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‚We need the structured rec ding of patient experiences‘

For many years, Prof. Dr. med. Max Geraedts, M. San., Head of the Institute for Health Services Research and Clinical Epidemiology of the Department of Medicine at the Philipps University of Marburg, has been conducting quality and patient safety-related health services research in the outpatient, inpatient and nursing sectors on the basis of primary and secondary data - primarily with the support of ministries, BMBF and with the help of the Innovation Fund. As an experienced researcher, he knows exactly what is possible on the one hand, but what would be possible on the other, if the necessary data were available. Monitor Versorgungsforschung‘ spoke with Prof. Geraedts, the congress president of the 22nd DKVF, about what the scientific community can expect from 4 to 6 October 2023.

Interview: Prof. Dr. med. Max Geraedts, M. San., Head of the Institute for Health Services Research and Clinical Epidemiology of the Department of Medicine at Philipps University Marburg

>> As congress president, you played a major role in determining the motto of this year's German Congress for Health Services Research, which is: ‚Health-related health services research - engine of evidence-based health policy'. There is either a question mark missing or the concrete classification of whether this statement is a postulate or a vision?

„Only with reported patient experiences will we be able to make healthcare even better.‘

Our motto is a postulate, but at the same time also a task for all health services researchers. What health services research can achieve can be seen very recently and very closely in the work of the government commission for hospital reform. Their work includes various studies from the field of health services research, which form the basis for their recommendations. Of course, there are always headwinds in the attempt to establish a health policy that is as evidence-based as possible, because there are simply too many and often very contradictory fields of interest colliding here. For me, however, the path in health policy is marked out from eminence-based to evidence-based. This is exactly what we as health services researchers want to do and can already do to some extent, but where we will certainly have to do much more in the future.

If only sufficient health data were available.

That's the way it is. We know that much of the data, which has often been available for a long time and with which we could further advance health research, cannot yet be used in the form that would actually be necessary to enable evidence-based health policy. This does not mean, however, that health services research is not already a motor of health policy, but that it wants to be even stronger in the future. However, this requires the necessary basis of existing data, coupled with the consistent utilisation of new data sources.

Which data streams do you have in mind above all?

The link between register and billing data from the health insurance funds is one thing. A huge data source that we still largely lack in Germany is a structured collection of patient experiences and patient-reported outcomes, commonly referred to as PRO and PRE. Since we actually lack the patient perspective for the most part in this country, it cannot be incorporated into health services research, thus into health policy and ultimately into health care. However, if we not only want to call this patient-centred, but also really want to consistently orient it accordingly, we need new access to data here.

Do we need a kind of structured, patient-centred Germany sample for the overall health system?

We would need a health care panel that surveys patients' experiences with health care on a longitudinal basis. We also need such a panel that would be informative for the whole of Germany and across regions; and - if you want to be precise - right down to municipal care. Then health services researchers could analyse exactly where something is going particularly well or badly, or where there are best practice approaches that could then be scaled up as quickly as possible - given the available evidence and depending on the local conditions.

If you then also had a description of the actual state before an intervention or change in the law ...

... we would be able to track the effects of innovations and the influence of health policy on real health care much better over time and - in the case of possible undesirable developments, for example in the case of misdirection - warn much earlier.

Here again, patient experience would help.

Even more so. What is the use, for example, of assessing structural or process innovations only in terms of mortality rates, when the experiences and results reported by patients in most areas of care would be much better and faster indicators that could be used to fine-tune or even redirect systems that are threatening to get out of hand? However, this does not only concern the care of sick people, but virtually the entire life cycle from birth to death. Only with reported patient experiences will we be in a position to design health care even better.

Is there any experience of this from abroad?

All Anglo-Saxon countries, but also the Dutch and the Danes are already much further ahead than we are. Even though I am surprised that the Americans are partly satisfied with small samples in their state-funded programmes, while the British can fall back on very large surveys of patient experience as part of their quality management, which they then also use to design their health care systems. What comes out in the end is another matter.

In other countries, there are citizens' parliaments and co-decision rights that are still denied to patients here - keyword G-BA. Probably the stakeholders of the system do not want the patients to have a say?

After all, the patient representation in the Federal Joint Committee has been given the right to participate, but a change could well take place in this legislative period so that it becomes a right of co-determination.

Let us not give up hope.

A right of co-determination in the G-BA would certainly be helpful, but it would be far from sufficient: patient participation at this level is no substitute for a structured collection of patient experiences, which unfortunately does not yet exist.

Perhaps we should suggest this together.

In the course of the further development of quality assurance and quality management in the German health system, this should definitely be part of the list of demands.

You just mentioned the work of the government commission for modern and needs-oriented hospital care. When one looks at the draft bill that emerged from this and the political discussions about the coming law on all-German hospital planning, one gets the following impression, as is so often the case: Politicians always pick out from a bundle of studies only those findings that fit into their own agenda or for a minimum consensus, but are miles away from what could satisfy the researchers who have put a lot of heart and soul into the studies.

‚Beyond classical research funding, we need translational funding.‘

We live in a democracy where all voices count. The health services research community can make its contribution to providing the best possible evidence base for sensible health policy decisions. The fact that these are not implemented one hundred percent and 1:1 in the political process is due to the fact that there are many other interests that all want to be represented. Our health care system is developing in an evolutionary rather than a revolutionary way, and perhaps it is sometimes a good thing if innovations are tested for a while before they are introduced on a broad scale.

Let's use an example to illustrate this.

If, for example, in one region or in one municipal setting it is found that a certain care innovation works well, that does not mean that it works everywhere. Moreover, replicating results that come to light in research studies in other settings is anything but trivial. That's why we need translational funding beyond traditional research funding, which would enable us to investigate scalability and the parameters needed to achieve it. This does not mean, however, that at some point almost all the results of health services research can be transferred to real health services, because political consideration processes and social or local circumstances simply run counter to this.

Recently, 15-year data on GP-centred care in Baden-Württemberg were presented at a press conference in Berlin - with impressive results (see MVF 03/23). How much science does it take before a health care innovation that has shown that it works becomes standard care? Or: When is evident enough?

The results presented by Gerlach and Szecsenyi are impressive and should really convince political decision-makers that it is necessary to redesign our health care system in this direction. Unfortunately, there seems to be resistance from some actors in self-administration in particular, which leads to the evidence being simply ignored. Because this is the case, a courageous decision is now needed on the part of politics, since it should not depend on where one lives how good health care is, when - bearing in mind all local structures - it could be better. But this cannot be blamed on the researchers, who present the results of their hard work with many scientific contributions, at congresses and press conferences, but are dependent on what self-government and ultimately politics make of it.

Where is the lobby for health services researchers?

In my opinion, we don't have an established lobby.

Perhaps health services research should be more courageous in pointing out shortcomings?

I can agree with that, if it takes place within the framework of proper science communication, which leads to the results of health services research being made clearer and, at best, leading to activities that in turn lead to better health services. At our Institute, for example, we conducted a study on patient safety in outpatient care funded by the Innovation Fund and published it internationally at the beginning of the pandemic. A positive recommendation by the G-BA then also encouraged the representatives of some of the banks to take note of the result.

Have they?

So far they have not. And this despite the fact that in this study (1), in which more than 10,000 German citizens over 40 years of age were surveyed, it was reported that they had experienced at least one patient safety-relevant event in the outpatient sector within the last year. We were able to show that, extrapolated, there are about two and a half million hospitalisations due to patient safety events in the outpatient sector every year. Nevertheless, our results have not had any political impact that would have led to a much stronger implementation of error management in the outpatient sector. Sure, you can blame this on Corona because our study results were either not published in the right place or simply at the wrong time, but I can't quite believe that.

Wouldn't you have to take a look at your own nose and demand that the German Network for Health Services Research, of which you are a board member, does much more science communication than it has done so far?

That is certainly an important point. We have set up a working group on this in the DNVF, but we do all this work on a voluntary basis. We need communication professionals to disseminate the many health services research results that my colleagues and I constantly produce in such a way that they are received and understood - adequately prepared for politics, society and, above all, the public media.

And in a language that is as easy as possible for all those mentioned?

You say something there. The information for patients and all German citizens in general should be made available in easy language. Until now, it was assumed in the USA, for example, that the appropriate language level was that of the eighth grade. Today, researchers in the USA estimate that the sixth grade level is more appropriate if one wants to reach as many people as possible, whether it is health information and patient guidelines or other information that is important for life in an understandable form.

But this is a task for which scientists are not trained at all.

We can't do it because we don't learn it. I hope that artificial intelligence will help us here. It can already shorten an 800-word abstract to 500, for example, without changing the context to any great extent. The same will certainly soon be possible with easy language.

Now we will soon go to the Congress, which you preside over as

President. This has been divided into three strands, firstly the description of the reality of care, secondly the evaluations and thirdly the translation. Let's go into the individual strands in more detail.

Of course, we know how many submissions there are for the different strands. The first strand, which is about the description and analysis of current health care, accounts for the majority of the submissions with 290 contributions out of more than 600. The second strand, which focuses on the evaluation of health care outcomes, and the third strand, which deals with the implementation of positively evaluated health care innovations in routine health care, account for about 60 and 140 contributions, respectively. In addition, there are about 120 on the topic of the further development of methods.

The bulk of the contributions deal with the question: Who provides care to whom, when and with what? And: How and why is care provided?

Correct. Because the description and analysis of health care is, in my opinion, an absolute focus of our activities and actions.

Although it is all too often said that we already know everything and only have an implementation problem.

We still have both a knowledge and an implementation deficit, whereby I believe that - the longer I deal with the matter - we do not know a great many things.

One detail?

That all want to be represented. Our health care system is developing in an evolutionary rather than a revolutionary way, and perhaps it is sometimes a good thing if innovations are tested for a while before they are introduced on a broad scale.

Let's use an example to illustrate this.

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Prof. Dr. med. Max Geraedts, M. San.

has been head of the Institute for Health Services Research and Clinical Epidemiology of the Department of Medicine at PhilippsUniversity Marburg since 2016 .He previously held the Chair of Health Systems Research at the University of Witten/ Herdecke (from 2009) and a professorship for Public Health at the University of Düsseldorf (from 2000) .After studying medicine and public healthand completing a DFG research fellowshipat the Institute for Health Policy Studies at UCSF and a postdoctoral fellowship in health services research there ,his research focus was consolidated inthe area of quality assessment and evaluation of health policy measures .He hasbeen advising the partners of self-administration on questions of quality assurance and evaluation for many years and is a member of the scientific advisory board of the IQTIG .Prof. Geraedts has been a board member of the DNVFsince 2018.

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Which was also caused by not collecting the necessary data at the right time, which should have been collected in order to be able to draw proper conclusions.

Which is what the German Network for Health Services Research has been calling for almost since the beginning of the pandemic. We have repeatedly pointed out how important it would be to carry out accompanying evaluations and, above all, which data are necessary for this. We have tried to actively influence politics, but have not been heard. That is why we now have these deficits in knowledge. This is true not only for Corona, but also for many other areas of the health care system. I have just come from the US-American Health Services Research Congress in Seattle, where one of the main topics is the influence of social determinants on health care. In Germany - despite the established congress ‚Poverty and Health' - we are still at the very beginning of taking these determinants into account in health care and researching them, although important topics such as access equity and health literacy have an enormous amount to do with social factors.

Or simply gender or age.

Exactly. Our institute, for example, con-

ducted a study (2), funded by the Innovation Fund, in the stroke field and found out that older people and women in Germany have less access to good care than younger people and men. At the same time, we were able to show that women and older people benefit just as much from appropriate treatment - especially in centres with stroke units. What we don ,t know yet is why these differences exist in the first place. There is still a lot of research to be done.

To stay with this example: What would have to be done to help this group, which seems to be underrepresented in stroke units, to get better care?

Quite simply: equal access for all, regardless of age and gender. And if you want to take it even further: regardless of social background and class. Above all, however, we need to sensitise those involved in care - from relatives to staff in care facilities, from emergency services to the medical profession - to the fact that although older people naturally have less chance of surviving a stroke, they can benefit just as much from excellent and guideline-based care in specialised facilities.

When Federal Health Minister Lauterbach is finished with his hospital reform, there will perhaps be 20 to 30 percent fewer hospitals and hopefully it will be precisely those that have already delivered insufficient quality.

Complex treatments simply cannot be guaranteed in facilities that are too small to treat enough cases to build up the necessary experience, or that simply lack the necessary equipment. However, this is common knowledge and has long been evidently proven; no new studies are needed for this.

In the second strand, the DKVF is primarily concerned with the evaluation of health care outcomes.

And here we come back to the topic of systematic recording of patient-reported outcomes and experiences. Here, too, there is a great lack of knowledge, because up to now we have judged care innovations according to whether they can influence morbidity and mortality in a clinically relevant way. This leaves out important parameters such as quality of life, social participation or functionality after care. What good is it to know what the mortality rate is for a knee arthroplasty, which - let's say - will be 2 in 100,000, but we don't record mobility, freedom from pain and other functional and social long-term factors as well as post-hospital complication rates and re-hospitalisations. Because we don't, something may be going wrong somewhere in the care chain, but we don't know that - and consequently we can't counteract it.

Here, our demand could be that everyone who has been discharged from a hospital is enrolled in a study that clarifies the real outcome after one or two years.

I believe that it will be necessary to carry out exactly this kind of outcomes research long-term studies, but not necessarily on all patients, but at least on a meaningful sample of exactly those for whom one can assume that negative long-term effects will occur. Only in this way will we be able to make profound statements about the quality of care across different care settings and their organisations or forms.

Accordingly, a kind of Germany cohort real care.

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A national cohort for experiences and long-term results of health care, which would have a different focus than the existing cohorts, which are mainly indication-driven. Something similar existed from 2001 with the Bertelsmann Foundation's Health Monitor, which unfortunately ended in 2016, but which could be reactivated. If we could do that in the next few years, I would be very happy, because you can really improve care with that.

Then let us also work on it!

That's what we should do. For example, in the German Network for Health Services Research we have launched a working group for regional health monitoring - such a real health care cohort would fit in well.

Now the second strand is about the question of which factors are particularly effective or significant for achieving the goals. This is something we have already addressed in the recommendations of the G-BA, which do not lead to visible results.

Here, too, health services research has to learn. The nature of such recommendations depends not only on political opinion-forming, but also on whether the accompanying process evaluation was meaningful enough. If an evaluation shows that certain results could be achieved by an intervention of whatever kind, but it is not clearly worked out and described in a generally comprehensible way what the driving attributive factors were, this points to a shortcoming in the study implementation. I know that this is anything but trivial in complex evaluations, but in my opinion, every evaluation of new forms of care funded by the Innovation Fund should include this. If this were done, the subsequent part of the transformation or translation into standard care would also be somewhat easier to manage. Somewhat, because other factors, especially contextual factors, also play a role.

And separate funding would also be necessary.

Of course. If you want translation, you have to create sufficient transitional funding to enable the process of moving from the project to mainstream care. Otherwise, there is a danger that the knowledge built up will simply be lost after the project ends.

In a very clever way, we have already arrived at the third strand of the upcoming DKVF, which deals with the implementation of positively evaluated care innovations in routine care.

One of the main questions to be answered here is which barriers stand in the way of implementing care innovations. In order to approach this question, first of all, a better availability of data is necessary. <<

Professor Geraedts, thank you for the interview.

The interview was conducted by MVF editor-in-chief Peter Stegmaier

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