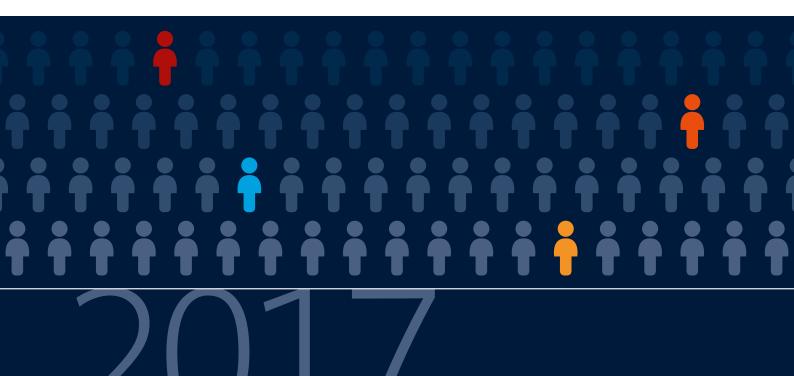
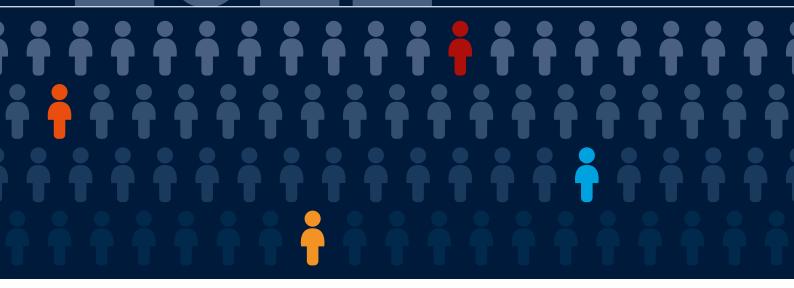


Care and Public Health Research Institute



A Healthy Society for Everyone

Self Evaluation Repor Case studies





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Citizen Science

It leads to a different kind of knowledge that is more relevant to society

CAPHRI gives citizens a voice in research

Public involvement in research, also known as citizen science, is a very common form of research at CAPHRI. "Citizen science comes in many shapes and forms. We use the term to refer to a form of research in which we really work together with citizens. It's a democratic way of doing research that lets citizens influence the course of the study. We consider their knowledge and experience to be just as important as our own knowledge. Ultimately, this approach leads to a different kind of knowledge that is more relevant to society", explains Sanne Raap.

Sanne is a PhD candidate at CAPHRI and one of the researchers involved in <u>Universiteit met de Buurt</u>¹ ["University in the Neighbourhood"]. The project is a living lab for research in Maastricht Noord-West, a neighbourhood where residents are in relatively poor health. Its goal is to work together with local residents to create a healthy and vibrant neighbourhood. Mare Knibbe, an assistant professor in Philosophy and Sociology of Health Sciences at CAPHRI, is also involved in the project. "The research is about citizens", she says. "It only makes sense to give them a voice in it."

The neighbourhood research project has been running for almost ten years, during which researchers and residents have organised various activities together. Take the Manjefiek lectures, in which hospital specialists answered questions from the public about conditions such as osteoarthritis and dementia. Or the philosophy café, established on the initiative of the neighbourhood, where researchers and residents discuss what it means to live a good life. Sanne also points to a concrete example of a problem that was solved by listening to local residents. Ambulances often used to arrive at the wrong destination in the neighbourhood. "The assumption was always that residents hadn't provided the correct address. But through their stories and a visit from EMTs to the neighbourhood, we were able to get to the root of the problem - the ambulance navigation system hadn't been correctly updated after the redevelopment of the neighbourhood."

A healthy city

Last year saw the publication of the book A Healthy City (Gezonde stad, uitsluiting en ontmoeting in de publieke ruimte), written by Mare and Professor Klasien Horstman. Together, they set out to find the main thread running through their research in the neighbourhood.

Klasien Horstman & Mare Knibbe

CONDICO Sized

Uitsluiting en ontmoeting in de publieke ruimte

A key conclusion is that people no longer feel comfortable with the focus on individual lifestyle as a starting point for public health policy. Health, the book concludes, is a social



phenomenon with many facets. One of these facets is the design of the physical environment - which is precisely why it is so important to draw on the knowledge and experience of the people who live in that environment. "What matters is what residents consider important for a healthy neighbourhood", says Sanne. The book clearly illustrates how involving the public leads to a different type of research results. According to Jet Bussemaker, chair of the Dutch Council of Public Health & Society, the book "makes a valuable contribution to the much-needed shift towards promoting health through social security, equality of opportunity, and the physical environment".

The Living Lab in Ageing and Long-Term Care

Another great example of citizen science at CAPHRI is the Living <u>Lab in Ageing and Long-Term Care Limburg</u>² (AWO-L). Ever since its inception 25 years ago, public involvement in research has been the norm at AWO-L. "Citizen science is essentially a new term for something we've been doing for a long time", says Jan Hamers, a professor of Care of Older People and chair and co-founder of AWO-L. "We use a very broad definition of 'citizen', encompassing everyone from healthcare practitioners and nursing home residents to informal carers, teachers, and administrators." These citizens are even involved in setting the research agenda. "Nine-and-a-half times out of ten, they're the ones who come up with the research questions. We then turn our attention to the questions behind the questions. This practice-driven approach has led to studies and lines of research on healthcare issues such as pain and involuntary care, advance care planning, staff composition, new forms of short-term and long-term care, and the care environment."



General Case studies: Citizen Science

Connecting Conversations

The AWO-L research process typically begins with analysing the existing situation, "so that the people involved become more aware of it", says Jan. The next step is involving people in the implementation of a new method or other innovation. "People come up with solutions themselves, together with us. We monitor the progress of the implementation and its results, involving citizens in data collection. For example, we have nursing home staff conduct observations in other nursing homes."

These observations are at the heart of <u>Connecting</u> <u>Conversations</u>³ (Ruimte voor zorg), a method for assessing quality of care developed in collaboration with healthcare professionals, nursing home residents, and informal carers. It involves an employee or member of the client council, preferably from another health organisation, conducting three separate conversations - one with a nursing home resident, one with a family member of that resident, and one with a professional caregiver involved in their care. All three conversations are recorded and summarised in a report in an app developed for this purpose. The method has proved an effective way for organisations to gain valuable insights from their clients.

A learning network

In essence, AWO-L is a learning network in which healthcare practitioners, clients and family members work together to improve the quality of nursing home care. All large organisations for care of older people in Limburg are represented in the network, as are two major vocational training schools and Zuyd University of Applied Sciences. Moreover, AWO-L researchers work in a healthcare facility for an average of one day per week. "This way, they stay in touch with what's going on." The same is true of the researchers in the neighbourhood research project. "It's how we get to the places that matter to people", says Sanne. It just makes sense to involve the public in research, all three researchers agree. They are eager to share their knowledge of citizen science with others, as they did with the book A Healthy City. "We write papers on our approach, and we provide coaching for universities that are interested in adopting it", explains Jan, "both in the Netherlands and abroad."



- ¹ | www.universiteitmetdebuurt.nl
- ² | www.awolimburg.nl
- ³ www.maastrichtuniversity.nl/research/caphri/our-research/ageing-and-long-term-care/%E2%8o%9Cwe-can-be-proud-fact-connecting

Quality Assurance

CAPHRI Quality Assurance system helps foster greater trust in research

Our focus is on how research is conducted

Supporting CAPHRI researchers in conducting ethical and high-quality research, leading to greater trust in research results among both other researchers and the general public - that is the power of the CAPHRI Quality Assurance (QA) system, say Laure Wynants and David Shaw enthusiastically.

Laure, an assistant professor of Epidemiology at CAPHRI, has been chair of the QA Committee for the past two years. David is an associate professor of Health, Ethics and Law; in 2019, he was approached to become QA Officer because of his experience in the field. David was happy to take on the position. "My focus as a QA officer isn't on research output, but on how research is conducted", he explains. "That said, improvements in the way research is conducted will, of course, ultimately have a positive impact on research results." Laure nods. "The system helps researchers be clear about the steps they have taken in a given study, from ethical approval and consent to choosing appropriate analysis methods and transparent reporting. I think it's very important for both other researchers and public trust."

Website and audits

The QA system consists of two parts: a website and audits. "I began by developing the website¹, which went live in late 2020. It gives a clear overview of all the rules and regulations research must comply with, making it easier for researchers to get it right", says David. For example, the website provides guidelines for ethics, data management, privacy, and working with research participants or subjects. The second part of the QA system consists of research quality audits, performed by David. The purpose of these audits is to determine whether a specific study was conducted in accordance with the guidelines. David understands that researchers may feel apprehensive about audits - but, he stresses, there is no need to be. The audit consists of completing an audit form and a "constructive dialogue", as David calls his meetings with researchers

Pleasantly surprised

In selecting researchers for an audit, David has access to a database of approved research projects. Sometimes his choice

of research is influenced by the subject. "For example, I may give priority to higher-risk studies, such as studies involving children or people with dementia." David has conducted 25 audits so far. "I must say that I'm pleasantly surprised by the level of research quality", he says. "About 95 per cent of CAPHRI research fully complies with the rules. For the remaining 5 per cent, there is room for improvement in certain areas. Sometimes people just don't know things. But I haven't yet encountered any major problems."



David Shaw *Quality Officer CAPHRI*

Positive feedback

Researchers' feedback on the audit meetings has been positive across the board. "I've noticed that the meetings let researchers see the rules in a new light. You see, they have to jump through a lot of hoops to get their study approved. The meetings help them better understand and appreciate the rules. Additionally, the audit confirms to them that their approach is the right one. Researchers also sometimes offer constructive criticism of the regulations and the QA system. I share their feedback with the QA Committee to discuss how we can improve the system. A better QA system can help improve research quality even more, ultimately resulting in better output."

Maze of regulations

Apart from the QA system, researchers are bound by the Maastricht UMC+ Research Code and the Netherlands Code of Conduct for Research Integrity. The maze of regulations is quite overwhelming, David and Laure agree, "although there is a great deal of overlap", says Laure. The CAPHRI QA system offers researchers a path through the maze. The website is constantly being updated, with a recent update adding information about support services for registering and storing data. "We aim to make the website as inclusive as possible", concludes Laure, "to help as many researchers as we can and encourage them to adopt best practices."



Laure Wynants Chair of the CAPHRI Quality Assurance Committee

 $^{^1 |} www.maastrichtuniversity.nl/research/caphri/our-research/ageing-and-long-term-care/\%E2\%80\%9Cwe-can-be-proud-fact-connecting and the second of the sec$

Research Line Collaboration: the DARTBAC project

Technology as a weapon against antibiotic resistance

Project "Dartbac"

The coronavirus pandemic has claimed more than a million lives. Though this is certainly dramatic, the rise of the silent killer antimicrobial resistance (AMR) in which bacteria are no longer susceptible for antibiotics is even more threatening and will claim many more victims. The expectation is that in the near future this number will ultimately climb to more than ten million a year worldwide. Researcher Chris Arts of Maastricht UMC+ is leading a major international study into alternatives to antibiotics, technological solutions and increased awareness of AMR. "We are heading for disaster if we do not recognize and address this problem."

Chris Arts does understand that the last thing we all need is a new nightmare scenario. After all, the world already has its hands full with COVID-19. "Absolutely true," he says, "but we'll beat the virus, sooner or later. Resistance to antibiotics is even more serious, however. Bacteria are even more stubborn than viruses, they don't weaken in strength and they also mutate. Currently, the only way to fight many serious infections is with antibiotics. If these drugs stop working, patients have to rely on their own immune systems. This often doesn't end well, leaving patients with serious permanent damage or even causing their death. For years, we have been seeing more and more bacteria becoming resistant to antibiotics and we have been warning about the risk of an epidemic for a long time. I hate to have to say it, but this is no longer science-fiction and happening at an alarming rate."



are much more cautious about the use of antibiotics and we are very strict when it comes to adding antibiotics to our food-chain and drinking water. The cause of resistance is actually very simple: if very low levels of antibiotics enter the bidy, bacteria can develop resistance and the antibiotics can no longer kill the bacteria. In France, Spain and Portugal it's easy to buy antibiotics. Six courses a year for a cold, diarrhea or other ailment; this is not an exception in these countries. People often don't finish these courses of antibiotics and the wrong types are used. Put all of these bad stewardship factors together and you get an explosive increase in resistance, also because there are hardly any new antibiotic variants being developed anymore. And don't assume we're safe here in the Netherlands; resistant bacteria do not stop at borders."



Period: 2020-2026

This project has received funding from: Dutch Research Council (NWA-ORC) Project website: <u>www.nwa-dartbac.eu</u>

Cautious

The orthopaedic researcher, who graduated as a human movement scientist in Maastricht and obtained his doctorate in Nijmegen, shows a map depicting the resistance to antibiotics for the life-threatening MRSA bacteria, among others. Several regions in Southern Europe and America in particular are turning an alarming shade of red. "This means that half the people who get infected can't be treated successfully with antibiotics. The figures are a lot more encouraging in the Netherlands and Scandinavia. Firstly, because these countries

Infection

The consequences are becoming more dire by the day. "Take hospital patients who develop an infection after surgery; we see them in our practice in Maastricht as well. And their numbers are only rising. This isn't immediately life-threatening, but it can be when antibiotics stop working. When this happens, a standard hip surgery, knee replacement or a thoracic procedure can prove fatal. At a minimum, it can lead to longer periods of care or admission to intensive care units and subsequent extended periods of rehabilitation. In Europe, 400,000 people are already ending up in intensive care because antibiotics aren't working. Given the current growth rates, this number is likely to rapidly increase tenfold. Extrapolate this to the Netherlands, and there will be more pressure on IC units and hospital care than we're now seeing from COVID-19. Now try to calculate how much this will cost. It's in the billions."

DARTBAC

Despite these shocking figures, awareness of the problem is still not very widespread. People and also health care professionals still have a false sense of security. The use of antibiotics is only increasing. The Netherlands is an exception in this regard and we describe significantly less antibiotics compared to other European countries.. Last year, the now awarded a subsidy of 9.8 million Euro to the Dutch Antimicrobial Resistance Technology development and Biofilm Assessment Consortium, or DARTBAC for short. The objective of this international alliance of more than 26 scientific institutes, companies and entrepreneurs is to provide material technology solutions to the growing AMR problem. This is a consortium that includes Maastricht UMC+ as the lead partner, and Chris Arts as a project leader. "It's no coincidence that we're in the lead," says the Brabant native, who co-directs a lab in Maastricht with 35 other orthopedic researchers and also conducts technical research at TU Eindhoven one day a week. "Here in South Limburg, we have a great ecosystem thanks to the Brightlands campuses. We have the best imaging facilities here, along with top researchers and institutes specializing in materials research. There are also crossovers with organizations in Germany, Finland and Belgium. We are able to conceive, develop and apply technological solutions here."

Materials

Technological solutions for antimicrobial resistance. So the goal isn't new antibiotics? "No it is not!, At DARTBAC, shortterm we're looking at combinations using antibiotics and other substances such as metals to improve therapy potency. We are also trying to create broad Societal AMR awareness. The focus here in Maastricht and the local area is on the development of material technology not based on antibiotics that repel bacterial attachment and biofilm formation or that destroy bacteria. Examples include hip and knee implants, plates used for fractures, but also materials for IVs, catheters, pacemakers, stents, and so on. There's always a chance of infection with any surgery, but we hope to minimize that risk and prevent the need for antibiotics. Prevention is always better than cure. We are developing coatings with antibiotics that attack the bacteria very locally; we are looking for materials that bacteria cannot affect, with a specific focus on biological materials. The developments at the campuses and MUMC+ are promising. For example, they're working on a coating with minuscule dots which make it impossible for bacteria to adhere to the surface and thus adversely affect bone or tissue. We use the M4I scanners, the best in Europe, to test whether or not this works and what the molecular mechanisms behind these processes are to determine how best to disrupt them."

Diagnosis and treatment

A major complication after arthroplasty surgery or trauma is bacterial infection or periprosthetic joint infection (PJI). The treatment of PJI is difficult, time-consuming and costly and almost always involves surgery. Despite aggressive antibiotic treatment, it often results in diminished quality of life. Our aim in the Dartbac project is therefore also to optimize diagnostic strategies that allow faster and more accurate pathogen detection, so antimicrobial treatment can be started or switched to the appropriate drug. We will evaluate different strategies to diagnose PJI. With respect to detection of bacterial causes of PJI bacterial culture techniques will be evaluated retrospectively. Further in prospective studies novel molecular diagnostic methods will be compared to standard bacterial culture e.g. IS-PRO technology (Inbiome) and 16S sequencing (Nanopore sequencing) and application of Raman Spectroscopy device (Nostics) to perform label-free identification of bacterial species. To optimize antibacterial treatment, we will use static and dynamic biofilm models to screen for successful antimicrobial coating compounds. These models will be used to investigate optimal methods for measuring antibiotic susceptibility in biofilm settings. By combining these data, we aim to optimize patient care for patients with various infection types.

Multidisciplinary collaboration

Over the next six years, the duration of the DARTBAC project, Chris Arts wants to clinically validate at least three groundbreaking technological solutions. At least ten more researchers will be hired in Maastricht to accelerate the research. "This definitely does not mean the danger has been averted. Material technology is only part of the solution. We'll be very happy if we can minimize the AMR effect in the Netherlands." In addition to groundbreaking technological solutions, it is therefore imperative to increase awareness about AMR. Especially in the Netherlands this topic needs attention, as in contrast to most other European countries the level of antimicrobial resistant bacteria is still very low. As a result, important target groups, such as general health professional, patients, and citizens, tend to underestimate the threat and to overestimate their sense of security. One of the pillars of DARTBAC is therefore solely focused on using expertise from the field of health promotion and communication to increase awareness among these three important target groups. Ultimately, we hope that the creation of awareness and a sense of urgency will catalyze future acceptance of new antimicrobial technologies.

General Case studies: Research Line Collaboration: the DARTBAC project

Involved partners

DARTBAC is an interdisciplinary, 23 partner consortium consisting of:

Academic partners

Maastricht University, Maastricht UMC+, Amsterdam UMC, Leiden UMC, the National Institute for Public Health and the Environment (RIVM), Delft University of Technology, Eindhoven University of Technology, UMC Groningen, UMC Utrecht and the University of Amsterdam.

Industry partners

B. Braun Aesculap (Germany), BiosparQ (Netherlands), Bonalive (Finland), CAM Bioceramics (Netherlands), DSM (Netherlands), MadamTherapeutics (Netherlands), OS-1 (Netherlands), PCI Biotech (Norway) and Healthcare Innovations Netherlands (Netherlands).

Other partners

AMR-Insights, Federation Medical Specialists Knowledge Institute, Dutch Orthopaedic Association and ReumaNederland.

"By involving social sciences, communication sciences, materials sciences, medical sciences as well as medical specialist organizations, the RIVM, communication experts, health funds and industrial partners straight from the start of the project, we create the opportunity to raise awareness around AMR and to develop and clinically apply possible material technical solutions more quickly."

Involved research lines

- Functioning, Participation and Rehabilitation
- Promoting Health and Personalised Care
- Health Inequities and Societal Participation

Our most important scientifice output

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Ageing and Long-Term Care (ALTC)

Case study 1: The ban on visitors really had a negative impact on the well-being of nursing home residents"; COVID-19 monitor in nursing homes

At the beginning of the COVID-19 pandemic, Professor Jan Hamers received a phone call from the Dutch Ministry of Health, Welfare and Sport. They asked the Living Labs in Ageing and Long-Term Care to help develop visiting guidelines for nursing homes, which had immediately been closed to all visitors when coronavirus hit the Netherlands. "Thanks in part to our research, they reopened their doors to visitors earlier."

COVID-19 monitor in nursing homes

Jan Hamers (professor of Care of Older People): "Soon after the COVID-19 pandemic broke out last March, Minister De Jonge of the Ministry of Health announced a ban on visitors to nursing homes. Shortly afterwards, I received a phone call from the ministry. Their first question was whether the Living Labs in Ageing and Long-Term Care could help them collect data: how many people in nursing homes were infected with coronavirus? How many residents, how many employees? They had no insight into those figures. And then there was the question of how to proceed, of course. I passed their request on to SANO, the network of Academic Collaborative Centres for Care of Older People. Amsterdam started working on those figures, Leiden and Groningen set out to analyse the meeting notes of nursing home crisis teams, and our own Living Lab in Ageing and Long-Term Care Limburg (AWOL) teamed up with the Nijmegen University Knowledge Network for Care of Older People (UKON) to study the ban on visitors.

Overestimated

"The ban was having a very significant impact, as we quickly learnt from both residents and their loved ones. After all, what is worse: not seeing your partner in person for three months, a mother with dementia no longer recognising her child after that amount of time - or the risk of getting infected with coronavirus? It was quite possible that people were willing to take that risk. Moreover, the number of cases in nursing homes had been overestimated; only half of all suspected cases were confirmed, and three or four out of every ten patients died. You might say that's a lot, but we shouldn't forget that this is the most vulnerable group of people.

The average life expectancy in a nursing home is eighteen months. I'd prefer to look at it the other way around: 60 to 70 per cent of those patients survived the virus."





Start project: May 2020

Project website: www.academischewerkplaatsouderenzorg.nl

Pilot study

"We wanted to do a small-scale pilot study into allowing one visitor at a time, under strict conditions. We would monitor the visits. People were increasingly calling for the restrictions to be eased, so the minister decided that one nursing home in each Dutch safety region could participate - that's 25 in total. At the end of May 2020, the general ban on visitors was lifted, under certain conditions. By that time, we were monitoring 76 nursing homes using questionnaires - the general monitor - and conducting in-depth monitoring at five homes, interviewing the people affected by the ban. These interviews were very emotional at times, particularly the ones with family members who were finally allowed to visit their loved ones again. They had been suffering terribly and were so relieved that the ban had been lifted, just like the residents themselves. The ban really had a negative impact on people's well-being. Importantly, the study didn't lead to any additional cases. Zero. We also found that visitors were quite capable of following the instructions. The only thing they struggled with was avoiding physical contact. The situation remained stressful for employees, though: they continued to experience high levels of work pressure and were still worried that people would get infected with coronavirus."

Research Line Specific Case Studies: Ageing and Long-Term Care (ALTC) | Case study 1

Never again

"In June, the ministry asked us to report on the lessons learnt. We passed this request on to nursing home administrators and our older adult advisory council at AWO-L, which includes representatives of client councils as well as representatives of the older adult advisory council of the Ministry of Health. They all said: never impose a general ban on visitors again, and let the homes develop their own visitation policies. So that's what happened in September and October 2020. We were on our third round of collecting data when the second wave hit, with outbreaks in 25 per cent of Dutch nursing homes. This time, the minister didn't impose a general ban on visitors; he left it up to the homes, as we'd advised. We checked with nursing home administrators, who said they weren't planning to close their doors to visitors again. You never know, though - in the spring of 2021, some of them did so anyway. But the government didn't impose a general ban on visitors again, and I think our research contributed to that. Internationally as well: we published our findings in an American journal, JAMDA, which even gave us an award because the article got so many hits in the US and the UK. It said: see, nursing homes don't have to close their doors to visitors."



Prof.dr. Jan HamersPrincipal investigator
jph.hamers@maastrichtuniversity.nl

Still reluctant

In the spring of 2021, when about 80% of nursing home residents and 60 to 70% of nursing home employees had been vaccinated, the researchers went back to collect more data. They found that most nursing homes hadn't further eased their visitation restrictions, despite these high vaccination rates. Nursing home residents also reported that they felt lonely due to the COVID restrictions. Says Jan Hamers, "This was reason for us to urge the care home sector to take the initiative and ease the restrictions after discussing it with residents, their loved ones, and employees. We knew that reopening the doors to visitors was the only way to improve the well-being of the residents."

Reports

Report 1

Gradual and controlled easing of visitation restrictions at nursing homes: Week 1 impressions (in Dutch).

Resultaten monitor verruiming bezoekregeling (18 mei 2020)¹
Factsheet Verruiming bezoekregeling verpleeghuizen (18 mei 2020)²

Report 2

"She was so happy to have visitors again".

Experiences with easing the visitation restrictions at nursing homes (in Dutch).

Resultaten monitor verruiming bezoekregeling (8 juni 2020)³
Factsheet Verruiming bezoekregeling verpleeghuizen (8 juni)⁴

Report 3

"Ready for a new wave?"

Monitor following the easing of visitation restrictions at nursing homes (in Dutch).

Resultaten monitor verruiming bezoekregeling (16 oktober 2020)⁵

Report 4

"Vaccinated – now what?"

Monitor following the easing of visitation restrictions at nursing homes (in Dutch).

Resultaten monitor verruiming bezoekregeling (19 april 2021)⁶

Report 5

"The pressure is high but we are in control".

Monitor following the easing of visitation restrictions at nursing homes (in Dutch)

Resultaten monitor verruiming bezoekregeling (23 december 2021)^Z

Partners

Science network elderly care Nijmegen (UKON), Radboudumc University Network Elderly Care - University Medical Center Groningen

Academic Collaborative Centers on Care for Older People (SANO) Tranzo, Tilburg University

UNO Amsterdam, Amsterdam UMC

In the Dutch media (selection)



21 April 2021

Most residents have been vaccinated, but nursing homes are still hesitant to ease restrictions:

Despite their high vaccination rates of about 80%, most nursing homes in the Netherlands have not yet embarked on a major easing of their visitation restrictions. The fourth report by the Living Lab in Ageing and Long-Term Care Limburg and UKON received a lot of media attention in the Netherlands.

NOS Radio 1 journaal⁸
Dit is de Dag - NPO Radio 1⁹
NRC Handelsblad ¹⁰



20 October 2020

Nursing home visitation remains a balancing act:

Are nursing homes ready for a new wave? How is the well-being of the residents? How much pressure are staff under? In the media, Jan Hamers explains the results of the study of the visitation policies of 76 nursing homes across the Netherlands after they reopened their doors to visitors.

NRC¹¹

<u>Dagblad de Limburger</u> 12 L1mburg Centraal (L1) 13



24 June 2020

Evaluating the easing of nursing home visitation restrictions:

Easing visitation restrictions did not lead to more COVID cases in the first nursing homes that were allowed to reopen their doors to visitors under very strict conditions. But easing the restrictions is difficult and time-consuming, and nursing home employees are worried about new outbreaks. In the media, Jan Hamers explains the results of the evaluation of easing nursing home visitation restrictions.

NOS journaal (vanaf minuut 6.09) ¹⁴ Nieuwssite van de NOS ¹⁵ Algemeen Dagblad ¹⁶

Our most important publications in scientific journals

Backhaus R, Verbeek H, de Boer B, Urlings JH, Gerritsen DL, Koopmans RT & Hamers JP. <u>From wave to wave: a Dutch national study on the long-term impact of COVID-19 on well-being and family visitation in nursing homes.</u> BMC Geriatrics 2021.

Hilde Verbeek, Debby L Gerritsen, Ramona Backhaus, Bram S de Boer, Raymond T C M Koopmans, Jan P H Hamers. <u>Allowing Visitors Back in the Nursing Home During the COVID-19 Crisis: A Dutch National Study Into First Experiences and Impact on Well-Being</u>.

Journal of the American Medical Directors Association. 2020 Jul;21(7): 900-904.

Raymond T. C. M. Koopmans, Hilde Verbeek, Annemiek Bielderman, Meriam M. Janssen, Anke Persoon, Ivonne Lesman-Leegte, Eefje M. Sizoo, Jan P. H. Hamers, and Debby L. Gerritsen. Reopening the doors of Dutch nursing homes during the COVID-19 crisis: results of an in-depth monitoring. International Psychogeriatrics 2021 Apr 5;1-8

Research Line Specific Case Studies: Ageing and Long-Term Care (ALTC) | Case study 1

Abstracts/ presentations scientific conferences

Gerritsen D, Backhaus R, De Boer B, Urlings J, Koopmans R, Hamers J, Verbeek H. The Impact of Visitation Guidelines During COVID-19 on Well-Being and Daily Life in Nursing Homes, Innovation in Aging, Gerontological Society of America, USA, 2021.

Backhaus R, Urlings J, Verbeek H, de Boer B, Gerritsen D, Koopmans R, Hamers JPH. Impact of Covid-19 vaccinations Dutch nursing homes. Nordic Congress of Gerontology, Odense, Denmark.



Original Study

Allowing Visitors Back in the Nursing Home During the COVID-19 Crisis: A Dutch National Study Into First Experiences and Impact on Well-Being

JAMDA 2021 Morley Award

A paper on visitors in the nursing home during the COVID-19 crisis has won JAMDA's 2021 Morley Award for its relevance and impact on policy and practice in post-acute and longterm care medicine.

Our most important output for societal target groups

Presentation 'Impact of COVID-19 vaccinations in Dutch nursing homes. Back to normal?¹⁷′, Judith Urlings. International workshop on Covid-19 and Long-Term Care Systems, December 2021.

Presentation 'What we learned from a year of corona18', researcher Bram de Boer, nurse Ellen Hermans and family caregiver Fon Kistermann. Online conference 'Figure it out' by Vilans (national centre of expertise for long-term care in the Netherlands), February 2021.

Presentation 'Monitor study easing of visitation restrictions in nursing homes', researchers Hilde Verbeek and Judith Urlings, nurse Melissa Bettink, Debby Gerritsen (UKON). Day of Geriatrics 2021 (online)

CAPHRI Societal Impact Team Award for research on COVID-19 in nursing homes

The team that investigates COVID-19 in nursing homes received the CAPHRI Societal Impact Team Award 2021 for



the great national and international impact their research has had on the well-being of nursing home residents. Thanks to the recommendations from their study, Dutch nursing homes reopened at the end of May 2020 after being closed to visitors for almost two months.

Ramona Backhaus, one of the researchers, was interviewed about the study. Read the interview www.maastrichtuniversity.nl/news/caphri-societal-impact-team-award-research-covid-19-nursing-homes

- ¹ www.awolimburg.nl/userfiles/files/nieuwsbericht/monitor eerste indrukken vws 18 mei 2020.pdf
- ² www.awolimburg.nl/userfiles/files/nieuwsbericht/factsheet_verruiming_bezoekregeling_verpleeghuizen_week_1_0.pdf
- 3 | www.awolimburg.nl/userfiles/files/nieuwsbericht/monitor_resultaten_vws_rapport_8_juni_2020.pdf
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- www.awolimburg.nl/userfiles/files/nieuwsbericht/covid-19_monitor_rapport_4e_meting_19_april_2021.pdf [
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- | https://nos.nl/artikel/2377615-meeste-bewoners-gevaccineerd-maar-verpleeghuizen-durven-versoepelingen-nog-niet-aan
- 9 | www.nporadio1.nl/fragmenten/dit-is-de-dag/91b954f7-9765-4016-abd4-42a12f155ddd/2021-04-21-kunnen-verpleeghuizen-meer-versoepe-
- 10 www.nrc.nl/nieuws/2021/04/20/bewoners-krijgen-wel-een-prik-maar-geen-versoepeling-a4040631
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- 12 | www.limburger.nl/cnt/dmf20201020_96515657
- 13 https://l1.nl/I1mburg-centraal-werkdruk-in-verpleeghuizen-nog-altijd-onverminderd-hoog-160336
- ¹⁴ www.npostart.nl/nos-journaal/14-06-2020/POW 04508585
- 15 https://nos.nl/artikel/2337238-geen-nieuwe-besmettingen-in-verpleeghuizen-waar-bezoekregeling-werd-getest
- 16 https://www.ad.nl/binnenland/geen-besmettingen-in-verpleeghuizen-waar-versoepelde-bezoekregeling-werd-getest~a392c135
- ¹⁷ | https://ltccovid.org/2021/11/09/the-impact-of-covid-19-vaccinations-in-dutch-nursing-homes-back-to-normal
- 18 | https://zoekhetuit.ccreader.nl/artikel/%E2%80%98ook-wij-hebben-het-familiecontact-het-meest-gemist%E2%80%99.html

Case study 2: We can be proud of the fact that Connecting Conversations is still of interest

Method to assess experienced quality of care continues to generate enthusiasm among organisations

How can we accurately describe the experienced quality of care in nursing homes from the resident's perspective? Six years ago, the healthcare organisations that are part of the Living Lab in Ageing and Long-Term Care Limburg (AWO-L) were in need of an answer to this question. The resulting research project led to the development of an assessment method called Connecting Conversations (Ruimte voor Zorg) and to several follow-up studies. "I think that now, six years later, we can be proud of the fact that our method is still of interest", says Katya Sion, researcher at the Living Lab, who won the UM Impact Prize 2021 for her work.

Healthcare organisations that have implemented the method, she says, are enthusiastic about it. "They often say, 'Wow, this is exactly what we wanted to know from our clients.' The method helps organisations become better and often more efficient at meeting their clients' needs, which is exactly what we wanted to achieve", says Katya. She completed her PhD thesis on Connecting Conversations in 2021 and is the project leader of the national implementation of the method, which is still being further developed. The project falls within the Living Lab's line of research that focuses on assessing quality, headed by Professor Jan Hamers. "Specifically, it falls under the topic of client experience", says Katya.



Connecting Conversations

Start project: 2016

This project has received funding from: ZonMw Project website:

www.awolimburg.nl/nl/projecten/ruimte-voor-zorg



Quality model

The research line is based on a quality model the Living Lab in Ageing and Long-Term Care Limburg designed together with healthcare professionals, nursing home residents, and informal carers, among others. "To measure client satisfaction, after all, you must first define quality of care. Together we arrived at a definition of care that is primarily about the everyday interactions with others and the wellbeing of residents." The conversations with care triads that characterise the Connecting Conversations method are based on this definition of care. An employee, preferably from another health organisation, conducts three separate conversations - with a nursing home resident, a family member of that resident, and a professional caregiver involved in their care. These three conversations, referred to as "triads", are recorded and summarised in a report. An app for this specific purpose has been developed with

Catalyst

The assessment method was developed in collaboration with healthcare professionals and client representatives, and tested in practice. Professor Gaby Odekerken-Schröder of the School of Business and Economics was involved because she specialises in customer-centric service, explains Judith Urlings, external cooperation coordinator at the Living Lab in Ageing and Long-Term Care Limburg. Steps were then taken to develop a similar method for home care. Connecting Conversations turned out to act as a catalyst for further research. For example, LEEV is a project about what healthcare professionals can learn from and do with the data collected from triads. Researchers have also begun to use text mining to analyse the summaries of the conversations.

Research Line Specific Case Studies: Ageing and Long-Term Care (ALTC) | Case study 2

Be flexible

"We've learnt that it's important to be flexible. For example, we've found that it is often difficult for organisations to exchange employees. Alternatively, an employee of a specific organisation may conduct triads in another part of that organisation", says Katya. "But exchanging employees is preferable to promote cross-organisational learning", adds Judith.Both Katya and Judith are excited about the current reach of Connecting Conversations. The project is supported by a steering committee that includes representatives from the Dutch Ministry of Health, Welfare and Sport (VWS), the National Client Council (LOC), and health insurance company CZ. In addition, the Netherlands Organisation for Health Research and Development (ZonMw) is funding research on adapting the method for assessing the experiences of residents who struggle to express themselves verbally. ZonMw also wants to find out how to implement the method nationally in a cost-effective way and how to include it in existing education programmes.

"Connecting Conversations captures what health care is all about - providing loving care."

- A client representative

Education and training

The educational institutions that are part of the Living Lab in Ageing and Long-Term Care Limburg have already been looking into this. For example, Zuyd University of Applied Sciences has introduced a module to train future nurses to conduct triads. Vocational training schools such as Gilde Opleidingen and VISTA college are also either already experimenting with or interested in experimenting with the method. To facilitate the national implementation of Connecting Conversations, the Living Lab now offers a training course - developed in collaboration with UMIO, the executive branch of Maastricht University School of Business and Economics - to teach healthcare professionals across the Netherlands how to conduct triads. The goal is to develop another training course to train coordinators within organisations to take over the organisation of triads from the Living Lab. "This would free up more time and resources for us to continue to develop new knowledge here", explains Judith. One need only look at Connecting Conversations to see the kind of success this knowledge development may lead to. "Connecting Conversations has had both social and scientific impact", says Katya. "We've shown that it is a valid qualitative method to accurately capture experienced quality of care. The project is also a great example of interdisciplinary research and citizen science."



Training Connecting Conversations

Our most important societal relevance output

Factsheet thesis 'Connecting conversations' (in Dutch): $\underline{link^{1}}$

Information flyer training 'Connecting conversations' (in Dutch) <u>link</u>²

Webinar 'Measuring quality of care', in collaboration with Noordhoff. link³

Podcast Methods Matter - Oral Histories

& Story Telling. <u>link</u>⁴

Article in Dutch professional journal:

Sion KYJ, Verbeek H, De Vries E, Zwakhalen SMG, Odekerken-Schröder GJ, Schols JMGA, Hamers JPH. Ruimte voor Zorg Meet Ervaren Kwaliteit in Verpleeghuizen door Verhalen te Verbinden. SENIOR, 2020; 1(4):3-9



Sion, K. Y. J. (2021). <u>Connecting conversations</u>: experienced quality of care from the resident's perspective:

a narrative method for nursing homes.
[Doctoral Thesis, Maastricht University].
Maastricht University.

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Sion, K. Y. J., Rutten, J. E. R., Hamers, J. P. H., de Vries, E., Zwakhalen, S. M. G., Odekerken-Schroder, G., Schols, J. M. G. A., & Verbeek, H. (2021). Listen, look, link and learn: a stepwise approach to use narrative quality data within resident-family-nursing staff triads in nursing homes for quality improvements. BMJ Open Quality, 10(3), [e001434].

https://doi.org/10.1136/bmjoq-2021-001434

Sion, K. Y. J., Verbeek, H., de Boer, B., Zwakhalen, S. M. G., Odekerken-Schroder, G., Schols, J. M. G. A., & Hamers, J. P. H. (2020). How to assess experienced quality of care in nursing homes from the client's perspective: results of a qualitative study. BMC Geriatrics, 20(1), [67].

https://doi.org/10.1186/s12877-020-1466-7 Sion, K., Verbeek, H., de Vries, E., Zwakhalen, S., Odekerken-Schröder, G., & Schols, J. (2020). Ruimte voor Zorg meet ervaren kwaliteit in verpleeghuizen door verhalen te verbinden. Senior, 1(4), 3-9. https://gompel-svacina.eu/product/senior-jrg-1-nr-4/

Sion, K., Verbeek, H., de Vries, E., Zwakhalen, S., Odekerken-Schroder, G., Schols, J., & Hamers, J. (2020). The Feasibility of Connecting Conversations: A Narrative Method to Assess Experienced Quality of Care in Nursing Homes from the Resident's Perspective. International Journal of Environmental Research and Public Health, 17(14), 1-22. [5118]. https://doi.org/10.3390/ijerph17145118

Sion, K. Y. J., Verbeek, H., Zwakhalen, S. M. G., Odekerken-Schroder, G., Schols, J. M. G. A., & Hamers, J. P. H. (2020). <u>Themes Related to Experienced Quality of Care in Nursing Homes From the Resident's Perspective: A Systematic Literature Review and Thematic Synthesis</u>. Gerontology and geriatric medicine, 6, [2333721420931964].

https://doi.org/10.1177/2333721420931964
Sion, K., Verbeek, H., Aarts, S., Zwakhalen, S., Odekerken-Schroder, G., Schols, J., & Hamers, J. (2020). The Validity of Connecting Conversations: A Narrative Method to Assess Experienced Quality of Care in Nursing Homes from the Resident's Perspective. International Journal of Environmental Research

and Public Health, 17(14), [5100]. https://doi.org/10.3390/ijerph17145100

Sion, K. Y. J., Haex, R., Verbeek, H., Zwakhalen, S. M. G., Odekerken-Schroder, G., Schols, J. M. G. A., & Hamers, J. P. H. (2019). Experienced Quality of Post-Acute and Long-Term Care From the Care Recipient's Perspective-A Conceptual Framework. Journal of the American Medical Directors Association, 20(11), 1386-1390. https://doi.org/10.1016/j.jamda.2019.03.028

Awards



Maastricht University Impact Prize Katya Sion received the Impact Prize for her thesis "Connecting conversations:

experienced quality of care from the resident's perspective: a narrative method for nursing homes". PhD candidates at Maastricht University are required to write a paragraph on how their research can be translated into social or economic value. The annual Impact Prize rewards research that has the greatest impact on society. The prize consists of € 3,000 - made available by UM and the University Fund / SWOL together - plus a work of art.

www.maastrichtuniversity.nl/news/um-impact-prize-katya-sion

Involved partners

Healthcare organisations

MeanderGroep Sevagram Envida Zuyderland Cicero Zorggroep Vivantes Ouderenzorg De Zorggroep Land van Horne Proteon

Educational institutions

Gilde Zorgcollege Vista College Zuyd University of Applies Sciences

Other

CodeART

CZ Health Insurance

School for Business and Economics, Maastricht University UMIO

Steering Committee

The whole research trajectory is supported by a national steering committee, consisting of representatives from the Ministry of Health (VWS), the National Health Care Institute (ZIN), the National Client Council (LOC), the Professional Association of Nurses (V&VN), the Health and Youth Care Inspectorate (IGJ) and the Board of Nursing Home Organizations.

- '| www.awolimburg.nl/userfiles/files/factsheets/factsheet-ruimte-voor-zorg.pdf
- | www.awolimburg.nl/userfiles/files/meetinstrumenten/awo-l-ruimte-voor-zorg-folder.pdf
- https://consultancy.noordhoff.nl/webinar-meten-kwaliteit-van-zorg
- 4 https://podcasts.apple.com/gb/podcast/methods-matter-oral-histories-story-telling/id1350258595?i=1000579133372

Research Line Specific Case Studies: Ageing and Long-Term Care (ALTC)

Case study 3: It's so important to involve patients in this type of research

I-HARP adapted for COPD

I-HARP is a tool to help healthcare providers timely identify and address the palliative care needs of people with heart failure. CAPHRI is currently conducting research aimed at adapting I-HARP to a similar tool for people with COPD. "It's so important to involve patients and their families in this type of research", says Mariëtte Simons.

As a person with heart failure, she was closely involved in the development of I-HARP. The tool was designed for people with severe forms of heart failure. They live with symptoms such as shortness of breath and fatigue and have an uncertain life expectancy. As their condition gradually worsens, they become increasingly dependent on care and their world becomes smaller. Treatment of patients with heart failure tends to focus on the physical/medical aspects of care. I-HARP helps healthcare providers timely recognise whether these patients would benefit from palliative care.



(Recognizing palliative care needs in patients with advanced heart failure) Start project: 2018



This project has received funding from: ZonMw

Quality of life

"Many people associate palliative care with terminal care, but that's not what this research project is about", explains project leader Daisy Janssen, professor in old age medicine. "The tool empowers healthcare providers to start a conversation about a patient's need for care that improves their quality of life. In other words, what does the patient need to feel better? It's about much more than just physical symptoms. I-HARP is an accessible way to help healthcare providers ask questions about things like the impact of a patient's disease on their mental health, social life and sense of purpose. This varies from person to person", says the professor, who specialises in personalised care for people with advanced chronic organ failure. I-HARP consists of three parts. The first part contains a number of open-ended questions to start the conversation and close-ended questions to identify the need for palliative care. The second part contains suggestions for additional questions. Finally, the third part contains tips and advice to address the care needs identified



Equal member

Mariëtte Simons suffers from heart failure, which runs in her family. She was approached to become involved in the I-HARP research project when she was a member of the Patient's Advisory Board at Harteraad, the Dutch centre of expertise for people living with cardiovascular disease. She finds it very important that doctors or other healthcare providers timely raise the subject of palliative care needs with persons with heart failure. "That's why I wanted to participate in the study. I know from experience that what the doctor thinks is important for a patient often differs from what the patient thinks. On top of that, doctors can be fascinated by the heart itself, but they also need to see the patient as a human being." The tool was not only developed in partnership with patients and their families, but also tested by them. "I tested it, too", says Mariëtte Simons. "I really felt like an equal member of the research team. I was a good match with Stephanie Ament, a researcher involved in the project. She and I also provided workshops on I-HARP for healthcare providers, such as nurses, together." Daisy Janssen nods. "Stephanie went into the project with an open mind. She was not biased by any preconceived notion of what the tool should look like. She was receptive to the ideas of people with heart failure."



Prof.dr. Daisy Janssen Principal investigator

Tool for people with COPD

The project resulted in a great tool, says Mariëtte Simons. "It facilitates in-depth conversations about all kinds of topics. The tool also meets the needs of the diverse patient population." A research project to adapt I-HARP for people with chronic obstructive pulmonary disease (COPD) was initiated last year in collaboration with nurse and nurse



Signaleren

Deel 1 bestaat uit 3 vragen om het gesprek te openen en 13 laagdrempelige signaleringsvragen. De antwoorden op deze vragen geven een indruk van palliatieve zorgbehoeften.



Doorvragen

As een patiënt of naast(en) een signaleringsvraag met 'ja' beantwoordt, is het belangrijk om na te gaan wat er precies aan de hand is. De doorvraagsuggesties n deel 2 van I-HARP kunne helpen bij het herkennen van specifieke zorgbehoeften



Richting geven

Tenslotte geeft deel 3 tips en adviezen om met geïdentificeerde zorgbehoeften aan de slag te gaan. Hier kist u (samen met de patiënt en naaste(n) welke zorg eventueel verleend kan worden.

i-HARP tool

scientist Daniël Huijten at Zuyderland Medical Center, with funding from the Dutch Foundation for Asthma Prevention. "As with persons with heart failure, the disease trajectory of persons with COPD is unpredictable and the prognosis is uncertain. Persons with COPD do tend to be a bit younger, which means they have other concerns. These differences will be reflected in the tool", says Daisy. Stephanie, now staff adviser person-centred care at the Maastricht University Medical Centre+, will advise on the project.

Finally, Daisy says that she and the Centre of Expertise for Palliative Care also plan to study how best to implement these tools, and what impact they have on patients and their families, healthcare providers and healthcare costs. "I don't think we should develop a new tool for each disease, though. It would be better to develop a generic tool with specific questions for specific diseases."



Mariëtte Simons Harteraad

Involved partners

Maastricht University Medical Centre+, Centre of Expertise for Palliative Care

Radboud UMC

Harteraad, Dutch centre of expertise for people living with cardiovascular disease

Our most important societal relevance output

I-HARP tool¹: Tool for timely identification of palliative needs in heart failure

I-Harp e-learning modules for healthcare professionals²
I-HARP workshop for healthcare professionals³
Implementation advice for hospitals⁴
Several lay summaries of scientific publications⁵

Our most important scientific output

Characteristics for a tool for timely identification of palliative needs in heart failure: The views of Dutch patients, their families and healthcare professionals. European Journal of Cardiovascular Nursing. Janssen, D. J., Ament, S. M., Boyne, J., Schols, J. M., Rocca, H.-P. B.-L., Maessen, J. M., & van den Beuken-van Everdingen, M. H. (2020). Tools to help healthcare professionals recognize palliative care needs in patients with advanced heart failure: a systematic review. Stephanie MC Ament, Inge ME Couwenberg, Josiane JJ Boyne, Jos Kleijnen, Henri EJH Stoffers, Marieke HJ van den Beuken, Yvonne Engels, Louise Bellersen8 and Daisy JA Janssen. Palliative Medicine 2020. Professionals guidance about palliative medicine in chronic heart failure: a mixed-method study. Stephanie MC Ament, Marieke van den Beuken-Everdingen, Jose MC Maessen, Josiane Boyne, Jos MGA Schols, Henri EJH Stoffers, Louise Bellersen, Hans-Peter Brunner-La Rocca, Yvonne Engels, Daisy JA Janssen. BMJ Supportive & Palliative Care 2020-002580. Hartfalen. Tijdig inventariseren van palliatieve zorgbehoeften. Dr. S. Ament, dr. J. Boyne, dr. R. Willemsen, drs. N. Uszko-Lencer, prof.dr. M. van den Beuken-van Everdingen en dr. D. Janssen. Pallium, jaargang 22, nummer 2, april 2021 What to consider when implementing a tool for timely recognition of palliative care needs in heart failure: a context-based qualitative study Stephanie M. C. Ament, Lisette M. van den Broek, Marieke H. J. van den Beuken-van Everdingen, Josiane J. J. Boyne, José M. C. Maessen, Sebastiaan C. A. M. Bekkers, Louise Bellersen, Hans-Peter Brunner-La Rocca, Yvonne Engels and Daisy J. A. Janssen. BMC Palliative

Implementatietips voor tijdig signaleren palliatieve zorgbehoeften bij gevorderd hartfalen. Hester d'Engelbronner en Pien Eras, Alumni Maastricht University, Daisy Janssen, hoogleraar ouderengeneeskunde Maastricht University en Ciro, Horn, Judith Coolen-Essers, hartfalenverpleegkundige, Nicole Uszko-Lencer, cardioloog en Stephanie Ament, stafadviseur Persoonsgerichte Zorg, MUMC+. Cordiaal 3/2022

Care (2022) 21:1

- 1 https://palliatievezorg.mumc.nl/onderzoek/i-harp/download-i-harp
- ² https://pznlsawebprod.blob.core.windows.net/files/i-harp-e-learning-final_1.2/index.html#
- ³ | https://palliatievezorg.mumc.nl/onderzoek/i-harp/volg-de-i-harp-workshop
- 4 https://palliatievezorg.mumc.nl/sites/palliatieve_zorg/files/2021-06/I-Harp%20Implementatietips.pdf
- ⁵ https://palliatievezorg.mumc.nl/onderzoek/i-harp/i-harp-achtergrondinformatie/publicaties

Creating Value-Based Healthcare (VHC)

Case study 1: Better economic evaluations of European health care systems through a standardised methodology

The PECUNIA project

Why do different European countries use such different methods to make economic evaluations? Health economists from various European countries are working closely together on three-year EU project PECUNIA to arrive at a standardised method for the economic assessment of health and health care interventions. The project focuses on the costs and especially the benefits of these kinds of interventions in other sectors of society. 'Methodological improvements can provide insight into cost savings in other sectors.'

Ask researchers in different European countries to assess the value of a health or health care intervention and you will get different results. Professor of Public Health Technology Assessment Silvia Evers wonders if there are real differences or if these differences result from the use of different methodological approaches. 'You can't compare results obtained from different methods.' The goal of EU project PECUNIA was to develop a standardised, harmonised method for the assessment of costs and benefits in European health care systems. 'Standardising the research framework and costing methods will facilitate fairer comparisons between countries.' What makes PECUNIA special within health economics is the fact that it takes a multi-sectoral perspective. This means that all relevant costs and benefits of economic evaluations, both within and outside the health care sector. are taken into account. The study which took place between 2018-2022 is part of a longstanding, innovative research line on intersectoral costs and benefits that has been ongoing since 2011 within the research unit on health economics and HTA and now as part of Maastricht Health Economics and Technology Assessment" Center (MaastrichtHETA). The Pecunia study focuses on mental health. Mental health disorders particularly often have financial consequences in other sectors than health care. Aggie Paulus, professor of economics of Education and Healthcare, provides several examples. 'Alcohol or drug addictions, for instance, can contribute to costs in the criminal justice sector. Depression in children can lead to school absenteeism and to costs in the educational sector.' At the same time, 'preventive health care interventions can produce benefits in other sectors of society as well, such as employment, education, safety, family life and leisure. 'However, so far, we do not yet know much about these intersectoral costs and benefits.





PECUNIA

(ProgrammE in Costing, resource use measurement and outcome valuation for Use in multi-sectoral National and International health economic evaluAtions)

Start project: 2018-2022

This project has received funding from: European Union's Horizon 2020 research and innovation programme under grant agreement No 779292

Rubik's Cube

To standardise the methodology, consensus must be reached about the research questions, measurement instruments and costing methods. 'The methodological approach to economic evaluations tends to vary from country to country', says Ruben Drost, assistant professor in the department of Health Services Research. 'What is the influence of a health intervention on the use of health care, education and criminal justice? What are the costs and benefits and how are they calculated?' The researchers will study which methods are used in these sectors and what their advantages and disadvantages are. Evers likens the study to a Rubik's Cube. 'We want to compare and standardise different methods and different sectors across different countries.' PECUNIA has been developing tools to align international methods, says Irina Pokhilenko. Pokhilenko has researched the costs and benefits that treatments have in the educational sector. Luca Janssen has been doing the same for criminal justice. 'The goal is to present health care providers and patients in each country with the same questions, about contact with the police, for example, or following specific types of education', says Pokhilenko. 'This way, the data obtained are comparable and transferable.' Janssen adds.

Broader perspective

The PECUNIA consortium consists of ten partners from six European countries, all exchanging methodological expertise. 'Our colleagues at the University of Bristol are experts in measuring economic evaluations', says Pokhilenko. 'Erasmus University Rotterdam knows a lot about productivity loss as a result of health care. Our team provides knowledge about multi-sectoral costs and benefits, especially in little-researched sectors like education and criminal justice.' The researchers also use each other's results so as to arrive at a uniform approach. 'And our working together increases the chances of the new method being applicable in other countries as well', says Janssen. The research team expects that a standardised assessment of health interventions will lead to efficient, evidence-based collaborative care models, both internationally and within the Netherlands. This will make it easier to determine the effectiveness and feasibility of a treatment. As Paulus explains, 'A treatment may be too expensive from a health care point of view, but still be interesting from a broader, multi-sectoral point of view because it has financial benefits in another sector of society. In other words, taking a broader perspective doesn't just have scientific and methodological value for health economics and value-based healthcare, but also practical and social advantages.' This may ultimately pave the way for multi-sectoral policy.

Sound methodology

The PECUNIA project also aims to show that a harmonised methodology will benefit health economics, both internationally and within the Netherlands. As Evers says: 'it's important to calculate health costs correctly. The costs and benefits of health interventions in other sectors of society will be ignored if you don't attach any value to them or don't take them into account financially speaking. This may lead to wrong decisions about interventions, based on incomplete economic information. Methodological improvements can provide insight into cost savings in other sectors.'

Involved partners

Medizinische Universität Wien
Universitätsklinikum Hamburg-Eppendorf
Corvinus University of Budapest
Erasmus University Rotterdam
Servicio Canario de la Salud
PSICOST Scientific Association
London School of Economics
University of Bristol
Eurice - European Research and Project Office GmbH

ProgrammE in Costing, resource use measurement and outcome valuation for Use in multi-sectoral National and International health economic evaluAtions: PECUNIA tackles the healthcare challenges of an evergrowing and rapidly ageing population in the EU by developing new standardised, harmonised and validated methods and tools for the assessment of costs and outcomes in European healthcare systems. Comparing and exploiting data across different countries and sectors, PECUNIA provides direct comparable solutions to improve chronic and mental healthcare in all EU health systems.

Our most important scientific output

PHD-Dissertations

Pokhilenko, I. (2022). <u>Costs and Benefits in Education:</u>
Addressing Methodological Challenges and Broadening the
<u>Societal Perspective in Mental Health Economics.</u> Maastricht
University. https://doi.org/10.26481/dis.20220630ip
Janssen, L. (2022). <u>Identification and Measurement of Criminal</u>
<u>Justice Costs in Mental Health Economics Crossing Lines.</u>
https://doi.org/10.26481/dis.20221118lj

Impact publications

Janssen LMM, Pokhilenko I, Drost RMWA, Paulus ATG, Thorn J, Hollingworth W, Noble S, Berger M, Simon J, Evers SMAA; PECUNIA Group. Methods for think-aloud interviews in health-related resource-use research: the PECUNIA RUM instrument. Expert Rev Pharmacoecon Outcomes Res. 2023 Apr;23(4):383-389. doi:10.1080/14737167.2023.2187379. Pokhilenko I, Janssen LMM, Paulus ATG, Drost RMWA, Hollingworth W, Thorn JC, Noble S, Simon J, Fischer C, Mayer S, Salvador-Carulla L, Konnopka A, Hakkaart van Roijen L, Brodszky V, Park AL, Evers SMAA; PECUNIA Group. Development of an Instrument for the Assessment of Health-Related Multisectoral Resource Use in Europe: The PECUNIA RUM. Appl Health Econ Health Policy. 2023 Mar;21(2):155-166. doi: 10.1007/s40258-022-00780-7.

Pokhilenko I, Kast T, Janssen LMM, Evers SMAA, Paulus ATG, Simon J, Mayer S, Berger M, Konnopka A, Muntendorf L, Brodszky V, García-Pérez L, Park A, Salvador-Carulla L, Drost RMWA; PECUNIA-group. International comparability of reference unit costs of education services: when harmonizing methodology is not enough (PECUNIA project). Expert Rev Pharmacoecon Outcomes Res. 2023 Jan;23(1):135-141. doi: 10.1080/14737167.2023.2152331. Epub 2022 Dec 15. PMID:36472303. Muntendorf, L. K., Konig, H. H., Janssen, L., Pokhilenko, I., Drost, R., Simon, J., ... & Konnopka, A. (2022). Calculation of Standardized Unit Costs of Mental Health in the Criminal justice Sector-Results of the PECUNIA Project for Germany. Gesundheitsokonomie und Qualitatsmanagement. DOI: 10.1055/a-1867-1458

Research Line Specific Case Studies: Creating Value-Based Healthcare (VHC) | Case study 1

Janssen LMM, Drost RMWA, Paulus ATG, Garfield K, Hollingworth W, Noble S,Thorn JC, Pokhilenko I, Evers SMAA. <u>Aspects and Challenges of Resource Use Measurement in Health Economics: Towards a Comprehensive Measurement Framework</u>. Pharmacoeconomics. 2021 Sep;39(9):983-993. doi: 10.1007/s40273-021-01048-z. Epub 2021 Jun 25. PMID: 34169466; PMCID: PMC8352823.

Pokhilenko I, Janssen LMM, Evers SMAA, Drost RMWA, Schnitzler L, Paulus ATG. <u>Do Costs in the Education Sector Matter? A Systematic Literature Review of the Economic Impact of Psychosocial Problems on the Education Sector.</u>
Pharmacoeconomics. 2021 Aug; 39(8):889-900. doi: 10.1007/s40273-021-01049-y. Epub 2021 Jun 14. PMID: 34121169; PMCID: PMC8298334.

Bremmers LGM, Evers SMAA, Drost RMWA, Janssen LMM, Pokhilenko I, Paulus ATG, Norton EC, Yoon J, Cuddeback GS, Morrissey JP. Intersectoral Costs and Benefits of Mental and Behavioural Disorders in the Education Sector: an Exploration of Costing Methods. J Ment Health Policy Econ. 2020 Sep 1;23(3):115-137. PMID: 33411675.

Pokhilenko I, Janssen LMM, Hiligsmann M, Evers SMAA, Drost RMWA, Paulus ATG, Bremmers LGM. The Relative Importance of Education and Criminal Justice Costs and Benefits in Economic Evaluations: A Best-Worst Scaling Experiment. Pharmacoeconomics. 2021 Jan;39(1):99-108. doi: 10.1007/s40273-020-00966-8. Epub 2020 Oct 7. PMID: 33026633; PMCID: PMC7790798.

Janssen LMM, Pokhilenko I, Evers SMAA, Paulus ATG, Simon J, König HH, Brodszky V, Salvador-Carulla L, Park AL, Hollingworth W, Drost RMWA; PECUNIA group. Exploring the identification, validation, and categorization of the cost and benefits of criminal justice in mental health: the PECUNIA project. Int J Technol Assess Health Care. 2020 Jul 27:1-8. doi: 10.1017/S0266462320000471.

Drost RMWA, Paulus ATG, Evers SMAA. Five pillars for societal perspective. Int J Technol Assess Health Care. 2020 Apr;36(2):72-74. doi: 10.1017/S026646232000001X. Epub 2020 Jan 31. PMID: 32000868.

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Conference contributions

For an overview of the many conference contributions and presentations, see: www.pecunia-project.eu/results

Deliverables/datasets/tools

See https://zenodo.org/record/4455364#.ZCQp83ZBxRY for a standardized costing template for selected costing approaches: criminal justice and education.

See www.pecunia-project.eu/tools for the resource use measurement instruments, tools and compendia that have been developed as part of this project. They include the following:

The <u>PECUNIA RUM Instrument</u>. This instrument is a comprehensive validated, generic, self-reported, multi-sectoral, multi-national harmonised instrument available in multiple languages that measures resource use in all relevant sectors for costing from a societal perspective in the adult population: health and social care, education, (criminal) justice, productivity losses, and informal care. The Pecunia Costing Concept. Cross-country comparability of the PECUNIA RUM is achieved by defining the measurement unit for resource use in all domains via the harmonised PECUNIA Costing Concept² which accounts for the specific requirements of each resource use type. All relevant resource use items are unambiguously linked to the other PECUNIA Costing Tools 2 via the PECUNIA Coding System, allowing valid comparisons and costing across countries and sectors by referring to activity-based rather than linguistic equivalence of services.

The PECUNIA Reference Unit Cost Templates. These templates (PECUNIA RUC Templates⁴) are a Microsoft Excel[©]-based set of tools that enable researchers to calculate unit costs comparable across countries and sectors (so called Reference Unit Costs (RUCs)) using standardized and scientifically validated methods. In total, there are six PECUNIA RUC Templates designed for developing RUCs in different sectors in any country affected by the (spill-over) effects of health interventions. The RUCs were developed using standardized and validated PECUNIA RUC Templates to introduce a higher degree of methodological harmonization and transparency in unit costs within and across sectors and countries. The PECUNIA Reference Unit Costs Compendium. This compendium (PECUNIA RUC Compendium⁵) is a Microsoft Excel®-based multi-sectoral, multi-country database of unit costs comparable across countries and sectors and developed using standardized and scientifically validated methods (so called Reference Unit Costs (RUCs)). In its current form the PECUNIA RUC Compendium contains 95 RUC estimates for 16 different service and resource use items for six countries (Austria, Germany, Hungary, the Netherlands, the UK (specifically England), and Spain.

The PECUNIA Patient-Reported-Outcome-Measure-Mental Health Compendium. This compendium (PECUNIA PROM-MH Compendium⁶) is a Microsoft Excel©-based electronic library of 204 non-disease specific PROMs used in mental health research. It provides meta-data information of existing, publicly available generic PROMs suitable for use in (mental) health research and their applicability in multi-sectoral, multi-national and multi-person (economic) evaluations.

Our most important output for societal target groups

Output for policy-makers

The results of the Pecunia project provide important insights into social challenges and can be of interest to policymakers, particularly those in the health and education sectors and the criminal justice sector. By highlighting the cross-sectoral economic impact of mental problems, the results of the Pecunia project are aligned with broader approaches to policymaking, such as Health in All Policies and systems thinking that stress the importance of collaboration across societal sectors to improve population health.

Output in terms of guidelines and manuals

Building on a previously developed guideline by Maastricht University on intersectoral costs and benefits (see herez), the results of the Pecunia project were incorporated into the existing and updated guideline of the National Care Institute (Zorginstituut Nederland) on economic evaluation (see cost manual in the guideline).

More information

<u>Twitter</u> @Pecunia_EU

Youtube:

- What is not measured is not counted: ECUNIA Resource Use Measurement (RUM) Instrument (2021, June 10).
- Introduction to PECUNIA Workshop by Judit Simon (2021a, June 10).
- <u>Flash statements of all PECUNIA Principal Investigators</u> (2021a, June 10).

Newsletters

"To make the right career choices, it is important to stay true to yourself, find honest people that can motivate and guide you, keep away from comparing yourself to others, acknowledge that you can make mistakes, go the extra mile and help others along the way."

Dr. Aggge Patitus
Professor of Economics of Education and Health Care
Masstricht University

PECUNIA 1

"It is important for women to be represented at all career levels in academia. I am very fortunate to be involved in a project with inspiring female researchers at the forefront of our discipline!"

Junior Researcher/PhD Candidat

"At every stage of your career, find an independent and senior mentor, with experience in your field, to offer critical support and to engage with you to spar with you as you do your research/teaching/policy development, and to encourage you going forward."

Principal Investigator in PECUNIA,
Professor of Public Health Technology Assessment
Maastricht University and the Trimbos Institute

"It is a blessing to work with this many female role models in the PECUNIA project!"

PhD Candidate, Health Sciences Research,



- $^{\scriptscriptstyle 1}$ | www.pecunia-project.eu/tools/rum-instrument
- ² | www.pecunia-project.eu/results
- | www.pecunia-project.eu/tools
- 4 | www.pecunia-project.eu/tools/ruc-templates
- | www.pecunia-project.eu/tools/ruc-compendium
- 6 | www.pecunia-project.eu/tools/prom-mh-compendium 7 | www.researchgate.net/publication/262484527_Handleiding_intersectorale_kosten-en_baten_van_preventieve_interventies_Classificatie_identificatie en kostprijzen
- * www.zorginstituutnederland.nl/over-ons/werkwijzen-en-procedures/adviseren-over-en-verduidelijken-van-het-basispakket-aan-zorg/beoordeling-van-geneesmiddelen/richtlijnen-voor-economische-evaluatie

Research Line Specific Case Studies: Creating Value-Based Healthcare (VHC)

Case study 2: Improved patient care and increased job satisfaction among GPs

The TARGET integrated care programme

General practice must change. There is no doubt about it among general practitioners (GPs) in Drenthe, the Netherlands. "The population is ageing rapidly, healthcare worker shortages are increasing, and GP workload continues to grow", explains associate professor and researcher Arianne Elissen. "We can improve the situation in general practice through an innovative data tool for gaining insight into the patient population; person-centred conversations to find out what is really going on with patients; and follow-up actions to address the real problems", says Rowan Smeets, who recently obtained her PhD on this topic.

In 2016, the primary care group Dokter Drenthe joined forces with the health insurance company Zilveren Kruis and Maastricht University to future-proof general practice in the Dutch province of Drenthe. They wanted to organise care for patients with less complex care needs as efficiently as possible, leaving more room for patients with complex care needs. The TARGET project explored how general practices can go about this.

TARGET

Start project: 2016

This project has received funding from: Zilveren Kruis Project website:

www.dokterdrenthe.nl/zorgverlener/zorg/zorg-op-maat/target

Insight into the patient population

Rowan: "The first step is to distinguish patients with less complex care needs from patients with more complex care needs. This requires insight into the patient population. We began by identifying and analysing patient data - such as care use data and demographic, socioeconomic, and biomedical characteristics - to determine which patients make the most use of GP services. We found that these are mainly people with multiple chronic conditions and additional challenges, such as low income. Our study focused on this group of 'frequent attenders'."



A personal and positive conversation

Arianne: "GPs then have in-depth, person-centred conversations with these patients to find out what is really going on with them. What is the root of the problem? Is the question the patient came in with the real question, or is there more - or something else - going on? Only when this is clear can a real solution be found. It may turn out that general practice can't solve the problem, but social care or other primary care services can. The GP will then refer the patient to get the right care in the right place." "A person-centred conversation takes much more time than a regular consultation", adds Rowan. "But we believe it's an investment that really pays off. This year, we will initiate a study to measure the long-term effects of the approach. The conversations are based on the concept of positive health. They don't focus on the patient's illness, but on what is going well and what the patient can still do. It gives a much more complete picture of the patient and their environment. The conversations are stimulating and positive, and have proved energising for both patients and GPs. Sometimes they help patients realise that their situation isn't as bad as it seemed, or that there are still a lot of things they can do. Some patients take up an old hobby again and take great pleasure in it. GPs have said that they enjoy connecting with patients on a deeper level. There are subjects that don't come up in regular consultations because there simply isn't enough time. Being able to discuss these things significantly increased their job satisfaction and made their work feel more meaningful."



Dr. Arianne Elissen



Dr. Rowan Smeets, PhD

The TARGET movement is growing

"In 2020, we launched a small-scale pilot study in which seven general practices participated", says Arianne. "Today, we have 50 participants. The TARGET programme is an experiment that was made possible by the financial support of Dokter Drenthe and healthcare insurance company Zilveren Kruis of Stichting Achmea Gezondheidszorg. Its success can partly be attributed to its flexibility; GPs can organise care in a way that suits their patient population, their own ideas, and their preferred way of working. The guidelines also leave room for general practices to decide what patient information is worth registering. The system doesn't dictate their every move - they're the ones at the wheel." Rowan: "We support general practices in implementing this new way of working. For example, we provide person-centred conversational skills training. We also instruct GPs on how to use a tool (De Zorgzwaartetool) developed by Niels Hameleers, a data scientist at Maastricht University. They can use this tool to download an up-to-date overview of their patient population each month, grouping patients by low, moderate, and high care use. The dashboard also has other filters. This insight enables GPs to respond proactively to changes in their patient population."

Long-term process

And what about patients with less complex care needs? Rowan: "Less complex care can be organised more efficiently, for example by making more use of e-health solutions such as video calling or by streamlining the healthcare process." Essentially, says Arianne, this new approach to general practice means a culture change. "It's a long-term process. That said, the positive results we have achieved so far make us feel very confident about the future. The province of Drenthe has taken the lead in this, and it hasn't gone unnoticed. TARGET has attracted a great deal of interest from regions and organisations across the Netherlands. Our research so far has mainly focused on its short-term effects. The upcoming follow-up study will focus more on its long-term effects and creating a network of health services in the region. The existence of such a network partly determines the success of this person-centred, integrated approach to health care."

Collaborating partners

Dokter Drenthe

Zilveren Kruis: Stichting Achmea Gezondheidszorg (SAG) > 50 General Practitioners in the Province of Drenthe

In the media

NOS Radio 1 Journaal, January 2023. Interview Rowan Smeets¹

Our most important scientific outputs



PhD dissertation

Rowan Smeets (2023). <u>Hitting the TARGET in primary care:</u> working towards integrated and person-centred care².

Articles in scientific journals

Smeets RGM, Hertroijs DFL, Mukumbang FC, Kroese MEAL, Ruwaard D, Elissen AMJ. First things first: How to elicit the initial program theory for a realist evaluation of complex integrated care programs. Milbank Q. 2022;100(1):151-189.

Smeets RGM, Hertroijs DFL, Kroese MEAL, Hameleers N, Ruwaard D, Elissen AMJ. <u>The Patient Centered Assessment</u>

Method (PCAM) for Action-Based Biopsychosocial Evaluation of Patient Needs: Validation and Perceived Value of the Dutch <u>Translation</u>. Int J Environ Res Public Health. 2021;18(22). Smeets RGM, Kroese MEAL, Ruwaard D, Hameleers N, Elissen AMJ. <u>Person-centred and efficient care delivery for high-need, high-cost patients: primary care professionals' experiences</u>. BMC Family Practice. 2020;21(1):1-9.

Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N, Ruwaard D. Identifying subgroups of high-need, high-cost, chronically ill patients in primary care: A latent class analysis. PloS one. 2020;15(1):e0228103.

Presentations (conferences, invited lectures)

Smeets RGM, Elissen AMJ, Spoorenberg SLW. Country practice example II: the Netherlands Coordination of chronic care management via care groups (networks in primary care). Seminar on skill-mix innovations by The European Observatory on Health Systems and Policies and l'Assurance Maladie, 16 September 2022 (invited lecture). Hertroijs DFL, Smeets RGM, Spoorenberg SLW, Ruwaard D, Elissen AMJ. Towards a focus on the person behind the patient: Is the TARGET integrated care program feasible and acceptable for general practice? International Conference on Integrated Care, 23-35 May 2022, Odense, Denmark (oral presentation). Smeets, RGM, Hertroijs DFL, Mukumbang FC, Kroese MEAL, Ruwaard D, Elissen AMJ. Learning how integrated primary care works: first steps towards a realist evaluation of the Dutch TARGET program. WONCA Europe Conference, 6-10 July 2021 (oral presentation).

Smeets RGM, Kroese MEAL, Ruwaard D, Hameleers N, Elissen AMJ. Primary care professionals' experiences with care delivery to high-need, high-cost, patients: a qualitative study. EHMA

Research Line Specific Case Studies: Creating Value-Based Healthcare (VHC) | Case study 2

Annual Conference, 17-19 November 2020 (oral presentation). Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N, Ruwaard D. Identifying subgroups of high cost, high need chronically ill patients in primary care: a Latent Class Analysis. Annual Research Meeting Academy Health, 2-4 June 2019, Washington DC, US (poster presentation).

Smeets RGM, Kroese MEAL, Ruwaard D, Hameleers N, Elissen AMJ. Experienced barriers and potential solutions with regards to care delivery to high-need, high-cost patients: a qualitative study in primary care. NHG-Wetenschapsdag, 5 & 11 February 2021 (oral presentation).

Our most important output for societal target groups

Reports, news articles

Samen beslissen: onlosmakelijk onderdeel van persoonsgerichte zorg. In Een Magazine, September 2022.

Frequente chronische patiënt vraagt om samenwerking. Skipr Ouarterly Magazine, 2022.

Nieuw zorgprogramma streeft naar toekomstbestendige huisartsenzorg³. Transmuraal Treant, 2022.

Verkiezingsmanifest 2021: Intensiveer de samenwerking in zorgnetwerken. Zilveren Kruis, 2021.

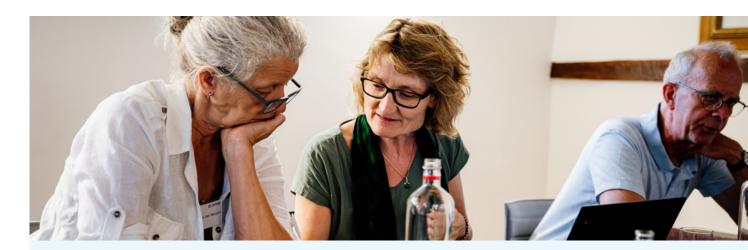
Smeets RGM, Elissen AMJ, Kroese MEAL, Wissink R, Ruwaard D. Chronische zorg over een andere boeg⁴. De Eerstelijns. 2020. Hameleers N, Elissen A, Kroese M, Ruwaard D. Op weg naar een integraal programma chronische zorg: resultaten deelonderzoek in de zorggroep Huisartsenzorg Drenthe⁵. Maastricht: Maastricht University; 2017.

Presentaties

Smeets RGM, Elissen AMJ, Spoorenberg SLW. Presentatie target - resultaten tot zover. InEen themabijeenkomst: Integrale en persoonsgerichte zorg, 7 April 2022, Utrecht (oral presentation). Smeets RGM, Elissen AMJ, Spoorenberg SLW. Aan de slag met zorgzwaartemodellen. InEen themabijeenkomst: Integrale en persoonsgerichte zorg, 7 April 2022, Utrecht (workshop). Smeets RGM, Kroese MEAL, Ruwaard D. Integratie van chronische zorgprogramma's: een andere kijk op de populatie. In Een conferentie 'De ketenzorg voorbij?', 11 February 2019, Soesterberg (workshop).

Ruwaard D, Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N. Integraal Programma Chronische Zorg: op weg naar een implementatie en evaluatie in co-creatie met de praktijk. Sandwichcursus HZD, november 2019, Dalfsen (oral presentation). Smeets RGM, Elissen AMJ, Weuring II. 'Doelgroepbepaling en scope van het geïntegreerde zorgprogramma'. In Een thema-bijeenkomst: Integratie chronische zorgprogramma's, 8 oktober 2019, Baarn, (workshop).

Ruwaard D, Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N. Op weg naar een Integraal Programma Chronische Zorg: Identificatie zorgzwaartemodel - voorlopige resultaten.
Sandwichcursus HZD, november 2018, Dalfsen (oral presentation).
Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N, Ruwaard D. Op weg naar een Integraal Programma Chronische Zorg.
Masterclass Eerstelijns Bestuurders, september 2018,
Amersfoort (oral presentation).



- ¹ | www.nporadio1.nl/fragmenten/nos-radio-1-journaal/7e19fced-8865-4630-9f8b-5e98758efafa/2023-01-13-experiment-in-23-huisartsen-praktijken-om-de-werkdruk-te-verminderen
- $^2 \mid \text{https:}'/\text{cris.maastrichtuniversity.nl/en/publications/hitting-the-target-in-primary-care-working-towards-integrated-and}$
- ³ | www.maastrichtuniversity.nl/file/transmuraal-treant12022targetpdf
- 4 | www.de-eerstelijns.nl/2020/06/chronische-zorg-over-een-andere-boeg/
- $^{5} \mid \text{https://cris.maastrichtuniversity.nl/en/publications/op-weg-naar-een-integraal-programma-chronische-zorg-resultaten-de}$

Case study 3: Real-world data helps to improve patient care, decision-making and health policy

Digitisation in healthcare has led to an increase in health data. Electronic patient records, billing data, data from administrative and regulatory agencies, and data collected by medical devices and wearables provide a wealth of information. "A great opportunity," thinks physician, epidemiologist, and researcher Rok Hrzic. "Because it is not only about more data, but also about data from target groups that were previously rarely involved in scientific research."

University lecturer and researcher Timo Clemens wholeheartedly agrees. "Real-world data (RWD) improve the foundation for research and decision-making by increasing the quantity and the kinds of data available. This allows us to answer questions we could not answer before, leading to better and sometimes timelier decision-making in diagnostics, care and policy making. Moreover, RWD require less time and effort to collect compared to data obtained from clinical studies. At the same time, we face significant technical and methodological challenges to the routine use of RWD in decision-making." Rok explains: "RWD data have been collected for purposes other than research and decision-making. This means they are stored in a variety of formats and encodings. There may be important semantic differences between datasets, and there may be biases that we don't yet fully understand." Timo: "In addition, there are legal issues. We know where the data are collected and stored, but that doesn't mean we can access them."



Timo Clemens, PhD
Assistant Professor, Department of International
Health



Rok Hrzic, MSc *Researcher, Depertment of International Health*

Use of RWD in Europe still in its infancy

In a study commissioned by the European Commission, colleagues from the Department of International Health, joined by other partners, assessed the use of RWD in scientific research, clinical care, regulatory decision-making, health technology assessment and health policymaking. Timo: "In this study, we mapped existing RWD initiatives and the data infrastructures, disease areas, methodologies for data pooling and analysis, and the questions they addressed. We also identified the challenges associated with using RWD. An important conclusion of the study is that the use of RWD in Europe is still in its infancy. While there are examples of best practices, they represent isolated solutions with limited synergy between them. The European Health Data Space, proposed by the European Commission in 2022, could solve most health data



exchange obstacles. An ex-ante assessment of this proposal for the Euregional cross-border effects conducted with colleagues from ITEM/Faculty of Law concluded that there is support from the field to address the challenges. But there has been scepticism about how far existing tailor-made solutions for bilateral data exchange can be scaled to the context of the entire EU."

One area of application where RWD provides advantages is rare diseases because it is a field of research where numbers are, per definition, small. Rok says: "Health professionals, patient organisations, health insurers, and Maastricht University have joined a project on rare diseases in the Euregio Meuse-Rhine (EMRaDi). Because each rare disease affects only a few people, it is difficult to get a good picture of it with traditional data. RWD, particularly electronic patient records and billing data from insurers, helped us better understand the burden of disease and demand for care for rare diseases in the region."

Avoidable Mortality Indicator

Another stream of Rok's work includes how RWD can support the development of healthcare quality indicators for cross-country benchmarking. For example, in a study for the European Commission, he examined whether the avoidable mortality indicator is suitable for comparing member states' health systems. Rok explains, "Avoidable Mortality is an indicator of healthcare quality in a country and compares healthcare systems in different countries. But does Avoidable Mortality give an accurate picture of healthcare quality? Is there a level playing field when you disregard context and differences in the incidence of certain diseases, disease burden and age structure, for example?" He found that indicators focused on the avoidable disease burden may better address the policymakers' needs, but that would require tapping into new data

Research Line Specific Case Studies: Creating Value-Based Healthcare (VHC) | Case study 3

sources on disease prevalence and incidence. Rok: "With better indicators of healthcare quality, (European) policymakers can work on policies to improve national and European health care."

The beauty of RWD

Timo concludes, "We are both driven by the beauty of RWD. These enable healthcare professionals and policymakers to faster, better, and at a lower cost, improve patient care and treatments, make well-reasoned decisions, and design policies with impact."

Collaborating partners

Tender Real World Data PPMI

Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus Tender Avoidable Mortality Euregio Meuse-Rhine Rare Diseases (EMRaDi) Christian Health Insurance Fund Verviers-Eupen, Belgium University Hospital Aachen with the Centre for Rare Diseases Aachen, Germany

Maastricht University Medical Center+, The Netherlands University Hospital of Liège, Belgium

National Alliance of Health Insurance Funds, Belgium National Union of Socialist Health Insurance Funds, Belgium Dutch national patient alliance for rare and genetic diseases (VSOP), The Netherlands

Our most important scientific output

Study on the use of real-world data (RWD) for research, clinical care, regulatory decision-making, health technology assessment, and policy-making (2021). European Commission Treatable Mortality in an International Perspective: Feasibility Study for Methodological Improvements (2020). European Commission



Functioning, Participation and Rehabilitation (FPR)

Case study 1: Personal health information made accessible, complete, neutral and comprehensible

The 360°CHILDoc dashboard presents a complete picture of a child's health situation at a glance. The tool can be accessed by healthcare professionals, parents and young people themselves. "It supports the active involvement of parents and young people in their health and facilitates shared decision-making", explains Miriam Weijers, a public health physician/child & youth health care physician, assistant professor and researcher/PhD candidate. "The 360°CHILDoc provides a solid foundation for clinical reasoning and promotes preventive health interventions", adds Carolien Bastiaenen, associate professor of Epidemiology.

The 360°CHILDoc (Child Health Integral Digital Overview) is a digital dashboard that provides insight into a child's health and development within four domains: Body Structures and Functions (both physical and mental), Activities and Participation, Personal Factors and Environmental Factors. Miriam: "To provide quality health and preventive care, you must take a holistic view of the child. This requires you to integrate and assess information from different domains. You must also be able to share that information in an accessible way in order to actively involve parents in thinking processes and shared decision-making about health interventions. But the electronic medical dossiers we currently use are unstructured, difficult to navigate and often incomplete. Importantly, this makes it harder to see connections in the data. That's what inspired me to think about possible improvements. Frans Feron, a child & youth health care (CYHC) physician and professor of Child and Adolescent Health, has been an important source of inspiration throughout the project. To ensure the integration of theory and practice, I involved him from the beginning. I developed a rough design and showed it to fellow CYHC physicians and nurses, parents and young people. They were extremely positive about the concept and its potential. From that moment on, I was given the opportunity to continue working on the project. I earned a master's degree in Epidemiology to expand my knowledge on the subject. For my final project, I conducted a pilot study of the 360°CHILDoc with Carolien as my supervisor."



Period: 2015-2022 This project was granted by: ZonMw Project website: <u>www.360child-profile.nl</u>



Ouick and reliable assessment

Carolien: "The master's project involved a pilot study of the reliability and validity of the rough version of the 360°CHILDoc. We investigated whether different CYHC physicians arrived at



similar assessments of overall functioning based on the same profile. This was repeated three months later. Both times, the assessments were sufficiently similar. We also investigated whether the assessment of a CYHC physician who spent five minutes studying a child's profile sufficiently corresponded with the perspective of the child's own doctor. These results were positive, too. We felt increasingly confident that the tool could support CYHC professionals in making adequate assessments quickly and efficiently."

Data visualisation and design

To take the development of the 360°CHILDoc to the next level, a grant was secured from the Netherlands Organisation for Health Research and Development (ZonMw). The project developed into a PhD project, with Frans Feron and Carolien Bastiaenen as supervisors. Miriam: "Data visualisation is an essential part of the tool. It is important to evoke the right mood and present information in such a way that connections are easy to see and understand. At Zuyd University of Applied Sciences, we found two lecturers and a media design & technology student who were happy to collaborate with us. They set up a one-year research project to develop the design, taking into account the purpose of the tool, the correct positioning of the different areas, the colour scheme, appealing icons, fonts, etc. They conducted experimental sessions, using methods such as eye tracking, to determine how people perceived and interpreted the design."



Drs. Miriam Weijers



Dr. Carolien Bastiaenen

Research Line Specific Case Studies: Functioning, Participation and Rehabilitation (FPR) | Case study 1

Neutral perspective

Carolien: "It is important that the tool offers a neutral perspective on 'hindering' and 'facilitating' factors - on what isn't going well and what is going well. The latter is often not recorded in electronic medical dossiers." Miriam adds, "But in communicating with parents, it's important to discuss all aspects of the child's development, particularly the strengths present within the child and the family. Rather than stating 'This is how it is, and this is how it should be', healthcare professionals should make room for everyone's perspective in decision-making processes." "The more complete a medical dossier is with relevant information, the better it translates into a 360°CHILDoc", says Carolien. "Once implemented, the tool may act as a catalyst for more complete and consistent registration of health data."

Status

Carolien: "The tool is fully in line with the concept of personalised child and youth health care. It focuses on prevention, personalisation of care, participation and prediction (taking health rather than disease as a starting point) - the four Ps. It is now up to the Dutch municipal health services to implement it." "We're hoping the PhD project will help generate publicity. We've been presenting the tool at conferences, have developed an online training course for healthcare professionals, and it has been included in the Dutch medical curriculum", says Miriam. "Our aim is to gain public support for the 360°CHILDoc, creating a bottom-up need as well as top-down power."

The 360°CHILDoc helps us paint the whole picture with parents. It ensures that we don't neglect or overlook anything.
- A CYHC physician who participated in the study

It's enlightening; it's useful to be reminded of how we were doing at the last consultation, of what was going well and what wasn't going well. It encourages me to think about how I can help my child get angry less often.

- A mother

Involved partners

Public Health Service of South Limburg (GGD Zuid-Limburg) Zuyd University of Applied Sciences



360°CHILDoc dashboard

Our most important output for societal target groups

Online training for youth health care physicians: <u>Clinical</u> <u>reasoning within personalized youth health care</u>.

Presentation for innovation workshop Dutch Center for Youth Health (NCJ), 2020

Presentation 'Online health information: It's all in the Picture²'. Post-academic aducation for youth health care physicians (PAOG Maastricht), 2019

Workshop: "Look ... a child!" Join us! Together we will construct an integral, personalized "360°CHILDoc" (child-profile)³. EUSHUM (European Union for School and University Health and Medicine) conference, 2017.

Our most important scientific output

<u>Personalized Preventive Child Health Care the</u> <u>"360°CHILD-profile" studies</u> (PhD thesis)

A digital dashboard for visual representation of child health information: results of a Mixed Methods study on usability and feasibility of a new CHILD-profile. Journal of Pediatrics, Perinatology and Child Health, 7 (1), 29-44.

A feasibility Randomised Controlled Trial as a first step towards evaluating the effectiveness of a digital health dashboard in preventive child health care: a mixed methods approach. Weijers, M., Boumans, N., van der Zwet, J. et al. Pilot Feasibility Stud 9, 25 (2023).

<u>Designing a Personalized Health Dashboard: Interdisciplinary and Participatory Approach</u>. Weijers, M., Bastiaenen, C., Feron, F. & Schröder, K., 9 Feb 2021, In: JMIR Formative Research. 5, 2, p. e24061 9 p., 24061.

Evaluation of a New Personalized Health Dashboard in Preventive Child Health Care: Protocol for a Mixed Methods Feasibility Randomized Controlled Trial. Weijers, M., Feron, F., van der Zwet, J. & Bastiaenen, C., 1 Mar 2021, In: JMIR Research Protocols. 10, 3, 9 p., e21942.

The 360 CHILD-profile, a reliable and valid tool to visualize integral childinformation. Weijers - Ottenheim, M., Feron, F. & Heuts - Bastiaenen, C., 2018, In: Preventive Medicine Reports. 9, p. 29-36

¹ | https://360child-profile.nl/online-scholing/

² | https://paogmaastricht.nl/programma/26-03-2019-e-health-hip-hype-of-heel-pragmatisch-blended-care-binnen-de-jeugdgezondheidszorgits-all-in-the-p-i-c-t-ure/

³ | https://www.vwvj.be/sites/default/files/import/w1_-_weijers.pdf

Case study 2: It's about how people deal with their pain

Researchers and practitioners in rehabilitation care working closely together

Chronic pain affects two million people in the Netherlands. Most of them suffer from chronic musculoskeletal pain, with back pain being the most common complaint. These are serious numbers, agrees Jeanine Verbunt. "And yet the impact of chronic pain is somewhat overlooked. Pain is often seen as a symptom rather than a disease. This may change now that the World Health Organisation has classified chronic pain as a disease."

Jeanine Verbunt is a professor of Rehabilitation Medicine at CAPHRI and Adelante Zorggroep, a rehabilitation centre. She also works as a consultant in physical medicine and rehabilitation for Adelante at the Maastricht University Medical Centre+. She knows what chronic pain can do to people. "I'm glad that chronic pain is now recognized as a disease, although this could also have a negative effect. Pain is part of growing older. Not all pain can be cured. It's about how people deal with their pain and how they live with it in such a way that they can continue to function as well as possible. If they can't get to that point by themselves, they need good rehabilitation care."

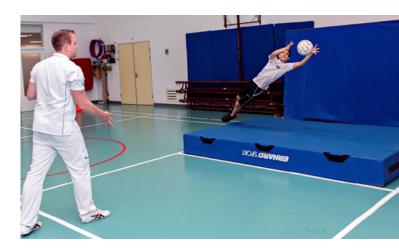


Expertise Centre Pain and Rehabilitation

Part of the Living Lab Rehabilitation Limburg www.maastrichtuniversity.nl/nl/onderzoek/de-academischewerkplaats-revalidatie-limburg

Working together

CAPHRI's research on rehabilitation care for chronic pain is characterized by researchers working closely together with health practitioners. For example, CAPHRI's Living Lab Rehabilitation and Adelante have established four expertise centres together. One of the centres, the Expertise Centre Pain and Rehabilitation brings together research and teaching on this type of care. Jeanine Verbunt is the research coordinator of the centre. "In our research, we work together with regional parties, from hospitals to primary care providers, as well as with research groups within the academic hospital, such as the pain clinic, orthopaedics and rheumatology."



Ivan Huijnen is affiliated with the expertise centre as a senior researcher in the Department of Rehabilitation Medicine at CAPHRI. He is also the manager of Center of expertise in Rehabilitation and Audiology, a knowledge centre that forms the Living Lab Rehabilitation together with CAPHRI's Department of Rehabilitation Medicine. In addition, since January 2023 he is appointed as lector at Zuyd University of Applied Sciences within the Research Centre for Assistive Technology in Health Care. Chronic pain has a significant social impact, says Huijnen, and not just because it prevents people from fully functioning and participating in society. "Ninety per cent of chronic pain symptoms are medically unexplained and cannot be treated. Because of this, patients are not always satisfied with the care they receive and continue to look for other forms of treatment to relieve their pain. This results in very high costs."



Prof.dr. Jeanine Verbunt
Coordinator Expertise Centre Pain and
Rehabilitation

Network Pain Rehabilitation Limburg

That is why researchers and health practitioners are joining forces to innovate treatments. They're taking a matched-care approach, explains Jeanine Verbunt. "As we learn more, we develop new treatment plans. Our goal is to help people function as well as possible and achieve the goals they set for themselves. We're not focused on relieving their pain as much as helping them to deal with it." As good treatments involve good patient support, the expertise centre established the Network Pain Rehabilitation Limburg. "Patient support in rehabilitation care is quite fragmented and varied at the moment. The same goes for the information patients receive. We want to streamline the patient's support", says Ivan Huijnen, project leader of the network. The Network Pain Rehabilitation

Research Line Specific Case Studies: Functioning, Participation and Rehabilitation (FPR) | Case study 2

Limburg was a pilot project in southeast Limburg. It involved various health professionals - allied health professionals, general practitioners, and GP assistants focused on mental health care - who worked working closely together. In the network the E-health application SanaCoach Pain Rehabilitation was used to support decision making of the health professional and self-management of the patient by making use of eLearning modules and diaries. The goal of the project was to create a unified vision of how to support and treat chronic pain patients in optimising their functioning despite pain. The organization of care was tailored based on the complexity of the pain complaints and the patient's needs. In this project, based on classification tools health care professionals were supported in their decision making. The parties involved worked more closely together and when possible the care was provided closer to home, at a lower level in the health system and when needed the patient was referred to secondary care. In November 2022 Cynthia Lamper defended her PhD thesis (PhD student CAPHRI) entitled: "Network Pain Rehabilitation: an integrated interdisciplinary care approach".



Integral view on health

Based on the results of this CAPHRI PhD project, further initiative are started to further improve the organization of care. First, a multidisciplinary rehabilitation treatment in primary care will be implemented in the upcoming months. In this innovative rehabilitation treatment in primary care, the treatment is provided by professionals from different disciplines who work closely together. Based on an innovation rule, this care is in the pilot phase financed and therefore accessible for all patients matching the indication criteria for this treatment. From the living lab, the scientific evaluation will be performed by Kirsty Musch, a second PhD student involved. Another innovatieve initiative based on the results of the Network Pain Rehabilitation Limburg is the implementation of an advice consultation of a consultant in rehabilitation medicine. Based on the opinions of healthcare professionals in primary care and especially the general practitioners, this consultation was recommended to implement to support the general practitioner in the decision making. Patients with more complex complaints seen by the GP can be referred to this consultation to get advice which treatment is recommended based on the patient's

complexity of complaints and/or to give education from a biopsychosocial perspective. Jeanine Verbunt nods. "That's why it is important to translate new insights in specialist rehabilitation care into primary care. Care will become more accessible and patients won't have to visit multiple healthcare providers." To prevent unnecessary visits, healthcare providers need to work from a broader perspective; an integral view on health. To be able to do that, healthcare professionals need to become more and more familiar with other disciplines and be able to work interdisciplinary. Also medical and paramedical health care professionals need to collaborate more intensively to provide this integral approach. Therefore, it is an important development that the new lectorate has recently started at the University of Applied Sciences. At these university, the future paramedics are trained and this integral view on health can be introduced during this training.

Exposure in vivo

The expertise centre has also evaluated a treatment called "Exposure in Vivo", which supports patients in regaining confidence in their ability to move so that they can resume the activities they had begun to avoid as a result of fear of pain or injury. The treatment teaches them that they can do more than they think, without making their pain worse. "This is a wonderful example of cooperation between the Department of Clinical Psychological Science, the research school EPP (Experimental Psychopathology) and the living lab rehabilitation", says Jeanine Verbunt. The treatment focuses on the patient's fear of pain or injury. The Department of Clinical Psychological Science provided the theoretical basis for the treatment, which the expertise centre in the living lab is evaluating for an increasing number of patient groups. If it proves to be beneficial, it will become a standard treatment. It is currently being given to adults with back pain, CANS (Complaints of the Arm, Neck and/or Shoulder), CRPS (Complex regional pain syndrome) and adolescents with chronic musculoskeletal pain. We are now studying the applicability of the concept for other pain problems with underlying diseases such as reumatoid artritis, cancer pain and pain in spinal cord injury. "The expertise centre can play a role in the implementation of new treatments, so that they can also be implemented in the rest of the Netherlands, by training health professionals in giving the treatments and integrating the interventions into regular healthcare education. The ultimate goal is to provide the right care in the right place."

Our most important output for societal target groups

Our treatments have been evaluated by effectiveness studies. For evidence based treatments, we developed courses for health care professionals in order to share knowledge and facilitate implementation of treatments in other rehabilitation centers. In addition, we wrote handbooks and organized several webinars for health care professionals.



Handbooks

Verbunt J, Swaan L, Schiphorst Preuper R, Schreurs K.

<u>Handboek pijnrevalidatie voor de eerste, tweede en</u>
<u>derdelijnsgezondheidszorg</u>. Bohn Staflue en van Loghum,
Houten 2019

Verbunt J, Smeets R. <u>Graded exposure, een cognitief gedrags</u>-matige aanpak. Bohn Staflue en van Loghum, Houten, 2016

Courses for rehabilitation professionals

<u>www.adelante-zorggroep.nl/nl/expertisecentrum-pijn-en-revalidatie/kennisoverdracht/#linkAanbodcursussen</u>

Webinars

We organize webinars for health care professionals that work with patients with chronic pain:

2023: <u>Advice consultation rehabilitation physician for chronic pain complaints</u>

2021: New developments in pain rehabilitation
We organize webinars for patients with chronic pain (as a joined production with patient organization <u>Pijnpatiënten</u> naar één stem):

2022: Healthy living with chronic pain



Patient webinar "Healthy living with chronic pain" (2022)

The patient webinar "Healthy living with chronic pain" focused mainly on people with chronic pain who are limited in their daily lives. Conversations were held with experts by experience, representatives of the patient association and healthcare providers with a focus on rehabilitation and chronic pain.

Our most important scientific output

Hartvigsen J, Hancock MJ, Kongsted A, Louw Q, Ferreira ML, Genevay S, Hoy D, Karppinen J, Pransky G, Sieper J, Smeets RJ, Underwood M; Lancet Low Back Pain Series Working Group. What low back pain is and why we need to pay attention. Lancet. 2018 Jun 9;391(10137):2356-2367. den Hollander M, Goossens M, de Jong J, Ruijgrok J, Oosterhof J, Onghena P, Smeets R, Vlaeyen JWS. Expose or protect? A randomized controlled trial of exposure in vivo vs pain-contingent treatment as usual in patients with complex regional pain syndrome type 1. Pain. 2016 Oct;157(10):2318-2329. Lamper C, Huijnen IPJ, Kroese MEAL, Köke AJ, Brouwer G, Ruwaard D, Verbunt JAMCF. Exploring the feasibility of a network of organizations for pain rehabilitation: What are the lessons learned? PLoS One. 2022 Sep 15;17(9):e0273030.

Award

In 2019, Marlies den Hollander won the VRA PHD award 2019 (best PhD thesis on rehabilitation medicine in the Netherlands) on her thesis on rehabilitation treatment for chronic pain ('Expose or protect? Fear of movement-related pain in patients with complex regional pain syndrome type 1).



Research Line Specific Case Studies: Functioning, Participation and Rehabilitation (FPR) | Case study 2

Our collaborating partners

National partners

Partners in the Living Lab Rehabilitation are three rehabilitation centers (Adelante Zorggroep, Revant revalidatie and Libra Revalidatie) and Zuyd University of Applied Sciences Specifically on the topic of pain rehabilitation, we collaborate in the Dutch Pain Rehabilitation Network with rehabilitation centers: Rijndam Revalidatie (Rotterdam), UMCG Groningen, Roessingh (Enschede)

We have a close collaboration on the topic of pain rehabilitation research with the University of Groningen and the Universities of Applied sciences Rotterdam, Utrecht and Zuyd (Heerlen).

International partners

On the topic of chronic pain, we have joint PhD trajectories with various Belgium Universities and a Swedish University: Leuven University, Gent University, Hasselt University, Antwerp University and University of Gothenburg. We are an official partner in the following international scientific networks on pain research:

Pain, Action and INterference (PAIN): Key objectives of PAIN are (1) to consolidate and extend research collaborations, (2) to facilitate research opportunities by synergy of expertise and of resources, and (3) to create a platform for translational and clinical research, in which the knowledge from the lab is implemented into the daily lives of those living with chronic pain. Pain in Motion: A multidisciplinary group of researchers and clinicians affiliated to different international institutions who combine forces to improve the understanding of biopsychosocial mechanisms of pain; and strive towards having a significant impact on health care for patients suffering from (persistent) pain.

Our project in the media

Rehabilitation medicine: Daring to move despite pain <u>De Limburger, 12 October 2018¹</u> Pain for life? Limburg can provide a breakthrough <u>De Limburger, 14 November 2017²</u>



- ¹ | www.limburger.nl/cnt/dmf20181011_00077245
- ² | www.limburger.nl/cnt/dmf20171113_00050639

Case study 3: 200,000 people sitting on the sidelines in Limburg

Researchers and practitioners in rehabilitation care working closely together

Chronic pain affects two million people in the Netherlands. Most of them suffer from chronic musculoskeletal pain, with back pain being the most common complaint. These are serious numbers, agrees Jeanine Verbunt. "And yet the impact of chronic pain is somewhat overlooked. Pain is often seen as a symptom rather than a disease. This may change now that the World Health Organisation has classified chronic pain as a disease."

Kant is one of the five professors who together initiated the 4Limburg programme. "We realised we could accomplish more by bringing together various disciplines." For years, sustainable employment of workers has played a major role in his research, which revolves around the question: how can employers help their employees stay fit and healthy?



Partly thanks to 4Limburg, IJmert Kant is also involved in a research project about returning to work and extending the concept of labour. "This project is specifically about people who fall within the Participation Act, which decentralised social assistance in the Netherlands. Municipalities are now responsible for social assistance recipients. Although the right to receive social assistance is the same in all municipalities, many municipalities are neither very efficient nor particularly successful when it comes to helping these people return to the labour market. Also, each municipality takes a different approach. Some offer half-hour conversations and that's it. Others provide intensive support, but don't achieve results either. This is also because not everyone is able to return to work. Finally, we see that some municipalities provide return-to-work support themselves, whereas others outsource it."

Starting date: 01-07-2019 end date 01-07-2022 Funding: Project was funded by the Province of Limburg

Project website: www.4-limburg.nl



Revolutionary

The question is, what is the best approach to reducing the number of people sitting on the sidelines? In other words, how can we help people become fit for work again? The municipality of Beekdaelen has developed its own concept which seems to be working well, says IJmert Kant. "I was immediately intrigued when I heard about it. In Beekdaelen, local and regional



companies have taken on the responsibility of providing return-to-work support. It's revolutionary. They have formed a cooperative that organises a weekly event where social assistance recipients and companies can meet each other and talk." The municipality facilitates the cooperative and provides support by, for example, helping residents pay off their debts before they participate in the event. "In Beekdaelen, people are indeed returning to work in a sustainable way."

Responsibility

The study, funded by the Netherlands Organisation for Health Research and Development (ZonMw), compares the Beekdaelen concept with the approach taken by the municipality of Landgraaf. Here, a company called the Mens Ontwikkel Bedrijf organises return-to-work support for social assistance recipients. People go through a process of conversations and gaining experience in workplaces set up for this purpose. "The Landgraaf approach also provides intensive support. The main difference with Beekdaelen is that the local business community in Landgraaf doesn't carry the burden of responsibility. In Beekdaelen, by contrast, the participating companies are responsible from the beginning. Rather than having to present their CVs, people are asked the question, 'How can we help you participate in society?' So, 'If you like working in the garden and being outside, let's make a professional gardener out of you!" Clubs and voluntary associations are now also being involved in the Beekdaelen cooperative, as participation isn't just about work.

Research Line Specific Case Studies: Functioning, Participation and Rehabilitation (FPR) | Case study 3

Self-esteem

In the study, researchers of the Occupational Epidemiology unit are working closely together with their colleagues from Work and Organisational Psychology. "As occupational epidemiologists, we study whether and why people return to work and the role their health plays in this. Psychologists look at other factors, such as what it means for people to regain their self-esteem and the role of labour force participation in this." Regardless of the results of the study, several municipalities in Limburg are already showing interest in the Beekdaelen concept. "This fits nicely with what we want to achieve with 4Limburg. The idea is to roll out the concept to seven medium-sized municipalities and have it evaluated by researchers until 2025", says IJmert Kant. He hopes that ZonMw, the Province of Limburg and municipalities will also be willing to support this new study financially. "We would like to add not just more municipalities, but also another target group: vulnerable young people. Finally, we want to study the effect of involving the voluntary sector in our cooperative approach."

4Limburg

The goal of 4Limburg is to create a strong, sustainable and inclusive labour market that is also accessible to vulnerable groups. 4Limburg is an integrated, multi-annual programme initiated by five professors at Maastricht University and developed by four faculties: Health Sciences, Social Law, Economics, and Work and Organisational Psychology. Their aim is to strengthen the socio-economic structure in Limburg in order to reduce the number of people sitting on the sidelines of the labour market. The implementation of the programme is in the hands of knowledge institutions, public administration, business partners and residents of Limburg. They focus on four themes:

- Proactive policy for young people and teacher labour market policy
- Increasing the sustainable employment of workers
- Inclusive organisations
- Extending the concept of labour

For more information, please visit: www.4limburg.nl



Prof.dr. IJmert Kant *Professor of Epidemiology, specialising in Occupational Epidemiology*

Our most important scientific output (Unit Occupational Epidemiology)

Jennen, J. G. M., Jansen, N. W. H., van Amelsvoort, L. G. P. M., Slangen, J. J. M., & Kant, I. (2022). Chronic conditions and self-perceived health among older employees in relation to indicators of labour participation and retirement over time. WORK-A Journal of Prevention Assessment & Rehabilitation, 71(1), 133-150. https://doi.org/10.3233/WOR-210436 Jennen, J. G. M., Jansen, N. W. H., van Amelsvoort, L. G. P. M., Slangen, J. J. M., & Kant I, (2021) Associations between depressive complaints and indicators of labour participation among older Dutch employees: a prospective cohort study. Int Arch Occup Environ Health 2021 Apr;94(3):391-407. doi: 10.1007/s00420-020-01584-9. Epub 2020 Oct 21. Jennen, J. G. M., Jansen, N. W. H., van Amelsvoort, L. G. P. M., Slangen, J. J. M., & Kant I, (2023) Associations between chronic condition(s), selfperceived health, and labour participation over time: a 16-year follow-up study; under review. Jennen, J. G. M., Jansen, N. W. H., van Amelsvoort, L. G. P. M., Slangen, J. J. M., & Kant I, (2023) The role of work engagement and chronic health conditions on different labour participation outcomes over time among older employees; under review Jennen, J. G. M., Jansen, N. W. H., van Amelsvoort, L. G. P. M., Slangen, J. J. M., & Kant I, (2023) Examining considerations towards early retirement across employees differing in health status and their implications for labour participation outcomes over time: a prospective study among older dayworkers; under review

Polina Putrik; IJmert Kant; Huub Hoofs; Rianne Reijs; Maria Jansen (2023) Prediction of school dropout outside school setting: potential for early risk stratification by Youth Health Care services in the Netherlands", submitted to Child & Youth Care Forum.

Thesis

Jacqueline Jennen: <u>Relations between health status and labour participation outcomes among older workers over time¹. Thesis was succesfull defended on March 22 2023</u>

Our most important output for societal target groups

As can be seen in the final report of phase 1, the 4Limburg program has produced a very high output for different societal target groups. Output included new assessment tools, instruments, methodology as well as results of data analysis and interventions. The final report including all the 21 sub reports: www.4-limburg.nl/resultaten-4limburg. Phase 1 of the 4Limburg programme was evaluated by the Advisory board and an evaluation committee installed by the Province of Limburg. Both committees were very positive about the 4Limburg programme. They found the program highly relevant and very positive about the results obtained. Therefore, both committees recommended the continuation of the programme (phase 2). Unfortunately due to political changes, the Board of the Provincial Executive of Limburg decided not to continue the 4Limburg programme.

4Limburg in the media

Newspapers

De Limburger, 30 March 2019. <u>Economische tijger Limburg</u> dreigt te verhongeren, maar de wetenschap helpt².

Radio / TV

L1 Vandaag. Theme week, March 2022: <u>How Limburg works</u>³ (interview IJmert Kant)

L1 Avondgasten, June 2017. More labour participation in Limburg: Launch 4Limburg⁴

Internet

Centrum Inclusieve Arbeidsorganisatie. <u>4Limburg: Samenvatting Inventarisatie Bouwbedrijf</u>^s

IDEAS (largest bibliographic database dedicated to Economics). 4Limburg: Kwaliteit re-integratie data CBS.⁶

HBO Kennisbank. <u>Nieuwe Start: kwalitatief onderzoek naar</u> de factoren die kunnen bijdragen aan (re-) integratie op de arbeidsmarkt: Onderzoek in het kader van het project 4Limburg.⁷



- $^1|\,\text{https://cris.maastrichtuniversity.nl/en/publications/relations-between-health-status-and-labour-participation-outcomes}$
- 2 | www.4limburg.nl/sites/intranet.mumc.maastrichtuniversity.nl/files/www_4limburg_nl/public_slideshow/wetenschap_dient_de_regio.pdf
- https://l1.nl/l1-vandaag-themaweek-hoe-limburg-werkt-4limburg-170103/
- www.maastrichtuniversity.nl/news/more-labour-participation-limburg
- /www.inclusievearbeidsorganisatie.org/4limburg-samenvatting-inventarisatie-bouwbedrijf
- https://ideas.repec.org/p/unm/umarot/2019004.html
- ⁷ | https://hbo-kennisbank.nl/details/sharekit_zuyd:oai:surfsharekit.nl:15ed2acc-cab3-4626-8095-3140de461d38?t-6-k=info%3Aeurepo%2Fsemantics%2Freport&sort-order=date&p=13

Health Inequities and Societal Participation (HISP)

Case study 1: The future of research is transdisciplinary

Fruitful collaboration across national and disciplinary boundaries

No, you certainly can't call the COVID-19 pandemic a gift. "But", says Christian Hoebe, "the pandemic did confirm to us that we at CAPHRI are on the right track with our transdisciplinary research on viruses and borders. In fact, collaboration across both disciplinary and national boundaries is very valuable. After all, bacteria and viruses know no borders - they cross them just as easily as we do."



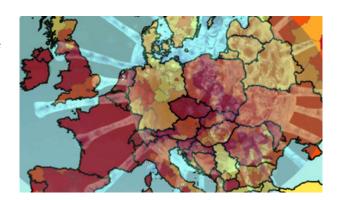
Christian Hoebe is a professor of Social Medicine, specifically Infectious Disease Control. He explains how these kinds of studies fit within the CAPHRI research line Health Inequities and Societal Participation (HISP). "Cross-border research helped us show, for example, that border control measures in the European Union did very little to prevent COVID-19 from spreading. We must therefore be extremely cautious about imposing those kinds of restrictions in future, as they do tend to have a major impact on cross-border life. Residents of border regions were deeply affected. They are used to simply crossing the border for work, family, groceries and health care."

All HISP departments are represented in CAPHRI's transdisciplinary research on viruses and borders - Social Medicine, Medical Microbiology, and Health Ethics and Society. The researchers work with various parties in the Netherlands and similar parties in adjacent countries, including health services, the Dutch National Institute for Public Health and the Environment (RIVM) and its German and Belgian equivalents. "Working across disciplines is actually not as easy as it may seem", says Petra Wolffs, assistant professor in the Department of Medical Microbiology. The main problem, she explains, is that the various experts don't speak the same language; a microbiologist is not a sociologist. It was partly due to Alena Kamenshchikova's research, which provided insight into this language barrier, that transdisciplinary collaboration within CAPHRI was able to gain momentum and is now bearing fruit.



control is managed in different countries to the way residents respond to that." It is particularly important to take a transdisciplinary approach and conduct cross-border research in border regions, as their residents are much more likely to be confronted with policy differences between countries.

Transdisciplinary collaboration within CAPHRI has so far produced approximately ten cross-border studies, specifically on antibiotic resistance and COVID-19. A study on vaccination willingness and compliance with COVID-19 restrictions in the three Euroregion countries revealed that both vaccination willingness and face-mask compliance were highest in Germany.



Wide range of topics

It all began around 2015, with Alena Kamenshchikova's PhD research on antibiotic resistance in the Meuse-Rhine Euroregion. Christian Hoebe, Petra Wolffs and Klasien Horstman (professor of Philosophy of Public Health) were her supervisors. Alena Kamenshchikova is now assistant professor of Health, Ethics and Society. "Infectious disease control touches on a wide range of topics", she says, "from bacteria and viruses crossing borders to public health, and from the way infectious disease

Border regions

There are currently five PhD students conducting cross-border and transdisciplinary research at CAPHRI. Christian Hoebe: "This type of research suits CAPHRI perfectly, as it has both international research impact and a clear positive impact on health in our own region. That's exactly what we aim for here at CAPHRI. We are a true pioneer in Europe and a role model when it comes to cross-border public health. The EU has 170 border regions, and over forty per cent of its population lives

in border regions. What sets our region apart from others is that we conduct cross-border research."

Petra Wolffs nods. "We hope that our research will contribute to policy harmonisation across countries, making policies easier to understand for people. Additionally, we would like to train our new researchers in transdisciplinary collaboration." Bachelor's and master's students will also be brought into the fold, adds Alena Kamenshchikova. All three agree that this is absolutely necessary. "After all", concludes Christian Hoebe, "working together leads to better solutions. The future of research is transdisciplinary."

Collaborating partners

EuPrevent GGD Zuid Limburg Gesundheitsamt Düren

The citizens of these three countries no longer experience any borders between them, which means that we as professionals must also be able to work 'without borders'. In a cross-border region like the Meuse-Rhine Euroregion, it's especially important to have good relationships with your immediate neighbours. So, let's work together and face these challenges together.

- Brigitte van der Zanden, euPrevent

Our most important scientific output

Kamenshchikova A, Wolffs PFG, Hoebe CJPA, Horstman K. <u>Transdisciplinary work against antimicrobial resistance</u>. Lancet Infect Dis. 2020 May;20(5):526-527. Kamenshchikova A, Wolffs PFG, Hoebe CJPA, Penders J, Park HY, Kambale MS, Horstman K. <u>Combining stool and stories:</u> exploring antimicrobial resistance among a longitudinal <u>cohort of international health students</u>. BMC Infect Dis. 2021 Sep 27;21(1):1008.

Kamenshchikova A, Wolffs PFG, Hoebe CJ, Penders J, Horstman K. <u>Complex narratives of health, stigma and control:</u>
<u>Antimicrobial resistance screening among non-hospitalized refugees</u>. Soc Sci Med. 2018 Sep;212:43-49.

Dieminger L, Kamenshchikova A, Hoebe CJPA, Horstman K. Perspectives of public health professionals on border control practices for COVID-19 management in Europe. Public Health. 2022 Sep;210:83-90.

van Hensbergen M, den Heijer CDJ, Wolffs P, Hackert V, Ter Waarbeek HLG, Oude Munnink BB, Sikkema RS, Heddema ER, Hoebe CJPA. <u>COVID-19: first long-term care facility outbreak</u> in the Netherlands following cross-border introduction from Germany, March 2020. BMC Infect Dis. 2021 May 4;21(1):418. Hackert VH, Hoebe CJPA, Dukers-Muijrers N, Krafft T, Kauhl B, Henning K, Karges W, Sprague L, Neubauer H, Al Dahouk S. Of fever: Evidence of a massive yet undetected cross-border outbreak, with ongoing risk of extra mortality, in a Dutch-German border region. Transbound Emerg Dis. 2020 Jul;67(4):1660-1670.

Kamenshchikova A, Hargreaves S, Chandler CIR. <u>Management of cross-border mobilities during the SARS-CoV-2 pandemic in Europe and implications for public health provision to migrants</u>. J Travel Med. 2022 Sep 17;29(6):taac093.

Demi ME Pagen, Daniëlle A.T. Hanssen, Inge H.M. van Loo, Casper DJ den Heijer, Nicole HTM Dukers-Muijrers, Christian JPA Hoebe. The association between SARS-CoV-2 seroprevalence and cross-border mobility for visiting family or friends among Dutch residents of a border province. Submitted.

Awards



Transdisciplinary research on viruses and borders has received praise and recognition from CAPHRI, with Alena Kamenshchikova and Volker Hackert winning the CAPHRI Dissertation Award in 2020 and 2021 respectively.

Alena Kamenshchikova: Resistant bacteria in society:
Travelling through practices of policy, healthcare and science Volker Hackert: Mapping underestimation in Q Fever: Insights from a major cross-border outbreak in the Meuse-Rhine Euroregion²

Research Line Specific Case Studies: Health Inequities and Societal Participation (HISP) | Case study 1

Our most important output for societal target groups

Several citizens' summits funded by the Interreg VA EMR project "euPrevent COVID" were organized in various border regions (Aachen, Düren, Eupen, Hasselt, Heinsberg, Liège and Maastricht). The goal of these citizens' summits was to give the citizens living in border regions the opportunity to exchange their personal experiences during the corona time. Read more about the results³.

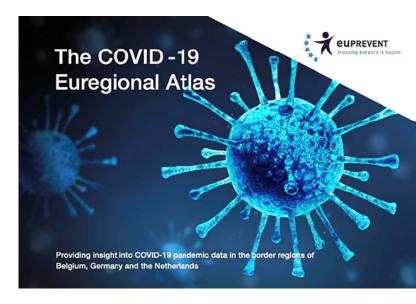
EUprevent report: <u>The development of COVID-19 in the border</u> area of the Netherlands, North Rhine-Westphalia and Belgium⁴

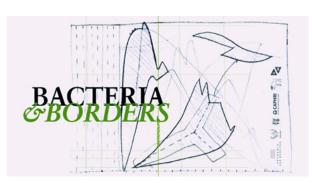
Collaboration between arts and sciences

Bacteria & Borders is a collaboration between visual artist Marlies Vermeulen and social scientist Alena Kamenshchikova. In a series of podcasts they tell more about their collaboration between science and art, the pitfalls and the unique chances. During the pandemic, their research became more current than ever.

This collaboration was made possible by the Mingler Scholarship, awarded to Marlies Vermeulen and Klasien Horstman in 2020. The Mingler Scholarship is an initiative of the Dutch Society of Arts and The Young Academy, part of the Royal Netherlands Academy of Arts and Sciences and is financially supported by the Niemeijer Foundation.

Read more about this project (in Dutch)⁵







- $^1|\ \text{https://cris.maastrichtuniversity.nl/en/publications/resistant-bacteria-in-society-travelling-through-practices-of-pole}$
- $^2 \mid \mathsf{https://cris.maastrichtuniversity.nl/en/publications/mapping-underestimation-in-q-fever-insights-from-a-major-cross-boundaries of the properties of$
- 3 | www.ggdzl.nl/fileadmin/files/ggdzl/documenten/corona/project_impact_van_covid-19_euregio/factsheet_citizens-summits-on-covid-19_en.pdf
- 4 https://euprevent.eu/new-report-the-development-of-covid-19-in-the-border-area-of-the-netherlands-north-rhine-westphalia-and-belgium
- ⁵ https://klasienhorstman.nl/nieuws/mingler-award-for-bacteria-and-borders

Case study 2: The challenge of growing social health inequalities in the era of participation

'Life at the bottom'

In the first two decades of the 21st century, many European welfare states have been transformed into participation societies: the state has rearranged responsibilities for care in such a way that citizens have to take care for themselves and others - the state assigns vulnerable citizens participatory obligations. In this third decade, the negative consequences can no longer be neglected. People with less education and in lower socioeconomic positions have a worse health status than their better-of counterparts. In The Netherlands, people in lower socioeconomic positions live six to seven years shorter than people in higher socioeconomic positions and their shorter lives are spent eighteen to nineteen years longer with all kinds of illnesses. Income inequalities do not tend to narrow.

On a global scale, the poor might have become less poor, but the rich have become much richer. Social security safety nets are increasingly trimmed down, leaving people increasingly on their own coping with adversities like unemployment, disability, illness, school dropout. If people do not have the economic, personal, or social resources on their own, lifestyles get negatively affected, societal and labour participation becomes compromised and the distance to the ones who have resources becomes increasingly unbridgeable, also in health terms. Apart from that we see that many lower educated people are not politically active and not represented in relevant political processes and public debates.

Hence, inequalities in health and wellbeing, in social networks and resources, and in political participation and power are piling up. In HISP, we give 'life at the bottom" a voice. We explore what health and participation mean for vulnerable people and we tap into often 'hidden' resources and knowledges of vulnerable people about the dynamics of health inequalities. To disentangle the dynamics and find targets for intervention, we also let numerical data speak. The focus is on whether and how unhealthy residential, work, social, and societal environments accumulate at the "bottom" and contribute to health inequalities in for example infectious diseases and type 2 diabetes. Giving voice is a part of solution in itself, as the Healthy HR project clearly demonstrates. In addition, our projects point at structural causes of health inequality that have been neglected for too long.



Prof.dr. Hans Bosma



Projects and people (examples)

The MAISE-toolkit: a dialogue-based approach to improve the health of workers with a low socio-economic status

Prof. dr. Angelique de Rijk

Dr. Inge Houkes

Prof. dr. Hans Bosma

Inequities in type 2 diabetes: the role of environmental injustice and chronic stress

Prof. dr. Hans Bosma

Dr. ir. Annemarie Koster

Canadian round table: Country differences in the health and income protection of low wage and digital employment in the context of the Covid pandemic

Prof. dr. Angelique de Rijk

Work-related support for MUMC+ patients with chronic health conditions: from policlinic to workplace & The Next Step

Prof. dr. Angelique de Rijk

Maarten Butink

Our most important scientific output

Hazelzet E, Houkes I, Bosma H, de Rijk A. How a steeper organisational hierarchy prevents change-adoption and implementation of a sustainable employability intervention for employees in low-skilled jobs: a qualitative study. BMC Public Health. 2022 Dec 17;22(1):2373.

Consolazio D, Koster A, Sarti S, Schram MT, Stehouwer CDA, Timmermans EJ, Wesselius A, Bosma H. Neighbourhood property value and type 2 diabetes mellitus in the Maastricht study: A multilevel study. PLoS One. 2020 Jun 8;15(6):e0234324. MacEachen, E., de Rijk, A., Dyreborg, J., Fassier, J. B., Fletcher, M., Hopwood, P., Koivusalo, M., Majowicz, S., Meyer, S., Ståhl, C.& Welti, F. (2022). Laws, Policies, and Collective Agreements Protecting Low-wage and Digital Platform Workers During the COVID-19 Pandemic. NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy, 32(3), 201-212.

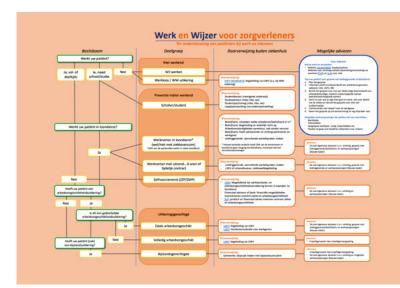
Research Line Specific Case Studies: Health Inequities and Societal Participation (HISP) | Case study 2

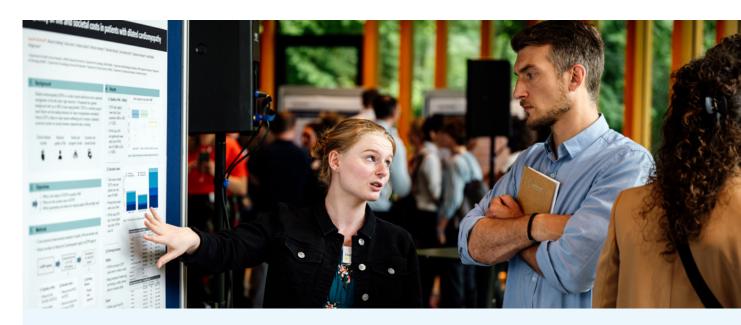
Societal impact

Social impact is created by looking for opportunities to improve the situation of disadvantaged or vulnerable groups. Targets are studied bottom-up by participatory methods that are common in action research. Targets are also sought in state of the art quantitative research aimed at finding environmental factors that more insidiously and negatively affect the health of people living in 'unhealthy' environments. Some examples are:

In the project of Rijk, Houkes, and Bosma, a <u>tool</u>¹ has been created aimed at improving the health and sustainable employment of low-skilled workers. The tool was created in dialogue and has to be applied in dialogue with workers to have tailored organizational interventions. HR managers are advised to use the tool, as it has been found effective.

In the project 'Work-related support for MUMC+ patients with chronic health conditions: from policlinic to workplace", which is continued with a grant from the MUMC+ the Next Step call, a tool (Werk en Wijzer²) was developed with 9 stakeholders representing hospitals, experts and patients, to support assessment of the patient's working situation and support possibilities. As 40% of the Dutch workers do not work under a permanent contract, they lack (continuous) access to an occupational physician. The tool was particularly developed to encourage health care professionals to point patients with vulnerable work statuses (e.g. zero-hour contracts) at their rights and possibilities for working in a healthy way.





- 1 | https://gezond-hr.nl
- $^2\bigm| www.maastrichtuniversity.nl/file/werkenwijzervoorzorgverlenersmei 20221pdf$

Case study 3: Involving employees in creating a healthy workplace

Health at the workplace for and with everyone?

Programmes to improve employee health often fail to have the desired effect, particularly for workers in manual occupations. "This is because they are not or insufficiently tailored to what employees actually need and care about", explains Agnes Meershoek. Inge Houkes adds, "A healthy workplace is about much more than just 'fruit and fitness', to put it bluntly. It's also about workplace design, planning and scheduling, physical and psychological safety, and - above all - about taking employees seriously."

Agnes and Inge, both associate professors at Maastricht University, conduct research on participatory approaches to promoting employee health (CAPHRI research line: Health Inequity and Societal Participation¹). Agnes: "Many companies invest in workplace health promotion interventions, but their effectiveness is limited." "This is because they mainly focus on promoting a healthy lifestyle", explains Inge. "Get more exercise, eat healthier, quit smoking... These interventions end up having little effect because they don't address actual employee needs." "Employees are often concerned about the impact of their work and working conditions on their health. If those aspects are neglected, lifestyle interventions just fall short of the mark for them", adds Agnes. Inge's Healthy HR research project (ZonMw) and Agnes's Health in Action research project (ZonMw and SBCM) sought to determine whether a different kind of approach does have a positive impact on employee health. Agnes: "Both studies investigated an innovative approach that actively involves employees and pays attention to their needs, skills, and experiences."

Work together

Inge is the project leader of the Healthy HR project, in which seven companies participated. It led to the development of "Healthy HR²", an online step-by-step toolkit that organisations can implement themselves. The toolkit was developed using focus groups in which employees shared their thoughts on health, sustainable employability, and what they need to enjoy their work. "The method takes as its starting point employee knowledge, skills, and experience; the employer's appreciation for employee expertise; and the will to use that knowledge and experience to create a healthier work environment", explains Inge. "Employees, HR managers, and supervisors work together to assess what employees need, decide on priorities, agree on short-term and longer-term actions, and implement and evaluate these." She adds, "The Healthy HR process sometimes reveals surprisingly simple issues that can be resolved quickly and easily. For example, there was a maintenance worker who was dissatisfied with the inefficient organisation of his work van. He was given the freedom to



reorganise the van as he saw fit. Eliminating this daily source of annoyance increased his job satisfaction and commitment. But even if an issue requires a major change that cannot be made immediately, it's useful to discuss it openly. Employees will usually be understanding if a supervisor can give a proper explanation of why the issue can't be resolved yet. Essentially, it's all about listening to each other and feeling heard."



Inge Houkes

The MAISE-toolkit, a dialogue-based approach to improve the health of workers with a low socio-economic status Funding provider: ZonMw (project number 5310014053)

Start and end project: 2018-2022 Project website: https://gezond-hr.nl

A sense of belonging

Agnes is the project leader of Health in Action, an ethnographic participatory research project in which four companies participated. "We likewise talked to employees, shadowing them at work and having one-on-one conversations with them. Their experiences gave us insight into their views on health and work. It turned out that for them, health was mainly about safety, unity, good communication, and a sense of belonging. People feel healthier at work if they feel taken seriously. They possess knowledge that can be used to not just identify, but also resolve processes with a negative impact on workplace health. For example, there was a sheltered employment facility where employees who had just completed a task weren't allowed to leave the shop floor. They were just

Research Line Specific Case Studies: Health Inequities and Societal Participation (HISP) | Case study 3

sitting there twiddling their thumbs, getting bored and frustrated. As a result of our conversations with them, they now have a toolbox with games, physical exercises, and practical activities on lifestyle and social skills." Another company now involves maintenance workers in designing production lines, to take safe maintenance into account at an early stage. The Health in Action project has produced concrete tools, such as a website (gezondheidmetdewerkvloer.nl), workshops for companies, and a guide with tips and examples.

It requires them to let go of the familiar and be receptive to employee feedback." "It takes a bit of courage", says Agnes. "The courage to experiment based on employee knowledge and experiences; the courage to change business processes and ingrained habits and routines. And it isn't a one-time thing, but rather a cyclical process of dialogue - participation - implementation - integration - evaluation/dialogue. We hope that many more companies will begin to realise that their employees deserve a say in creating a healthy workplace, in the broadest sense of the word."

Us-versus-them mentality

Both projects clearly show that there is a sharp divide between the shop floor and the office. Workers on the shop floor possess a wealth of knowledge and expertise, but things are constantly being imposed on them from above. "This leads to an us-versus-them mentality", explains Agnes. "It makes employees feel underestimated and unheard. I have a good example of a forklift operator who got a new safety helmet. The helmet obstructed his view of the rear-view mirror, so he kept having to take it off for safety reasons. It would have saved him a lot of frustration if he had simply been included in the purchasing process. Or take companies where production workers don't have key cards to access the office, but office workers can enter the shop floor. This creates a sense of inequality, which negatively affects job satisfaction - and ultimately work commitment, vitality, and sustainable employability."



Agnes Meershoek

Health in action, a participatory ethnographic research into work place health promotion for employees with low social economic position (SEP)

Funding provider: ZonMW (project nr 5310014064) & SBCM Start and end project: 2018-2021

Project website: www.gezondheidmetdewerkvloer.nl

A bit of courage

Organisations can implement the Healthy HR toolkit and the Health in Action website themselves. "It may sound simple, but it isn't", cautions Inge. "Changing organisational culture can be difficult for both employees and supervisors. Employees aren't used to being asked for their opinions. And we were quite surprised to discover how difficult supervisors find it to really talk to their employees. It can be confronting.

Collaborating partners

Researchers have many local, national, and international partners with whom they collaborate, sometimes already for decades. Some of the partners with whom shared output was created (e.g. articles, Phd theses, interventions) are reported below.

Partners project 'The Maise toolkit'

EQUANS

Interduct

5 companies from industrial, financial and hospitality sectors Mulder Arbeid en Gezondheid

Partners project 'Health In Action'

SBCM, Kenniscentrum en A&O-fonds sociale werkgelegenheid AWVN, Algemene Werkgeversvereniging Nederland Cedris, Vereniging voor een inclusieve arbeidsmarkt Kenniscentrum inclusieve en sociale werkgelegenheid 4 companies *Our employees are more aware of their own health (project leader)*

Our most important scientific output

Researchers in this group chose journals with high impact factors in the field of public health. Recent examples are shown below.

Hazelzet, E., Bosman, H., Rijk, A. de, & Houkes, I. (submitted). Giving voice to employees in low-skilled jobs works: Effect and process evaluation of a participatory sustainable employability intervention.

Hazelzet, E., Bosma, H., Rijk, A. de, & Houkes, I. (2020).

Does dialogue improve the sustainable employability of low-educated employees? A study protocol for an effect and process evaluation of "Healthy HR". Frontiers in Public Health, 8:446. https://doi.org/10.3389/fpubh.2020.00446

Hazelzet, E., Houkes, I., Bosma, H., & Rijk, A. de (2022). How a steeper organisational hierarchy prevents change-adoption and implementation of a sustainable employability intervention for employees in low-skilled jobs: a qualitative study. BMC Public Health 22, 2373. h

ttps://doi.org/10.1186/s12889-022-14754-w
Hazelzet, E., Houkes, I., Bosma, H., & Rijk, A. de (2021). Using intervention mapping to develop 'Healthy HR' aimed at improving sustainable employability of low-educated employees. BMC Public Health 21, 1259.
https://doi.org/10.1186/s12889-021-11278-7
Mignon, P., Hazelzet, E., De Rijk, A., Bosma, H., & Houkes, I. (2022). Validation of the Maastricht Instrument of Sustainable Employability (MAISE-NL) Adapted for Employees in Low-Skilled Jobs (MAISE-Basy). International Journal of Environmental Research and Public Health, 19, 7977.
https://doi.org/10.3390/ijerph1913797
Biermann-Teuscher, D., Thissen, L., Horstman, K., & Meershoek, A. (re-submitted) Safety: A collective and embedded competency.

A. (re-submitted) Safety: A collective and embedded competency. An ethnographic study of safety practices at an industrial workplace in the Netherlands, Journal of Safety Research Thissen, L., Biermann-Teuscher, D., Horstman, K., & Meershoek, A. (re-submitted) (Un)belonging at work: an overlooked ingredient of workplace health, Health Promotion International

Our most important output for societal target groups

Social impact is created by looking for opportunities to improve the situation of employees at the workplace, employees in lower skilled jobs, through participatory approaches.



Healthy HR

The project Healthy HR has a societal impact at different levels: the micro-level (i.e., the individual becoming more



aware of health and SE, getting a voice and more job control,

and feeling responsible), organizational level (i.e., organizations being enabled to start a dialogue with employees, improving working conditions and becoming more attractive on the labour market), and the societal level: The findings of this project can be relevant to the Dutch government, including policymakers. It advocates for a radical change towards a more progressive view on work and prevention. The project resulted in a practical online toolkit which can be applied by work organizations (https://gezondhr.nl) and an instrument (including a manual) for the measurement of sustainable employability from the perspective of the employee in a lower skills job, the MAISE-Easy (Maastricht Instrument for Sustainable Employability) (Mignon et al., 2022).

Health in Action

The project Health in Action has a societal impact as it developed a participatory approach for workplace health promotion in which employees and management together can improve workplace health. It provide insight in conditions under which implementation of the approach can be successful. The project resulted in a website

(www.gezondheidmetdewerkvloer.nl), a practical guide and a workshop to introduce employers and employees in the ethnographic-participatory approach to workplace health and provide handles and tips to tailor and implement the approach in their own organization.

Biermann-Teuscher, D., Fermin, B., Horstman, K., Meershoek, A. & Thissen, L. SociaalBestek, tijdschrift voor werk, inkomen en zorg (2021). <u>Gezondheid met de Werkvloer: Een etnografischparticipatieve basis voor vitaliteitsbeleid⁵.</u>

SBCM (July 2021). <u>Gezond op de werkvloer: meepraten en</u> meedoen⁶.

MTB, Personeelsblad Fier. <u>De Vitaal Week, Wat een energieke</u> week was dat!^z

Horstman, K. & Meershoek, A.. Podium voor bio-ethiek, 2019, 26(2), 16-20. Vitaal en bevlogen werknemers? Een pleidooi voor etnografisch-participatief onderzoek.

- $^1 | www.maastrichtuniversity.nl/research/school-caphri-care-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-inequities-and-public-health-research-institute/our-research/health-research-institute/our-research/health-research-institute/our-research/health-research-institute/our-research/health-research-institute/our-research/health-research-institute/our-research/health-research-institute/our-research-insti$
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- https://projecten.zonmw.nl/nl/project/health-action-participatory-ethnographic-research-work-place-health-promotion-employees-low
- ⁵ | https://sociaalbestekpremium.nl/sociaal-bestek-2021-editie-6/gezondheid-met-de-werkvloer
- $^{6}\ |\ https://www.sbcm.nl/actueel/2019/gezond-op-de-werkvloer-meepraten-en-meedoen$
- 7 | https://gezondheidmetdewerkvloer.nl/MTB Personeelsblad Fier.pdf

Optimising Patient Care (OPC)

Case study 1: KOALA study and LucKi Gut study: Complementary feeding during the first six months of life. Yes or no?

Language barrier

For years, children's healthcare centres in the Netherlands advised young parents to feed their baby only breast milk for the first six months of life. Exclusive breastfeeding was thought to reduce the risk of infants developing food allergies (such as cow's milk, egg and peanut allergies) and eczema. "A substudy of our KOALA study found that the reality is a bit more nuanced." says Carel Thijs, associate professor in the Department of Epidemiology at Maastricht University. The guidelines have since been updated.

Carel Thijs is the initiator of and lead researcher on the KOALA study. "KOALA is a longitudinal cohort study of the health and development of approximately 2,800 children born between 2000-2003. We've been following these children, who are now young adults, from pregnancy. During pregnancy, during the first years of the children's lives and during their teenage years, their parents have been completing questionnaires about their health, diseases and all kinds of relevant factors such as diet and lifestyle. The children, now 17 to 20 years old, recently completed a questionnaire themselves. We've also taken blood, breast milk and stool samples at various points in time. I initiated this study more than twenty years ago because I was interested in the development of allergies and asthma, partly in the context of the hygiene hypothesis. Simply put, the hypothesis suggests that our immune systems don't get enough exposure to stimuli due to better hygiene. It doesn't learn to distinguish between relatively harmless and more harmful stimuli (like microbes and food components), resulting in overreactions and allergies."

Subproject: complementary feeding during the first six months of life

"The aim of the KOALA study is to gain a better understanding of what causes allergies, eczema and asthma", explains Monique Mommers, a fellow researcher, biologist and epidemiologist who is an assistant professor in the Department of Epidemiology at Maastricht University. "It looks at factors such as exposure to microorganisms (vaccinations, gut microbiota, infections), diet, exercise, lifestyle and genetics. The cohort includes parents and children who follow the 'standard way' (including vaccinations etc.) as well as parents who, for example, hold a more anthroposophical worldview, who choose not to vaccinate their children and are more cautious about the use of antibiotics. The KOALA study has produced a wealth of data over the course of more than two decades. Subprojects developed over time, one of which was research into complementary feeding during the first six months of life."



KOALA study

Child, parents and health: lifestyle and genetic constitution Period: 2001-now

Project website:

English: KOALA Birth Cohort Study | KOALA study¹

Nederlands: KOALA | KOALA study²

Exclusive breastfeeding: yes or no?

"For a long time, parents were recommended to feed their baby only breast milk for the first six months of life", says Thijs. "The idea was that hypersensitivity to certain types of food could be



prevented by not exposing children to them until a later age. We wanted to find out if this was true. The data from the KOALA study provide insight into the health of children who - for a certain period of time - were exclusively breastfed; fed a combination of breast milk and formula; exclusively formulafed; or fed combinations involving complementary feeding such as fruit and vegetable purees or porridge. We carefully analysed when, what and how much these infants had been fed. We expected to find that infants who received cow's milk-based formula before the age of six months were more likely to develop a cow's milk allergy. Or, depending on the complementary foods they were offered, a peanut allergy or a chicken egg allergy. But we actually found that the opposite was true."

Findings confirmed

"Our study was among the first of its kind", continues Thijs. "Its remarkable findings were further investigated and confirmed in various randomised controlled trials in England and Australia, among other countries. The Dutch guidelines have since been updated to reflect these findings; they now recommend that children start receiving complementary foods from the age of four months. The Netherlands Nutrition Centre provides guidelines for introducing complementary foods from four months onwards. This is particularly good news for working mothers, who often find it difficult to exclusively breastfeed for six months. Introducing complementary foods earlier makes breastfeeding more manageable, giving children more time to enjoy the benefits of breast milk for their immune systems."

Solid foods and the gut microbiome

The findings have also inspired a follow-up study, says Mommers. "The LucKi Gut study is looking into the impact of introducing solid foods on gut microbiota development in young children. The children in question were born from 2016 onwards, so they're growing up with the updated Netherlands Nutrition Centre guidelines. Our focus is on the development of gut microbiota and allergies, based on the concept of tolerance development as a counterpart to the previous notion of how allergies develop. The LucKi Gut study examines stool samples from babies and compares them to those of participants in a similar study in Canada. The results show that introducing a wider variety of foods leads to greater gut microbial diversity. The study has also revealed significant cultural differences with regard to first foods for babies. In Canada, for example, children are introduced to meat and eggs at a younger age. Further research is required to determine the effects of a more varied diet on the gut microbiome and allergy development."

LucKi Gut studyProject website: <u>www.luckigut.nl</u>



Involved partners

Carbohydrate Competence Center Biobanking and Biomolecular Resources Research Infrastructure Maastricht Centre for Systems Biology

Our most important scientific outputs

Scientific articles

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^{1 |} www.koala-study.nl/koala-birth-cohort-study

² www.koala-study.nl/koala

Case study 2: Studying the Healthy Primary School of the Future

Children have more energy and behave more socially

In 2015, four primary schools in the Parkstad Limburg region embarked on the Healthy Primary School of the Future programme. Their goal was to become schools that don't just educate children, but also teach them how to live healthy lives. All four so-called intervention schools introduced longer school days with more physical, social and cultural activities. Two of the schools also introduced a daily healthy lunch. Maastricht University studied the effects of the programme for four years, obtaining promising results. "The children have more energy and behave more socially", says project leader Onno van Schayck, professor at CAPHRI.

The study is a good example of close collaboration between researchers and partners in the region, which began with a programme to restructure the school day. To realise this idea, local educational board Movare - of which the four schools participating in the Healthy Primary School of the Future programme are members - worked together with Maastricht University, the Living Lab Public Health Limburg, the South Limburg Public Health Service, and two childcare organisations. They obtained support from several organisations, including the municipalities of Landgraaf and Brunssum and local social organisations, to implement the programme.



The study, which was co-funded by the Province of Limburg, focused on determining the effects of the Healthy Primary School of the Future programme. To this end, researchers measured the children's weight and height and assessed their dietary and physical activity behaviours. They took baseline measurements during one week before the start of the programme. Measurement weeks were subsequently held once every year. The last one was held in 2019. Postdoctoral researcher Maartje Willeboordse coordinated these weeks. "It was a lot of fun, but also very hard work. We wouldn't have been able to do this without the cooperation of the schools. They were so flexible. I think it's important for us researchers to realise how valuable that is."

Results

Measurement weeks were also held at the four control schools that didn't introduce any changes during this time. After four years, the researchers compared the results of these control schools with those of the intervention schools. "The effects of the programme were greatest in schools that had introduced both a daily healthy lunch and more exercise. Pupils there developed different, healthier eating habits - which makes



sense, as they were offered healthy food choices. But I think it's quite remarkable that we could see the effects of this in their BMI scores after already one year. Similar studies didn't show such clear results after one year", says postdoctoral researcher Nina Bartelink. Pupils in the intervention schools had slightly lower Body Mass Index scores (BMI: a person's weight in relation to their height), whereas pupils in the control schools clearly had higher BMI scores. "This is shocking", says Onno van Schayck. "I'm so glad we were able to reverse that trend in the intervention schools."

Healthy Primary School of the Future





Paul Blokhuis, State Secretary for Health, visits a Healthy Primary School of the Future

Research Line Specific Case Studies: Optimising Patient Care (OPC) | Case study 2

Turnaround

Nina Bartelink did her PhD research on the Healthy Primary School of the Future programme. She assessed its process and effects by, among other things, interviewing the people involved. Her results show that the daily healthy lunch in particular caused a turnaround and set changes in motion. "Introducing both more exercise and a daily healthy lunch had the most impact. Those schools thought of themselves as healthy schools, so they gave their pupils water bottles, for example, or changed their policy for birthday treats. At the two schools that only introduced more exercise, the effects were less pronounced, though definitely still present: pupils there also had slightly lower BMI scores."

An unexpected side effect of the programme was that the children began to behave more socially. Less bullying behaviour was observed during the course of the programme. As the researchers hadn't asked any questions about this, they conducted additional interviews with teachers and professionals. Eating together clearly had a positive social effect, as did the skills children developed during the physical, social and cultural activities introduced in the programme. Pupils also simply had less time to engage in this kind of behaviour, as the programme added more structure to the school day.

Example

Onno van Schayck emphasises that the researchers do not yet know whether the effects of the programme are permanent. "That is still to be investigated." Several primary schools in Limburg have already decided to follow the example of the intervention schools. The Dutch government also wants to investigate whether the programme could be rolled out nationally. Maastricht University will be involved in this investigation. "We ultimately want to achieve proportionate universalism", says Maria Jansen, former professor of Population-Focused Health Policy at CAPHRI. "Universal' here means that each child needs to be provided with proper education, a healthy lunch, and a longer school day with more room for physical, social and cultural activities. We'll take proportionate action to help disadvantaged children by offering them extra support for maths and literacy, for example. This approach aims to reduce health and wellbeing inequalities that result from social $inequalities. {\tt "}\underline{www.degezondebasisschoolvandetoekomst.nl"}$

In the Media

Healthy Primary School of the Future

- online talkshow

16 March 2021



Children become healthier when they have healthy lunches at school, exercise in different ways and learn about healthy behaviour while at school. This is the result of the Kennis As project Healthy Primary School of the Future. For four years, Maastricht University scientists compared more than 2200...

Research shows urgent need to teach healthy habits in primary school

21 September 2020



Children's health improves if they have a healthy lunch at school, get varied exercise and are taught in class about healthy behaviour. These are the findings of the 'Healthy Primary School of the Future' project, the final results of which will be announced during a symposium in Venlo on Tuesday...

Nina Bartelink wins CaRe Award 2020

2 June 2020



Oue (former) VHC colleague Nina Bartelink has won the "CaRe Award 2019" for her Cum Laude PhD thesis "Evaluating health promotion in complex adaptive school systems: The Healthy Primary School of the Future".

Collaborating partners

Maastricht University (FHML, SBE, FPN, FoL)

Provincie Limburg

Movare

GGD Zuid-Limburg

Gemeente Brunssum

Gemeente Landgraaf

Kinderopyang Humanitas

Maastricht Universitair Medisch Centrum

Open Universiteit

Sodexo

Speeltuinwerk Limburg

Park ter Waerden

Kennis-As Limburg

CZ

Kinder Opvang Parkstad

Topsport Limburg

The Move Factory

Alles is Gezondheid

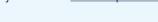
Case study 3: COVID precise: Living systematic review of diagnostic and prognostic prediction and machine learning models for COVID-19

In March 2020, the COVID-19 pandemic plunged the world into turmoil. Doctors everywhere found themselves confronted with questions. Which patients were at risk of severe illness? And what were an individual's chances of survival in the intensive care unit? Laure Wynants immediately realised that she, as a statistician, could help them find the answers by identifying accurate prediction models. Her initiative was eagerly embraced by experts in the Netherlands and abroad. Together, they developed a plan to systematically review models and papers being published on the topic. Through high-quality methodological research, Wynants and her team were able to provide doctors and policymakers on the front lines with a useful tool. The living systematic review was even adopted as the standard by the WHO. It received praise for its speed, relevance, and methodological quality. And that wasn't all. More generally, Wynants's approach has served as a wake-up call for the quality of prediction models.

Precise Risk Estimation to optimise COVID-19 Care for Infected or Suspected patients in diverse sEttings Start project:

Project website: www.covprecise.org



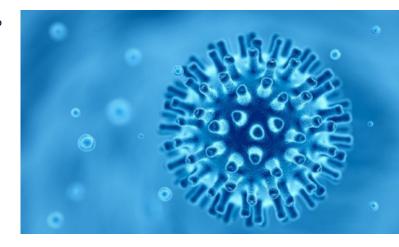


Important decisions

With the pandemic threatening to overwhelm all national health services, it was essential to make early predictions of disease progression to guide preventive, diagnostic and therapeutic decision-making. Studies had already shown that prediction models could be used for various diseases. The same must be true for COVID, thought Wynants. Predictions could then help inform all kinds of important decisions. For example, when testing capacity was still limited: does this person need to be tested? Or, at the GP surgery: can this patient recover at home or do they require hospitalisation? In the hospital: can this patient be admitted to the COVID ward or do they need intensive care? And in the ICU: what is the prognosis for this patient? How long will we continue to provide care?

The gold standard

From the moment Wynants began her search for useful prediction models, the initiative took off. Some 50 researchers and 40 institutes in the Netherlands and abroad were keen to work with her. The BMJ, a renowned journal, invited Wynants



and her colleagues to conduct its first-ever living review. In the absence of tools available for use in clinical practice, the WHO adopted their recommendations. The team continuously updated the review, identifying accurate tools and offering suggestions. They reviewed tools ranging from traditional prediction models based on regression models and machine learning to automatic artificial intelligence-based CT image analysis. At each stage of the pandemic, they selected the best state-of-the-art tools. Wynants's review became the gold standard for practitioners, researchers and policymakers alike. By bridging the gaps between these stakeholders, it had a significant positive impact on society.



Laure Wynants, PhD

Quality

But the review was not just a powerful weapon in the fight against coronavirus. It has also highlighted the importance of conducting sound methodological research. Most models were found to be of poor quality, especially those published in the initial phase of the pandemic. Several models turned out to be even worse at predicting disease progression than using age as the only predictor. The number of high-quality, representative and large datasets did grow over time, albeit slowly. But the vast majority of studies continued to be at high risk of bias due to poor methodologies and statistics - a problem that could easily be prevented or solved by focusing on adequate methods in teaching, research funding and publications. Wynants's international team ended up screening 126,978 titles and including 412 studies describing 731 new prediction models or validations. They were able to identify just a handful of reliable tools. The Qcovid models, the PRIEST score, Carr's

Research Line Specific Case Studies: Optimising Patient Care (OPC) | Case study 3

model, the ISARIC4C Deterioration model, and the Xie model were the only models to show adequate performance in predicting COVID-19 disease progression in studies at low risk of bias.

What's next? Three main issues

The pandemic is over, and the living review has been closed. But Wynants's work is far from done. She is turning her attention to three main issues. Firstly, she would like to draw up recommendations for model developers - judging from the sheer number of citations of the living review, there is a knowledge gap to be filled. Secondly, she plans to use the data for international validations to see if specific models perform equally well in other circumstances. One such validation study has already been published in the BMJ. Most of the models reviewed were developed using data and variables from wealthy countries; in collaboration with the WHO, a validation study has now been launched in low- and middle-income countries. There are lessons to be drawn from this. It is necessary to develop versions of models for low- and middle-income countries using only patient characteristics and widely available clinical tests as input variables; in addition, it is important to support data collection in those settings and to develop tools to combat the continued existence and growth of inequality. Finally, a model has been developed for general practitioners. GPs were largely left out in the cold during the pandemic, when it was they who often had to make important decisions - such as which patients needed to go to hospital or receive antiviral treatment.

Collaborating partners

KU Leuven, Belgium Julius Center for Health Sciences and Primary Care, UMC Utrecht, The Netherlands

Our most important publications in scientific journals

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In the media

The study attracted a lot of media attention (in national and internatiol media).

A selection

NRC newspaper (May 2020): <u>Zet er corona op en je onderzoek</u> <u>krijgt aandacht¹</u>

UM website (April 2020): <u>Good prediction models for</u> <u>COVID-19 are urgently needed²</u>

Het Belang van Limburg newspaper (August 2020): "Coronastudies blijken al te vaak haastwerk" 3

Observant (March 2021): Which model can predict how COVID-19 will progress?⁴

MIT Technology review (July 2021). <u>Hundreds of AI tools have</u> been built to catch covid. None of them helped.⁵
Volkskrant newspaper (August 2021): <u>Nut van inzet kunstmatige intelligentie bij diagnose covid twijfelachtig.⁶
Tagblatt Swiss newspaper (August 2021). <u>Doktor Frankenstein verwirrte die Künstliche Intelligenz²</u></u>

Our most important output for societal target groups

Policy impact

Several citations in policy documents. A selection:
Cited by the EU Department for Economic, Scientific and
Quality of Life Policies (European Parliament), "Impacts of the
COVID-19 pandemic on EU industries"
Cited by the WHO "COVID-19 Clinical management Living
Guidance document"
Citied by the OECD, "OECD Health Working Papers No. 128:

Laying the foundations for artificial intelligence in health"10

Awards

2021 award Oral Presentation award of the Dutch
Epidemiological society (VvE, 250 EUR)¹¹
2020 award Edmond Hustinx Scienze Prize for science (15000 EUR)¹²

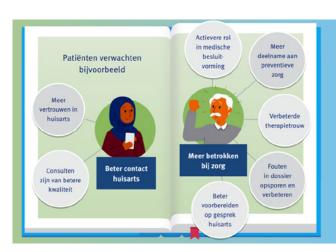


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- ¹² www.maastrichtuniversity.nl/news/edmond-hustinx-prize-2020-goes-laure-wynants

Promoting Health and Personalised Care (PHPC)

Case study 1: The OPEN project: Online access to medical information in primary care: the patient's perspective

From 1 July 2020, all patients in the Netherlands have the right to access their medical information online through their primary care physician. General practices play an important role in this, as most Dutch people have a general practitioner (GP) who keeps their medical information in a file that often extends over many years. But it will be quite a task for general practices to meet the legal and social requirement to provide patients with safe and easy access to their medical information. To help GPs with this and accelerate the process, a 4-year programme called OPEN was launched by the Dutch College of General Practitioners (NHG), InEen, and the Dutch General Practitioner's Association (LHV), supported by a grant from the Dutch Ministry of Health, Welfare and Sport.



One study, 3 subsets

The aim of the project is to ensure that at least 40% of all Dutch people will view their medical information online by the end of 2022. This percentage is currently 7%. Progress is being monitored on the OPEN website1, updated weekly. "But it's about more than just meeting targets", says Rik Crutzen, professor of Behaviour Change and Technology at CAPHRI of Maastricht University. "It's also important to know how online access affects patients, GPs, practice staff, and the organisation of general practices in the Netherlands". Crutzen and his team are studying these effects together with 2 other research institutes: the Netherlands Institute for Health Services Research (Nivel) and IQ healthcare of Radboudumc. "We put our heads together to discuss the best way to approach this project", says Crutzen. "We ended up dividing the study into 3 subsets, which we divided based on individual expertise. Nivel is focusing on the healthcare provider's perspective and the effect of the actual use of online access on the organisation of general practice, using data from the Dutch GP Information System (HIS). IQ healthcare is studying what online access means for patients, healthcare providers, and the interaction between them. Our research focuses on the patient's perspective. How do patients feel about having online access to their medical information? What factors encourage or discourage them to view their own file? And how does it affect them? For example, one of the goals of online access is to help patients become better informed so that they can make betterinformed treatment decisions together with their doctor. Do patients feel like this is the case?"

SOPEN Period: 2020-2022 This project was granted by: VWS Project website: www.open-eerstelijn.nl

Advantages and disadvantages from the patient's perspective PhD candidate Rosa Thielmann conducted in-depth interviews with many patients about their expectations of online access. "In the next phase of my study, I will follow a representative group of about 1500 people over time. I'll observe who does and does not end up viewing their medical information online, as well as their motivations, personal characteristics and experiences. So far, I've observed that most patients welcome the opportunity to access their own medical information online. It actually feels quite normal to them. But there's also scepticism. Some patients are worried that they might not understand the information in their medical files. And quite a few patients have security and privacy concerns. But they also see advantages: they can read the record of their consultation with their GP in their own time, which makes it easier for them to understand and remember what was said. It may also help them better prepare for consultations with their GP or a specialist they've been referred to", says Thielmann.

Results in infographics

According to Crutzen, the study will not just result in 3 separate research reports. "Researchers from the three institutes have already been sharing knowledge and expertise. We complement each other. It's our intention to also collaborate on publications. We worked together to create an infographic showing the results of the first part of our study. In addition to scientific publications, more infographics will follow as the study progresses. This way, our results will hopefully reach GPs. Our recommendations will also be included in GP training modules to help GPs better inform and support patients in accessing their medical files online. Ultimately, we hope that it will become normal for interested patients to access their medical information online, and that this will improve doctorpatient relationships, and consequently health outcomes".



Prof.dr. Rik Crutzen



Rosa Thielmann, MSc

Our most important output for societal target groups: Infographics



This fourth and final infographic (in Dutch) provides a summary of the research that was done regarding the effects of online access to medical records in the scope of this project. Go to the infographic https://open-eerstelijn.nl/wp-content/uploads/2022/12/OPEN-Infographic-Wetenschap-eindresultaten-A4.pdf



In this infographic (in Dutch) you can read the results of the sub-study with the following research questions: Do treatment plans of general practitioners and preferences of patients match? And what can we learn from the first practical experiences with online access to medical information in primary care?



In this infographic (in Dutch) you can read what is needed for optimal use of online access to medical information and how this would change the organisation of general practices?



What are the effects of online access on patients, GPs, practice staff and the organisation of GP practices? In this infographic (in Dutch) you can read the findings of a literature study and what will be further studied in the coming period.

Involved partners

InEen IQ healthcare (Radboudumc) Landelijke Huisartsen Vereniging (LHV) Nederlands Huisartsen Genootschap (NHG) Nivel

"Each of the three research institutes involved in the study has its own area of expertise and is responsible for one subset of the study. There is a lot of overlap between the three subsets and our areas of expertise, which makes it easy for us to share knowledge and support each other in the research process. We're working very well together!" - Jelle Keuper, researcher Nivel

Our most important scientific output

Thielmann, R.R.L.C., Hoving, C., Cals, J., & Crutzen, R. Relevant determinants of patients' informed decision-making process and use of online access to their medical records in general practice. Health Information Management Journal, 2023 Jan 19. Thielmann, R. R. L. C., Hoving, C., Schutgens-Kok, E., Cals, J., & Crutzen, R. (2022, January 27). Patient online access to general practice medical records: A qualitative study on patients' needs and expectations. https://doi.org/10.31234/osf.io/eq2mh [preprint]

 $^{^1 \, \}big| \, \text{https://open-eerstelijn.nl/voortgang-open} \,$

Research Line Specific Case Studies: Promoting Health and Personalised Care (PHPC)

Case study 2: SCALA: Prevention of heavy drinking in Latin America

Prevention of heavy drinking in Latin America

Talking about their use of alcohol helps patients. But how can doctors and other health care providers be encouraged to bring up this topic with their patients, especially if they don't usually do so? The SCALA project (Scale-up of Prevention and Management of Alcohol Use Disorders and Comorbid Depression in Latin America) is investigating whether scaling up an intervention programme for alcohol problems is more effective in the presence of municipal action and support. 'We want to teach health care providers how to screen, advise and refer patients.'

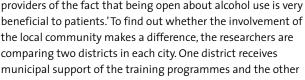
Alcohol use can have serious adverse effects on both individuals and society as a whole. Although there are intervention programmes to prevent and control excessive drinking, their implementation often has little impact. The SCALA project is implementing and testing a screening and intervention programme that proved successful in the past and is now being scaled up. The Latin American cities taking part in the project are Mexico City, Mexico, and Lima, Peru, as well as three small cities near Bogotá, Colombia. The hypothesis is that the intervention will lead to more screenings by embedding primary health care activities into the local community through municipal support and training individual health care providers.

providers of the fact that being open about alcohol use is very district doesn't. **Ownership**



Local community

The intervention programme is expected to succeed because of two specific activities, explains Adriana Solovei, one of the coordinators of SCALA together with Daša Kokole. 'It will teach health care providers how to bring up the topic of alcohol consumption during patient interviews and how to subsequently advise or refer patients if necessary.'This currently doesn't happen enough. 'Doctors think drinking alcohol isn't harmful, avoid the subject or don't have time to engage in prevention activities', explains Kokole. Solovei adds, 'We're testing how we can make it easier for health care providers to implement this intervention more often.' One hypothesis is that this won't really work without another



activity: the support of the local community. As Solovei explains,

'These interventions have to be supported by stakeholders

such as municipal health services to, for example, facilitate

communication campaigns to constantly remind health care



Adriana Solovei

The SCALA implementation will last eighteen months. It's a huge project: in each country, almost twenty health care institutions and about five hundred health care providers are participating. Each health care institution is expected to screen 800 to 4000 patients. According to the researchers, the project is special in that they are evaluating not just the effects of the implementation, but also the processes and costs involved. 'I focus on how the intervention is implemented and what changes are needed in the local context, for example', says Kokole. 'Adriana examines whether it's worth the investment. Are there any (financial) barriers that prevent people from participating?'

The intervention is currently being introduced in the cities. It's too early for results, but a first observation is that the participating health care providers are very motivated. 'According to the protocol, doctors only have to bring up the topic with patients who engage in risky alcohol use, but they bring it up with other patients as well', says Kokole.

The implementation also appears to be more successful thanks to certain stakeholders who 'take ownership of the intervention', says Solovei. 'A hospital employee in Colombia did this. As a result, we were very successful in recruiting health care providers.'

International collaboration



Daša Kokole

A consortium of several international universities in both Europe and Latin America are working together on SCALA. The Department of Health Promotion is coordinating the project. According to the researchers, a lot of knowledge about interventions and process evaluation is being exchanged. Newcastle University, for example, is specialised in tailored clinical interventions, Fundació Clínic Barcelona in developing training programmes and University Medical Centre Hamburg-Eppendorf in mental disorders. Alcohol problems and depression often go together. The project partners based in Latin America provide local expertise.

In addition to facilitating knowledge sharing, this international collaboration opened up the possibility of receiving European funding. SCALA already received funding from Horizon 2020. 'A project carried out by a consortium like this is more likely to receive funding', explains Kokole. 'One condition for these kinds of projects is that you have to know your partners, know they are reliable and know you can work together with them.'

Global research

SCALA is a wonderful example of a project in which global research is relevant at the local level. 'This shows from the way our project is organised', says Solovei. 'It was prepared through international cooperation and then implemented locally in city districts. But the lessons learnt locally can later be applied in different contexts.'

The social importance of SCALA is obvious. 'At its core, the project is about creating connections within a community', says Solovei. 'We want to gain insight into processes to involve the community in the interventions.' Ultimately, the goal of the project is to successfully scale up the interventions to a national level. Kokole adds, 'If this health care intervention succeeds - taking contextual, local and cultural adjustments into account - it should theoretically work anywhere'.

Involved partners

Cayetano Heredia Peruvian University, Peru
Corporación Nuevos Rumbos, Columbia
Fundació Privada Clínic per a la Recerca Biomèdica, Spain
Fundación ESADE (ESADE) Spain
Nat. Institute of Psychiatry, Ramon de la Fuente Muniz, Mexico
Newcastle University, UK
Universitaetsklinikum Hamburg-Eppendorf, Germany
Technische Universitaet Dresden, Germany

Our most important output for societal target groups

SCALA Implementation framework

The main output of the SCALA project is the SCALA Implementation framework, which is freely available on the SCALA project website: www.scalaproject.eu. SCALA framework¹ This framework can be used to guide the implementation of health programmes in various regions of the world, being relevant to e.g., program directors and managers working in primary health care centres and municipal health departments; professional groups supporting primary health care providers; and, primary health care providers themselves who are active in their communities to help decrease heavy drinking and the harm done by alcohol.

SCALA training package

Moreover, in SCALA a training package (in Spanish) was developed, which implementable in the three participating countries and beyond. This training package is freely available on the SCALA project website and can be used for training health care providers on the topic of providing alcohol screening and brief advice to their patients. <u>SCALA training package²</u>

Communication campaign materials

Also, communication campaign materials that have been developed in the three participating countries on the topic of alcohol screening and brief advice (e.g., posters, leaflets, videos) are freely available on the SCALA website. Project outputs (scalaproject.eu)³

Youtube videos

Five video focusing on the most important research outcomes of SCALA can be seen on the project YouTube channel:

- The SCALA Study tailoring a primary health care programme for alcohol and co-morbid depression
- <u>Tailoring the SCALA programme to local contexts in Peru,</u> <u>Colombia and Mexico</u>
- The SCALA Project in Latin America Experiences, challenges and lessons from Peru, Colombia and Mexico
- The SCALA Project Outcomes Can we improve alcohol and depression measurement in primary health care?
- <u>The Economic Outcomes Is it worth investing in alcohol</u> <u>measurement in primary health care?</u>

Research Line Specific Case Studies: Promoting Health and Personalised Care (PHPC) | Case study 2

Cordis

The results of SCALA, have been disseminated on CORDIS - a website of the European Commission focusing on dissemination of EU funded research.

Regional Health Office Peru

In Peru, the Regional Health Office disseminated several communication materials developed in SCALA on their website and social media channels (examples of the disseminated videos are included in the links below): www.diresacallao.gob.pe/wdiresa/documentos/extras/FILE0008312021.pdf

www.diresacallao.gob.pe/wdiresa/documentos/extras/ FILE0008352021.pdf

www.diresacallao.gob.pe/wdiresa/documentos/extras/ FILE0008362021.pdf

 $\frac{www.diresacallao.gob.pe/wdiresa/documentos/extras/}{FILE0008372021.pdf}$

www.diresacallao.gob.pe/wdiresa/portal/contenido/15/

Our most important scientific output

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² https://ec.europa.eu/research/participants/documents/downloadPublic?documentIds=0801664515433483&appld=PPGMS

³ https://www.scalaproject.eu/index.php/project-outputs

Case study 3: Shared Decision-Making benefits all patients

Studies on the implementation of a communication process

Doctors and patients making treatment decisions together benefits patients as well as the healthcare system in general. CAPHRI PhD candidates Ruben Sars and Romy Richter are convinced of this. They are both conducting research aimed at improving and implementing this communication process, called Shared Decision-Making. Their focus is on people with low health literacy. "There's still a lot of progress to be made in that area", says Ruben.

People with low health literacy are not a homogeneous group, the PhD candidates explain together. Having difficulty with reading and writing may be a reason, as well as having a migration background or a low socio-economic status. "About 28 per cent of the Dutch population has low health literacy. And almost half of the population has low to average health literacy", says Ruben. But what does that mean in practice? "The idea is that you understand what your doctor is telling you and properly understand medical information. This group of people struggles with that. They also find it difficult to make active choices for their own health and often don't dare to ask questions", explains Romy. During her research master's in Health Sciences in Maastricht, she already did research on shared decision-making, which she has continued as a PhD candidate. Her PhD research consists of two projects, one of which is funded by ZonMw.



The ZonMw project revolves around a Shared Decision-Making process in which doctors and patients first discuss treatment options together. They also discuss the advantages and disadvantages of these options (and, finally, they discuss what matters most to the patient; this is what Romy's second project focuses on). In addition to a literature review and an analysis of Dutch decision aids, the study involves focus groups consisting of doctors, patients and experts. For this part, Romy is collaborating with the Netherlands Institute for Health Services Research (Nivel), the Dutch Centre of Expertise on Health Disparities (Pharos) and the Netherlands Patients Federation. "The research is still in progress, but it's clear that Dutch health care is still sometimes paternalistic. We often see that doctors think they're doing a good job, while the patients in the focus group feel differently. We've also found that patients often understand well-explained information better than doctors expect", says Romy.



Ruben Sars



Effective strategies to better involve patients with multimorbidity and limited health literacy in decision-making in general practice

Period: 2022-2026

Funding: ZonMw (Kennisprogramma Huisartsgeneeskunde) Project website: https://projecten.zonmw.nl/nl/project/ effective-strategies-better-involve-patientsmultimorbidity-and-limited-health-literacy

General practice

That's also Ruben's experience. "Patients' wishes are not always taken into account", he says. Ruben trained as a neuropsychologist and was working as a researcher at the Amsterdam University Medical Centre when his eye fell on this vacancy at CAPHRI. "I had previously worked in Leiden, where I did a lot of research with patient populations. That's why this PhD research appealed to me. My focus is specifically on people with low health literacy who have multiple health conditions (multimorbidity). Shared Decision-Making is very important for them. What are the effects of the different treatments, for example, and which treatment should be prioritised? How can their quality of life be improved?"

Ruben's research focuses on general practice, where an average of two-thirds of patients who come in for consultations have multiple health conditions. Various organisations are participating in the study, including Nivel, the Netherlands Patients Federation, the Dutch College of General Practitioners (NHG), health insurance company CZ and twenty general practices in Maastricht and Amsterdam.

Research Line Specific Case Studies: Promoting Health and Personalised Care (PHPC) | Case study 3

Current situation

Ruben began his research in February of this year. The first step is to assess the current situation in the twenty participating practices by observing consultations. Next, he will conduct focus groups with general practitioners, patients and academics. "Shared Decision-Making is usually about hospital care. This study wants to co-create a solid Shared Decision-Making intervention for general practice with all stakeholders. We also have a patient panel that will represent the target population throughout the study. This way, the people it's about can discuss what is going well and what isn't. After that, we want to test the intervention we've developed together in practice. In hospital care, this often involves an e-learning course, but we have yet to decide what to do for our intervention", says Ruben.

What is certain is that shared decision-making can be promoted by presenting information in a simple way, also by using illustrations. "Simple is better", agree Ruben and Romy. Finally, they emphasise that Shared Decision-Making comes with better patient compliance and fewer unwanted/unnecessary treatments. And that, they say, will not just benefit patients with low health literacy, but all patients.



Romy Richter

Project: Involving all patients in decision-making. How to improve 'option talk' and risk communication in general practice for patients with limited health literacy?

Period: 2021-2022

Funding: ZonMw (Kennisprogramma Huisartsgeneeskunde) Project website https://projecten.zonmw.nl/nl/project/ https://projecten.zonmw.nl/nl/project/ https://projecten.zonmw.nl/nl/project/ https://projecten.zonmw.nl/nl/project/ https://projecten.zonmw.nl/nl/project/ https://projecten.zonmw.nl/nl/project/ https://projecten.zonmunication https://projecten.zonmunication <a href="mailto:involving-all-patients-decision-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-talk-and-risk-communication-making-how-improve-option-making-how-improve-option-making-how-improve-option-making-how-improve-option-making-how-improve-option-making-how-improve-option-making-how-improve-option

Project: Improving patient-centered care in oncology, an implementation study of a conversation tool.

Period: january 2021- April 2023 Funding: Citrienfonds

More information (in Dutch) https://oncologienetwerken.nl/nieuws/artikel/de-kijker-gesprekshulp-optool

Involved partners and collaborations

Project: Effective strategies to better involve patients with multimorbidity and limited health literacy in decisionmaking in general practice

20 general practices in Maastricht and Amsterdam. CZ: Health insurance company NHG: Dutch College of General Practitioners Nivel: Netherlands Institute for Health Services Research Patiëntenfederatie Nederland: Netherlands Patients Federation

Project: Involving all patients in decision-making. How to improve 'option talk' and risk communication in general practice for patients with limited health literacy?

Nivel: Netherlands Institute for Health Services Research Patiëntenfederatie Nederland: Netherlands Patients Federation

Pharos: Dutch Centre of Expertise on Health Disparities

Publications

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Colophon

Text: Karin Burhenne, Hans van Vinkeveen, Margo van Vlierden, Eline Dekker Translation: Emdash, Maud Bovelander Photo Training Connecting Conversations: Harry Heuts Graphic design: Emilio Perez







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