the position of every single participant.

A maximum of seven participants and a moderator were seated at each table. Keeping the group to this maximum number was an essential part of the group's success. This allowed all participants at the round table an opportunity to tell their story, give their opinion and contribute to the topics. Moderators chaired the round tables. Ten round tables were formed per citizen summit.

Due to the fact that the round tables were organised in a cross-border setting, it was crucial that participants knew in advance that they could speak in their mother tongue, i.e. in one of the three languages of the EMR: French, German or Dutch. This was realised by sorting the participants into groups in which everyone spoke the same language.

Theme-Centred Interaction ²² (TCI) was used as a baseline for the discussion. TCI is a concept or tool that assists in giving the floor to – and including – every participant.

With TCI, it is important to comply with certain conditions, which were explained to participants in advance:

1. Everyone matters;
2. Represent yourself when speaking. Use the words *I* not *we* or *one*;
3. When you ask a question, explain to the others why you asked that question, so that they will understand you;
4. Be authentic when communicating and think before you speak;
5. Try to avoid interpreting others;
6. Try to restrain from generalizations. Speak about you;
7. If you comment on someone's behaviour, explain to him or her how his or her behaviour affects you;
8. Only one person may speak at a time. If several people want to say something at the same time, ask them to just mention key words so that they can elaborate on it later;
9. If side discussions erupt: let them. They would not happen if they were not important; perhaps not for the topic at hand, but they may actually be of great help to the group;
10. Watch your body language and that of others.

The moderators emphasised at the beginning of the round tables that it was vital that participants shared their personal opinion and not contribute based on their function. They were asked to introduce themselves and to share – voluntarily – a personal experience with the other members.

3.2 MODERATORS

Ten moderators were needed to chair the round tables per citizen summit.

German and French speaking moderators were needed for the citizen summit held in Eupen (Belgium). For the second citizen summit held in Aachen (Germany), Dutch and German speaking moderators were needed. From a practical point of view this meant that eighteen moderators had to be trained to make sure all tables had a native or near-native speaking moderator.

The regions of the EMR selected the moderators. The criteria for selecting moderators were:

- They should already have some experience in moderating or guiding small groups;
- They need to understand and speak English;
- They need to be able to come to the mandatory moderators' training.

In addition, EPECS made sure that some extra bilingual moderators were selected to step in for an absent moderator when needed. At each summit, an extra moderator was present who could step in if necessary.

Three weeks prior to the first citizen summit, the moderators received the guidelines for moderators so they could prepare for the mandatory training. The moderators attended a special moderators' training provided by a professional trainer ²³ with whom EPECS members discussed the guidelines prior to the professional training. This was done to make sure that all moderators obtained the same background information and were taught and prepared the same way. During this training the moderators practiced with the tips and tricks for moderating the round table discussion and they learned about potential stumbling blocks. The moderators received guidelines with background information on the topics, supportive questions and tips and tricks to keep the discussion going in a positive and constructive way. They received a standard document on which they could write down the input of citizens.

The moderators were supported with material that they could use to create an informal and trusting environment to make citizens feel open and comfortable about sharing their experiences and ideas. On every table were large sheets of coloured paper with coloured felt-tip pens, so the participants could express themselves in every possible way.

3.3 PARTICIPANTS

For practical reasons, EPECS chose to invite 120 citizens. By inviting just 120 citizens, the consequences for conclusions due to bias was taken into account and accepted.

The five regions were each asked to select and invited 24 citizens to attend the citizen summit.

In order to get a good mixture of participants, the EMR regions were asked to invite citizens aged 18 years and older and who were a good representation of the inhabitants of each region, taking into account gender, ethnical background, employment status, social status and education. Preferably, neither health care professionals nor active politicians were to be invited.

During the course of the selection process, the regions struggled with the selection criteria. They focussed more on getting citizens interested in participating than inviting citizens who met the desired criteria.

The feedback given by the moderators was that there were participants with different ethnical backgrounds and a variety of age groups. They felt that participants had been included who have different social backgrounds and employment status. Health care professionals were present at some round tables. The moderators were prepared for that, and were able to ask them for their personal opinion and not (just) their professional one.

The moderators said that during the discussions the participants were active, open and non-judgemental towards other participants, thus creating a friendly and open atmosphere. They respected one another's opinions and sympathized with the shared stories, which were sometimes emotional.

The feedback EPECS received from the citizens was that:

- they found it very informative and constructive.
- often one hour per topic was not enough. The citizens often needed more than 60 minutes to discuss a topic.
- they expressed the sincere hope that this concept could be repeated and they were almost all willing to participate in any follow-up meeting.
- they had the feeling that they were well-guided by the moderators and really had an opportunity to express their opinion and share their story.
- They were however sceptical about whether the WHO really would take their opinion into account.

3.4 TOPICS

EPECS prepared the content for the citizen summits, with input from the WHO RHN and euPrevent. The three main topics were the same as the topics that will be discussed by the professionals during the conference: equity, participatory approach and human resources in health. The overall goal was to ask the participants how these three topics could enhance and aid sustainable development.

For every topic the WHO RHN prepared a background paper to explain the topics.

Based on this input and EPECS' experience with round tables, a number of questions were prepared which helped the moderators to get the necessary input.

For the topic equity, the moderators were instructed to find out what equity meant for participants and if they ever faced problems involving equity or the lack of it when receiving health care.

For the topic participatory approach, the moderators were instructed to ask participants if they had ever been involved in discussing health and its future prior to that moment. They also asked for their experience and views on their contribution to participating in health care and social policy, chances and difficulties. And how, according to them, the relationship between health care professionals and patients should develop in the next few years.

For the topic human resources, the moderators were instructed to ask participants if they would consider a job in health care. Furthermore, they were asked how health care professionals should act to encourage citizens' behaviour in sharing information and realising equality. They also discussed with the participants where professionals and services should be located in the community and why.

The next few chapters describe and discuss the outcome of the summits. The intention is to give as accurate as possible a rendition of what the participants said. It is not the aim – nor did EPECS strive – to write an academic article, nor to fulfil any academic standard. Even if – by chance – the moderators or EPECS concluded that some topics touched on by participants were different from what the participants thought, the opinions of the participants were noted – verbatim – and used. The contents of the chapters should not be viewed as either *right* or *wrong*. The contents are to inform the professionals attending the June conference about how participants perceive the topics and what their thoughts are, to give them food for thought.

3.5 RECOMMENDATIONS FOR USING ROUND TABLES

Involving citizens is necessary but finding ways to involve them is challenging.

The following was kept in mind in order to make the round tables/summits a success:

- Being personal is a must. Round tables with less than 10 participants is the best way to ensure the personal touch;
- Enough time must be available;
- Moderators of the round tables must be trained, understand the content and be willing to actively participate in the round table based on their own personal situation;
- If possible, round tables should take place in small rooms, as the noise in a large hall with 10 tables could be distressing and distracting.

CHAPTER 4 EQUITY

Health equity is, according to the WHO ²⁴, “the absence of systematic differences in health or health outcomes where everyone has a fair opportunity to attain their full health potential and no one is disadvantaged from achieving this potential. Resources, policies and program are distributed and designed in ways most likely to lead to equitable health outcomes of the entire population.”

Participants were provided with information on the topic prior to the summits and a presentation on equity was given on the day itself. Also, each of the moderators explained the term in relation to health at their round table.

The participants had hardly heard of the word *equity* in relation to health care. When asked what equity meant *for them*, they said:

- equity is “person-oriented”;
- equity is “tailor-made”;
- equity is “adjusted equality”.

Even though the participants had not heard the words equity and health care mentioned in relation to one another, they *did* have a clear view on what *should be done* in order to *achieve* more equity in health care.

4.1 ACTIONS TO BE TAKEN TO REACH EQUITY

Participants felt that equity in health care could be reached on different levels:

- A. by changing accessibility to health care;
- B. by offering affordable care and nutrition;
- C. by changing communication;
- D. by establishing innovations;
- E. through community initiatives;
- F. by cross-border care.

These six levels will be elaborated upon in more detail in the next few paragraphs.

4.1.1 ACCESSIBILITY OF CARE

In today’s world, people feel that they have to fight for the care they want. To obtain it, they need to have the latest and most accurate information and they also need to have sufficient communicative skills to ask for that information and ask for the care they want. But a large part of society isn’t equipped for this and the consequence is that they receive what is offered and not necessarily what is best or what is the better option. They remain oblivious to other and/or better options. In this context, equity in accessibility of care means that there should be a “one-stop shop”, where a case manager assigned to a specific number of patients guides those patients and actively helps them to interpret all the rules and regulations.

Other participants mentioned that there should be a system of guidance in which there is one person who is neutral, who you can trust, who is well-informed about everything, who really knows the organisations, what they have to offer and the possibilities that exist, and who guides you personally and follows you through the entire process.

'Care should be accessible for everyone. It should be demand-oriented and not supply-oriented.'

An example given was that of a patient with complex care needs. People often have to look for solutions themselves. They need to know where to ask for help, and therein lies the problem. It takes a lot of time and effort to find the right way, irrespective of the outcome. Even organisations do not always know where to send patients or who might be able to help the patient. If they don't know, how can private citizens be expected to know?

The way help is organised differs even between cities and municipalities, let alone between countries, which makes it such a tangle. Plenty of support is available, but patients need to be able to draw up a plan in order to find their way around. Hospital care is also becoming increasingly specialised, making it even more difficult to find the right path to the best care, i.e. the right hospital and the necessary care afterwards. If you don't know what is available, how can you decide?

One participant talked about undergoing hip surgery. The "classic" treatment method could well entail you being unable to live as full a life as you did before surgery, and in a few years' time you may have to have further surgery. A different, new method could ensure that you can carry on living your "old normal life". But that information must be made available to you and you must be given an opportunity to make that choice, regardless of how articulate you are.

For citizens, equity also means that:

- there is one system, so that the burden of administration is diminished.
- the gap in society should diminish, but instead it is widening, partly due to differences in empowerment between social classes which in itself influences equity.
- there is more synergy between older and younger care workers. Generational differences are perceived regarding the care provided by professionals.
- the quality of health care should be sustainable health, instead of economic efficiency which is the current guiding principle
- experiential knowledge and findings from other medical systems (e.g. Chinese medicine) are permitted.

4.1.2 AFFORDABLE CARE AND FOOD

Health care is very expensive. Equity also entails that the costs of receiving health care are literally more equal for everyone. Large inequalities are perceived between e.g. the Netherlands and Belgium in terms of benefits and subsidies. Citizens are aware of this because of cross-border mobility in the EMR. Care should be made affordable for everyone. Because of financial problems, people do not always receive or look for the care they need. It is a vicious circle: no money, no care, and even more health problems; necessary care becomes even more expensive.

Treatment takes place according to certain procedures and step-by-step plans (not applicable to everyone). A lot of money is wasted on unnecessary treatments. Customised treatments can offer a solution to this problem. Large price differences in treatments and materials are felt to exist in the EMR. These should be equalized, especially in border regions where people depend on cross-border cooperation to have equal access to health care.

A number of participants said that it is unclear why a smaller institution only receives EURO 1,000 for a particular client and a larger institution receives EUR 12,000 for the same client: that's inequality. The reason for this inequality should be made transparent. It is perceived as "unfair".

"If I am financially sound, I can afford more in the health service."

The system is very focused on the middle and upper classes. Finding your way is easier for those who have no financial worries. They are able to obtain the latest and more accurate information and are sufficiently communicative to ask for that information and ask for the care they want. There should be more transparency about possibilities in a given area of care, even for people on a low income.

Participants mentioned especially (regardless of nationality or country of residence) the German insurance system, which is divided into a statutory (general) and a private health insurance. The participants feel this is an unsatisfactory system that actually increases inequity. The private health care system pays a health care professional higher wages for each patient that asks for a consultation. This only leads to more services being provided for private patients than for patients with general health insurance (leaving aside for the moment the question of whether the service is really needed). Naturally, it is difficult for employees and doctors to earn money in the system, but the system actually stimulates inequality. Citizens who are more socially challenged are only insured for receiving statutory health care. In practice, this means that they wait for two to three hours to get a consultation with a health care professional. In comparison, a privately insured inhabitant is seen without any waiting time. Privately insured patients are preferred and receive more and better health care than patients in the public setting. Treating private patients is financially more advantageous for health care professionals.

“As a private patient, you benefit, and that gives you a bad feeling.”

Just as care should be affordable for everyone, so should obtaining healthy food. Healthy food is part of a healthy lifestyle, which leads to healthy people. Not everyone receives the right information or support in choosing healthy food and some cannot afford the healthier options. Children who grow up in such families do not learn to choose healthy food. When they become adults, they mimic the behaviour and choices of their parents. Health education should start early. Exercise should be the key. This should be worked out and promoted more, right from the beginning; starting at “kindergarten”, in schools, in the streets and in districts, to bring this notion to a higher plan. A great example are city gardens. In Germany, children receive school lunches: but these lunches should be healthier, and nutrition should be better organised. Participants feel that far too little is being done in the field of prevention. Far too little attention is being paid to exercise, healthy eating and the influence of alcohol and drugs among young people.

“If young people don’t have muscles, they shouldn’t go to the doctor but instead they should exercise more.”

“Better health. It should be integrated into everyday life”.

4.1.3 INTERVENTIONS

The participants came up with suggestions on interventions to stimulate healthy behaviour and to increase mental health. Municipalities, local governments, should offer more exercise programmes and other interventions to stimulate health, e.g. for the elderly and the underprivileged. It wouldn’t be a bad thing if applying for those interventions were to be mandatory for certain groups.

Participants addressed the fact that everyone is in a vulnerable position. People are increasingly living alone; assistance and a safe haven in a community is no longer offered and/or is no longer a matter of course. This forms a risk of diminishing mental health. No progress has yet been made in terms of equity for people with a mental illness. Mental health and working and living together are not yet equity issues.

“Are we prepared to make a difference in individual situations?”

4.1.4 COMMUNICATION

Participants feel that there should be a change in people's attitudes; equity should be approached differently.

"A new movement must be set in motion."

"When equity has been put into place, you feel heard, you are a person".

Examples given were:

- A stoma patient needs certain facilities because of his disability (e.g. when they travel), but these are often not available.
- Buildings should be adapted for use during every stage of a person's life. E.g. enabling someone to house an elderly person who has difficulty walking upstairs, a single person just out of school or a family of four.
- If someone wants to obtain help to make some adjustments in their home, why are they often only allowed to choose between 2 carpenters or 2 specific contractors? Why can't a person choose one they already know and are familiar with?
- The nursing home at Sint Truiden (Belgium) offers its clients fitness equipment.

Examples given:

- In 2017 the flu shot for public patients was equipped with three factors, the flu shot for private patients with four factors. The flu virus in 2017 was one that could only be eradicated by the fourth factor. The flu wave cost the lives of thousands of people who did not receive fourth factor vaccination protection. One might ask whether this is just a coincidence or an example of inequity.
- Medication is largely controlled by the pharmaceutical industry and is often prescribed on a flat-rate basis; individual decisions are rarely possible. No consideration is given to whether drugs are really necessary, for instance, in the "precautionary" administration of broad-spectrum antibiotics. An example cited how for 13 years health insurance covered the prescription of expensive drugs for rheumatism, but refused to refund acupuncture. Only after receiving many letters and many complaints did the health insurance even consider looking into acupuncture.
- Many Dutch citizens cross the border to find accessible care in Belgium. These are precisely the people who are financially sound and are able to ask for care. This does not happen the other way round, from Belgium to the Netherlands.

The fundamental new way of thinking lies with young people. Young people, for example, are more open to having discussions. Sharing experiences, commitment and new leadership can contribute to equity, brought to us by young and enthusiastic citizens. Young people are the future. Instil them with more confidence by asking them to become ambassadors for care organisations. Let them see that the older generation has faith in them, believes in them.

However, the way they communicate is different and this needs to be taken into account. Social media and the Internet must play a role in reaching citizens and providing them with information. We must therefore ensure that information given via the Internet and social platforms is correct.

Organisations must take up communication pro-actively. This may seem an open door, but communication and mind-set really must be tailored to the target group. You should connect with people where people naturally already meet and adapt your policy accordingly.

"We will visit you and offer you a suitable package".

You get support if you can hold the collective to account for the same values, as happened with the issue of smoking: all it needed was a shift in mentality.

Participants also mentioned the preferred way professionals should communicate with patients and citizens. They want personal equivalence and to be seen first as a person and second as a patient. They ask that care providers really listen. This is often not happening anymore due to a lack of time. Allocate an advisor whose sole aim is to determine what is still possible for you as an individual. The disease is only one part of a person; they are so much more. When meeting a child or a person with dementia, speak to them and not only to the person accompanying them.

"It would be very helpful if workers were native speakers. It makes it easier to share your feelings and experiences with someone who speaks your language, or better still, your dialect."

Participants also said that there is a difference in how 'experience experts' are perceived versus skilled experts. The latter should not be placed on a pedestal either by themselves or by their organisations. Ensure equality for patients and their next of kin by seeing them and speaking to them as 'experts by experience'.

Participants suggested linking medical students to a patient and letting them actively participate in examinations and conversations with the patient's doctors. Make sure they look after only the interests of their assigned patient. Design it on the buddy principle. This will teach students social communication and to look out for their patients and see challenges through their eyes, which will help them when they subsequently become health care professionals. The patients are helped because they will always have a buddy helping them and giving them a voice when they don't have the strength.

More in-depth examples mentioned, were:

- **Guidance:** Informal caretakers need guidance and knowledge on how to deal with the disease of the person they are caring for. In the past and in certain cultures, it was a matter of course that children took care of their parents. This is increasingly disappearing, making it more difficult to find the right care and help.
- **Buddy:** Citizens who are having a difficult time due to negative past experience can end up in a vicious circle. They are suspicious of the whole system. They may feel, for instance, that the system is not tailored to them, language may be a problem, or cultural differences (e.g. taboos, habits). They may be afraid to expose all their problems, resulting in high thresholds. Asking for help, and being able to receive it, means giving up your independence, which is not always easy either. Give them a buddy.
- **Hierarchy:** The distance between health care professionals and disadvantaged groups is very large due to differing social backgrounds. Because of that distance, health care professionals may come across as patronising, threatening, dictating to patients. Naturally, the intention is to give well-meaning advice, but it may be brought in a way that is detrimental to sound communication. Perhaps professionals could use experience experts to support them in communicating with patients.
- **Time:** A lot of time is lost in communication and coordination between social workers. This does not always take place efficiently. Technology could be used to improve this.
- **Equal:** There must be equal contact between health care professionals and patients; this can be promoted by exchanging as much information as possible and, in the event of a multidisciplinary approach, sharing information. The impression is that the way health care professionals' approach and treat patients is too one-sided or with too little information.
- **Listen:** A patient should feel that he's being listened to seriously, taking into account his individual situation. Patients may not always be mature or skilful, but their involvement and thinking along with health care professionals is important.
- **Prevention:** "Tailor-made care" could be promoted by paying timely attention to prevention versus treatment and by taking timely account of the effects of ageing.
- **Cooperation:** The structure of health care, and the way to obtain health care, is insufficiently clear to individual patients; often there is insufficient cooperation between different health care organisations and between different disciplines.
- **Point of view:** Care is often standardised and formalised. Management should focus more on the ultimate quality as perceived and experienced by the patient.
- **Information:** The transition from inpatient to outpatient treatment usually takes place without comprehensive information about subsequent comprehensive therapeutic structures – either for to patients themselves or to their family. Medical diagnoses, health insurance notifications, etc. should be communicated in plain language and, if necessary, in the patient's language (and this should already be confirmed at admission). This includes a language interpreter if required. Problems arise when the social or private situation changes radically and care has to be requested from 'foreign' third parties. The parents of one participant were admitted to a nursing home, which had a negative effect on his parents due to an insufficiently coordinated and negligent care provision.

4.1.5 INNOVATIONS AND COMMUNITY INITIATIVES

Some participants mentioned the use of robots in health care. Others were hesitant about using robots as the need for “personal contact” will be neglected. This might increase citizens’ sense of “loneliness” instead of them feeling they were really being listened to and helped. Another suggestion was to use animals in nursing homes, etc., to enhance mental well-being.

Communities need to be in control in order to change our perspective. They should do more and play an active role in guiding citizens on the above-mentioned matters.

4.1.6 CROSS-BORDER

Even across borders, little is known about what specialised care is available within a radius of 50 km for outpatients and inpatients in order to make the respective service available to all citizens. Until now, patients feel they have had to pay extra if treatment abroad is more expensive. Many people cannot afford this. This results in economic selection.

The IZOM agreement between the Belgian, German and Dutch health insurance funds enabled patients in the German-speaking community to receive adequate health care in Germany. In a particular part of Belgium there are only a few specialists and not all specialisms are represented, since the total number of inhabitants is too small (77,000). Again, the principle applies: economic efficiency takes precedence over sustainability and over patients’ needs. The health insurance funds did not continue this agreement partly based on a decision at a Belgian national level. Participants question that decision.

We need independent patient advisory centres within regional reach, staffed by people who are able and willing to listen, who have the time and broad professional know-how about existing structures across the border. As some said during the summits: the Belgian system is unclear to German inhabitants even if they are just visiting the country for a vacation. Some Belgian participants mentioned that Dutch people sometimes come to Belgium to benefit from the fact that privately insured people in Belgium have priority. This results in Dutch patients having priority over the Belgian population. Right or wrong, this is how it is perceived by the participants of the summit.

But the cross-border aspect is not only related to topics important for the EMR. Participants also brought up the topic of the EHIC system – which is important for every citizen of the European Union. Discussing this, it became clear that the EHIC is still unknown to a lot of participants. Some only realised at the summit that they actually had an EHIC in their pocket.

4.2 CONCLUSION

Health equity is, according to the WHO ²⁵, “the absence of systematic differences in health or health outcomes where everyone has a fair opportunity to attain their full health potential and no one is disadvantaged from achieving this potential. Resources, policies and program are distributed and designed in ways most likely to lead to equitable health outcomes of the entire population.”

Citizens of the Euregio Meuse-Rhine, participating in the two citizen summits, appeared to be unfamiliar with equity as a concept. It had to be explained to them, after which they were able to refer to practical situations they had encountered via their own experiences or as seen in their surroundings.

Participants were very clear on how to achieve equity. For the majority of the citizens, “accessibility for all” is fundamental to achieving equity. Furthermore, there must be affordable care and nutrition, methods of communication must change, innovations should be established and community initiatives and cross-border care should be encouraged and nourished.

Participants suggested that for receiving appropriate health care, whether in their country of residence or in a neighbouring country, they needed “a one-stop shop”, or one person to guide them through the system(s). According to the participants, equity should go hand in hand with tailor-made approaches focusing more on the person concerned.

The citizens identified communication as an important item within the framework of equity. It was made clear by the participants that communication has to be addressed to foster equity, in relation to e.g. paying attention to speaking native languages, rewarding informal care-givers and interacting with the younger generation. As the Germans say: communicating “auf Augenhöhe”, equality or equivalence in the relationship between health care workers and citizens is estimated to be of the utmost importance to furthering equity.

CHAPTER 5 PARTICIPATORY APPROACH

According to the Institute of Development Studies, the Participatory Approach “includes a range of activities with a common thread: enabling ordinary people to play an active and influential part in decisions that affect their lives. This means that people are not just listened to, but also heard; and that their voices shape outcomes”.²⁶

EPECS used a participatory approach by asking participants about their views on sustainable development and how they would like to be involved in sustainable development.

By doing so they were acknowledging citizens as the end-users who are directly affected by sustainable development policies. This gave the WHO RHN, as well as the CoR, EMR and euPrevent, a unique chance of acquiring the views of citizens.

In this respect it is interesting to learn whether or not citizens have ever (been asked to) participate(d) in discussions on (the future of) health in general and health care in particular. Citizens were asked to give their personal views and/or experiences on their role in health care and social policies.

At the end of the discussion, EPECS asked the participants what they would take home from the summit and what they hoped the WHO RHN, CoR, EMR and euPrevent would take home with them.

5.1 PARTICIPATION IN DISCUSSIONS

The majority of the participants had not previously been involved in discussions on health and the future of the concept of “health” or “health policies”. Their contribution was generally via elections and referenda.

Those who had cited the following examples:

- Many years ago, the citizens of Eupen (Belgium) were asked for their opinion regarding prevention by “Stadsportbund”, a sports association on a city level.
- Some participants from Hasselt (Belgium) had joined in working groups with professionals in order to spread ideas of the concept of Positive Health among professionals and citizens.
- Two participants said they were able to give their opinion upon receiving an invitation to fill out a questionnaire sent either by Radboud University Medical Centre (Nijmegen, The Netherlands) or by Statistics Netherlands (CBS).
- In the city of Brunssum (the Netherlands), there are “district inspectorates” who look at the welfare of the citizens in that district. Members of these district inspectorates included a local resident, a welfare worker and a municipal official. As a citizen, you can sign up for a position in the district inspectorate. Accessibility is very high from that perspective. The only doubt is whether the results will be taken into account by the municipality. And the group also wonders when/ how the results of consultations with the council are communicated with the citizens. Without informing the municipality and feedback on decisions of the municipality to the local residents, participants question whether this will lead to sustainable improvement.

Some participants gave examples of participation in health on an individual level:

- At the Maastricht University Medical Centre (The Netherlands), a treatment plan is developed for each individual patient regarding treatment, treatment plans and corresponding discussions, where client, health care professional and family work out a health care plan together.
- At the Maastricht University Medical Centre (The Netherlands), in the event of an accident, the family can actively participate in decisions regarding treatment. But in order to do so the family member consulted must be of age.

The overall question is: if and when citizens are asked to participate in discussions, what will be done with the outcome? Will participating have any effect on policy-makers?

5.2 ROLE OF CITIZENS IN HEALTH CARE AND POLICIES

Participants discussed some ideas regarding the role of citizens in health care and policies.

They mentioned:

- The aim should be to identify gaps in one's own system, practices, hospital and/or care in order to query, check and develop improvements.
- Social cohesion is a prerequisite for engaging citizens (encouraged by associations, local newspapers).
- Attention must be paid to quality management, so that health care and services will be beneficial and accepted by citizens.
- Efforts and resources should be made available for further development of the level of health care.

Participants also gave some practical ideas:

- Citizens should be asked for their know-how (e.g. via feedback forms), and their thoughts and know-how should be included in further developments. The citizens involved should be representative of the entire population, so that discussions are diverse, and the outcome will represent a good cross-section of society.
- There should be more citizen conferences attended by representatives of each population group, not just representatives of the population groups with a higher education.
- Organisations could stimulate participation of patients by periodically organising small-scale patient/citizen meetings (possibly with families) on an easily accessible/common theme.

And on a more local level:

- Waiting room discussions could be organised at a General Practitioner's office ("gossiping about care providers"), the minutes of which are handed in to the GP anonymously so that he/she can improve the quality of care provided.
- Self-help groups/contact groups contribute to changing opinions about a disorder.
- There are many platforms, but they are not (only) about health. Use these platforms to include visions on health policies.

Example given:

The “Frühe Hilfen” in Germany. All families with new-born children are advised via a family midwife (an independent institution, not the Youth Welfare Office) who gives help and information as and when needed. This helps to strengthen the personal responsibility and the self-confidence of families. The same procedure could be used for the initial school examination.

The participants also mentioned what could and should be done on a local level to achieve a participatory approach and who should be responsible for it.

Examples given:

- We need counselling services in neighbourhoods to facilitate low-threshold dialogue in a timely manner.
- Comprehensive medical-social counselling should be made available.
- Schools (primary and secondary) have an important role to play in the participatory approach. There are a lot of initiatives, but they get stuck or are not being rolled out.
- Changing our own behaviour, and that of all people, is difficult. This is not sufficiently taken into account in the participatory approach. Often people only take action when it is too late.
- An important tool in rolling out the participatory approach is establishing peer groups, which can greatly strengthen behaviour within the peer group in a positive sense when it comes to health, because the group standard as such is a tool that always works in a group and it can now be used in peer groups for health too.
- The industry also has a major role to play. Group fitness at lunchtime helps, so it should be offered more.
- Health care systems in which patients and nursing staff are seen as competent partners and are asked for their opinion. This should be a continuous process: Survey – evaluation – measures, as in “plan – do – check – act”.

It is felt that large institutions are not in a position to change procedures. Their focus should be on improvement. Not only for patients but also by improving the workplace and thinking about things that could help to empower employees and keep them healthy.

Lack of transparency (responsibilities/limitations and specialisations) prevents participation.

When discussing their personal experiences and/or views regarding their role in health care and health policy, the participants discussed their ideas on how the relationship between health care professionals and patients should develop in the coming years. Regarding the topic “human resources”, in paragraph 6, participants also mentioned a lot of the examples and views mentioned in paragraph 5.3.

5.3 DEVELOPING THE RELATIONSHIP BETWEEN PROFESSIONALS AND CITIZENS

Within the framework of the participatory approach, equality between care provider and patient should be promoted. Too many people are still in awe of their care providers. The thresholds are still high. Cooperation between doctors and patients must improve. There is not enough customisation. Information is still poor.

The general practitioner plays an important role, both in the Netherlands and in Belgium. Unfortunately, this is not the case in Germany. The relationship between a general practitioner and a patient is based on trust and it takes time to build. Attention must be paid to this when considering successors. There is still a world to be gained in responding better to the whole of mankind.

The participants would like to have health care systems where doctors see themselves as providers of services, where there is more understanding and respect for the overburdened situation of nursing staff and doctors, and where all demonstrate a friendlier approach to one another.

A health care system should be put into place where people have recourse to other occupational groups and support in the provision of care – i.e. not all work has to be done by specialists.

“As a patient, you sometimes don’t know what your needs are, but through interaction with health care professionals, the latter will know more about what you need”.

Health care professionals should ask their clients to repeat what he/she has just said. The professional is then better informed about what a client really understood and will take home with him/her. This also applies the other way around, in order to be sure there is clarity on the part of the professional. The participants acknowledge that – by doing this – doctors will not have enough time, so they suggested that more practical assistants (pa) should be introduced to allow doctors more time to hold the above-mentioned conversation. Investing time in listening means allocating resources by management for more staff. They need tools to empower patients to engage in conversation.

Municipalities must promote the idea that citizens should take their network with them to meetings and/or involve them in their road to recovery or change: because their network knows the person as a whole. In other words, talking together as a network with the municipality.

An example given:

Look at the new concept in France at Hospitals: department ETP Education Thérapeutique du Patient.

Try to incorporate that in other countries.

From a cost point of view, the problem of patients who ask for 'unnecessary' care, should be addressed. And so, should the problem of health care professionals who administer/prescribe unnecessary medication/treatment.

Insurance companies should be more open and much more transparent about procedures and rules. They often amend the terms of the contract without informing citizens. In Belgium competition exists between mutual health organisations, which is unnecessary. At the level of management and administration, in Belgium there is no known involvement of citizens, with the exception of the occasional member of a supervisory board. In the Netherlands too, health insurers do not sufficiently involve their clients in the development of their policies and their annual contracts.

In Belgium, it is not possible to simply switch from one to another general practitioner. There are all kinds of thresholds in the system. These are bound to a certain mutuality and sometimes, if people change jobs, they are obliged to change their mutuality because the employer cooperates with another mutuality. Mutualities are managed by the trade unions. Participants describe the system as segregated and complex.

Participants also mentioned that positive changes in developing a relationship between professionals and citizens will only truly be embedded in society in the long run by educating students from a school age.

In general: do not allow access to medical studies to be decided by grades alone. Great students may make terrible nurses or doctors.

Make sure that an internship as a ward nurse is compulsory in the medical curriculum and emphasise the importance of the concept of "communication and accessibility to health care" during classes. Students must be made aware that patients who do not talk about their condition cannot be helped properly (at an early stage). As future health care providers, they are responsible for leading the conversation.

In addition to the formal structure of health care (general practitioners, hospitals, etc.), more account will have to be taken of the future living environment on a district or neighbourhood level. The population will be ageing, with more individualisation and less social or family network, which will give rise to the need of a mutually recognisable 'platform' – for care or service providers or patients/clients – on which not only basic care but also other forms of social services (e.g. domestic help, meals, chores) can be organised in a professional manner. Organising this on a small-scale level with all possible actors may result in a more 'familiar' and accessible picture of the existing care structure and could prolong or facilitate independent living in the current environment. The professionalization of such a 'platform' on a district or neighbourhood level should include both formal financial frameworks and coordination with the possible presence of volunteers or informal carers.

Other suggestions and examples mentioned were to use existing networks to share knowledge. The design of future health care can be promoted by consistently communicating transparently and clearly; this will require agreements on how to deal with comments, proposals, advice ("quick and clear feedback") as well as more modern and customer-friendly information exchange in contacts with health care professionals.

The approach to extolling the benefits of e.g. stopping smoking and giving up alcohol should be positive rather than negative.

5.4 CROSS BORDER

The fact that citizens were invited to cross-border citizen summits was perceived as seeing them as equals. Overall, the exchange of cross-border experiences was perceived as very interesting. One of the participants said that “theoretically, patient orientation is taught during my (current) studies, but here I perceive much more concrete views”. Not only did we, as writers and readers, profit from their views and opinions, but the participants also mentioned that they gained a lot of information from their peers, not only in general, but also regarding cross-border topics. This meant for them that their views and opinions concerning cross-border sustainable policies were necessary and helpful. The general request was to organise round-table discussions more often and also to organise them with citizens from neighbouring countries to exchange experiences and share knowledge. That was often an affirmation of one’s own story/experience, but also a real eye- opener.

5.5 POINTS TO PONDER

Participants were asked what they wanted the organisers of the July 2019 conference to know and to ponder. Participants wonder whether the outcome of the summits will be used by organisations. Will their contribution make a defining contribution to the work of the professionals attending the June 2019 conference?

- Citizen participation must be developed and used more often in order for health developments to take effect and for prevention to bear fruit.
- More prevention measures should be put into place and more investments should be made for prevention. More attention should be given to mental health care.

Some quotes:

“Strengthened the role of prevention workers.”

“Grow from prevention to prediction.”

“Please pay attention to those who have more difficulty expressing themselves and those who are really ill at home. “

“Take your curiosity and desire to participate in health care everywhere with you – not only to established organisations but in your lives.”

“Please don’t dwell so much on the current costs of health care; in the long run the costs of health care will automatically decrease through prevention.”

“A growing awareness: taking the initiative yourself, share with one another. There is a need for change.”

“Strengthen and improve the reputation/prestige of nursing staff.”

5.6 CONCLUSION

Participants have scarcely been involved in discussions on health and health policies in the past. They were glad to have the opportunity to do so at the summits. Organisations and policy-makers should actively ask citizens for their know-how via citizen conferences or via other means. The goal will be to have a good cross-section of society, i.e. not limited to citizens who are able to express themselves more eloquently or are more financially sound.

There should be more counselling, not just for the citizens but also for the professionals. They should be taught early during their training how to communicate with their future patients, thereby promoting the idea that patients should involve their network more actively in the whole process.

CHAPTER 6 HUMAN RESOURCES

“Human resources for health or health workers comprise all people engaged in actions whose primary intent is to enhance health; and play a central and critical role in improving access to high quality health care for the population. They include physicians, nursing professionals [.....] as well as health management and support personnel; also, those who may not deliver services directly but who are essential to a health system that functions effectively, including health services managers, medical records and health information technicians, health economists, health supply chain managers, medical secretaries and others. They provide essential services that promote health, prevent diseases and deliver health care services to individuals, families and communities based on the primary health care approach .” ²⁷

Participants were asked how health care professionals should act to encourage the desired behaviour in citizens, equality and further the sharing of information. The participants also discussed where health care professionals should be located. Moderators asked if the participants would consider a job in health care and for their thoughts on fulfilling a job in health care.

6.1 PROFESSIONALS’ ATTITUDE AND WORK ETHICS

The participants have a clear view of the current behaviour of health care professionals. Although distinct differences were noticeable in participants’ opinions of that behaviour, much more consensus existed on what was lacking or what the preferred behaviour should be.

Some participants said that health care professionals make time for them and see them as human beings and not just as patients. However, the majority said that professionals do not see them as individuals. They see them as a “standard illness that needs to be treated”.

At one table, participants said that first and foremost the behaviour of the aid workers has to change from cold, distant, non-human, to decent – especially in hospitals.

“Kindness, humanity, and manners are very important.”

The causes of such behaviour should be sought in the demand on professionals to work within certain financial constraints. In the eyes of citizens, management and/or health care insurance companies put a lot of pressure on staff. The time professionals get to spend on each individual patient is too limited, leaving no room for actual interest in the patient and tasks being executed in great haste. Health care professionals should to be guided more by compassion than by their agenda and billable hours.

Examples given:

Participants felt that a lot of professionals hold the doorknob in their hand, on the point of leaving before the patient’s intake has even started.

Another comment made is that the power of money determines the care. The pharmaceutical industry and health insurance companies have too much power. The result of this business-approach and, for example, temporary contracts, is that health care work is increasingly becoming a ‘job’ (a salaried livelihood) and less a ‘profession’ (vocation, personal involvement).

Participants had almost consonant views on the preferred behaviour of health care professionals. The answers focussed on preferred (social) behaviour. During contact moments, professionals should schedule more time for their patients in order to ask questions about their personal life, household, their burdens, work, studies, social issues and family. They should regard the need for care as just one aspect of the patient and make sure that they see the entire person. They should not deliver standard solutions but a patient-targeted approach, meaning no unnecessary actions and not medicalising too much and too quickly. Health care professionals should be more open, friendlier and capable of creating an environment of trust for citizens.

"They should create a high level of "hugging", meaning that the professional sees us as persons, takes the time for us as human beings and look at us and not at their task. Specialists should look at us as a whole and not compartmentalise."

Examples given:

One of the participants said they would prefer to see a Positive Health approach in communicating with and helping patients. "You should be taking care of yourself, together with the professional. Not the other way around." Hence switching to the patient's perception of health care.

They should be active listeners and initiate conversations. They also should reduce hierarchies and health care professionals shouldn't be overbearing or intimidating. Otherwise patients will not dare to ask questions, start a conversation or make a complaint.

"The patient has to become a professional, the doctor has to become more human".

"Look at the patient's point of view in a demand-driven way, and not from the perspective of supplying a "product".

A lot of participants suggested tools for implementing the desired behaviour, whether via education or via investments. The desired behaviour should be learned and encouraged during the course of studies such as medicine and at nursing schools. It should be made a key part of the curriculum. Participants suggested that patients should give students feedback during their study. "Let patients talk more to the students. By doing so the latter will learn more social skills." During the study, more attention should be given to what the students will have to deal with, as professionals, later in life: death, serious illness, loss, etc. Ensure that they can speak to experts in groups.

There should be an interim check on patient satisfaction with progress and results of treatment, possibly with agreements on "after-care". Unnecessary treatment or those that are too expensive can be prevented by improving the exchange of information and training in expectation management between health care professionals and patients.

- A patient suffering with dementia was admitted to the ER with severe pain. Due to the dementia, the patient did not receive treatment for up to 5-6 hours and was discharged. Back home the patient developed great fear due to the pain. Adequate skilled staff were not available to help this patient, either in the clinic or at home.
- A patient presented to the ER. In the patient's file they filled out the wrong name, wrong diagnosis (kidney instead of lung) and hence the patient was subjected to the wrong diagnostic procedures and the wrong kind of drugs were administered. An explanation was given only after several days, but feedback to the patient did not take place. In this example the patient's name-tag was not read, and the staff did not introduce themselves. The patient and/or family-members could not identify the staff by name, rank and/or function. They were at a loss.
- An example of how not to communicate is that of a man living in a nursing home. His wife of many years was still living at home. She passed away suddenly. Health care professionals at the nursing home were attentive to the couple's children and paid attention to the children's loss and grief. However, they forgot about giving attention to – and acknowledging the grief of – their patient, who was living in the nursing home; the husband of the woman that passed away.

6.2 WHERE TO LOCATE HEALTH CARE PROFESSIONALS

The key is that health care professionals should be nearby and very accessible, not only in the city but also in regional or rural centres, in neighbourhoods and municipalities.

They may do their work at home (e.g. during house calls), in a nursing home or in a hospital or in a specific workplace, e.g. having a physiotherapist or general physician at work ensures that employees stay healthy.

A lot will depend on the frequency of visits. For a specialist, one is willing to travel some distance, but clinics should be in the vicinity, even if it means crossing the border. Preferably concentrated according to specialisation (e.g. not every hospital needs to be specialised in all aspects of medicine). The link with the social network remains important and after-care must be available in patients' own region. Positions should exist in schools and companies, where professionals have the task of promoting health in that (working) environment.

Others said they would like to see health care professionals where "the spirit of the house" is perceptible, e.g., respect and patient-orientation.

Participants also want to see health care professionals working in an environment where the interests of the professionals are considered in order to create a positive and more friendly and open atmosphere.

6.3 CAREER IN HEALTH CARE

Participants have mixed feelings about working in health care. Some are adamant in their answer when saying that they would definitely not want to work in health care. Others are employed in health care or were in the past. There is another group that would consider working in health care if certain conditions were met, e.g. if the administrative burden were to be reduced. According to some, shortages in the labour market are partly the result of the fact that more people are consciously opting for a better work-life balance. Many people do not necessarily want to work

full-time. A growing number of people are self-employed in the care sector, which can also cause problems in the long term. The solution is to involve more people and to make more use of technology. Greater appreciation for care professions might encourage more young people to choose care. At the moment, care professions often have the image of involving long, hard working hours for little pay. You have to have a high level of social awareness in order to work in the care sector. A lot of patience and humour is required in order to work in health care.

Some had specific examples and/or solutions:

Nursing training in Germany should be improved: 2 years of basic training, followed by specialisation in children/patients and care of the elderly would be good. Better education deserves better pay.

New experience in processes and developments – cross-border – could be achieved via ERASMUS programmes for health professionals, in order to make new things possible and initiate new learning processes. Public and private investment is important in this regard, and it is important to facilitate specialised care (e.g. within dementia care).

6.4 TASK OF HEALTH CARE PROFESSIONALS

Participants also discussed if others could do tasks now done by health care professionals.

The general perception is that high workloads in health care are a huge problem and due to those high workloads, the personal connection with patients is being lost. The participants want to ease the burden of those who work in health care by changing patients' attitudes, by deploying volunteers, deploying more staff or using new technology. Some say that the focus should be on the role of the patients' own behaviour and taking personal measures to influence your own health and discussing this with professionals. Creating the "new elderly". Ageing and loneliness will be major problems in the future. Everyone agrees that the solution lies in the neighbourhoods themselves. Someone has to approach people in person and motivate them to become active, e.g. to take part in activities in the neighbourhood centre. (Socio-cultural) associations are also a very good way of reaching people. Unfortunately, these associations are increasingly stagnating both in Belgium and the Netherlands. The biggest problem is finding people who want to commit themselves to accept a position, e.g. to take the lead. The intensity of engagement required no longer outweighs the voluntary nature of their engagement. Much more is involved nowadays.

For example: service flats in combination with child-care or families consisting of different generations living together in one house. Create the desired neighbourhood by changing the housing criteria.

The participants would also like to ease the workload of current health care professionals by deploying and make more use of "volunteers". Appeal more to family and informal caretakers. Voluntary work will also be very important in the future in order to be able to provide everyone with the necessary care. Volunteers could assist by performing supportive tasks and low-level medical care, e.g. bandages, sprays, etc. Doing voluntary work should not be seen

as something that is free of commitment. It will only work if you can actually rely on the volunteers. That they feel committed, even if the weather outside is beautiful and they would rather go to the beach. You have to give volunteers something for their efforts, as is done for carers in Germany.

Others say that you cannot ask family-members for more help if they work 40 hours a week and have a family of their own. They strongly denounce the idea that volunteers should be involved in health care. They feel this is not a reliable basis for changing personnel planning, or they simply question why the health care sector should use volunteers.

“There is not a single car manufacturer who claims to have built the latest car model by using volunteers. Why should the health care sector always have to rely on volunteers? Why don’t they just get the paid skilled personnel they need?”

Staff shortages could also be resolved by deploying (qualified) migrants, by appealing to pensioners who still want to work or by deploying the unemployed for a small fee. But make sure there are care assistants who support specialists when giving treatment and care. Allow a greater diversification of professions, as is the case in the Netherlands.

Other suggested solutions were to deploy robotics/home automation in cure and care: careful and gradual experimentation with new technologies, making sure they are properly tested for affordability and patient acceptance. Technology will help enormously to strengthen the process and to develop health care professions in the right direction. Promote and stimulate the use of e-health.

Set up digital platforms for supply and demand in care, social and societal domains, both for professionals (e.g. care domain) and for citizens (e.g. cubigo, wehelfen). Look into remote monitoring and remote consultation. By breaking with tradition, altering systems and lifting them to a different level, it may be possible to support (innovative) frontrunners.

6.4.1 DIVIDING CERTAIN TASKS

Volunteers could establish a personal and trusting relationship with patients for tasks that health care professionals cannot do due to lack of time. In a network of family and friends, informal caregivers could do some household chores (washing, ironing). We should work towards a longer life, living independently by living in shared houses with several occupants of different ages and needs. This will require the same mindset and ideas about supporting and caring for one another. It must be possible to get professional help on demand. However, it is important to have a sense of community so that fewer professionals are needed (people taking care of one another). Bear in mind that this too is culture-dependent.

Participants also made suggestions about rearranging tasks for some health care professions. Nurses should do “the whole package of care”: seeing a patient as an entire being and not just his/her disease. Different care providers often help patients: one is allowed to do “x” and the other is allowed to do “y”. As one participant explained: as a result, a patient suffering from Parkinson’s disease had to wait a long time before the care worker who is allowed to administer the pain medication arrived on the scene. Participants want a key figure to help them to obtain care relating to prevention, health, etc. This could be a key figure located in a community health centre, who will literally take you by the hand to see the health care professional. It could be a family nurse who follows the family in terms of health and

prevention at different stages of life, gently nudging people in the right direction. The specialist must support the generalist, as the latter drops out of the picture too quickly. Let the municipality, as a “contractor”, go shopping for its citizens and do not leave it up to citizens to continually shop from one counter to the next.

We need sufficient personnel, so that people want to become vocationally engaged in this field again. In order to achieve this, younger people should be motivated, the profession should be made attractive by allowing people to design how they work for themselves. Give them more time for patients instead of for administrative tasks. There should be a greater appreciation of the ‘profession’ and greater use of longer-term permanent contracts would improve the labour market for health care professionals.

Example given: Some tasks can be delegated, e.g. to assistant general practitioners, as is customary in the Netherlands, but not in Germany.

Nevertheless, voices were heard saying that things are going in the right direction. Commitment is required on both sides: patients and doctors. Patients must realise that health care workers may be afraid of losing their jobs. A cultural change in all areas of society is necessary and will take time. We would do well to look ourselves in the eye and see what impositions we make and what we do in our various roles as consumers, patients, professionals, insured parties, care-givers, parents, etc.

It is important that people in neighbourhoods get to know one another and take care of one another again. Many people are lonely; they shut themselves off from their neighbours. They have to realise the importance of this. More should be invested in strengthening social contacts in neighbourhoods and communities. Some feel that every citizen should take more personal responsibility and that people are pampered too much. Too often people think that self-determination is what is most important, but they tend to think mainly of themselves and fail to see the bigger picture or the size of the impact. Others don’t think this at all; they think that everyone should be free to live the way they want to live. People may be motivated by the government or companies to live healthier lives, but they are not obliged to do so. Freedom and self-determination are the key. Doing more by yourself as a patient, but with supervision and structural education.

6.4.2 TERMS AND CONDITIONS

In order to put the above-mentioned solutions successfully into place, special attention should be paid to the relationship between professionals and volunteers. Often professionals feel threatened by volunteers and volunteers are frowned upon. However, there is no reason for this. Make it easier – from a regulatory point of view – to ask volunteers for assistance. Make sure volunteers are insured and compensated accordingly. Help them with statutes, book-keeping, etc. Make sure that the working class who want to work as volunteers are given the chance by their employer by being allowed so many hours per week to do so while still receiving their benefits or salary according to their normal working hours. Supervise care-givers and guard them from getting a burnout. People are often care-givers alongside their professional work and raising their own children, etc. Allow them to keep their wages if they

become care-givers and allow continuation of their pension accrual.

Regulate companies so they have an active vitality policy for stress reduction and prevention at a young age and get companies to convert the financial “profit” that results from this back into support for informal carers. This is a policy choice that must become a regulation/obligation. Give a central role to the caretaker. Make sure – when asking families to help – that every family-member is engaged, so that not just one family-member is doing everything.

Establish social networks for people to fall back on. In order to stimulate this, individual social contacts need to increase and improve. This is not only an individual responsibility but also the responsibility of the government. Attention should be paid to more neighbourhood initiatives, supporting organisations that bring people out of social isolation, creating awareness of the importance of a social network, investing in one another because we’re going to need one another, making sure that voluntary work is voluntary, but not without obligation.

Policy and management in health care institutions are extremely important. They have to deal with people and resources in an efficient way. Good policy takes into account the quality and importance of personal contact.

For example, people have experienced that in some private institutions in Belgium, the culture among staff is much better: they help one another. For instance, a cleaning lady – when she has finished cleaning – also helps to dress patients and assists during dinnertime. In this way, the professional is helped and the patient receives care that is better and much more humane. Other institutions (often public ones) have a completely different culture. An example was cited of a health care professional who reads the newspaper when (s)he has done his/her mandatory tasks. But instead of reading the newspaper, they could assist colleagues or give some extra attention to those in need of care. Therefore, a lot depends on the culture within institutions and there is still a lot of room for professionalising management.

A general fear is that the above-mentioned work ethic will result in price differences, which will create inequity, as it might only be affordable for those with higher incomes.

6.5 CONCLUSION

In general, the participants want professionals to be nearby and to be very accessible, regardless of whether they live in a city or in the suburbs. They are willing to travel for specialised care, but this should mean allowing them to visit the nearest specialist even if the latter does happen to practice in the bordering country.

The majority felt that professionals do not see patients as individuals, but rather as if they were their illness. The cause for this behaviour should mainly be sought in the lack of time professionals have to really listen to patients. The employment of volunteers, families or informal caretakers would provide professionals with the time they need. A volunteer could help by performing supporting tasks. Others strongly denounce the idea that volunteers should be involved in health care. Other suggested solutions include the deployment of pensioners or migrants or even robotics/home automation. The only way the above-mentioned solutions could work is if there is proper regulation, e.g. for volunteers.

CHAPTER 7 CONCLUSION AND RECOMMENDATIONS

This chapter describes the overall conclusions and recommendations. These are the conclusions and recommendations drawn by EPECS based on the input of citizens during the citizen summits held in February 2019.

The questions that capture the essence of what participants wondered and wish for are those that appear on the title page:

Do you see me as a human being when helping me?

Do you think of me when planning health care?

I would love to share my story and my experiences; will you give me that opportunity?

The June Conference is entitled “Keeping people at the centre of health and sustainable development policies”.

If you compare this title with the questions asked by the citizens, the discrepancy is immediately noticeable. Citizens want to be seen as human beings, as individuals. For the conference in June the word “people” has been used, disregarding the individual. Changing the word “people” to (individual) citizens would acknowledge that sustainable development policies are about individuals and it would be a constant reminder for the professionals who attend that it is all about individuals.

In answering the question of how the stories, opinions and recommendations of the participants can further sustainable development policies, it became clear that participants had a clear and almost unanimous vision regarding the road to take.

7.1 EQUITY

The participants expressed a common feeling that the solidarity-based health care systems in Belgium, the Netherlands and Germany are very important for delivering good health care to all citizens. In addition, health care should become more tailor-made over the next two decades.

Access for all, although it is the basic principle in all three countries, is encountering difficulties in each country. Based on comments citizens made regarding equity and sustainable development, EPECS concludes that citizens cherish equity. It is regarded as essential. It encourages solidarity, which is one of the pillars of European health policies. The participants felt that equity in health care could be reached by changing the accessibility of health care, by offering affordable care and nutrition, by changing communication methods, by means of innovations and community initiatives and by cross-border care. New was that equity should go hand-in-hand with tailor-made approaches that focus more on individual patients.

Participants suggested that in order to obtain appropriate health care, whether in their country of residence or in an adjacent country, they needed “a one-stop shop”, or one person who will guide them through the system(s).

Based on this suggestion, EPECS concludes that people do not receive the information and/or help they need via existing pathways (and in particular for cross-border care, the National Contact Point).

EPECS recommends that stakeholders and policy-makers should make “equity” part of their daily concern, whilst improving health and the health care system in Europe. They should not just look at equality but also strive for equity. It is easier to do this by asking patient organisations for their input or implementing round table discussions with citizens from all kinds of backgrounds. This will broaden the field of vision, benefit policies in a more constructive way, and thus work on sustainable development.

7.2 PARTICIPATORY APPROACH

It was made clear by the participants that the participatory approach was new for them and that very few participants had been involved in health care policies in the three countries. Participants greatly appreciated the opportunity to share their point of view, insights, ideas and stories. The summits proved to be useful and suggest the way forward. On the one hand, the participatory approach was discussed as a tool for citizens’ participation in making health care policies, on the other hand participants expressed their strong hope that their situation should be dealt with on the basis of equivalence, meaning that citizens thus feel they are being invited to take responsibility for their own health. The conclusion is clear: the participatory approach needs to be elaborated upon, right at the heart of Europe, in the Euregio Meuse-Rhine

Having said that, EPECS recommends using the participatory approach to make sure equity is reached. By using the participatory approach, stakeholders and policy-makers can discover that involving citizens in health care policies is not in fact difficult, while it contributes a great deal to the content of policies and to the sustainable development of those policies. In order to be sustainable, the participation of citizens should be organised on three general levels: the macro, meso and micro level:

Thinking level	Complexity level	Policy level	Citizens’ organisations
strategical	macro	National, international	European Patient Platform Active Citizens’ Network Self-help, etc.
tactical	meso	Regions, cities, organisations	Client councils, Senior organisations, Patient organisations, etc.
operational	micro	Human beings	Exchange of personal stories to understand the lives of citizens in the world of systems and policies.

THINKING LEVEL

For citizens, it is helpful to understand how to provide structural input and feedback and how to create interaction with policymakers, so the latter are guided to incorporate them in policy. By adapting to the thinking level of policy-makers, citizens will be heard more and will be better understood. EPECS feels that this would ask a lot of citizens. You would be asking citizens to think strategically and to make strategic proposals. This may be too much to ask. This is why EPECS recommends that policy-makers should be the first to make a U-turn, namely, to involve citizens in policy-making and to bear in mind that citizens find it very important to give actual individual examples when assessing and reflecting on the health care sector. It is up to the policy-makers to clarify the underlying basis, with the help of citizens, so that this can be translated into policy. It starts with round tables and seeing citizens as equals; accepting and respecting the fact that they speak by quoting personal examples. It is up to the professionals and the citizens to figure out the overall message and how it can be incorporated on a policy level.

A lot still has to be done in order to achieve the desired two-way interactive participatory approach. For all parties involved this is a huge change with a lot of implications.

COMPLEXITY LEVEL

EPECS strongly feels that citizens' participation and influence will improve greatly when citizens are informed about the complexity of it all at each level. This does not necessarily mean that they should fully understand it, but enough to be able to achieve the goals set out regarding the participatory approach. At a micro level that would entail, e.g. making sure that more information is given in private by local pharmacists about the use and effects of medication.

TACTICAL LEVEL

At a meso level (tactical level), in all three countries a small number of participants was/is involved in very different operational health care policies and/or organisations. It was emphasized that self-help groups are very helpful but not yet well-developed, although Germany has already a very elaborate system nationwide. Citizens should understand that the rules and laws that bind communities, local services and health care providers cannot be changed overnight, but that there is room for adaptation in local situations. The outcome will be affected positively by involving citizens at that meso level and by keeping in mind the suggestions made by the citizens.

EPECS emphasizes the added value of exchanging ideas, best practices but also failures. The bottom line is that all the citizens wanted the same thing: to be heard and seen as individuals and regarded as equals in discussions and decisions regarding their health.

At a macro level (strategical level), in all three countries national patient organisations are engaged in national policy developments, although differently in each country. The impact of that engagement is not yet clear; nevertheless, it exists and should be encouraged. EPECS strongly feels that the suggestions of the participants to teach from a young age engagement in community work, social work and to emphasize a healthy lifestyle should be taken into account and implemented in Europe.

Regardless of the level, the participants generally agreed on one thing: more participation of citizens is necessary to maintain sustainable health care and the social system in every country.

7.3 HUMAN RESOURCES IN HEALTH

Working out this theme proved to be challenging. EPECS asked for citizens' opinions on how to tackle the shortage in health workers, to translate their ideas into policies and solve issues like working together with volunteers, increasing the number of volunteers, increasing wages and differentiation in jobs, and engaging more people at different levels. The participants had some difficulty formulating comments on those questions. Of course, in detail, citizens gave a lot of input, both on the way they want to be treated by workers, and about the fact that in general all people at the summits agreed that the health care workforce should be based on personal motivation.

It can be concluded that the topic of human resources should be better elaborated on in order to profit even more from the input from citizens.

Nevertheless, during the summits, the citizens made clear that personal motivation to do health care jobs, having affinity with health, health care and people in need of health care services is essential now and will remain so in the future. EPECS concludes that this in itself makes it clear that human resource policies will not simply address and solve the shortage of staff, as influencing personal motivation is not easy. Increasing salaries would only be helpful in the short term as it is not the main reason for working in health care. The proximity of health care workers was a clear wish, offered in local health care centres working together with the community, so training these people is a serious issue that needs to be addressed by schools, communities and policy-makers. Improving the work-life balance would also be helpful because over the next two decades the majority of the workforce in health care will be women.

Equivalence was a strong wish of citizens, which emphasises the motivational aspect of health care jobs. How to influence the above-mentioned topics, and how to encourage this is no easy matter. Citizens did not have the final or best answer.

Therefore, as mentioned earlier, EPECS strongly recommends elaborating on this subject further and discussing it with citizens during future round tables.

7.4 CLOSING REMARKS

The comments made and the stories told by citizens confirmed that the SDG and WHO goals are indeed a mirror of the wishes of people in their role as citizens.

"It is important to identify opportunities, and suitable tools and methods to involve people," noted the main organiser of the citizen summits, Brigitte van der Zanden, Director of euPrevent. "The citizens have brought crucial topics to the forefront, such as how health professionals deal with patients and how we can together address the challenges of demographic change and healthy ageing."

Making direct use of what the citizens have said, EPECS will adjust the wording of our text as follows:

“Health is all about individual citizens.

Without individual citizens there is no health, no perception of health, no demand for health care, no struggles in obtaining health care, no discussions on health care policies, no feelings of happiness or sadness regarding the ability to obtain health care.”

8 REFERENCE LIST

- 1 In alphabetical order
- 2 “Institute for Positive Health” at www.iph.nl.
- 3 Article 2 of European Convention on Human Rights
- 4 Article 8 of European Convention on Human Rights
- 5 see: www.un.org/sustainabledevelopment/development-agenda/
- 6 see: www.un.org/sustainabledevelopment/development-agenda/
- 7 see: www.un.org/sustainabledevelopment/sustainable-development-goals
- 8 see: www.un.org/sustainabledevelopment/sustainable-development-goals
- 9 see: www.un.org/sustainabledevelopment/health/
- 10 see: www.euro.who.int/en/about-us/networks/regions-for-health-network-rhn/about-rhn
- 11 see: <http://cor.europa.eu/en/activities/interregionalgroups/Pages/health.aspx>
- 12 see: https://www.who.int/topics/health_equity/en/
- 13 see: <https://www.participatorymethods.org/page/about-participatory-methods>
- 14 see: https://eacea.ec.europa.eu/europe-for-citizens_en
- 15 see: ec.europa.eu/commission/future-europe/consultation-future-europe_en
- 16 see: www.euro.who.int/_data/assets/pdf_file/0018/318141/RHN-Trentino-health-plan-20152025.pdf
- 17 see: www.g1000.org
- 18 Klasien Horstman, Universiteit Maastricht
- 19 WHO Regions for Health Network
- 20 see: www.prb.org/2018-world-population-data-sheet-with-focus-on-changing-age-structures/
- 21 WHO Regions for Health Network
- 22 Developed by the psychoanalyst and psychologist Ruth Cohn, Norman Liberman, Isaac Zieman and others.
- 23 Mrs. Raphaela Yomha, Köln, Germany, www.rafaela-yomha.de.
- 24 see: www.who.int/healthsystems/topics/equity/en/
- 25 see: www.who.int/healthsystems/topics/equity/en/
- 26 see: www.participatorymethods.org/page/about-participatory-methods
- 27 WHO Regions for Health Network

“

Health is all about individual citizens.

Without individual citizens there is no health, no perception of health,
no demand for health care, no struggles in obtaining health care, no
discussions on health care policies, no feelings of happiness or sadness
regarding the ability to obtain health care.

”

The project 'Citizen Summit' is possible thanks to funding from People to People project Interreg V-A Euregio Meuse-Rhine,
with support from the European Regional Development Fund (ERDF).