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Introduction

The issue of "Zeszyty Naukowe Ochrony Zdrowia. Zdrowie Publiczne i Zarządzanie" ("Scientific Issues of Health Protection. Public Health and Governance") you are reading is devoted to the problems of information and communication in health care. Both lines of research are very important for the quality of health care, effective measures in the area of disease prevention, organizational solutions, in fact – for everything we do in the health care sector. Without good distribution and effective dissemination of research results and other kinds of data, as well as without efficient communication between professionals and patients, scientific achievements, our knowledge, and even the best ideas can remain unknown, unused forever. We all know how significant that is, but still there are not enough investigations in this field, even fewer implementations, despite the fact that so much is being told about the information era, knowledge society, and evidence-based decision making.

So many basic questions arise. Why do specialists in public health institutions in Poland do not have free access to the only (and publicly financed) database of scientific publications in our field, Polish Medline – Polish Medical Bibliography? Medical professionals can use PubMed, but what about health promotors, health managers, health economists who often need research data to be well-grounded in local reality? Do we know what sources of information they use, how they cope with its lack, what barriers they encounter?

Why the specialized libraries operating in Polish hospitals until the 1990s, have never been re-established according to contemporary standards? A remark that "something like this" should be in a hospital, brings a smile of disbelief to the participants of the continuing education course in Health Care Institutions Management, who usually know the realities of such institutions all too well. After all, we expect evidence-based treatment, evidence-based procedures, and our doctors and nurses to have reliable and up-to-date knowledge.

To find and to use the existing evidence we need developments, tools and intermediaries. Anybody who has attempted to glean layers of research, sometimes looking for information in vain, knows what I mean. Often we get discouraged and settle for what we have found via Google, and which can turn out to be well-positioned promotional information, not necessarily the best, most appropriate or reliable. And definitely incomplete. Do we have the skills necessary to search for, evaluate and adjust information to our real needs? That is why we need intermediaries – health information specialists, information brokers, and scientific information processing and dissemination infrastructure. In Poland we have an institution whose goal is to provide research information for the needs of health policy making – The Agency for Health Technology Assessment and Tariff System, we have a budding Cochrane Collaboration centre at the Jagiellonian University Medical College – is this enough? Surely not.

Another problem is that although much is said about the low level of health literacy of our society and the bad consequences of self-treatment, do we ask ourselves what we are doing in order for our citizens to reach sources of good, up-to-date and trustful knowledge about health and treatment? Do we have a publicly available, obvious to everyone, website which provide basic, one-hundred percent reliable health information? There is no such source of information, although it would certainly bring tangible benefits both for the health of our society and the health care budget, and possibly would contribute to improving citizens' health competency.

Let us lose ourselves in the world of fantasy for a moment. Let us imagine that in our hospitals doctors and nurses have the time and space to access research evidence during their work hours, on site, and, in case of doubt, they can count on the assistance of an information science specialist, who will provide them with necessary publications/data and supply it to their desk; that they have such desks, that we have institutions which process and disseminate scientific data, just like the British York Centre for Reviews and Dissemination; that we have scientific journals addressed not to scientists but to practitioners; that before we withdraw sweet buns from school cafeterias we study recommendations developed by scientists, saying how we effectively change nutrition behaviour of children; that our decision-makers, before they implement a specific solution they will read a systematic review of research or natural experiments, and on this basis they will choose the optimal solution, etc. It would be nice, wouldn't it? Is it possible? Yes. But, under the condition that we study and learn about information needs, that we facilitate access to selected high-quality and easy-to-use knowledge, that we raise information skills and communication skills, that we establish institutions which process scientific information and that we educate health information professionals the way they are educated in many countries.

Dear Readers, please forgive me that this introduction is more of a list of deficiencies, complaints and dreams rather than an overview of accomplishments. But that is the reality. However, I do hope that research in the area of information processing, its dissemination and use will flourish. I also hope that those who need information will exert more pressure and insist that more effort be put into changing this rather unsatisfactory state of affairs.

In this issue you will find articles reporting specific research and analyses in the area of scientific information dissemination, communication or computerization in health care. I am certain there will be more to come!

Barbara Niedźwiedzka

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Moving Beyond Effectiveness: On Evidence Based Health Information (EBHI) as a Complex Intervention

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Abstract

Over twenty years evidence based practice has become established as a dominant frame of evaluation within health services management and public health. Its influence extends to all aspects of information and communication. Evidence Based Health Information (EBHI) seeks to get the best available evidence used by patients, clinicians, managers and policy makers and to use evidence based methods to communicate them. Increasingly the public health community is shifting its collective attention to so-called complex interventions, from 'what works' to 'what works for whom under what circumstances'. The author briefly reviews the background to these developments before giving examples of the practical value of this wide lens approach. The author uses a recent case study to illustrate how health service managers and public health decision makers can benefit practically from recommendations produced as a result of using a complex interventions based approach.

Key words: evidence based public health, logic models, realist synthesis, systematic reviews, literature searching

Słowa kluczowe: zdrowie publiczne oparte na dowodach naukowych, modele logiczne, synteza realistyczna, przegląd systematyczny

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Introduction

More than twenty years ago the phrase 'evidence based public health' entered the world's vocabulary. While many might argue exactly when this occurred and who was the first to use this new phrase, we can reconstruct two starting points. Retracing our steps teaches us much about our contemporary world of decision-making and how this impacts on our day-to-day practice. One of our two starting points derives from research, the other from the medical community.

Type the phrase 'evidence based public health' into the PubMed MEDLINE database and the earliest bibliographic reference originates from 1996, *Hand searching the Journal of Epidemiology and Community Health as part of the Cochrane Collaboration* [1]. The article describes the efforts of two public health practitioners to identify the evidence base for effective treatments and policies so that policy makers could make effective decisions. The two authors painstakingly combed through every single printed issue of one of the key public health journals from 1947 to 1994 looking for reports of randomised controlled trials. This salvage operation sought trials that had previously been missed on the MEDLINE database. Having eluded the 'dragnet' of National Library of Medicine indexing these studies were carefully fished out one by one by two investigators armed with a 'fishing rod'. Thirty one previously unidentified trials were found by the pair of authors; eight that predated MEDLINE (i.e. pre-1966) and 23 not retrieved from a literature search even though they were included on the MEDLINE database.

What can we learn from this nostalgic journey? Three lessons come to mind. First, this activity was conducted 'as part of the Cochrane Collaboration' [1]. Over the last twenty years this international network of volunteers has

transformed evidence production, championing the methods and achievements of systematic reviews. Second, the trials were identified to populate the Cochrane Library, the world's largest database of controlled trials. The 82 trials found by the two authors in 22 hours of searching 48 volumes of the journal from cover to cover add to what are now 887,455 trials on the Cochrane Library to benefit the international health community. Finally, the fact that only 51 of 74 trials (69%) were retrieved from MEDLINE even though they were known to be on the database emphasises the key role played by skills in finding the evidence. In short these lessons focus on the evidence producer end of the production line.

Type the phrase 'evidence based public health' into Google Scholar, the academic full-text search engine, and a handful of the results date back even further – to 1994. 1994 was a key date for evidence based medicine in the United Kingdom. In that year Professor David Sackett came to Oxford to set up the Centre for Evidence Based Medicine. Appropriately the first result is a brief tutorial in the British Medical Journal (BMJ) by David Sackett, entitled Understanding Clinical Trials [2]. He describes how the randomised controlled trial has 'revolutionised how we decide whether a treatment or intervention does more good than harm'. He then describes trials as a cornerstone. not only for evidence based medicine but also 'for evidence based public health, evidence based hospital administration, evidence based purchasing, and evidence based consumerism' [2].

What can we learn from our second nostalgic trip? Three further lessons come to mind. First, as with the article from "Journal of Epidemiology and Community Health", Sackett links trials with decision-making. Rather than being a remote and detached academic exercise evidence based practice is about making decisions, making changes that matter. Whether these changes affect an individual patient, a population, a health service or a jurisdiction – evidence based practice is about making a difference. If we don't want to practice evidence based public health then we don't want to make a difference – to people's health, their quality of life or even in saving their lives.

Second, Sackett's paper highlights that it is important to be able to read a research study critically. Sackett points out that presenting research results as relative, not absolute, measures makes treatments seem more effective than they actually are. Of course relative results are what pharmaceutical companies use to make their treatments seem better [3]. Sackett advocates use of 'the number needed to treat' a more meaningful metric for any decision-maker. As a member of the Evidence Based Medicine Working Group, based in McMaster University Canada, Sackett contributed to a series of Users' Guides to the Medical Literature designed to help a busy health practitioner or manager to make rapid sense of a published research study and how it informs their practice. These User Guides were originally published in JAMA – the Journal of the American Medical Association – and fundamentally remain the basis for most contemporary published checklists on how to read a paper [4].

Finally, although David Sackett did himself contribute to the systematic review movement, as a founding member of the Cochrane Collaboration and its first Chair, he focused on the consumer (i.e. patient, clinician, manager, and policy maker) end of the evidence production line. His Centre for Evidence Based Medicine in Oxford was set up to spearhead attempts to get research evidence into practice.

What about the remaining items retrieved by this Google Scholar search? One letter, again from the BMJ in 1994, illustrates how dramatically evidence based public health shook the existing paradigm and polarised debate. This letter, entitled 'Evidence Based Public Health' counterposes 'objective measures of health gain, efficiency, and effectiveness' against professional judgement [5]. In support of his defence the author cites Britain's Lord Kelvin's observation: 'until you have measured it, you don't know what you are talking about'. I am reminded of the comment by Professor Sir John Muir Gray, the person who lured David Sackett to Oxford, that evidence based practice must never lose its ability to stimulate and to irritate!

These complementary streams hold personal meaning – in 1995, I attended the first UK Evidence Based Medicine Workshop at the Centre for Evidence Based Medicine in Oxford. Lacking a medical specialty, such as paediatrics or emergency medicine, I was thrown among a heterogeneous group of those working in public health and health management. In 1996, I attended my first Cochrane Colloquium in Adelaide, Australia the start of a more than twenty-year association that continues to this day. Subsequently I have been involved in both producing evidence, as a systematic reviewer, and in teaching doctors, nurses, managers, librarians and public health students how to be informed consumers in using and interpreting research evidence.

In summary what have we rediscovered? That evidence based public health is about better decisions about treatments and interventions, based on high quality trials and systematic reviews [6]. It is supported by key skills of searching for, and critically appraising, the literature. It seeks to engage at both the producer and consumer ends of the evidence production chain And if evidence based practice doesn't stimulate you it should at least irritate you [7]. How do we take these reminders forward into our own day to day decision-making?

Evidence Based Health Information

While evidence based public health can be considered the 'envelope' the message itself takes the form of Evidence Based Health Information (EBHI). If we want to make a reliable and appropriate decision we need to be informed on the best course of action in our particular circumstances. Evidence Based Health Information (EBHI) seeks to get the best available evidence used by patients, clinicians, managers and policy makers and to use evidence based methods to communicate this evidence [8].

As a busy decision maker, whether clinician, manager or policy maker, you require information that is reliable

and that is easy to comprehend and action. Reliable public health information rests on four pillars of information quality – we use the abbreviation CART (Completeness, Accuracy, Relevance, Timeliness) to remember them [9].

First comes Completeness – to make a reliable decision, we need to be sure that we have the full picture. If any part of the picture is missing, then at best the information is inadequate, but at least we can identify what is missing. At worst, however, the information is not only incomplete it is also biased. Not only are we now less likely to make a right decision we are also more likely to make a wrong one. Importantly the presence of bias means not only can we not trust the information as reliable but we don't know how much of an effect the bias is exerting – we do not know exactly how wrong the information is going to be. Suppose, for example, a decision maker is planning to introduce a healthy eating policy and an enthusiastic nutrition expert provides several papers that show how the policy has worked. If they do not also submit papers that show when the policy does *not* work this selective evidence would create a worryingly high expectation of success. We would not know how many times the policy would fail. Suppressing information on the failures would also deny us important contextual detail on when and under what circumstances the policy does not work. The same is equally true for studies of patients, operations, or managerial decisions. If we do not have all the information we require then the next best alternative is to have a very clear picture of what information is missing.

Next comes Accuracy – to make a reliable decision we need to be confident that the information that we have is a reasonable representation of the truth. A precise result that is later revealed as wrong might lead us confidently to make the wrong decision. We would rather have an approximate answer bounded by estimates of the best possible result and the worst possible result. We could then be reasonably confident that the actual true result lies somewhere between the two. If the best possible result and the worst possible result are both beneficial we can be confident that we are making the right decision. Furthermore, the closer the two results are to one another the more confident we become. Suppose, for example, that multiple studies consistently show a particular immunization programme to have a success rate of between 70% and 80% we can be reasonably confident that the result for a similar programme in our locality, all other factors being equal, lies within this same range. Furthermore, we can calculate the cost-benefit ratio for both the best case and the worst case and decide whether we can afford to implement the programme.

Third, comes Relevance – to make a reliable decision we need to be confident that the information that we have is appropriate to the context in which we plan to use it. Of course, this is a very subjective decision. Typically, we can either argue that two contexts are similar or, equally, that the same two contexts are different. Suppose, for example, we compare Poland and the Czech Republic – an outsider might reason that these countries lie in close geographical proximity so their context is similar. Alternatively, you might bring to bear detailed knowledge of differences in the population, the culture or the health systems of Poland and the Czech Republic and conclude that these contexts are very different. In our international project on the transferability of research findings [10] we observed that in a relatively 'uncontrolled' environment, such as lay health workers working in the communities of low and middle income countries [11], differences in context are likely to be very important. In contrast, in controlled environments such as an intensive care unit [12] differences in context across health systems are likely to be less important, unless they relate to the availability of resources, such as skills, facilities, and equipment.

Finally comes Timeliness – to make a reliable decision, we must be confident that the information that we have is the most up-to-date that is available. The closer the point in time between when we make a decision and when the research was conducted the more confident we are that the situation has not changed. In the past delays in research studies getting published, delays in readers of journals or textbooks finding out about the research and delays in putting research into practice resulted in a long and slow dissemination pipeline [13]. Nowadays open access routes, plus the greater speed of the production process, lead to research being published more speedily. Even more critically the advent of the World Wide Web means that it is far easier to identify that research has been published and to gain access to research articles than under the previous paper-based system.

Why reviews?

The brief description of the CART requirements above identifies systematic reviews as a possible response to what decision makers need, and may even want. With regard to Completeness a systematic review takes precautions to ensure that the review team assembles the most complete set of studies possible to answer a particular well-defined question. As a consequence information specialists supporting a systematic review team search across a wide range of relevant databases. They also take precautions to ensure that their search strategies do not omit search terms that would miss a substantive quantity of the available literature. According to a *Dictionary of Epidemiology*, *a* systematic review is 'the application of strategies that limit bias in the assembly, critical appraisal, and synthesis of all relevant studies on *a* specific topic' [14]. A decision maker reading *a* well-conducted systematic review can therefore have *a* reasonable degree of confidence that they are viewing *a* complete picture of evidence relating to the very specific review question. This is achieved through strategies that limit the effect of bias.

In connection with Accuracy a systematic review pays careful attention to the quality of the studies that are included. Put simply a review either sets a quality hurdle so that only studies that meet or exceed this standard are included or else a review admits studies of variable quality but alerts the reader to the quality of each individual study. In some cases the review team informs the reader what the review would look like both with and without

the included studies, what is called technically a sensitivity analysis [15]. A decision maker reading a well-conducted review can therefore have a reasonable degree of confidence that the review is as close a representation of the true effect as is possible given the identified limitations of the existing research.

With reference to Relevance a systematic review seeks to ensure that it includes sufficient information for the reader to gain a picture of the context in which the original studies have been conducted. A review team extracts as much data as they consider necessary to capture the relevant context [16]. In the past quantitative systematic reviews have been criticised for essentially stripping away important contextual detail from the contributing studies. Increasing awareness of the complexity of public health interventions, together with the contribution that qualitative evidence can make to decision-making, has led to an increasing number of methods that seek to preserve this important detail. A decision maker reading a well-conducted review should be able to identify the extent to which the body of evidence, that is all the studies collectively, or individual studies included in the review, match the context for their own particular decision.

Finally, concerning Timeliness systematic reviews are conceived as 'live' documents that seek to incorporate new studies that can contribute to the review question as soon as possible after they are published. The Cochrane Collaboration originally aspirated to updating its systematic reviews on a two-yearly basis although this has proved difficult to achieve in practice [17]. As a consequence, methodologists have focused attention on methods for updating reviews and for methods of identifying which reviews need updating most urgently [18]. It is helpful to identify the 'tipping point', i.e. how many studies with how many patients are needed to overturn the existing take-home message of an existing review? If new studies appear in the literature have they included sufficient participants to make a difference? It is interesting to note that many journals, when accepting systematic reviews for publication, now require that an update search is conducted within 12 months of proposed publication. Clearly timeliness is an important characteristic. A decision maker reading a well-conducted review can therefore assess how much the findings of that review still apply to their context or whether the existing studies have been superseded. I am reminded of colleagues who spent several years conducting a randomised controlled trial only to find that, by the time of publication, the control was no longer the most valid comparator for the new treatment [19].

The role of reviews – and other evidence based products in public health

The previous section rehearses arguments for the information quality of systematic reviews. Clearly systematic reviews carry many hallmarks for high quality evidence based health information. A further important consideration relates to how this evidence based information is communicated. Notwithstanding the attraction of systematic reviews as a 'package' within which complete, accurate, relevant and timely information is bundled together, they can tend to be lengthy, dense, measured scientific studies that do not fit well to the brief windows of managerial decision-making or policy-making [20].

Fortunately, the evidence based health information movement has achieved much in attempting to steer these unwieldy juggernauts. First attention has focused on producing plain language summaries, aimed initially at members of the public but equally useful for the busy decision-maker, who seeks to gain an initial understanding of a complex technology [21]. In conjunction with plain language summaries the systematic reviews community has sought to make systematic reviews structured and navigable; just as a qualified driver can more or less get into any car and start to drive the experienced systematic reviewer encounters a common structured and easily navigable format when reading most reviews. Cochrane reviews follow a standard template whereas, more generally, systematic reviews and now even protocol documents, are required to follow standard reporting formats such as PRISMA [22], ENTREQ [23], and PRISMA-P [24]. Use of these standard formats also makes it easier to assess systematic reviews for quality and applicability as the checklists are designed around a generic review structure.

Of course an initial challenge relates to how to navigate around the evidence landscape in the first place; how does a busy decision-maker find the item of evidence upon which he can subsequently base his/her decisions? Information specialists at McMaster University have devised the 'Six S pyramid' [25], an information seeking hierarchy where you drill down through successive layers (or types) of evidence until you find an item that addresses your question. The six layers are shown in **Table I**.

Looking for evidence and appraising it for quality

When looking for evidence for a particular decision the decision-maker therefore follows a three step process. First, they clearly specify the information that they need. Next, they work their way through the pyramid drilling down until they find evidence that looks appropriate to their question. Finally, they assess that item of evidence to determine whether it is good enough (internally valid) and whether it is appropriate (externally valid) to the decision-making context.

So how does this apply in practice?

A Realistic Scenario
30% of Halfway's adults and over 20% of children (at age 10) are 'obese' – worse than national/regional averages. A task group is set up to review healthy eating among children and young people in Halfway. The Task Group wishes to start by targeting sugar-sweetened drinks, being particularly concerned at the high consumption of these drinks in the local kindergartens, primary schools and secondary schools. They ask you to lead on identifying appropriate evidence for producing a 'Sugary Drinks Policy'.

Table I. *6S Evidence Seeking Pyramid Schema*

Layer	Definition	Example
Systems	Systems integrate information from further down the hierarchy with individual patient records/population data, offering an ideal resource for decision-making.	Proprietorial decision support systems
Summaries	**Summaries** are regularly updated guidelines or textbooks that integrate evidence-based information about specific problems.	National Guideline Clearinghouse; DynaMed Plus, UptoDate
Synopses of syntheses	**Synopses of syntheses**, summarize information found in **systematic reviews**. They focus on the conclusions from products further down the hierarchy presenting only sufficient detail to support decision-making.	Cochrane Summaries; Cochrane Podcasts
Syntheses	Best known as systematic reviews, a synthesis represents a comprehensive summary of all relevant evidence for a clearly defined review question.	Cochrane Library
Synopses of single studies	**Synopses of single studies** summarize evidence from high-quality studies and are typically found in evidence-based abstract journals.	Evidence-Based Medicine ACP Journal Club
Single studies	**Studies** represent reports of unique research conducted to answer a specific question.	MEDLINE, CINAHL, PsychINFO

Source: Own elaboration based upon G. Guyatt, Users' Guides to the Medical Literature: a Manual for Evidence-Based Clinical Practice, 2nd ed., American Medical Association. Evidence-Based Medicine Working Group, McGraw-Hill Medical, New York, London 2008 [4].

Table II. *Populated 6S framework for sugar-sweetened drinks*

Layer	Reference
Systems	None Available.
Summaries	A duty on sugar-sweetened beverages. A position statement.
Synopses of syntheses	Sugar-Sweetened Beverages and Obesity among Children and Adolescents: A Review of Systematic Literature Reviews [26].
Syntheses	Evidence that a tax on sugar-sweetened beverages reduces the obesity rate: a meta-analysis [27].
Synopses of single studies	Children who consumed sugar-sweetened beverages between meals ≥4–6 times/week at 2.5–4.5 years of age were more likely to be overweight at 4.5 years of age [28].
Single studies	Grab a Cup, Fill It Up! An Intervention to Promote the Convenience of Drinking Water and Increase Student Water Consumption During School Lunch [29].

Source: Own elaboration.

A framework, such as that shown in Table II, can be populated relatively efficiently by using five principal resources:

1. **PubMed Clinical Queries** – http://www.ncbi.nlm.nih.gov/pubmed/clinical – a filtered resource offering a subset of only clinical studies and systematic reviews from the PubMed database.
2. **Cochrane Library** – http://www.cochranelibrary.com/ – premier source of references and full text reviews covering systematic reviews and controlled trials.
3. **PubMed Special (Health Service Research) Queries** – https://www.nlm.nih.gov/nichsr/hedges/search.html – a filtered resource offering a subset of only health service research studies and qualitative research studies from the PubMed database.
4. **TRIP (Turning Research Into Practice)** – https://www.tripdatabase.com/ – a meta-search engine of high quality evidence sources.
5. **SumSearch 2** – http://sumsearch.org/ – another meta-search engine that searches high quality medical sites.

Shifting the focus to complex interventions

Increasingly practitioners, policymakers, and researchers within the public health community are shifting their collective attention to the evaluation of so-called complex interventions. What is a complex intervention? The United Kingdom Medical Research Council's (MRC) guidance 'A framework for development and evaluation of RCTs for complex interventions to improve health', published in 2000 [30] and revised and extended in 2008 [31] describes complex interventions as being 'built up from a number of components, which may act both independently and inter-dependently' [30]. These components include behaviours, behaviour parameters and methods of organising those behaviours, and they may have an effect at individual patient level, organisational or service level or population level (or all of these in some cases):

> The canvas on which public health operates is broader than [clinical medicine]. It also works at the levels of individual human mind and collective social behaviour and its delivery is at community, population and societal levels. This introduces disciplines which do not have the same analytic foci as biomedicine and operate with differing epistemological precepts, different methods and produce different types of evidence [32].

Other features contributing further to this complexity include the numbers of components and their interactions, behaviours, organisational levels and outcomes, the variability of desired outcomes and the degree to which flexibility or tailoring of the intervention is permitted.

This interest in evaluation of complex interventions derives from an imperative to further develop the evidence base on the effectiveness of healthcare and public health interventions. Furthermore it marks increasing awareness that evaluation must acknowledge the challenges faced as we move along the spectrum from 'simple' towards more complex interventions [33]. This focus on complexity is also driven by ongoing debate about the most appropriate methods for evaluating health systems. Increasingly the dialogue is being framed not just in terms of whether health system interventions 'work', but also about when, why, how and in what circumstances such interventions work well [30, 31].

There is some debate about whether the complexity is a feature of the intervention, the context or the lens through which the decision problem is being viewed. Commonly observers label an intervention 'complex' purely as a negative attribute, that is not being 'simple'. However, it is challenging to define any intervention as 'simple'. Take, for example, taking a pill or tablet. Superficially, this intervention looks simple [34]. A patient takes a tablet, the tablet affects the patient's metabolism to a greater or lesser degree and in a reasonably predictable percentage of cases the tablet achieves its desired effect. In this case the causal chain appears reassuringly short and simple. However, is the taking of the tablet truly the beginning of the causal chain? What factors determined whether the patient would present to the doctor in the first place? How does the doctor decide that the tablet is required? Does the patient believe that the treatment will work? Does the doctor believe that the treatment will work? What further influences impact on the decision – the patient's friends and relatives, the doctor's experiences with other patients? Is the patient a priority when compared with the needs of other patients with differing degrees of severity? Will the patient keep taking the tablet outside the initial evaluation period? Will there be harmful effects?

For many of us the presence of any human interaction or motivation makes an intervention complex. While such a view makes undoubted sense it is poorly able to discriminate between interventions. While the intervention itself may not necessarily be delivered by a human (in contrast to human-mediated interventions such as counselling, physical therapy or speech and language therapy) it is almost certainly going to be prescribed by a human and, failing that, it relies on the attitudes and behaviours of a human, a patient, in order to achieve its effectiveness! In this sense, then, all interventions are complex. Consequently, it makes more sense to describe the evaluation lens as being either simple or complex. We can examine a decision problem through a simple evaluation lens, such as a Population-Intervention-Comparison-Outcome (PICO) question [35], requiring a limited number of evidence sources (e.g. on effectiveness and cost effectiveness). Alternatively, we can scrutinise that same decision problem through a complex evaluation lens, requiring mapping using a logic model [36, 37], and an almost infinite number of types of data; quantitative and qualitative, textual, numerical and graphical, local, national and international, from research or from anecdote etcetera [38].

> Trying to apply the laser-like RCT approach [from clinical medicine] is akin to trying to light up a football field with a slowly moving laser pointer – very precise, rigorous, and artificially intense but not very illuminating [39].

Consequently, Petticrew evokes the terminology of design in describing the challenges of representing what are known as 'wicked' real world problems [40].

To explore the inherent complexity of simplicity let us further examine the example of sugar-sweetened beverages. On the face of it the decision as to whether to have drinks vending machines in school is a fairly simple one. To have a drinks machine or not have a drinks machine – that is the question. It can be framed in a standardised PICO format:

Population – school children
Intervention – a drinks vending machine
Comparison – a water cooler, or no vending machine
Outcome(s) – consumption of sweetened beverages, sugar intake, and ultimately childhood obesity.

However, when we start examining the problem more closely we identify greater complexity. For example, if sugar sweetened drinks are not available in the school would children bring them from elsewhere? Might this lead to them being late for school or leaving the school premises at break times? Could this have implications for road safety and the likelihood of pedestrian accidents

among this age group? Might it be preferable to offer a limited number of lower sugar drinks in the school than for them to purchase cheap high sugar content drinks elsewhere? Could it be that by making a decision to prohibit vending machines the school authorities are actually missing the chance to influence the children's nutritional behaviour in a more directive, positive manner?

As mentioned above, the evidence based healthcare narrative has thus moved in recent years from 'what works' to 'what works for whom under what circumstances' [41]. This recognises that, for example, under one set of circumstances or contextual factors removing the vending machines is the correct decision. However, under a different set of circumstances, as in a different population, the correct decision is to keep them. So, for example we may establish that older teens are less likely to be at risk outside the school premises during their lunch break but that 11–13 year olds are at a high risk of pedestrian accidents. We may make different recommendations for these two different populations.

Recent years have seen increased interest in engaging with theory when seeking to interpret evidence from systematic reviews. Reasons for this include recognition that use of theory may result in a more generalizable explanation for how a complex intervention is thought to work. In considering theory, we need to understand essential differences between grand-, mid-range and programme theories. A grand theory, for example a theory of social inequality, is formulated at a high level of abstraction. Grand theories are designed to facilitate generalisations across different domains [42]. In contrast, mid-range theories are theories with a specific area of application that lie between 'minor working hypotheses' and the 'all-inclusive speculations comprising a master conceptual scheme'. Typically designed by academic researchers, mid-range theories may help those developing and delivering a service by helping them to understand a decision problem. Programme theories are 'small' theories that are specific to a particular programme or intervention [42]. Programme theories are purposely designed to be practical and accessible. As a working model a programme theory seeks to specify (i) components of a programme (or intervention) intended to mitigate or solve a decision problem, an intervention's expected outcomes and the methods for assessing those outcomes, often taking the form of a logic model; (ii) the programme's 'theory of change', that is the rationale and assumptions about mechanisms that link a programme's processes and inputs to intended and unintended outcomes, as well as specifying the context necessary for effectiveness. Thus a fully specified programme theory contributes both pictorial and narrative features to help understand a complex intervention [42]

Clearly this level of complexity is much less likely to be captured by the monolithic PICO question formulation. Increasingly therefore, as mentioned above, those reviewing the evidence use logic models to capture the complexity of the initial decision problem, to guide the extraction of data and to communicate and present the final results. Logic models are narrative or graphical depictions of processes in real life that communicate the underlying assumptions upon which a specific activity is expected to lead to a specific result. Logic models thus illustrate a sequence of cause-and-effect relationships on a path towards a desired result [43].

Box 1. *How Do Things Work? (Programme Theories, adapted from Tille) [41]*

Mechanisms whereby reduction of sugar-sweetened beverages may impact on childhood obesity:

a) If children view ads containing sugar-sweetened beverages they are **more likely to view consumption of such drinks as normalised behaviour and purchase those drinks**.
b) If schools prevent children from purchasing sugar-sweetened drinks at school then students are more likely to compensate with **external purchase of inferior drinks with a higher sugar content**.
c) If soft drink manufacturers sell sugar-sweetened drinks in larger bottle sizes then **children are more likely to consume higher quantities of sugar-sweetened drinks**.
d) If children drinking sugar-sweetened beverages do not feel as full as from the corresponding amount of calories of solid food then they are **less likely to compensate by drinking less**.
e) If children consume higher quantities of sugar-sweetened drinks then they find themselves at **higher risk of type 2 diabetes**.

…etcetera.

Towards new evidence products

A new generation of review products seeks to pay attention to conceptual (i.e. theory) or contextual detail within the process of synthesis. Recently a group of methodologists within the Cochrane Collaboration has sought to explore diverse ways in which theory might be incorporated within a review [44]. Review methods such as best fit framework synthesis [45–47] seek to use an initial theory as a scaffold and then to populate this with data from included studies. Data can either be qualitative or quantitative. Furthermore, systematic review teams are starting to use new methods of review such as realist synthesis [38] underpinned by the same cause-and-effect logic that underpins logic models. Realist review is attractive in offering a flexible alternative to traditional systematic review approaches, recognising that health services are delivered in a complex, multi-faceted and dynamic environment [48]. Given the continual changes that take place within a particular context and population, and even within a single intervention, it becomes of limited value to be able to say that an intervention works on average or to a certain extent.

Realist review seeks to provide explanations for why interventions may or may not work, in what contexts, how and in what circumstances. For example, Greenhalgh and colleagues sought to explain the apparently limited success demonstrated by a Cochrane review of school feeding programmes [49]. Applying the realist review approach they demonstrated that while school feeding programmes might guarantee that the recipient has nutritional intake from at least one meal a day this efficacy was subverted because parents of a child participating in such a programme displaced that child's food at home to their siblings.

As the above suggests the realist approach involves identifying underlying causal mechanisms and exploring how they work under what conditions. The stages of a realist review do share some similarities with conventional systematic reviews. They include defining the scope of the review, using methods such as concept mining and framework formulation; searching for and scrutinising the evidence; extracting and synthesising the evidence; and developing the narrative, including hypotheses [48]. Generally however this tends to be an iterative and recursive process, moving between generating theory and then testing it using data from included programmes. Realist synthesis lends itself to the review of complex interventions because it accounts for context as well as outcomes in the process of systematically and transparently synthesising relevant literature. While realist synthesis demands flexible thinking and the ability to deal with complexity, it offers potential for more pragmatic conclusions than alternative systematic review approaches. Of particular relevance to this paper is that realist synthesis offers a mechanism for making use of other types of data in explaining exactly what is going on within a particular programme. This also requires detective work in the form of following up leads to all possible reports associated with a particular study [50].

A case study – TURNUP

Put simply a realist synthesis looks for patterns in the evidence (such as variation in outcomes) [51]. The synthesis then seeks to explain the relationships underlying these patterns through the use of theory [52]. So, for example, we might sort a group of studies on baseline attendance rates for particular health services from highest to lowest. We then might observe that studies that send out a general non-personalised invitation (such as for donation of blood) have lower baseline attendance rates than those that represent a personalised invitation. At the top of the list we might identify studies where a patient is scheduled to receive a particular intervention, as opposed to a general examination, or preparation for a future health event (such as a pre-operative assessment) or studies where parents are bringing their children to an appointment. We might theorise that the greater the extent to which an invitation to appointment secures a commitment from the patient the more likely that patient is to attend. Related to that parents may demonstrate more commitment to an appointment for their child than for their own appointment. We can then use quantitative and qualitative data to explore these hypotheses and articles accessing theory to suggest what commitment involves [53].

The advantages of realist synthesis are best illustrated by an example. In 2012 a team of reviewers from the two universities in Sheffield were commissioned to conduct a systematic review of Appointment Reminder Systems [54]. We aimed not only to review the plentiful effectiveness literature but also to gain a better understanding of how such systems achieve their effect. Using realist evaluation principles, we sought to gain an insight into whether particular technologies, such as SMS messages, emails, phone calls, or postcards worked better for particular populations. The review of effectiveness revealed little if any difference in effect between appointment reminders received one week before an appointment from those received two weeks prior to the appointment.

Furthermore, while the literature problematized 'the forgetful patient', evidence suggests that forgetfulness is a minor consideration [54]. Patients miss appointments for all sorts of reasons – claiming to have forgotten their appointment (a simple mistake) is typically viewed less judgementally than missing the same appointment because something better had come up (a deliberate choice). Therefore, a patient may consider it more acceptable to claim to forget even where this was not their genuine reason for non-attendance. This explains, at least in part, the minimal difference between reminders sent one- or two weeks ahead of the appointment. Having dispelled an overall 'myth of the forgetful patient', although the myth undoubtedly pertains in some cases, we can then choose a reminder system that facilitates the filling of slots that have become vacant with replacement patients who are given sufficient notice (counter-intuitively two weeks rather than one week) to attend. Scheduling of the appointments is thus privileged over the assumptions of the universally forgetful patient. Other behavioural insights included the fact that posting an announcement of how many people kept their appointments was more efficient than posting a similar announcement with how many people had missed their appointments [55] – the latter risks legitimising the problem behaviour of non-attendance. The movement within this review from single lens complexity to the realisation that evidence operates within complex systems theory is an important advance in evidence production [56–58].

Although we tried to answer 'which appointment reminder systems work for which populations under what circumstances' we encountered difficulties in using the evidence base. Existing trials reported an average for appointment attendance over the entire population, not figures for individual population subgroups. However, we were able to challenge other persistent 'myths' about appointment attendance. For example, researchers often assume that people who live local to a hospital or clinic are more likely to attend than those who live more remotely. In actuality there was limited evidence to suggest that patients 'batched up' their visits to hospital to make them more efficient [59]. Having multiple appointments on the same day may increase the perceived importance of the appointed day making a patient travelling from distance more likely to attend.

In addition to realist synthesis methodologies, relating to cause and effect, we can improve our understanding of what is happening within a given context using narrative-based approaches to review of the evidence [60]. For example, Swinglehurst and colleagues, when studying repeat prescribing, identified three different narratives for what was taking place within a primary care setting [61]:

1. local artefacts such as repeat prescribing protocols (**the proxy routine**);

2. abstracted understandings held by staff of how a routine is enacted (**the so called ostensive routine**), arrived at by asking 'what gets done, by whom, and how?'; and
3. the range of ways in which the routine is actually enacted (**the performative routine**), arrived at by direct observation.

The existence of multiple narratives has implications for any evaluation activity. If the received wisdom on an intervention varies so greatly then we need to combine documentation (to identify what should be done), narrative (to capture what is understood about how things are done and observation (to perceive what is actually done) [61].

Other types of evidence

The literature on decision-making tells us that other forms of evidence are important when contemplating innovation:

> Public health questions are only sometimes answered by RCTs and that evidence drawn from other methods and designs would have to be appraised. It was recognised too that the data and evidence that would be drawn upon in the public health work would be broad and go beyond medical science to include the social sciences [32].

Such a conclusion is unsurprising given a shortage of RCTs in many areas. Take housing for example – it is estimated that a good RCT only appears in connection with housing once every twenty years [62]. In this 'gold standard vacuum' good practice from other, preferably comparable, settings or contexts may help to inform our choice of interventions. However, we should recognise that such good practice is typically unevaluated good practice. The criteria by which a project is labelled good practice are often unclear. In performing reviews of the evidence for health service delivery for the National Institute for Health Research we have found it important to identify relevant initiatives from the United Kingdom, even where they are unevaluated. A useful useable report therefore includes both rigorous and relevant material. Each type of evidence has its place but it is important to recognise that these types of evidence are not interchangeable. We can compare their respective roles to the stages of brainstorming where the generation of items (what could be done – good practice) is separated from deliberation on their value (what should be done – research evidence). Both RCTs and good practice are ways of improving the coverage of the evidence base:

> Building an evidence base is analogous to laying a floor-on the one hand you could cover the terrain with large carefully interlocking research studies rather like laminated flooring, on the other hand you could painstakingly piece together a myriad of service evaluations like a Roman mosaic [63].

In addition to challenges associated with the assessment of good practice significant obstacles relate to the actual identification of good practice. Good practice examples offer a compelling way to demonstrate actual instances where a planning system has been able to contribute to a healthier local environment. They are thus able to help to identify where partnerships between public health and planning departments have succeeded in the past, with the implication that such success can be replicated in future programmes. However, the multidisciplinary nature of public health and health services research has important implications for the sources being utilized. 'Practice-based' evidence (case studies from areas that have attempted similar work), are afforded a low subordinate place in the typical hierarchy of evidence and yet typically prove valuable for decision-makers. This explains in part why commentators prefer to refer to taxonomies of evidence, rather than the single monolithic evidence pyramid.

Consider for example if we were conducting a desk-based review on the topic of the influence of the environment on obesity. Clearly we would have to start by narrowing down the topic; there are so many different ways in which the environment might have an impact. We might start by producing some form of conceptual framework, logic model or evidence-based map of obesity drivers. From this we might identify clear families of intervention types. For example, we might seek to control unhealthy consumption of certain types of food and drink, for example by introducing restrictions on hot-food takeaways. Alternatively, we might take positive steps to increase the availability of healthy food and drink, for example by offering incentives for the sustainment and growth of farmers' markets. As yet another alternative we might seek to increase opportunities for local food production, for example by offering incentives for the redevelopment of allotments and agricultural land.

We can already identify how diffuse the evidence base might be if we were to produce a briefing on just these three policy options. We might seek to facilitate international comparisons so that we can determine whether countries with higher densities of fast-food outlets actually have higher levels of obesity. In contrast reviews of smaller scale studies may report conflicting findings on the fast-food/obesity association, given that fast-food takeaways frequently cluster around schools. From socio-economic studies we might find good evidence that poverty and area deprivation act as barriers to the purchase of fresh or unfamiliar foods. However, some social commentators may maintain that culture and habits exert a stronger influence on eating patterns than spatial planning.

Academic evidence linking the built environment to diet and health is likely to prove suggestive, but not conclusive. Questions about causality persist, particularly as it is not feasible to establish cause and effect through RCTs. We would also seek to examine existing public health policy which might be more influential among planning colleagues than an uncertain academic evidence base. They might reason that if planning decisions are aligned with existing policy demonstrates willingness to balance potentially competing interests (e.g. health and economic growth). Other important evidence might include guidance from evidence producing bodies such as the World Health Organisation or national bodies such

as the National Institute for Health and Care Excellence (NICE).

Last, but by no means least, we would seek to access good practice. This may lie in diffuse and relatively uncontrolled sources. We may seek to identify innovation from details from research in progress, from academic web pages or from research registers, or from the Web pages of funding bodies. Beacons of good practice are often included as case studies in government reports or those produced by independent organisations or consultancies. Innovation may also be captured through early-stage reports such as feasibility studies, pilot studies and unpublished process evaluations. Typically, in a UK context, we conduct searches of the general Web limited to health service (nhs.uk), academic (ac.uk), or government (gov.uk) web sites [64, 65] and this approach is likely to be transferable to other countries.

What is wrong with the evidence we have?

Many feel that we have not yet realised the full potential offered by systematic reviews of the evidence. Essentially the systematic review process strips study reports of their all-important context in a quest to facilitate comparison between otherwise different looking published reports. However detail of context is needed if users of the reviews are to understand how the context of included studies has contributed to the success or failure of particular programmes and the extent to which lessons learnt from elsewhere can be applied to a target population and context [66, 67]. This requires that those producing systematic reviews expand their brief to cover these important contextual issues or adopt a wider or more versatile toolkit of review methods in order to deliver what decision-makers need for the future. Paradoxically this may require that review authors utilise those aspects of a report previously left on the 'cutting room floor'. Such elements may include the Background and Setting of trial reports, the Discussion section as a potential source of theorising and accompanying process evaluations that supply important contextual detail.

The way forward?

What is required to take evidence based decision-making into a new age? First, we need more joining up of health services research (the content of the evidence base) and health informatics (the delivery mechanism for the evidence base). This requires development of both information professionals and decision-makers so that information specialists achieve a better knowledge of the characteristics of well-constructed evidence:

> Public health decision-making requires knowledge of not just whether something works under particular circumstances but also how, when, and why for broad application [39].

As implied above, such a multi-faceted view of what works under what circumstances requires that evidence producers and stakeholders work together on surfacing theory, context and mechanisms. Correspondingly managers need to develop a greater awareness of the potential of information technologies to deliver that evidence. Over the last decade several information professionals and managers have sought to identify and document that knowledge [68–70]. This requires that all disciplines exploit the unique multidisciplinary nature of evidence based health information.

It may prove most feasible to target 'quick wins' where short causal chains can be identified, so as to demonstrate a direct and immediate effect on population health and well-being. The mention of health and well-being is significant here. The increasing greying of the population and the increasing burden on health service expenditure requires a transfer of attention from 'sick care' and health services to more upstream interventions targeting achievement of a healthy population. Greater involvement of multi-agencies, from outside the health sector, further requires understanding of the use, value and production of evidence within these different sectors. So, for example, in the United Kingdom evidence based social care contributed a focus on individual client needs and preferences, offering a useful counterpoint to the population emphasis of evidence based public health [71]. While challenges of building research and evaluation capacity exist for all sectors we can conclude that public health is much further evolved than its counterparts in social care [72] and other aspects of public management (e.g. housing, transport and employment).

Above all we require to effect a cultural transformation such that 'evidence based' becomes so pervasive, as the preferred way of making resource decisions, that we no longer need the label to imply that this is something different or special. It should be just the way it is!

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Competencies of Information Employees in the Context of Dynamic Information Needs of Health Care Staff

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Abstract

The article describes the functions of information employees in modern health care. Selected surveys of librarians' educational needs are presented and discussed, and a list of professional competencies indispensable in answering health professionals' information needs is proposed. The potential of academic training of librarians and information professionals offered by Polish universities is also discussed. The unique value of information employees' competencies in offering information services to different groups of health professionals and patients, their responsibility and partnership in either research or therapeutic teams are accentuated.

Key words: **embedded librarianship, medical librarian, informationist, information competencies, health competencies, training, information employee**

Słowa kluczowe: **bibliotekarstwo uczestniczące, bibliotekarz medyczny, informacjonista, kompetencje informacyjne, kompetencje zdrowotne, kształcenie, pracownik informacji**

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Expectations regarding librarians and information professionals are modulated in response to changes in the pace and manner of human communication, the development of science and technology, as well as become adapted to the life of the modern man, including his functioning in the workplace. These factors, affecting the functioning of libraries and information centres, can be observed and experienced also in the sphere of health care learning and practice, in its various institutions, disciplines, professions, etc. Library service meeting the information needs of health care workers has a long tradition, in many countries of the modern world deriving from the collections gathered by medical associations, although today its implementation has a completely different nature.

An important element shaping information work in this area has always been a growing variety of supported users – ranging from scientists and practicing physicians, the remaining medical staff, administration employees, to patients and the general public. Meeting their needs invariably involves enormous responsibility arising from risk (threat to life and health), which may be associated with supplying inadequate or incomplete information [1]. There is a growing resource of information and referring publications, and a greater access to full texts and databases collecting different types of data from the area of health sciences. There is also a growing group of tasks related to training users in the area of information literacy, copyright protection, the ability to prepare materials for publication, sharing digital collections (see below), many of which are due to the development and application of digital technologies. Because medical librarians are continually obliged to adjust their competences to the changing requirements of the supported environment, this professional group has always been perceived in the milieu as a kind of a role model.

As a result of the changing library practice, related jobs and responsibilities assigned to them become differentiated. Given the dynamics of that evolution, the process of formulating the competences required of the

staff information and tasks they have to carry out working in health care facilities is actually a continuous process requiring constant analysis and updating skills and activities.

The following text is a presentation of the specific scope of activities of health care information employees, taking into account their different places of work – medical universities, clinical centres, hospitals – and the ways they cooperate with the supported environment. Based on the literature, the users themselves have formulated a list of indispensable competencies in today's use of information. Selected studies of the analyzed theme were presented, as well as the potential use of educational programmes for information specialists in the area of health sciences working in academic units currently conducting studies related to library and information science (as the law does not put limitations on how the educational offer is shaped, the studies function also under non-traditional names).

Competencies of information specialists in the field of health sciences

In the Polish milieu of health information employees, a term that would be short, unambiguous, yet easy to use in different situations *and* describe the person responsible for information services involving the processes of scientific, practical and therapeutic communication implemented in health care, has not yet been formulated. Traditionally, for many years the group has been referred to as *medical librarians*, which reflects well the specificity of the job: both in terms of place of activity (library in the classical sense), and the subject. The term *librarian* remains valid, especially if the name of the institution or its branch is equally traditional; however, in the literature[1] also specific determiners clarifying the tasks of this employee can be found (e.g. *biomedical librarian*) or their high specialization (*embedded librarian, research-embedded health librarian, outreach librarian*), as well as other terms, corresponding more to information services offered (e.g. *informationist, information specialist in context*). According to the proposal of Barbara Niedźwiedzka, the *informationist, information specialist in context* (Polish: *informacjonista, asystent informacji w danym obszarze*) is an employee specializing in information services meeting the specific needs of a small group of clients, who remains in contact with them, and knows and actively pursues the objectives of that group [2, p. 39].

The consequence of the development and diversification of medical sciences and health sciences [3] is that the job titles of library and information positions have come to include terms related to a particular specialization or business profile. Based on a literature review, I. Diane Cooper and Janet A. Crum, extracted the following names: *clinical informationist, bioinformationist, public health librarian, nursing librarian, disaster informationist* [4, 5]. In turn, some of the terms reflect a formal diversity of the employee's duties, for example: *systematic review librarian, emerging technologies librarian*, *continuing medical education librarian*, *grants development librarian*, or *scholarly communication librarian* [4]. As can be seen from the above examples, the evolution of this professional group can be observed mainly abroad, in Polish information literature the prevailing term still being *medical librarian*, albeit other terms are being proposed, such as *net-librarian, digital librarian* [7] or *clinical librarian* [8].

The competencies of the health sciences information employee include primarily a set of qualifications which a graduate in bibliology and information studies should have. These include skills regarding the implementation of information processes relating mainly (but not exclusively) to documentary information, and therefore preserved in various forms and in various types of media. This group of processes begins with the collection of own tools or tools providing access to resources (electronic, as well as printed). The next step is a wide range of activities in developing formal and material collections (creation of metadata), which will allow them to be found by the user – on a shelf, in a catalogue, full-text database, etc. The last step is making the resources available (own and those of other centres, via the Internet), which also includes many activities, such as contacting users and meeting their information needs or maintaining repositories of publications by employees of the institutions of the home institution (very common in the case of medical schools libraries, research institutes and teaching hospitals).

Undoubtedly even a partial knowledge of medicine or related disciplines is a great added value, because it definitely facilitates understanding the information needs of users. Almost until the end of the twentieth century in many medical libraries (albeit not Polish ones) the possession of such insight was regarded a condition of employment [9], as lacking knowledge of specialist terminology or orientation in the literature was considered to significantly impede work. Today it is the librarians themselves [10] who see that the lack of field knowledge is an initial barrier, which can, however, be quite quickly overcome, especially with the high intensity of contact with users.

The above-mentioned basic information processes and their components, preceded by library and information studies, implemented in libraries that support specific areas of research or professional activity, are of course adapted to their specificity (the pace of work, daily and annual schedules, the allocation of tasks, etc.) and needs (e.g. the level of detail of information queries, chronological range of data searched, its credibility, etc.).

The basic skills (and equally tasks) expected from information employees include advanced browsing competencies [11, 12]. The modern *medical librarian* needs to be versed in the content and formal diversity of electronic resources in the field of medical and related sciences, including repositories and database containing e.g. research reports, full texts of articles, information on clinical trials, health technology assessment, etc. They must know artificial (information-retrieval) languages used to describe collections in order to be able to find the most accurate answers to the questions posed; use advanced

search tools, in the formulated queries combining all the essential features of the desired information [13]. In view of the specific needs of users – doctors, nurses and other members of the health care team – whose work requires a specific, rapid and reliable response, scarcely ever do they prepare bibliography lists or supply full-text articles. More and more often, though, they provide literature reviews of various profiles (*scoping reviews, evidence reviews*), results (*rapid evidence assessments*), records of health policies, etc. [14] carry out bibliometric and webometric analyses [15], focusing on providing precise data corresponding to equally precise questions. Carrying out such actions – expert search, analysis and evaluation of its results – also requires knowledge and proper application of adequate research methodology. This content, i.e. the network of specialist information resources ('medical Internet') and the methodology of specialist search are also the most commonly reported training needs of information employees [e.g. 16].

In addition to information retrieval and results analysis, the group of the most important and most frequently undertaken tasks includes educating users in the field of information literacy [11–13, 17, 18]. Its implementation requires both constant updating of knowledge sources and search tools, as well as competencies within the specific area of teaching adults – an effective transfer of knowledge, most frequently in rather uncomfortable circumstances (taking into account for example the lack of time, difficulty in arranging classes, disparate needs of different groups of employees, some user-unfriendly search tools). Nevertheless, people working in health care must be familiar both with current and valuable sources and with how to properly use them. Teaching information literacy refers not only to health workers or students (in academic institutions), but also patients – especially in hospital libraries.

Information staff teaching more and more often includes the issue of intellectual property protection and recognition of copyright because of the diversity of legal types of content sharing, especially on the Internet. Tasks related to the popularization of the Open Access movement also include helping authors to publish research results, organize and maintain institutional repositories containing either text or raw research data [19], and even carry out publishing activities (e.g. preparing and publishing grants reports). They come under the area of activities related to knowledge management, a responsibility of information employees, and include the documents related to the functioning of the institution, collecting and sharing publications of their own authors (keeping repositories, mentioned above), data management (bioinformatics, research) and metadata, as well as cooperating in developing domain and inter-institutional [20] resources or promotional actions.

Both education and Internet activity require soft skills, which include exceptional competence in the area of interpersonal communication, requiring not only the knowledge of certain techniques and behaviours, but also certain predispositions [11, 12]. This ability is essential in working with the user, in an effective and swift clarification of their information needs, as well as in building the authority of the information employee as a person competent in retrieving and evaluating the knowledge available on a given subject [13].

In many cases, leadership skills prove to be significant, including entrepreneurship (in view of constant financial difficulties), innovation and creativity in the search of new solutions in many areas of information activities [21]. These – in tandem with communicativeness and awareness of new technologies – are useful in managing sites and portals of the library and the parent institution, including specialized portals dedicated to selected health issues or offering information for patients, as well as social media profiles [5].

Librarians and information employees adapt their functions to the overall strategy of the institution, more and more often becoming partners in the implementation of research and treatment tasks. Having skills that help precisely formulate the subject of the planned research, write grant proposals, prepare literature reviews and identify data gaps, they form part of research teams. For example, such are the responsibilities of information employees working at the Biomedical Library University of California in Los Angeles [15]. Employees of hospital information departments are full members of care teams, not only taking part in staff meetings, but also being present in the wards almost all the time. They participate in doctors' rounds and daily patient care, ensure the precise naming of information needs, and carry out information searches almost at the bedside [8, 10, 15]. Given the observed trend of personalized medical procedures, visible i.a. in the individual selection of drugs in cancer treatment based on the results of genetic testing, they mediate in finding and delivering the necessary data [22]. They provide information to the patients in a manner appropriate to their level of health information literacy.

This significant change in the role of information employees in the structures of health care institutions, their partner contribution to the implementation of the institution's key functions (education, research, clinical care), follows directly from the execution of the *evidence-based healthcare* approach, strongly emphasizing the decisive influence of the latest available knowledge on the implemented therapeutic measures. The level of commitment is reflected in the terminology used – observed primarily in the work of the above-mentioned *embedded librarian*, completely 'immersed' in the issues that 'his' or 'her' users deal with on an everyday basis.

Such an active function in the team means that another very important competence of information employees is their ability to cooperate – initiating and maintaining contact with users, going out of the library, being present wherever there is need for information [10], being responsible for interinstitutional contacts, direct and mediated (network) communication. In the United States the catalyst for a greater involvement of librarians in research activities in the field of medical and related sciences may have been the introduction of the policy of the dissemination of public access to information (including scientific research results [4]) by the National Institutes of Health in 2008.

The process of improving and updating the professional competencies of information employees is often confronted with barriers, such as the lack of a matching information offer, or lack of time or resources for training [4]. One way to cope with the lack of time, made possible by technological solutions, is the elimination of jobs that have ceased to be crucial for effective information activities. These include: providing information services (since the employees are directly involved in research or care), maintaining printed collections, cataloguing (since descriptions can be transposed) [4].

Studying the competencies and learning needs of medical and related information employees

Both information employees themselves and information scientists, noticing changes in intensity and the manner of implementing information services in the health sector, carry out research projects whose aim is to monitor the competence with respect to the needs of the supported communities. Below are some interesting examples illustrating the issues that are being dealt with.

The purpose of the British research [23] into the training needs of public health (NHS) librarians was to analyze both examples of good educational practices addressed to this group of recipients, as well as guidelines for the design of the Lifelong Learning Programme, to be implemented by the National Library for Health. The priority needs included: specialist browsing and research skills, knowledge management using ICT and research needs of users, leadership and strategic management. There was also reference to the then relatively new (2005) roles and ways of working of clinical librarians operating partly outside their unit, ward, or in the field. They were above all involved in searching and evaluating literature, contacts with the user, conducting training, use of ICT and network resources in information activities, but also research, among other things. Moreover, they helped users to solve dilemmas related to data protection and compliance with copyright law, while retaining the right to information. They managed their subordinates, introduced changes, led marketing and promotional activities, communicating with patients and the social environment [23, pp. 15–16].

As a result of this project we identified 4 basic expected learning outcomes of future information employees:

- establishing and maintaining cooperation between different departments, improving (changing) services, project management, promotion and evaluation of services addressed to new user groups;
- finding educational support for various professional groups, including e-learning packages, knowledge resources; assessment competence and ICT;
- supporting scientific research: its design, choice of methodology, implementation and critical evaluation;
- supporting initiatives in the field of knowledge management and intranet development [23, pp. 16–18].

Looking at a narrower group of respondents also working in libraries associated with the NHS and limited to the British region of the Thames Valley, it was studied [9] whether (and to what extent) people educated in an area other than medical sciences and health sciences and holders of a library science diploma (Master degree), can successfully work in the health sector.[2] So education and training needs of librarians educated in the area of science as well as humanities and arts, and also people working in the health sector and in higher education establishments, were compared. Constant changes in health sciences and nursing practice have proven to be the cause of the significant demand for various forms of lifelong learning, especially in terms of teaching skills, researching information needs, management and marketing, research skills, subject knowledge and specialist terminology. When asked, medical librarians identified the most urgent training needs as follows: focusing information services on the patients' needs (including improving their safety, monitoring health outcomes), functioning in the event of significant inequalities in access to health information in the field of public health, as well as research and browsing skills [9, p. 169]. As shown in the list above, medical knowledge and care have not proven to be a priority competence. The listed needs may, however, be reflected in the amended science information educational programmes, which include expert browsing skills, education of adults, project management, research methodology and many hours of practice – especially for students holding a bachelor's degree in areas other than science [9, pp. 174–175], since this last group is much better skilled at counting, statistics and analytical tasks.

An atypical example of librarian responsibilities was described by Niamh Lucey and Anne Madden of St. Vincent's University Hospital in Dublin [24]. They showed that librarians have unique specialist skills useful in clinical audits, especially in the implementation of the first two stages, i.e. the recognition and naming of the problem / issue being examined and the determination of the evaluation criteria. The Head of Library & Information Services of the same hospital and one of its employees have been full members of the audit team from the beginning, that is since 2005, and have participated in the process as such. Therefore, librarians' expertise in the field of the search process contributes to improving the condition of the patients [24, p. 3].

Questionnaires and focus group interviews with Canadian librarians participating in research, the so-called *research-embedded health librarians* (REHL), was used [25] in order to learn the specifics of this position. The responsibilities of this type of employee include the implementation of information services in the research team working in the area of medical and/or health sciences, of which they are a full member [25, p. 288], including ongoing orientation in the current available publications on the topic, literature search, analyzing it and formulating proposals, participation in team meetings. Besides, they can e.g. manage the project (and its budget), maintain a website, prepare grant applications [25, p. 289]. They should be able to use the research methodology and ICT tools, prepare written statements in different genres and forms. Their personal qualities should include: comuni-

cativeness, the ability to adapt, meticulousity, ability to work under stress, cooperation, network competence, and also independence [25, p. 292]. Respondents have proven to be satisfied with their assigned duties, mainly with belonging to the research team and being committed to an ongoing project throughout its duration, with the possibility of establishing relations with other team members. At the same time, though, their feeling was that they were working rather like researchers than librarians, and complained about the insulation of their original occupational group, as well as the relatively low job security, resulting from its 'project' character.

The Health Association Libraries Section of the Medical Library Association at various time intervals (1980, 1996, 2003, 2011) has been testing a small group of libraries, medical societies, checking their condition and the pace and direction of their evolution [26]. In the last edition, it included the following new emerging tasks: archiving of publications of the home society and information activities in this area, help in editorial and publishing activities for the members of the organization, maintaining electronic documentation and website, participation in marketing.

Academic training of information employees in Poland

Academic education of future information employees in the field of bibliology and information science, is currently (2015) conducted by departments or institutes at universities in Krakow (two), Torun, Katowice, Wroclaw, Lublin, Lodz, Kielce and Warsaw. Despite recent higher education reforms, courses of study offered at undergraduate and graduate levels are not predominantly referred to by the former name of 'scientific information and library science' (in several variants), but other courses are offered, such as: information architecture (Pedagogical University, Krakow; Nicolaus Copernicus University, Torun; Maria Curie-Sklodowska University, Lublin), information management (Jagiellonian University, Krakow; Nicolaus Copernicus University, Torun), scientific information and library science (University of Silesia, University of Warsaw, Wroclaw University) and digital and Internet publishing (University of Wroclaw). Nevertheless, graduates are taught key competencies to work with information, such as the efficient search for information in various types of sources and resources using advanced tools, the use of modern technologies, creating digital documents and collections, testing and implementing users' information needs, science communication. These are skills usable in different types of information establishments and at work with clients representing different types and areas of activity.

However, issues directly linked to information processes accompanying research and health care practice [6] are difficult to be found in educational programmes. Specific issues relating to bibliotherapy, which have for years been the characteristic specialization of the educational offer at the Institute of Scientific Information and Bibliology at the Nicolaus Copernicus University in Torun, can be an asset, for example, in information services offered to patients, including people with specific health problems and the elderly. They form a good basis for the development of domain knowledge required in medical libraries. At the Institute of Scientific Information and Bibliology at Warsaw University there are some optional courses addressing the issues of health: Health Information (undergraduate) [27] and Information Health Competencies (graduate level) [28]. The aim of the latter is to introduce students to the broader issue of health information and carrying out research projects on these particular competencies among different groups of users, or possibly another aspect – of the availability and quality of health information created or distributed by different entities.

In 2009–2010 the same Institute came up with the idea of post-graduate studies in the field of health information management, the aim of which was to teach information literacy to graduates of other fields of study, especially those related to the area of medical sciences and health sciences. In this project, the division of knowledge, skills and attitudes that should be obtained by the potential graduate was applied, including i.a.:

- the necessary knowledge of the specificity and complexity of the health system that affect the diversity of information needs of multiple groups of users (people of different professions, patients, the wider public);
- specialist knowledge of linguistic tools: domain classification of subject, information retrieval languages, ontology;
- the capability of finding, evaluating and selecting sources and information, regardless of their form or medium;
- analysis of the material obtained and the preparation of applications, summaries, statements or other replacing documents;
- self-preparation of Internet materials, including the maintenance of websites;
- trainings for different groups of users and preparation of customized information materials [29].

Unfortunately, this project was not implemented due to the low interest of potential participants. Although the offer was directed not only to medical librarians, but also to people connected with the sphere of administration in health care or with health policy, it failed to attract the sufficient number of people. Perhaps educational needs in this area are not yet strong enough. Among librarians these practical skills are probably developed and improved by mentoring or participation in the so-called *communities of practice* – ranging from simple tasks to those with a higher risk due to the patient's welfare and quality of clinical studies [6, 13, 18]. A good educational support, especially at the beginning of career, can also be provided by the textbook in teaching health information skills, resulting from a joint Polish-Norwegian project [17].

It is to be hoped that the information staff working in the field of health care will be improving their information and domain skills to match the changes in their environment. Perhaps also in Poland and in the foreseeable future, precision in naming information needs, efficient search for information, together with the ability

of its evaluation and selection, the efficiency of creating digital documents and collections, communication with employees and patients through a variety of media and channels, will make that information employees will be – like in foreign teams – partners in research projects or patient care practice.

Notes

[1] See References.

[2] In Great Britain, studies in the field of scientific information and library science (LIS – library and information science) are conducted mainly at the graduate level, as an extension of first-degree studies completed in an area of other sciences.

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Translational Medicine and its Perspectives in Poland

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Abstract

This article presents Translational Medicine (TM), one of today's 'buzz words'. Moreover, it seeks to identify the factors which stimulate or impede TM's development in Poland, based on desk research and a series of expert interviews conducted in four countries. TM is a new trend in research and clinical practice. It stems from two sources: observation of how ineffective the traditional drug development process is, and from the public need for innovative therapies. Strategies developed within the translational approach optimize medical innovation development so that the chasm between impressive scientific discoveries and poor pharma productivity is filled. Our diagnosis shows that Poland is a minor player on the market of new technologies, particularly drugs. However, Polish scientists and industry do have a potential that will enable them to play major roles in international research teams that work on innovative, global projects.

Key words: **translational medicine, pharmaceutical industry, R&D, innovations, SWOT, project SPIN**

Słowa kluczowe: **medycyna translacyjna, sektor farmaceutyczny, B + R, innowacje, SWOT, projekt SPIN**

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Introduction

Translational Medicine (TM) is a new trend in biomedical research and clinical practice, which has been gaining growing international popularity for several years. The aim of this article is to assess whether the idea and practice of translational medicine is likely to take root in Poland, thus supporting medical innovations based on Polish companies and R&D staff. The following paragraphs provide a detailed description of the concept of translational medicine in its many meanings typical of the different groups participating in the development of new medical technologies. We refer mainly to the major assumptions and postulates made by practitioners of translational medicine. Next, we present results of the SWOT (strengths, weaknesses, opportunities, threats) analysis in order to assess the prospects for the development of translational medicine in Poland. The presented facts, opinions and conclusions are based on the results of a study carried out as part of the project titled 'SPIN – Model of Innovation Transfer in Malopolska'. The study included the analysis of existing data (review of scientific literature, own calculations based on publicly available data) and a series of in-depth interviews. All respondents are professionally involved in the development of new medical technologies (at its different stages), or in their implementation in clinical practice. The pool of sixteen interviews included six interviews with scientists, five with representatives of the pharmaceutical industry (or persons conducting clinical trials on behalf of private companies), and another five with representatives of the institutions supporting the development of medical technologies, including one American, one Swiss and one German company. All interviews were conducted in the second half of 2012.

Poland is a peripheral player on the market of innovative therapies, and so we think that it is not possible

to realize all stages of drug development – from their discovery to implementation in clinical practice – using national (financial, technological and human) resources. However, based on the conducted analysis, we believe that Polish scientists, universities and companies *can* be an important partner to international consortia working on drug development.

What is translational medicine?

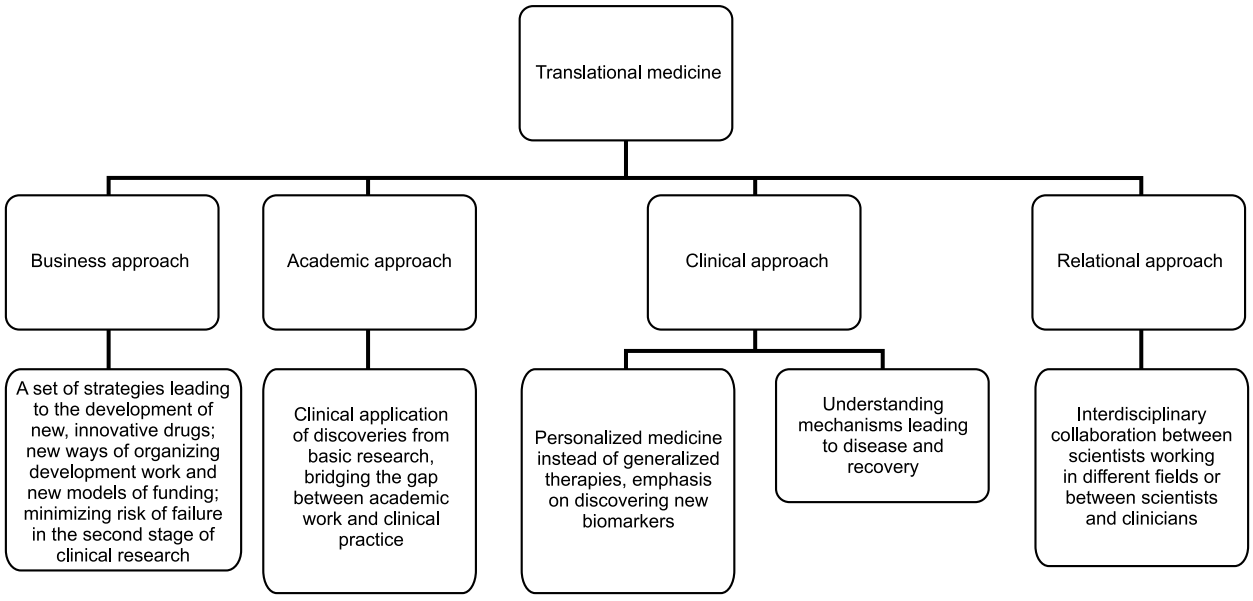
Translational medicine is a relatively new field of knowledge and medical practice, which aims to bridge the gap between impressive results of basic research (especially in the field of biotechnology and genetic research) and a modest number of new medical technologies that are available to patients. This is to be made possible by 'translation', usually understood as a transfer of basic medical research results to direct use in clinical practice. Translational medicine demands that basic medical research be inspired by real clinical problems and targeted practical solution. The process of translational medicine, understood as the implementation of innovative medical technology in clinical practice, may be applied to any medical technology, e.g. a drug or therapy, vaccine, medical device, surgical technique, or diagnostic method. In practice, however, translational medicine is most frequently mentioned in the context of drug development, and it is so also in this article.

Translational research, rather than competing with basic or clinical sciences, bridges the two by leading to the development of new, more effective or safer therapies, broadens the spectrum of diagnostic and preventive possibilities, and improves the comfort of treatment [1]. Exemplary translation responds to the real need of patients and helps to reduce the clinical problem; is efficacious and safe (which has been confirmed in thoroughly conducted and documented clinical trials) and is not only legally available but also practically accessible to patients e.g. reimbursed and/or adequately propagated in the medical community.

This young discipline has already gained both recognition and criticism. The critics evaluate this new approach primarily as a fad or a new label for the long-running development research. The best example of a successful translation is the discovery of penicillin, a side effect of Louis Pasteur's other research. The cynically predisposed also point to the incredible effectiveness of research projects bearing the translational tag in obtaining public funding [2], suggesting that the main task of 'translational medicine' is simply gaining public support, which will launch new financial streams for further research and development [3]. Interestingly, these critical voices can be heard mostly in the corridors or in popular science press. An open, systemically argued scientific criticism has so far been lacking.

Figure 1 is a graphic summary of the most important ways of understanding translational medicine, typical of different groups of stakeholders. The key points presented in this figure will be developed later in the article.

Figure 1. *Translational medicine – academic, business, clinical and relational perspectives*



Source: Own elaboration.

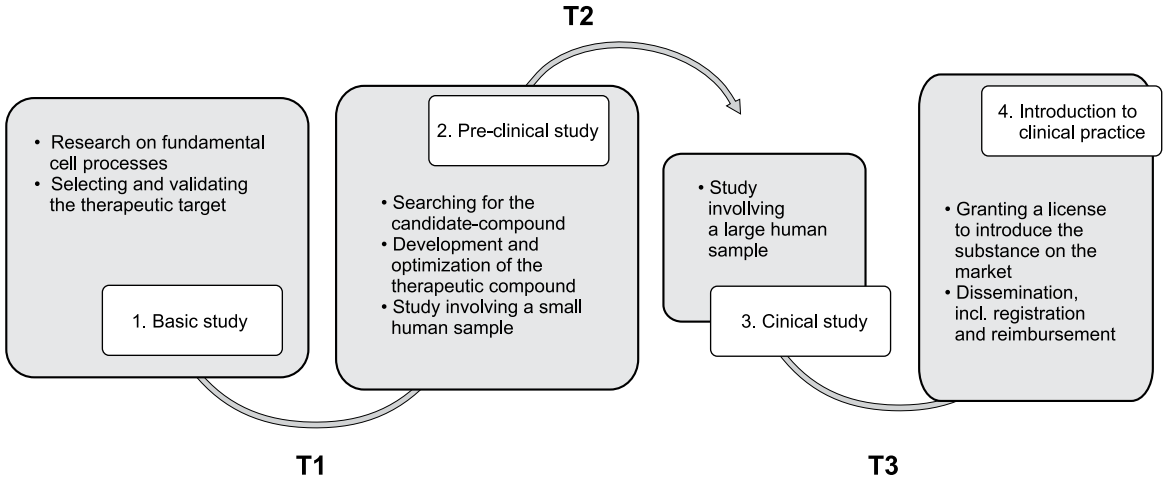
Translational medicine gives hope of overcoming the pharmaceutical crisis

To understand the need for and popularity of the new 'translational' narrative in life sciences, one has to refer to the crisis of the pharmaceutical sector, announced a few years ago. Despite increased spending on research and development in this field, the annual number of new medicinal compounds registration[2] (in other words, therapeutic active substances which may be marketed as drugs) has remained relatively constant since the 1950s [4]. The exception was the 1995–1996 period, the time of a significant increase in the number of new registrations [5]. Therefore, it is often erroneously stated in the literature that the crisis of innovation in the pharmaceutical sector is due to the ever-decreasing number of new registrations. In fact, the essence of the crisis is increasing the cost of introducing new medical compounds on the market [5]. The crisis is believed to have been caused also by the fundamentally flawed cycle of innovation.

Four stages can generally be distinguished in the process of developing a new drug[3] (see **Figure 2**). The purpose of the first stage, known as basic research, is to define the therapeutic target – the protein located in the human body whose activity is associated with the disease. In the second stage scientists develop a therapeutic compound which is able to interfere with the functioning of that protein (either by blocking or stimulating the protein's activity) [6]. The search for such a compound is a difficult task, which involves selecting the most promising molecule among thousands of others. For this purpose, laboratory studies on isolated cells or computer simulations, as well as medical experiments on animals are conducted. In the third step large-scale observations are carried out in order to observe the effect of the therapeutic compound on the human body, in particular its safety and efficacy. This traditional, linear model of developing new drugs does not lead to broadening the spectrum of therapeutic possibilities, at least not on the scale that would be expected, given the increasing expenditure on research and development in this field [7]. An especially critical stage in the development cycle of a new drug is the second phase of clinical trials [8] (3rd stage shown in Figure 1). It is time-consuming, costly, and typically involves hundreds of patients – an insurmountable barrier in the case of as many as 9 out of 10 carefully selected molecules [9], e.g. in oncology [10].

In a sense, the pharmaceutical industry and the scientists involved in the development of new drugs became a victim of their own success. The starting point for most of drug development projects are advanced biomolecular studies. In recent years, this domain of science has made an unprecedented progress, which resulted in an impressive number of potentially efficacious therapeutic targets and their corresponding drug molecules [7]. The number of such molecules is too high to allow for testing them all in clinical, or advanced pre-clinical studies. Even if that were possible from the organizational and financial points of view, it would take hundreds, if not thousands of years, while medication is needed here and now. Therefore, it is important to be able to make an accurate and early assessment of the safety and efficacy of thousands of potentially therapeutic molecules. For several years it has been indicated that 'easy therapeutic objectives' have become exhausted, which led to the increasing complexity of drug development [11]. In

Figure 2. *Translational stages (T1, T2, T3) and a new drug cycle*



Source: Own elaboration.

addition to that, the most popular methods of early drug validation – studies in cell cultures and in animal models – are proving to be increasingly unreliable in the case of very complex pathophysiological mechanisms occurring in the human body [12]. The second reason given to explain the rising cost of launching new molecules emphasises the aggressive strategy of large pharmaceutical companies, investing in costly and high-risk projects, with the hope of high returns in the case of an exclusive development of a niche [4, 7].

In summary, the poor productivity of new drug development is determined by its three characteristics – high (and continually growing) cost, and the time and risk involved. Some estimate that the introduction of one new drug to the market costs an average of $ 1.8 billion [13]. The whole process, starting with the first laboratory test and ending with the registration, takes at least several years. At the same time the risk that the compound developed in the course of basic and pre-therapeutic research does not show sufficient or any therapeutic efficacy in clinical trials involving patients as a result of insufficiently accurate pre-clinical selection of molecules, is very high [14]. The chasm between progress in basic research, increasing spending on research and development in the pharmaceutical industry and the small number of innovative drugs has given rise to the aforementioned discussion of a fundamentally flawed development cycle of medical innovation. Translational medicine, in particular the new way of organizing research and development that reduces the risk of failure during the second phase of clinical trials, is considered to be the answer to the failure of the traditional linear development cycle of new drugs.

Early validation using biomarkers

A unique role in a translational research project is played by the earliest possible pre-clinical validation of potentially therapeutic compounds, which usually takes place with the use of biomarkers. Biomarkers – objective, measurable indicators of the physiological state of the body [8] – bridge the tangible, concrete, measurable laboratory work with a multi-dimensional reality of the disease, experienced by the patient, and the clinician. From the point of view of the academic world, the considerable importance of biomarkers is not only to facilitate the introduction of a given substance on the market. A key benefit of exploring and discovering new biomarkers is to better understand the mechanisms controlling the disease in question, which in turn creates the opportunity for a more effective and safer therapy.

A completely new field for the diagnosis and treatment was opened with the mapping of the human genome (the particularly important part of the DNA) [9], preparing the ground for the so-called ‘personalized medicine’ that uses genetic biomarkers to determine e.g. the kind of disease the patient is most susceptible to or drugs that they will best react to [15]. This enables e.g. the stratification of cancer patients to those who can be effectively subjected to traditional low cost-therapies and those who will need to undergo an extremely costly treatment with innovative drugs. The interest in biomarkers is shared by personalized medicine and translational medicine, making the latter sometimes (wrongly) identified with genomics. It is far too narrow an understanding of this broad and largely vaguely defined term.

Early validation in human studies

The use of biomarkers for early, pre-clinical validation requires that the first tests in humans take place earlier than it would traditionally be the case. This approach and the denial of linearity of the medical innovation process are common features of many translational projects. If one were to indicate the most recognizable slogan accompanying translational medicine, it would surely be: ‘from the bench to the bedside’ (i.e. ‘from the laboratory to the bedside’), reflecting the emphasis on the practical application of new discoveries. The essence of translational medicine is better expressed using another slogan: ‘from the laboratory to the bedside and back’ [16] which takes into account the two-way flow of knowledge in translational projects – on the one hand, scientific discoveries are developing clinical capabilities, and – in return – the clinical observations provide scientists working in labs with important insights and data for further work. In this sense, the process of discovery and implementation of new medical technology into clinical practice is neither one-way, nor linear. It does not need to start with the discovery in the field of basic sciences, and is characterized by multiple feedback loops at the interfaces between the subsequent stages of new drug development. Interestingly, such approach towards creating a medical invention is typical also of the general modern concept of innovation generation. The constituent feature of this modern concept is the transition from a supply model, where the science sector plays a major role, to the demand model, assuming the earliest possible involvement of practitioners/users in the process of creating new solutions [17].

Interdisciplinary communication

Good communication between scientists and clinicians know the problems and needs of patients is a key to success of a non-linear and two-directional translational project. Ideally, the same staff are involved at different stages of the translational – both scientific and clinical – process. However, this postulate is made very difficult by the vast amount of knowledge one person needs to have to fulfil these two roles well [12]. The development and specialization of science separates not only scientists working in basic fields, theoretical doctors and medical practitioners. Also within the researchers working in related areas – such as, genomics, molecular biology, neuroscience, bioengineering and bioinformatics, cell culture, biotechnology, biophysics, pharmacology and pharmacokinetics – a common language and good communication are often lacking. Translation is therefore often understood also as an interdisciplinary agreement of representatives of a wide spectrum of basic scientific

fields, and translational medicine becomes the banner under which they work jointly with clinicians, pharmaceutical industry, and finally the patients themselves to generate new quality in health care [18].

New models of financing the development of new drugs

The traditional model of new drug development involves a large commitment of public resources for early, preclinical stages of the development cycle. One of the instruments of this funding is – among other things – supporting basic research in life sciences. The cost of later stages of this process i.e. research on the proper dosage of the drug substance, the best form of administration, general safety and efficacy, are typically borne entirely by the pharmaceutical companies. Between the early and late stages of drug development extends the so-called 'valley of death', where potentially effective substances become halted. The high cost of conducting further work on them and the huge risk of failure in the clinical trials stage causes a lot of potentially successful projects to be abandoned[4] [19]. Meanwhile, there is enormous demand of aging European societies and the rapidly developing Asian and African societies for new pharmaceuticals. There is also immense public pressure for greater translational efforts, resulting in new funding sources coming from different areas, e.g. governments and supranational organizations, charities [9] or public collections. For example, the Wellcome Trust has earmarked 91 million pounds for the Seeding Drug Discovery project subsidizing various stages of developing pharmaceuticals. The development of new drugs is also sponsored by other charities, for example The Bill & Melinda Gates Foundation which supports the fight against malaria and tuberculosis in developing countries. Another new model of financing the development of new drugs is the public-private partnerships, for example the Innovative Medicines Initiative, with a total budget of 2 billion euros, covered in equal parts by the European Union and the EFPIA, the European Federation of Pharmaceutical Industries and Associations.

It is important to realize to what extent the development of new drugs is financed (though not always directly) from public budgets – in the first place by funding basic research in life sciences, and later through targeted grants for science and business partnerships and by training scientific personnel and finally through the massive purchase of new medicinal products. This means that governments and societies providing funding for research and development may demand that new discoveries in life sciences be carried out with a practical clinical application in mind and then made available in open models. An 'open innovation model' implies openness in sharing research results between commercial and non-commercial research teams. This approach assumes that the increase in the number of people trying to solve the same R&D problem will result in a prompter success [20]. Open innovation is likely to be effective in developing new solutions, but poses a major challenge for the business model of pharmaceutical companies, most of which have the tendency to restrict knowledge rather than to open it. From their point of view, only a patent guarantees returns of the development investment. Very few companies see open innovation not only as the noble aim to improve public health, but also an opportunity to break the deadlock of the pharmaceutical sector. Hence, for example, Eli Lilly took the initiative to share their research results as part of the Open Innovation in Drug Discovery project.

New organizational models

New translational projects are no longer conducted in a centralized way, in research departments of large pharmaceutical companies. The increasingly common business partnership with the academic world can produce synergies since the two communities will focus on what they know best [16].

The scientific component of the project is now mainly realized within the walls of the university and to a large extent it is the scientists who play the role of the project leaders [9]. Often a few scientific research teams work within one project and each of them focuses on the selected aspect of the research problem [14]. Joint research programmes contribute to creating a network of researchers and build the competencies of the people involved. With time, this can lead to the creation of purely academic units aiming at new drug development, such as the Institute for Cancer Research, Centre for Cancer Therapeutics in London (England); Imperial College Drug Discovery Centre, London (England); Texas Therapeutics Initiative of Houston (USA) and the Centre for Drug Research and Development in Vancouver (Canada).

In turn, the industry generates a business model and coordinates the entry of the product into the market. It also provides management solutions and ensures that the scientists' work meets stringent quality requirements. These organisational enhancements can truly improve some phases of the process of discovery, testing, and deployment of pharmaceuticals; however, whenever the results depend primarily on the discovery, the serendipity factor is crucial.

Translational medicine and public health

Translational strategies go far beyond the laboratory, and far beyond the process of discovering new drugs. An integral element of the translational process is its implementation into clinical practice, often made possible only through reimbursement and promotion. This has led to the emergence of the idea that a molecule in the development stages should be optimized for economic evaluation which it needs to undergo before being launched. Obviously, reimbursement of new therapies brings serious consequences not only for the budgets of the ministries of health and insurance companies, but also for public health. However, the relationship between translational medicine and public health is more complex. For example, Ogilvie [21] proposes a comprehensive model indicating a multidirectional relationship between life scienc-

es, social health sciences, pro-health behaviours, health status and public policies. On the other hand, Kardas [22] points to the consequences of the implementation of new technology, especially bio-informatics, into the practice of family physicians and epidemiological research.

Prospects for the development of translational medicine in Poland

The interest in translational medicine has reached also Poland. In 2011 Warsaw hosted a Polish-German seminar titled 'Translational research in diseases of the cardiovascular system' [23, 24]. In 2012, a new consortium was established – the Centre of Chemistry, Biology and Translational Medicine Poland, working in cooperation with the prestigious American centre engaged in oncology research, MD Anderson Cancer Center, University of Texas. Last but not least, OMICRON – the first modern genetic testing laboratory was set up at the Faculty of Medicine of the Jagiellonian University, followed by the Malopolska Centre for Translational Medicine. The latter initiative was funded by the Malopolska Voivodeship, whose authorities chose life sciences to be one their 'intelligent specializations' (i.e. strategic areas) [25]. In addition, a number of highly advanced research projects are being conducted in Poland and although they do not bear the translational label, they are part of this research trend. A good example is the EU-funded study of epilepsy and tuberous sclerosis. The aim of this project, run under the name EPISTOP by the 'The Children's Memorial Health Institute', is to understand the mechanisms of these diseases through the identification of diagnostic biomarkers. The results of these studies can be used in the future to develop new targeted therapies.

There is no doubt that high-quality research projects in the field of life sciences can be successfully implemented in Poland. The question is whether we are able to successfully carry out the translational work from the beginning to the end, which is to actually apply new solutions in the clinical setting. Table I contains a summary of the most important decisive factors. Following the SWOT methodology, these factors have been divided into four categories. The internal factors that have a positive effect are listed in the upper left corner (relating to the characteristics and resources of Poland) – these are the strengths. The internal factors impacting negatively are listed in the upper right corner – these are the weaknesses. In the bottom half of the table external factors related to global rather than local conditions of translational medicine are presented – these are the opportunities and threats for the development of translational medicine in Poland (**Table I**).

The factors listed in the table are arranged in several thematic issues, which are discussed below in four sections – Clinical trials in Poland, Innovation efforts at Polish pharmaceutical and biotechnological companies, Polish scientists and innovation and the Functioning of universities.

Table I. *SWOT analysis for the development of translational medicine in Poland*

Strengths	**Weaknesses**
✓ very good pool of patients for clinical trials because of the large absolute number of population, and prevalence often higher than the European average [w adz] ✓ very good academic background, well-equipped laboratories [w] ✓ many good specialists working in narrow fields [w*] ✓ stream of government funding for innovation in medicine [w adz]	× high rate of patient resignation from participation in the study × very low innovation of Polish pharmaceutical companies [w adz] × a relatively small market for innovative therapies (dominating market of generic drugs, little chance for reimbursement) [adz] × lack of experience in the development of new drugs [w] × lack of appropriate regulations for the conduct of clinical trials, or imprecise regulations [w adz] × scant tradition of cooperation between science and business (both in medicine and in other fields) [w] × lack of curricula adapted to the needs of translational projects [adz] × low innovation of researchers (poor knowledge of the industry, lack of interest in the implementation, copying foreign research) [w] × little interest of university, little interest of professors in applied research, erroneous understanding of basic research [w]
Opportunities	**Threats**
✓ compared to Poland, much higher labour costs, even specialized, in the most technologically advanced countries	× global oligopolistic nature of the very competitive pharmaceutical market [w adz] × cost of the process – no possibility of financing it entirely from its own business resources or grants [w adz] × insufficient availability of funds covering *proof of concept* [w] × decreasing role of venture capital funds in the life science industry [w]

The 'w' index indicates the factors that have been identified in the course of in-depth interviews. The 'adz' index means the factor emerged in the course of existing data analysis. The asterisk * indicates the factors for which there were conflicting opinions in a series of interviews.

Source: Own elaboration.

Clinical trials in Poland

Due to the ease of patient recruitment, Poland is one of the most attractive markets for conducting clinical trials in Europe. A large absolute size of the population, and a suboptimal health status of the population, allows a relatively prompt collection of the necessary pool of patients. The patients agree to participate in research on experimental drugs relatively willingly as new, innovative therapies are seldom funded by the National Health Fund [26]. However, the benefit of the rapid recruitment for a clinical trial is to some extent undermined by a large percentage of those who drop out of participation in the course of the project. This factor is crucial because maintaining the highest possible proportion of patients correctly using the new therapy during the clinical study is essential for results credibility. Losing data on the progress of the disease for more than 5% of patients jeopardizes the entire time- and cost-consuming project involving hundreds (and sometimes thousands) of participants [27]. One of the experts, who otherwise speaks very positively about Polish doctors, suggested that they often lack soft skills which would facilitate convincing the patient to continue treatment and participation in a clinical trial. The fear of losing patients involved in the study is discouraging the pharmaceutical industry from recruiting participants to experiments based in Polish clinical centres. At the same time, imprecise regulations on clinical trials impede or prolong the negotiations between clinical centres and pharmaceutical companies (called sponsors). The former are often afraid of being accused of double funding of medical procedures, especially because the precise separation of components of the procedure paid for by the National Health Fund and those covered by the sponsor, is difficult and tedious. Pharmaceutical companies interested in conducting clinical trials in Poland become discouraged by the long duration of the bureaucratic procedures required to run the study, and often transfer their trials over our eastern and southern borders to countries, such as Ukraine or Hungary.

Innovation efforts at Polish pharmaceutical and biotechnological companies

A good patient base for clinical research could be useful for the pharmaceutical companies in Poland. According to INFARMA estimates – the Employers' Association of Innovative Pharmaceutical Companies – as many as 450 pharmaceutical companies [28] operate on the Polish market, and there are countless companies offering medical devices and services. According to INFARMA, sixty-two are innovative companies which conduct research on new therapeutic compounds. However, the vast majority of companies operating on the Polish market, including almost all native Polish companies, produce only generic drugs, whose chemical formula has been developed by foreign research centres.

It should be realized that the Polish market for generic drugs is extremely absorptive and has been increasing since 2004 [26]. The National Health Fund is willing to buy and reimburse drugs that are cost-effective but is very reluctant to finance innovative therapies. Polish companies showing interest in the production of new drugs must therefore expect to compete on the international, oligopolistic market of giants, who have mastered the process of managing the development of new drugs. For many companies, the entry barrier may be too high. According to information received from our respondents the pioneers and key players in the domestic innovative pharmaceutical market are two Warsaw-based companies: Adamed and Polpharma, as well as a biotechnological company Bioton. These few cases of independent, extensive work on new therapeutic substances require a large mobilization of resources and rapid training of the involved personnel. Quick learning, however, is not sufficient as the search for new drugs, the so-called drug-hunting, requires many years of experience. According to our expert, people with such experience and competence are simply not to be found in Poland. It is for this and other reasons that the venture towards the discovery of a new molecule must be supported by external, foreign consultants.

> (We lack a person) who would be able to plan the project, choose a variety of options, and then to interpret the results and to see if (the molecule – editor's note) meets the criteria, whether it is the right one or not, and so on (…). We need to combine these blocks, that is what we are missing, because we have never worked towards a common goal so far, have we?
>
> *Scientist working on the discovery of new therapeutic molecules*

In recent years, one of the Polish pharmaceutical companies actually reached an advanced stage of new drug development, a precedent on a national scale. The molecule, obtained in a Polish laboratory, underwent the pre-clinical phase and was qualified for the first phase of clinical trials. These studies, however, were not performed in Poland but abroad. According to an expert we interviewed, this decision was rational in the light of the partnership with a foreign organization that had already had the know-how and experience in first-phase clinical trials. The second important factor in favour of the continuation of research in another country was probably the shorter path to potential registration of the drug by the American FDA (Food and Drug Administration). This situation is hardly surprising. The innovative drugs market is a global one, and new discoveries are created in a global context. Even if an institution manages to develop a medicinal product based on their own internal resources, the process leading from the laboratory through clinical trials to market entry may not be possible without international financial support. The above-mentioned molecule developed by Polish scientists passed the first phase of clinical trials, but work on its further development was suspended because of the enormous cost, the long duration of the process and the high risk of failure. In other projects, conducted perhaps with less momentum, the financial barrier is sometimes too high. At the initial stage of innovative work, a com-

mon barrier is insufficient funding sources of the so-called *proof of concept*, or prototype. As indicated by an expert, the prototype is a necessary element of communication at the stage of establishing science-business partnerships. It allows, for example, to clearly present to an interested party the features and capabilities of the technology developed by scientists. However, prototypes are not easily funded – they cannot be covered by grants from the National Science Centre, and at the early stage they are not interesting for the industry, also the universities themselves cannot provide the funding, at least not on the scale which is required, according to the expert. In addition to that, funds from capital funds allocated to life sciences projects are shrinking. Some investors, discouraged by the very high risk which the innovative drugs market is burdened with, direct their interest to the flourishing IT sector. Some help is presented by the new streams of funding cooperation between science and business, launched by the National Centre for Research and Development, such as the INNOMED programme.

Polish scientists and innovation

However, not all respondents indicate the financial difficulties to be the main barrier to innovation in pharmaceutical and related industries. Some of them argue that the biggest challenge is the low innovation predisposition of Polish scientists, who do not have a good insight in their fields, do not follow the latest discoveries, and are instead satisfied with small successes on a local scale. According to the expert (employed in one of the institutions supporting the transfer of knowledge), scientists do not understand patent law and cannot use patent databases. Sometimes praising their new discovery, they are not even aware that a similar one has already been patented. The issue of the quality of work of Polish scientists was described differently by other respondents, who indicated their excellent preparation for work in a narrow field, and relatively low remuneration compared to the scientists from the international market.

Perhaps it is true, then, that Polish science has a group of great professionals who are, however, unable to work together, making it very difficult to achieve common, complex goals, which the development and introduction of new technology on the market always is. Here is another remark by the already-quoted expert:

> And this [the creation of a new drug – editor's note] may therefore be unsuccessful, because our transplant specialists are great, our behaviourists are great, our oncologists are great, but the drug is a very complicated thing, even a 'drug candidate' because the drug is so much more than that. Meanwhile we are missing reviewers, consultants, good project leaders, but we're not lacking specialists, and equipment not in the least.
>
> *Scientist working on the discovery of new therapeutic molecules*

The same issue is indicated by Guzik [12] and other Polish scientists. Prof. Jerzy Naskalski [29] called upon the members of the College of Translational Medicine in 2010:

> (...) teaching new people who take on jobs in different departments of laboratory medicine is done in a way that preserves the traditional divisions into specializations described using specific names of university Chairs and Departments. This happens despite the fact that in practice there are no technical nor intellectual premises for these divisions.

So the question arises, why medical schools maintain outdated teaching methods that do not meet our rapidly changing reality, in the world of science, and also in the quickly evolving clinical practice? With all certainty, policymakers *are* aware of the shortcomings of the current curriculum, but there is probably no academic consensus as to the desired direction of change, needed to start radical reforms. According to one respondent, exceptionally good results of translation could occur if the system supported a way of frequent interaction of different research teams and design – including interaction unconnected with science. Others, however, do not attach to the issue any importance. There is also a group of distinguished professors who are opposing the ever-increasing pressure that science be useful and that implementation efforts be undertaken. This is one of them speaking:

> We are primarily interested in scientific research, because we believe that this is the fundamental vocation of any scientist: to discover the truth, to attempt to explain the functioning of the systems that we deal with. But since we deal with, for example, a field [field name] where some application may arise ... may, but may not, and so it is not our main objective.
>
> *A prominent scientist in the field of life sciences*

The functioning of universities

From the point of view of university authorities, innovative research projects in partnership with entrepreneurs bring a certain prestige and acclaim. Some university authorities look favourably on innovative and implementation work, and even support them. However, this dimension of university activity is not considered a priority by many decision-makers and influential professors. Despite the fact that for several years there have been ongoing attempts to try to open up the possibility of cooperation with industry, Polish universities are still a very difficult partner. As indicated by one of the respondents and the experience gathered during the running of the SPIN project, the wording of the consortium agreement between the university and the company is a very difficult task, requiring patience, willingness for concessions, and time. Our respondents indicate that universities have to face the challenge of the excessive ambition of their scientists who do not allow their research project to be too strongly intervened. On the other hand, entrepreneurs do not understand the specifics of university work and demand a corporate mode and pace of work which universities find unattainable and often undesirable. These difficulties in science-business cooperation probably result from the limited experience of Polish universities and businesses in this arena. It should be expected that with time a path will

be paved for subsequent research teams to follow. So far, two solutions to this impasse can be seen in Poland. The first is the creation of Centres of Technology Transfer, in which employees are familiar with the nuances of the commercialization process and rules for the distribution of intellectual property rights, the so-called brokers, aiming to combine the two often incompatible worlds of business and science. The second solution, commonly used, is to extend collaboration with the university beyond its walls, e.g. through 'brain drain' or employment of academic specialists in research and development departments of private companies, using civil law contracts.

According to one respondent, the faculty is to some extent interested in the prestige associated with conducting cutting-edge research; however, this approach is discorded by the fear that the researchers involved in innovation activities along with their business partners, will neglect their academic work. Meanwhile, the amount of ministerial subsidies financing statutory activities of academic units is dependent on the assessment of scientific achievements – above all publishing – affiliated with individual researchers. According to our respondent, the authorities of university units are very much afraid that this output be reduced, their fear strengthened by the fact that commercialization or application activities are not treated as a purely scientific achievement and that in the current assessment system of scientific institutions and scientists, they do not generate sufficient profits.

Whatever the reason, there are very few truly innovative translational actions that would indeed be directed to the implementation of new discoveries into clinical practice. One of the respondents involved in a major translational project, summarizes this issue:

> [Such projects] are rare because people do not believe that they can achieve something, they do not invest because they are afraid that it is a very risky business. Nor do we know if we will achieve something, in fact, we have a greater chance of failing than succeeding. 'The attrition rate', i.e. the percentage of candidate-compounds that are rejected, is huge, so why invest in something like this? People are afraid; they prefer to [invest] in generic drugs. [...] If you make a lot of them, you can earn quite a bit of money, you can live on it somehow, it's predictable, manageable, and the process is repetitive. I'm not saying that it is not difficult: the market is very aggressive, prices erode in connection with reimbursement activities, and so on, but the level of the complexity of the process is incomparably [lower]. And companies they just don't want to do that, they don't believe it will work. And if this approach continues, it won't work, because they won't do it.
>
> *Scientist working on the discovery of new therapeutic molecules*

Discussion

Poland is a peripheral player in the field of developing innovative medical technologies, including medication. The key decisive factors are the global nature of the pharmaceutical market and the huge time and cost requirements of the drug discovery process, combined with an extremely high risk. Polish companies and researchers usually lack cooperation experience and the competence to independently carry out a very complex project of a multidisciplinary and implementation nature. Highly complex undertakings require technical and financial support of many partners, and drug development is generally a global process and business. The need for such collaboration, however, is actually in accordance with the general objectives of translational medicine. Therefore, instead of asking questions about whether in Poland we can independently conduct complex translation projects, we should ask whether we are able to participate in these international endeavours as equal partners. We are convinced that, thanks to well-educated staff and good technological facilities, our scientists *are* attractive partners. In turn, Polish pharmaceutical companies have high competence and efficiency of production and distribution of generic drugs. These experiences can be their capital also on the innovative drugs market. In Poland, life sciences are regarded as a priority and strategic area for innovation, as it is the case in the Malopolska Voivodeship. This will lead to a growing public pressure on achieving and promoting the social benefits of investment in the area of life sciences. Our SWOT analysis shows that the new policy to encourage innovation in medicine should be aimed at facilitating the efforts of Polish entrepreneurs and scientists to build various international partnerships. In the early stages of development of new medical technologies it is worthwhile to promote scientific and business partnerships and finance prototypes, for example within start-ups. Providing subsidies for Polish pharmaceutical companies, e.g. by the National Centre for Research and Development, should be associated with realistic expectations as to the outcome of their work – although new drugs cannot be introduced on the market using state subsidies, certain stages in the development cycle of new drugs can be finalized and can form the basis of negotiations with investors. It should be expected that the most attractive projects, including those financed with public money, will be introduced on the international market. The advantage of entering the global markets will be increased know-how in the field of drug discovery, clinical testing, and process management, as well as developing a network of international business contacts. However, the vision of the independent development of new drugs we find unrealistic.

An important factor in the formation and development of translational medicine are the global trends in the international scientific community. The concept that science be open to cooperation with institutions operating in its environment: businesses, regional authorities and non-governmental organizations, is currently gaining popularity [30]. These are not easy partnerships to establish and maintain; therefore, there is need to introduce institutional arrangements that will intensify cooperation between science and stakeholders interested in practical application of the research results.

An example of such a solution is the Malopolska Centre for Translational Medicine which operates at the interface of science, business and public administration. One of the elements of its strategy is focusing on personnel training so that they will be able to support the

processes of translational medicine and life sciences. It is open to projects that generate small costs (compared to those incurred by the search of new drugs) and at the same time have implementation potential. In our view, initiatives such as the search for new diagnostic and preventive measures, construction of medical appliances, planning new therapeutic regimens – can be of great importance from the point of view of public health, and at the same time it is indeed feasible to implement them based entirely on internal, Polish resources. A similar strategy is assumed by some prestigious world universities. For example, University College London (Wolfson Institute for Biomedical Research) is primarily involved in screening and medical chemistry [9], while Stanford University operates the SPARK programme, bringing together scientists, entrepreneurs and other experts to monitor and support medical projects developed there.

Summary

Translational medicine, understood as a new trend in research and clinical practice has grown out of – on the one hand – the observation of how inefficient the traditional development cycle of new drugs is, and – on the other – from the social expectations that the scientific community and the pharmaceutical industry provide new life-saving and health-promoting solutions [31]. The very concept of translational medicine is not precisely defined, and its general understanding as "the process of implementing new medical achievements in clinical practice" gives rise to many interpretations. A very narrow business understanding of the term is that it is a set of strategies used to increase the chance of success of a new drug in the second phase of clinical trials. A slightly wider academic approach puts greatest emphasis on the clinical use of discoveries from basic research, reducing the enormous gap between the rapidly increasing number of promising results of basic research in life sciences and the very small number of new therapies [12]. The optimization of research and development efforts, in this sense, is to also lead to the reduction of the period from the first observations in the laboratory to the registration of new therapies and bringing them into general use, which may even take 30 years. From the point of view of clinicians, the definitional element of 'translational medicine' is its interest in bio-markers (primarily genetic), whose discovery facilitates the exploration and understanding of complex disease processes. In effect, it leads to a better diagnosis and personalized therapy (e.g. by means of targeted therapies). In the broadest sense, the translational approach emphasizes the need to join forces in a number of specialized teams to make a new medical technology possible. Translational medicine is to be an approach that will unify the goals and means of communication of these diverse groups, which will enable the optimization of the innovation process and a faster implementation of new technology in a clinical setting.

To our knowledge, there has not been any systematic analysis serving to decide whether the philosophy and tools offered by translational medicine actually accelerate the discovery of new drugs and their introduction into clinical practice. However, in the face of the pharmaceutical crisis and high social expectations, it is necessary to search for new solutions to meet the growing demand of the increasingly informed and demanding patients. Poland should participate in this process, and not just as a donor of patients for clinical trials.

In our opinion, the financial requirements, and technological and organizational challenges of new drugs are too demanding to enable a full cycle of translating new drugs based on only indigenous resources. Nevertheless, Poland can still be an attractive place to conduct specialized research. The high level of competence of at least a part of Polish scientists and the vast experience of Polish companies in the production of generic pharmaceuticals make them valuable members of international research consortia. This is how we imagine the future of translational medicine in Poland.

Notes

[1] The authors were involved in the foundation of the Malopolska Centre for Translational Medicine, funded by the SPIN Project (www.spin.malopolska.pl).

[2] NME (*New Molecular Entities*) and *biologicals*.

[3] Reference to the so-called target-based approach, a modern technique based on the understanding of physiological mechanisms, typical of the projects developed since about 1990 [15].

[4] This is problematic especially in the case of potential drugs for rare or tropical diseases.

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The Therapeutic Power of Contact: Physician–Nurse–Patient. Innovative Education of Medical Staff in the Perspective of Health Psychology

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Abstract

Introduction. The role of physician and nurse in the therapeutic team depends on the prevailing medical model of health: biomedical or holistic and functional.

Purpose. The theoretical basis of the therapeutic role of doctor–nurse–patient contact from a psychological perspective is the Functional Model of Health created by Helena Wrona-Polanska.

Material and methods. 141 people after bone marrow transplantation were examined at the Hematology Clinic of Jagiellonian University. To examination were used the questionnaires of stress, coping strategies, personal resources, and grading scales of health and anxiety.

Results. Analysis of the results revealed predictors of subjective health and difference between subjective and objective health.

Conclusions. Author's Functional Model of Health used in the analysis of nurses work shows the complexity of the physician–nurse–patient contact: instrumental function, cognitive function, emotional function as a basis of innovative educational program for physicians and nurses.

Key words: **health, therapeutic contact, patient, education**

Słowa kluczowe: **zdrowie, kontakt terapeutyczny, pacjent, edukacja**

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Introduction

In the issue of health, from the therapeutic and health-promoting point of view, the relationship that plays a crucial role is the contact between a patient and his physician, nurse, psychologist, and generally with a therapeutic team which significantly and actively determines the convalescence process. Marek Motyka [1] presents the problem of therapeutic communication, emphasising in detail its multifaceted advantages in a relationship nurse-patient. In his opinion, the core of a therapeutic contact is a conversation with a patient. However, a contact with a human being, also with a sick person, is not only limited to verbal aspects. Sometimes non-verbal communication based on empathy and common understanding is more significant. The base of such a contact is the trust in a physician, a nurse or a psychologist, which builds the sense of security and reveals positive emotions that mobilize to take up action for their own health. Such a contact has a therapeutic nature, gives hope for regaining health, and thus, has a sanative power. It is an extremely important problem, which is going to be discussed in detail from the author's point of view of the Functional Model of Health.

Professor Julian Aleksandrowicz was an example of a therapeutic contact between a physician and a patient. He was a prominent physician-humanist, internist and haematologist, a director of 3rd Clinic of Internal Medi-

cine, and later a director of the Haematology Clinic of Jagiellonian University of Collegium Medicum. He was also an initiator of research on health and a 'hope-giver' for incurably sick children suffering from leukaemia.

In 1972 he organized a conference in Cracow whose main objective was: "to saturate awareness of young and adults with the knowledge of factors which aid health of individuals and a society" [3]. The conference became a beginning of a scientific-humanistic revolution whose aim was to increase the health awareness of the whole international community [4] and was named around the world as the 3rd health revolution. Beside the entrance to the Haematology Clinic of Jagiellonian University of Collegium Medicum there was also an inscription: "the Clinic does not only cure but it also teaches how to live to maintain health".

To analyse the therapeutic power of contact in detail, it is necessary to refer to health which is its main objective, because a type of the contact largely determines the understanding of health, which was changing significantly throughout centuries.

The issue of health dominated the 2nd half of last century, although the first source of information about health comes from Hippocrates (4th c. BC) who is considered the Father of Medicine and who equated health with well-being and pointed to indissoluble relationship between a human and his vicinity and individual lifestyle as important factors that influence health [5]. Systematic concern for health is connected with development of social movement in favour of health promotion and formation of health psychology [6, 7].

The changes in the way of thinking about health and its conditioning are connected with changes at the turn of 19th and 20th century. Treatment of infectious diseases and the use of vaccinations appeared to be insufficient while non-medical influence on the environment turned out to be necessary to increase the level of hygiene of peoples' lives [8].

The development of industry contributed to the spread of lifestyle diseases and a significant increase in mortality caused by cardiovascular diseases, cancer and accidents at work [9]. The research aimed at identifying causes of the diseases in work environment and lifestyle were started, which required an interdisciplinary approach to scientific research and treatment. Behavioural medicine emerged also at that time, which treated a human being as a biopsychosocial individual [10, 11]. The approach resulted in epidemiological research aimed at identifying risk factors of the diseases in work environment, lifestyle and behaviours dangerous for health. It also showed the possibility to influence an individual's own health through the increase in social and individual awareness within the scope of health care and health promotion.

The non-medical influence directed at physical and social conditions, lifestyle and awareness of an individual and society helped to create holistic and functional model of health, its conditioning and promotion.

The objective of the article is an attempt to answer the question: What does therapeutic power of a contact physician-nurse-patient rely on from the perspective of health psychology and the Functional Model of Health of Helena Wrona-Polańska [12], which defines health is a function of creative coping with stress.

The answer to this question will be a theoretical base for presentation of a new prospect in education of medical staff from the perspective of author's Functional Model of Health, health psychology and novelisation of educational program which will involve meeting needs and expectations of patients and their families.

1. Models of health

There are two models of health: biomedical and holistic and functional, also called biopsychosocial or ecological model [13]. Both models come from different visions of the world, human and his relationships with social environment, which results in different understanding of health and its conditioning.

In health psychology we may also find socio-ecological model [14], which only elaborates the sources of social conditioning.

1.1. Biomedical model

Biomedical model is based on Cartesian dualism and the mechanistic vision of the world and man. It contributed to the development of narrowly specialised medicine [15]. In this model, health is an objective category of a negative nature, diseases are caused by genetic factors which are results of objective factors – bacterium, viruses and fungi. In a relation physician-patient, a dominant role is played by physicians with a specialized knowledge and practical competences, while patients are subjects of their treatment.

A strict assessment of medicine which does not take into consideration needs of a patient [16] and the research, which showed that emotions may decrease resistance of an organism and cause psychosomatic diseases, contributed to extending the model of health on the biosocial one [17–19].

1.2. Holistic and functional model, biopsychosocial

The specificity of the approach to health in this model is taking into consideration the wide context of its conditioning while a systemic theory, which relies on the hierarchism of systems and the autonomous nature of each of them, is the basis of the model.

The systemic vision of the world with a human being in the central position of the ecosystem is best conveyed by the Mandala of Health – a Model of the Human Ecosystem [20]. The most distant systems that influence a human are: biosphere and psychosocial environment, that is culture, while the closest is family which intercedes between a man and biosphere and culture. Health is determined by Lalonde's 4 fields of life: biology of a human, physical environment, psycho-socio-economic environment and behaviour of a man. There are multiple relationships and common interfusions between these systems.

The Mandala of Health indicates the complexity and multidimensionality of relations between a man and the world which result in the need to consider health in a holistic way from the functional perspective and take up interdisciplinary research on health issues which define practical activities aimed at increasing or restoring health potentials and forming pro-health beliefs [12, 21].

1.3. Salutogenesis model

This model is closest to health psychology because it refers to assumptions of psychological theory of stress of Richard Lazarus and Susan Folkman [22]. In salutogenesis approach, the core of health is the activity of the subject which heads to keeping a dynamic balance between requirements of the vicinity and the potential of a man and his confidence about his own competences and sources of support.

In the processes of balancing, an important role is played by 4 stressors (their type and nature) which come from biological and psychological structure of a subject and their relationship with the vicinity, generalised resources of resilience (biological-genetic, psychological and social), and the sense of coherence which is crucial for health [23]. Strong sense of coherence, i.e. inclusiveness of cognitive and emotional factors, determines the cognitive assessment of stressors and activation of adequate resources to overcome them and reganing and maintaining good health.

The salutogenesis model became an inspiration for several research connected with health which also concerned its verification as a whole or some of its variables, especially the sense of coherency. The works of Polish authors such as: Barbara Mroziak and Adam Frączek [24], Helena Sęk [25], Helena Wrona-Polańska [12, 26] and Władysław Łosiak [27] deserve exceptional credit.

2. Conceptions of health

In biomedical model, health is defined as a state in which none disease entity included in International Classification of Diseases comes forward [28].

However, it is difficult to agree with the definition as lack of symptoms is not always the indication of health, especially in somatic diseases of inauspicious prognosis, cancer, whose beginnings are often unseen not only for a sick person but also for a physician, and the diagnosis involves technical examinations, e.g. in blood cancer.

The first definition of health of the positive and holistic nature was formulated by World Health Organisation in 1948. It equated health with plenitude of physical, psychological and social well-being, and not only with lack of sickness or disability [29].

It was the first holistic approach to health which involved both subjective and objective factors and its wide social context. However, the weak point of such a definition of health was its static nature, difficulties in operationalization of the plenitude of health, i.e. welfare and idealistic approach.

Development of social sciences contributed to consideration of health in the categories of resources (disposition and health potential) and the process heading to keep the health balance.

The health in the categories of resources was defined as "the man's ability to achieve the top of one's own physical, psychological and social potential and react to challenges of environment, which subjects to changes" [20, p.38].

According to Julian Aleksandrowicz, health is "a state in which a person is able to confront stimuli from the environment in such a way, that the adaptive process does not disturb homeostasis between soma, psyche and environment, and consequently does not harm the organism" [30, p. 80].

The definition emphasises the dynamic and processual nature of health, although it defines it as a 'state'.

For Julian Blicharski [as cited in 4, p. 80], "health is a self-steering process of keeping balance between anabolic (formation) and catabolic (decomposition) processes on somatic ground, integration and disintegration on psychological ground, syntony and dystony on the social ground and the balance between these three grounds in the boundaries assumed as normal".

It was the first approach to health as a process which resulted from consideration of a man as an indivisible and functional entirety, with his wealth of experiences and personality, embedded in a social context [12].

The research on health is continued by students of professor Julian Aleksandrowicz: Aleksander B. Skotnicki – from the medical aspect [31], Jan Dobrowolski – from the ecological aspect [32], and Helena Wrona-Polańska – from the psychological aspect [12, 21, 26, 33, 34].

In salutogenesis model, health is a process of searching and keeping a dynamic balance between a man's potential and requirements from the vicinity. It is based on a relationship between mutually influencing "resources available for a man, his behaviours and requirements of everyday life" [35, p. 51].

The resources are: vital energy, biological immunity of an organism, subjective resources – positive self-esteem, sense of coherency, sense of control, vital optimism and external resources – natural and social, and also pro-health and pro-ecological values included in systems of individual and social beliefs [3, 12].

The research of the author carried out among 299 healthy people [12] showed that for the emphatic majority, health is a synonym of happiness, positive attitude to life, but also helps to deal with difficulties in a better way. In uninhibited dicta, the respondents defined health as a resource, disposition, and process lasting in time, and healthy people as active and easily dealing with life and job difficulties.

From presented research of the author it may be concluded that colloquial awareness of health is a basis of assessment of subjective health, which is considered as the sense of internal harmony, comfort related to positive attitude to life and life responsibilities.

The holistic and functional model of health as a process includes not only the assessment of working of one's

own organism, i.e. the balance on the somatic level, but also the psychological balance (referring to mental regulation systems), social balance (concerning relations with other people) and balance in the deepest psychical layer (concerning Sacrum). As the research of the author showed [26], the latter plays a significant role for majority of the sick.

Summarizing, presented models and conceptions of health showed how understanding and approach to health have been changing throughout years. In biomedical model, health was defined as lack of diseases, while the aim of physicians' and nurses' activities was remission of the symptoms.

In holistic and functional model the influence of medical team are headed to regain health in all its aspects and dimensions and good quality of life, which requires the interdisciplinary cooperation and systemic influence of a patient.

The research literature and clinical practice show that a role of a physician and a nurse in a therapeutic team depends on the model of health that prevail in medicine – biomedical or holistic and functional, and consequently the assumed conceptions of health.

3. Functional model of health

The source of the author's research on health comes from clinical experience at work with patients suffering from leukaemia and results of own research in the Haematology Clinic of Jagiellonian University of Collegium Medicum managed by professor Julian Aleksandrowicz. They showed a significant role of psychological defensive mechanisms in coping with anxiety, and especially the positive role of repressive defensive mechanisms and regulative function of self-concept of patients in coping with leukaemia. Those patients who denial the illness and were repressive the anxiety had an unrealistic but positive self-concept of themselves which assured the stability of the self-concept and keeping own identity. It triggered positive emotions and fostered the acceptance of oneself as a sick person and active cooperation with medical team in favour of one's own health [36–39].

The results of the author's own research, the willingness to continue Cracovian research on health and aspiration to promote health among teachers and educators, who together with parents are the first animators of children's health, became an inspiration to research on health.

The aim of the research was to analyse health, its conditionings and mechanisms, and not negative consequences of stress which was taken into consideration in a completely different semantic context. Stress in the salutogenesis model plays a regulative role (through the mobilisation of resources) in contrast to its threat role in a patogenetic model .

The Functional Model of Health was based on assumptions of holistic and functional model of health, systemic theory and results of own research.

As the theoretical basis of the model of health a few theories were accepted: the theory of stress of Richard Lazarus and Susan Folkman [22], the theory of stress in a model of resources by Stevan Hobfoll [40], the theory of salutogenesis by Aaron Antonovsky [23] and Creative Problem Solving (CPS) (pol. TroP... from Twórcze Rozwiązywanie Problemów) of Edward Nęcka [41].

The Functional Model of Health is presented in **Figure 1**.

The level of health in the author's model depends on the assessment of stress, ways of coping with it and subjective resources. Creative coping with stress, according to TroP (Creative Problem Solving) means nonstereotypical dealing with a problem, which is always adjusted to a situation, with the use of both rational and irrational (i.e. defensive) strategies. The choice of strategies is determined by the cognitive assessment of the situation which depends on own resources, i.e. attributes and potential which in a stressful interaction play a positive defensive role and thus buffer negative influence of stress [40, 42].

In Functional Model of Health [12, p.100] resources were divided into subjective and situational. Subjective resources are divided into: biological, cognitive and behavioural. Situational resources are divided into: material and social. On the basis of literature and own results, an assumption was accepted, i.e. in creative coping with stress, an important role will be played by cognitive subjective resources: sense of coherence understood as the inclusiveness of cognitive and emotional factors in coping with stress, the sense of control and self-control as a dispositional factor which determines the struggle and positive self-esteem as individualistic disposition which motivates and mobilizes to take up actions in aid of health and behavioural resources, i.e. behaviours which promote health.

The verification of Functional Model of Health based on research on 299 people, who represented various jobs, showed that health is a function of creative coping with stress, which every time is adjusted to the assessment of the situation and from the perspective of one's own potential [12, p. 210].

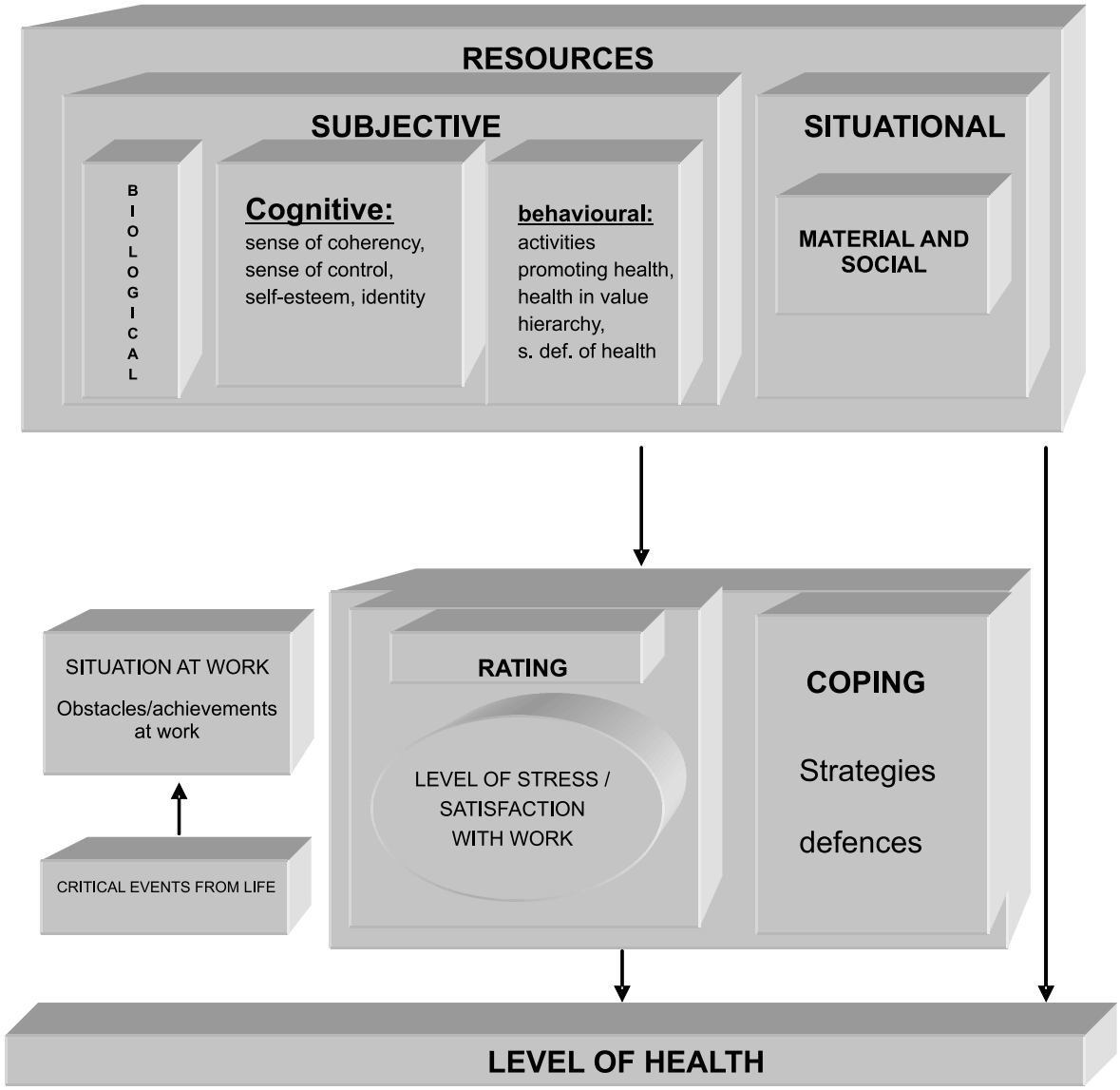
The Empirical Functional Model of Health is presented in **Figure 2**.

Cognitive subjective resources are important psychological mechanisms of health. These are: sense of coherence, sense of subjective control and positive self-esteem. They create pro-health personality which directly and indirectly influences on health. The resources influence the assessment of situation and choice of effective strategies – solving the problem, positive redefinition, search for support and concentration on other thing than emotions and defensive mechanisms of coping with stress (humour, altruism).

According to TroP [41], the process of creative coping with stress requires continuous informational and emotional reinforcement which has source in subjective resources.

The sense of coherence, especially the component of understanding serves as informational reinforcement, which is confirmed by own author's research [12], which showed its proportional character to age of a patient and

Figure 1. *Functional Model of Health*



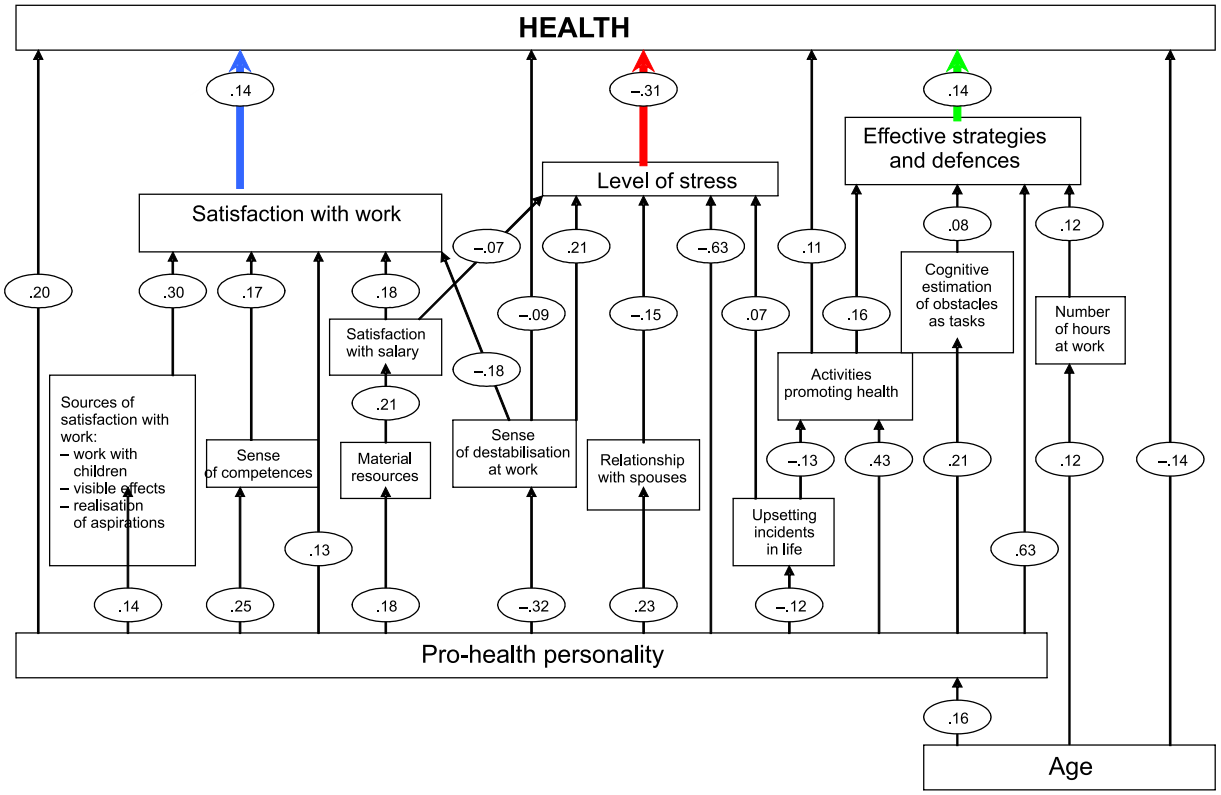
Source: H. Wrona-Polańska, Zdrowie jako funkcja twórczego radzenia sobie ze stresem, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2003: 100 [12].

knowledge and experience he gathered. On the other hand, the function of emotional support is served by the sense of meaningfulness of emotional-motivational nature [23] and positive self-esteem as the evaluative aspect of *self concept*, which triggers emotions that motivate and mobilise to take up actions in favour of health. It is also confirmed by own research of the author [36–39].

As a result of complex analyses of stepwise regression and the analysis of paths, three paths were isolated which determine the way subjective resources, creating pro-health personality, influence health. These are: competence, emotional and the tension – (stressful) pathways

As the graphical presentation of a model of health conditioning presents (Figure 2), pro-health personality has the strongest influence on kompetence path, i.e. coping with stress and with the same strength it influences counteract stress – stressful path, which is visible in the same values of path indicators (.63, –.63). It means that creative coping with stress, adjusted to own assessment of the situation based on awareness of owned resources, results not only in solution of the problem but also reduction of experienced stress. There is no direct connection between stress and strategies of coping with it because stress is always assessed from one's own perspective which triggers effective strategies and defences to deal with it. The Functional Model of Health proves the theory of Richard Lazarus and Susan Folkman, according to which, the cognitive assessment of a situation is only triggered by the process of coping.

Figure 2. *Empirical Functional Model of Health of examined persons*



Source: H. Wrona-Polańska, Zdrowie jako funkcja twórczego radzenia sobie ze stresem, Wydawnictwo Naukowe Akademii Pedagogicznej, Kraków 2003: 210 [12].

Behavioural subjective rules, i.e. behaviours that promote health, especially positive psychical attitude concerning health and conscious taking up activities on its favour strengthen the process of coping with stress.

Biological resources: age and related work experience influence health in such a way, that the older the people were, the worse somatic health was examined and better health of functional nature. The latter is based on experience resulting from work experience which is seen in the increase comprehensibility as a component of sense of coherence, visible in author's research [12].

Emotional path is mostly influenced by situational, material and social resources, which are the source of positive emotions resulting from good professional and social functioning, and consequently in good quality of life. A very important variable, from the perspective of health, is the sense of destabilisation at work as a an indicator of the surveyed, socio-economic changes, reform of education and baby bust. The sense of destabilization at work is directly and indirectly dangerous for health, decreasing the quality of life and being an additional source of stress.

After seven months, the comparative research showed the tendency of respondents to increase their self-esteem in the situational context of decreased social resources and proved that self-esteem functions as buffer to keep balance in resources, and consequently stay healthy [12].

The research showed the regulative role of self-esteem in the process of staying healthy, proving the results of author's research concerning the regulative role of one's own image and self-esteem in effective coping with leukaemia [43–45].

Summarizing, the empirical verification of Functional Model of Health showed the complexity and dynamic nature of psychological mechanisms of health and its conditioning represented with path indicators from the analysis, which allow for identifying mutual influence of examined variables in the process of creation of illness/health. The Functional Model of Health has a dynamic nature in which the level of stress is an indicator of illness/health, i.e. the balance or its lack in the system human-world, and the level of health is determined by pro-health personality, i.e. subjective resources.

4. Functional Model of Health and Illness

The author's Functional Model of Health was used as a theoretical base in research on patients suffering from leukaemia and cured with Bone Morrow Transplantation.

Leukaemia, is one of the most dangerous forms of blood cancer's involving the whole organism, were an enormous problem for patients, physicians and also medicine which had ineffective methods of treatment until recently. It caused particularly strong stress in patients

[22, 36] which resulted from a risk to health and life, social roles that the patients played and loss of a value. The stress was escalated by negative and anxious attitude related to the type of cancer which was tantamount to death [46].

Contemporary methods of treatment for leukaemia, such as: Bone Marrow Transplantation (BMT) or Stem Cells Transplantation (SCT), which allow for successful treatment, contributed to a change of psychological image of leukaemia, from life-threatening to a illness which may be successfully cured [26]. However, low number of marrow donators, the age of patients and their state of health limits the chances to 50% of survivors [47, 48].

Literature of the subject and clinical practice show that leukaemia as a group of cancers need intensive and differentiated treatment [49, 50], including biomedical and psycho-social factors in a diagnosis and therapy [51–55]. Bone morrow transplantation and stem cells transplantation are only the beginning of a patient's way to recovery. The efforts of the whole medical team – a physician, a nurse, a psychologists, activity and cooperation from a patient and his/her family [56, 57] are also necessary in the process of regaining health.

On the basis of the author's Functional Model of Health [12], considered a the theoretical base, a hypothesis was accepted: patients' health is a function of stress, strategies of coping with it and owned resources.

4.1. Method, research techniques and characteristics of patients

The research considered three variables: health, resources, stress and coping with it. In the research, the method of medical interview and observation.

Health was defined in the operational way, with distinction of two indicators: sense of health and sense of calmness which are evaluated in 10-point rating scale, where 1 denoted sick, 10 – healthy and 1 denoted anxious and 10 – calm. The average calculated from results of sense of health and sense of calm was the indicator of subjective health. Whereas objective health was evaluated on 10-point scale by a haematologist.

The level off stress/anxiety was evaluated on the basis of Spielberger's STAI test [58]. It consists of 2 scales including 20 statements each. The first one X-1 allows for measuring the anxiety-state, and the second one, X-2, measures anxiety-quality, used in the research as an indicator of anxious personality.

The techniques of coping were measured with CHIP (Coping and Health Injuries and Problems), in adaptation of Kazimierz Wrześniewski [59]. It consists of 32 statements divided into 4 strategies: Distraction from the disease, e.g. *I dream about nice things*, limitation of stimulation, e.g. *I stay in bed. I sleep a lot*, instrumental coping, e.g. *I do what the physician recommends me to do*, concentration on negative emotions, e.g. *I get angry because it happened to me*.

CISS questionnaire (The Coping and Inventory for Stressful Situations) in adaptation of Kazimierz Wrześniewski [59] consists of 48 statements. It served to analyse 2 styles of coping with stress: a style concentrated on a task – *I concentrate on the problem and I try to solve it*, a style concentrated on emotions: *I worry that I will not deal with it* and a style concentrated on avoiding which may take a form of devoting to substitutive activities – *I traipse around shops* or seeking for social contacts – *I try to hung out with other people.*

The sense of coherency was researched with Antonovsky's Life Orientation Questionnaire SOC-29 [23]. It consists of 29 questions which create 3 subscales: the sense of understanding – *When you talk to other people, do you feel they understand you?*; the sense of self-help – *Were you disappointed by people who you counted on?*; the sense of reasonability – *For you daily activities are a source of: 1 – great satisfaction and contentment, 7 – annoyance and boredom?*

The level of self-esteem was measured with Rosenberg's scale of self-esteem in which 5 statements consider the positive self-esteem – *I feel I am a valuable person,* while 5 consider negative self-esteem – *I sometimes feel that I am useless*. The statements are evaluated in 10-point scale.

The research was conducted from 2001 to 2010 in the Haematology Clinic of Jagiellonian University of Collegium Medicum. 160 patients after bone marrow transplantation were surveyed during control examinations. In the analysis 141 patients were taken into account – 61 females and 80 males, usually 20–40 years old. The majority of patients represented secondary education, and the average time from the transplantation was 2.5 year (SD = 2.8).

The results were analysed with STATISTICA programme, using such tools as: variance analysis, Student's t-test, Pearson's correlation analysis, multiple regression analysis and path analysis [60]. As a criterion which determined the detection of regularity, significance of .05 was accepted in the analysis.

4.2. Level of health of patients

The comparison of subjective and objective estimation of health showed that the average level of the former is M = 6.69 with SD = 2.52, while of the latter M = 7.77 with SD = 2.09. The difference between these variables is M = –1.01 with SD = 2.60, and significance of the difference between the averages calculated with Student's t-test for depending groups was: $t = -4.5900$, $df = 139$, $p \leq .001$.

The higher level of objective health, which results from the knowledge of a physician, in comparison with respondents' own estimation of their health was statistically significant on $p \leq .001$ and may testify that transplantation is an effective method of treatment in case of leukaemia. However, the multistage treatment with polchemotherapy, which significantly encumber patients, may cause the conviction about impossibility of the fully successful treatment and the necessity to perpetually stay under medical care and treatment. It may be testified by a statement of one of the patients: *When I go to my regular visit to Cracow I pack my whole suitcase as I am sure that I don't feel fully healthy yet and I will have to stay in*

the clinic for further treatment. After the regular examinations, the physician informs me that everything is fine and I can come back home and it is the third time when I come back home with my suitcase full.

The lower level of subjective health in contrast to the objective health may negatively influence patients' functioning as the subjective sense of health, as the literature and clinic observations showed, has more regulative influence on patients' behaviour than objective health [34, 61].

4.3. Coping with stress and resources of patients

Techniques of coping with stress and resources of patients are presented in **Table I**.

The level of stress has the strongest influence on the style concentrated on emotions and the strategy of concentration on negative emotions which is strongly intensified by anxious personality. The style concentrated of on the problem and related strategies of instrumental coping and distraction from the disease and the style concentrated on avoidance, especially the substyle of seeking for social contacts, which significantly intensifies the strategies, counteract the stress.

Meaningfulness, as emotional-motivating component of sense of coherence, significantly counteract stress and the strategy of concentration on negative emotions and intensifies positive strategies: distraction and instrumental coping.

These results testify that creative coping with stress is connected with activity for health and regulation of emotions through distraction from the disease, limiting stimulation and seeking for contact with other people, art and music.

Creative coping which uses rational (instrumental coping) and irrational strategies (which help to regulate negative emotions), strongly intensifies the conviction that life has sense and it is worth to take up activities to regain health, which confirms the CPS theory and generally the hypothesis which results from the Functional Model of Health.

4.4. Predictors of patients' health

The stepwise regression analysis was conducted to analyse the predictors of health (**Table II**).

The multiple regression analysis showed that subjective health of respondents strongly depends on objective health and meaningfulness, which is a component of emotional-motivating sense of coherence which stimulates and motivates to take up activities good for health and aimed at regaining it. Stressfull and ineffective coping with it through concentration and accumulation of negative emotions threaten health and life of patients.

The research on patients after bone marrow transplantation confirmed the Functional Model of Health by showing that health may have both: objective nature, which may be measured with medical indicators and subjective nature, which depends on psychological mechanisms of a man, as a creator of his own health. However, it is subjective health that determines daily functioning of respondents.

5. Functional Model of Health/Disease as a base for therapeutic contact

The Functional Model of Health shows psychological mechanisms of a man – pro-health personality, i.e. cognitive subjective resources which influence health through 3 paths.

A competence path which is based on creative and effective coping and requires informative reinforcement: knowledge about a illness, projected treatment, applied diagnostic and therapeutic treatments, foregoing effects of treatment based on regular examinations. The knowledge is necessary to solve problems connected with health. According to Antonovsky, a problem has always a dual nature – it requires cognition to choose adequate

Table I. *Correlation coefficients between the level of stress, strategies and styles of coping with illness and resources/deficits*

Variables	Level of stress	Distraction from disease	Reducing stimulation	Instrumental coping	Concentration on negative emotions
Coping styles					
Task-oriented	–.29***	.39***	.15	.32***	–.02
Emotion-oriented	.51***	–.14	.22**	.14	.63***
Avoidance-oriented	.05	.39***	.10	.24**	.15
Distraction	.13	.22**	.17*	.14	.12
Seeking social contacts	–.21*	.50***	–.01	.25**	–.07
Resources/deficits					
Meaningfulness	–.48***	.38***	–.08	.27**	–.31***
Anxious personality	.76***	–.28***	.21*	.02	.56***

Significance: * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

Source: Own work.

Table II. *Models explaining subjective health of respondents*

Explained variable R i R^2	Effect	Regression equation parameter		Regression coefficient significance test		Beta coefficient
		Value	Standard error	T	p	
Subjective health R = .712 R^2 = 50.7% corr. R^2 = 48.1%	Absolute term	3.77986	1.93671			
	Level of stress	–.05860	.02126	–2.757	.007	–.285
	Objective health	.43479	.08617	5.046	.000	.413
	Meaningfulness	.07245	.02809	2.579	.012	.244
	Concentration on negative emotions	–.06764	.03301	–2.049	.044	–.193

Source: Own work.

strategies of solving it and regulating emotions, as too strong negative emotions may preclude effective functioning.

A enormous role is played here by physicians and nurses. A physician should gradually inform a patient about diagnostic and therapeutic treatments that he/she is going to go through, their course and effects, while a nurse who prepares a patient to the treatments should inform the patient about the particular treatment in details to decrease the anxiety connected with a new situation. The anxiety results from cognitive dissonance by lack of knowledge in this field. The redundancy of information may intensify already high anxiety about the patient's own health and life, however a deficit of information may be a source of sensory deprivation, and consequently cause increase in stress and anxiety [62].

It is extremely important to inform a patient but not about the diagnosis itself (even if the patient asks: *Do I have leukaemia?*), as the patient does not know its patomechanisms. It is important to partly inform about 'here and now', so that the patient may understand what is happening to him right now, make conscious decisions and consciously take part in the treatment. The type and quality of the information depends on a health situation of a patient. If the situation requires decision about surgical operation, the patient should be informed in detail about all benefits and risks, so that he can make a decision concerning the treatment. It is a role of a physician but also a nurse who prepares and accompanies the patient helping to alleviate the pain and suffering, and decrease stress. Never can the situation be constrained to informing the patient about the necessity to sign the agreement for a treatment only. It is a mistake in art to delegate a nurse to do the task, which (as clinical practice shows) often happens and consequently increases the anxiety that inhibits the treatment.

During informing process, a psychologist plays a role of an advisor who suggests information that may be given to a patient depending on his perception ability in a given situation, e.g. according to Kubler-Ross theory of adaptation [63], giving an information in the phase of denying the disease is a mistake in art. The way and quality of informing a patient depends on the phase of a disease, a style and strategies of coping [64]. It is a very important task for the whole medical team – a physician, a nurse and a psychologist – which should be treated as a priority in clinical practise.

From the psychological point of view, such proceedings may be described as informational support which results in reduction of fear connected with a disease and staying in hospital. The author's clinical experience showed that if a patient asks about a diagnosis of a disease of inauspicious prognosis, e.g. leukaemia, on the one hand, he expects negation of his worst concerns, but on the other hand, he communicates to us that he cannot emotionally cope with the increasing anxiety which results from the situation. It is a message 'care about me', 'help me'. In such a situation, it is necessary to open the problem by asking 'what happened that you ask me about it?' to help a patient reveal negative emotions of fear and anxiety which result from uncertainty.

The problem of informing concerns a physician but with cooperation with a psychologist, who may suggest what the patient's expectations are, what information he should be given at the moment, so that he may accept and assimilate it. The problem of informing patients about a illness is extremely difficult, has multifaceted conditioning and is also important in the nurse-patient contact. It is only possible for a nurse to effectively serve the informational role, if she is adequately prepared for it, i.e. she is aware of her role in this field, has satisfactory substantive preparation and an adequate level of empathy. Otherwise, she may be a source of additional anxiety.

The Functional Model of Health also indicates emotional path as the one, which is extremely important for health of a man (cf. fig. 2) The path is a source of a patient's activity for his health, acceptance of the illness and himself as a sick person and it is a crucial condition for taking up cooperation with the therapeutic team to regain health.

The physician-nurse-patient contact may have a therapeutic power, i.e. it is a source of positive emotions, if the medical team feel satisfied with their work. Attending to a patient, alleviation of pain and suffering, accompanying a patient and ability to hear him out should be the source of satisfaction for a nurse. In the case of contact

physician-patient, the satisfaction should result from diagnostic and therapeutic, and informational proceedings which are realised by a physician. The progressive commercialization of health care and its consequences, formalizing and limitation of the contact with a patient to basic questions: 'full?', 'rested?', is a source of danger for a patient and his health. What is more, the spread of technology in medicine, which accelerates diagnostic process, may, on the other hand, become another danger for a patient and cause additional anxiety and suffering.

In the therapeutic contact nurse-patient, the awareness of served role is important. It is connected to the consciousness of one's own professional competencies which result from substantive and occupational preparation, clinical experience, and also awareness of boundaries of the competencies that cannot be exceeded. A conviction that could have been observed recently is that a nurse may play a role of a psychologist because psychology is in the curriculum of the faculty. Psychology is a science concerning mechanisms of a man's functioning. The role of a psychologist is to diagnose the mechanisms to use them in psychotherapy, prophylaxis or health promotion. Thus, basic knowledge about psychical phenomena and processes is not enough. It results in another important competency – strong professional identity i.e. identifying with the role of a nurse, a physician or a psychologist and good cooperation between all of them in a therapeutic team out of concern for weal and health of a patient.

An important factor that decreases nurses' quality of life is the problem of low earnings in the sector of health care which are a source of dissatisfaction, and consequently cause decrease in their quality of life, create additional source of stress, which is shown by emotional path of Functional Model of Health. To solve the problem, it is necessary to appeal to macrostructures that are responsible for health care sector and ability to manage human resources in the context of nurses' job.

In Functional Model of Health (cf. fig. 2), the axis of health is a path of stress – the level of stress, which is highly buffered by pro-health personality. It also intensifies support from family and spouses which is so important in social professions (– .15). An important source of stress is the sense of destabilisation at work which is connected with reform of health care sector, its formalizing and commercialization. It is directly harmful for health and indirectly decreases satisfaction from work, being an additional source of stress. It requires applying to macrostructures which are responsible for the reform.

6. The use of the Functional Model of Health and Illness as a theoretical base for innovation in education of medical employees

The author's Functional Model of Health shows directions for innovation in education of medical employees which are based on health psychology. Introduction of such a subject as Health Psychology should be the base of the reform in medical education. The knowledge about mechanisms of health and illness will allow for better understanding of patients, their needs and expectations, and consequently adjusting the influence on patients through continuous cooperation with a psychologist.

The Functional Model of Health and Illness (FMHI), should be a theoretical base for education in medical sector as it presents psychological mechanisms that determine regaining health, its promotion and health in general. To regain health, it is important that patients accept themselves in the role of a sick person and actively cooperate with a medical team for their health. It depends of the acceptance of the illness and treatment which is based on the knowledge about contemporary methods of treatments that give a hope for full recovery.

The Functional Model of Health and Illness shows that health is a function of creative coping with stress which always depends on estimation of the situation based on subjective resources that the patient has and that triggers rational and irrational defence strategies of dealing with the illness. The model points not only to a complex nature of therapeutic contact, which requires theoretical preparation, but also to psychological mechanisms which are the base for such a contact.

The author's Functional Model of Health and Illness presents three functions of physician-nurse-patient contact: instrumental, cognitive and emotional. They are realized by a medical team in cooperation with a psychologist. Therapeutic function of a nurse has a complex nature. It consists of: instrumental-behavioural function which concerns alleviation of pain and suffering, the cognitive function – informing the patient about diagnostic and therapeutic treatments and how he should prepare for them and the emotional function which is aimed at reduction of stress and release of positive emotions which are necessary for convalescence.

Functional Model of Health and Illness also suggests that the therapeutic role of a nurse or a physician should be realised by building up patients' subjective resources and especially positive self-esteem which mobilizes and motivates to take up actions in favour of one's health. The presented research on patients after BMT showed the complexity of issues of health which involves objective and subjective health. As the research showed, subjective health is profoundly influenced by objective health and psychological mechanisms, these are: meaningfulness, stress and strategies of coping with it. Objective health, however, is influenced not only by the medical treatment, but also by its time and the patient's own activity for his health and cooperation with therapeutic team.

The author's Functional Model of Health and Illness helps to analyse subjective health of a patient which, as the literature and own research show, plays more important role in regulation of behaviour (it determines behaviour) than objective health, which is a result of treatment and activities of a therapeutic team. Thus, regaining and further maintaining of health require activity of both a patient and the whole medical team. The latter is aimed at regaining health in somatic, psychical, social and spiritual dimensions, which ensures good quality of life. To achieve this aim, it is necessary to implement a relevant innovation of curriculum in medical faculties concerning

widely understood health, its conditioning and psychological mechanisms. Such a change would help to prepare physicians and nurses for realisation of completely new assignments which require knowledge and social competencies. On the other hand, it is also necessary to apply to macrostructures, so that physicians and nurses could concentrate on patients, their needs and regaining their health through active cooperation with them, instead of focusing on medical documentation.

Summary and conclusions

The objective of this article was to show healing power of therapeutic contact from holistic and functional point of view on the basis of the author's Functional Model of Health and Illness of Helena Wrona-Polańska [12, 26], which is a base for an innovation in medical education.

The models and conceptions of health described in literature and presented in the introduction of the article helped to show that the function of a nurse or a physician in a therapeutic team depends on the model of health which prevails in medicine (i.e. biomedical or holistic and functional model) and accepted conceptions of health, which is seen in clinical practice. Thus, it was necessary to present the issues as widely as possible, especially because the addressees of the article are not health psychologists.

In biomedical model, in which health is equivalent to the lack of symptoms, the therapeutic role of a nurse and a physician in a relationship with a patient, was limited to instrumental function of alleviation of pain and suffering only.

Contemporary conception of health is based on the holistic and functional model and systemic theory, which show multidimensional nature of health and its conditionings included in Mandala of Health. It poses new challenges to medical employees and disposes them to broaden their knowledge and gaining new social competences.

Clinical experience acquired during work with patients with leukaemia and results of the research conducted under professor Julian Aleksandrowicz and professor Maria Susułowska, encouraged the author to take up research on health. On the basis of accepted theories: theory of stress [22,40], salutogenesis [23] and TroP (Creative Problem Solving) [41], a theoretical model of health was constructed and empirically verified on the basis of results from research on healthy people who represented social professions.

As a results from the analysis of paths [60] and stepwise regression, the author's Functional Model of Health (FMH) [12] was obtained, which showed psychological mechanisms and conditionings of health. Then, FMH was subjected to verification in the research on patients suffering from leukaemia after bone marrow transplantation and extended to FMHI [26], presenting psychological mechanisms which determine convalescence. FMH was verified in research on patients with psoriasis [65], adults [66] and youth [67].

Thus, the use of FMHI to show complexity of therapeutic relationship between a medical team and a patient seems to be justifiable, as the model involves both sick people and healthy people, who represent social professions, like: physicians, nurses and medical rescuers.

The innovative nature of the Functional Model of Health comes from its dynamism. Its graphical depiction with numerical indicators from the analysis of paths (cf. fig. 2) shows the dynamic conditioning of health, which let us analyse the interplay of psychological variables in the process of health/illness creation.

The essence of Functional Model of Health is not only to show that the level of health depends on the owned resources/deficits and creative, i.e. always adjusted to the situation, rather than stereotypical coping with stress. Due to stepwise regression analysis and path analysis, it also reveals in detail correlations between described psychological variables represented by the value of indicators of path analysis. FMH is a base for a dynamic concept of health and consideration of man as its subject – a creator of his own health.

The dynamic and procession presentation of Functional Model of Health and its conditionings allows for its implementation in the clinical and educational practice, both in diagnostic process and in promotion of health, showing if a patient is a creator of his health or an illness. Subjective resources play a significant role in the model as they directly and indirectly – through competence, emotional and stressful paths – influence health.

The three paths in Functional Model of Health, that were defined through stepwise regression and path analysis, show 3 functions of therapeutic physician–nurse–patient contact, i.e. cognitive, instrumental and emotional. The cognitive function of the contact is connected with the path of stress and represents verbal contact, i.e. communication with a patient, informing about health/illness, projected treatment and methods of curation. Quality of the information and the way in which a patient is informed may decrease or increase a patient's anxiety, which is often intensified by members of medical team. The competence path determines instrumental function of the contact which, according to FMH, is connected with creative coping with stress, which as a process requires information and emotional contribution and results from subjective resources, i.e. pro-health personality. Informational contribution comes from the sense of coherence, especially the component comprehensibility, whose level increases with age and professional experience [12]. On the other hand, the source of emotional contribution is meaningfulness, which gives meaning to work with patients and positive self-esteem motivates and activates to take care them. On the other hand, emotional path of FMH determines emotional function of the therapeutic contact, which is based on empathy and alleviation of pain and suffering through applied treatments, showing emotional support and counteracting the sense of isolation .

The contact between the medical team and a patient which is realised in these 3 paths brings visible results, giving satisfaction with fulfilled professional role, and consequently increases the quality of life of a patient and

a medical team. However, as FMH shows, the source of positive emotions of medical staff is satisfaction with professional role which results from its effects, realized aspirations, consciousness of own professional competences, which requires continuous further education (cf. fig. 2, emotional path).

The Functional Model of Health also presents factors that may decrease medical employees' quality of life and be harmful for their health. They come from the emotional path and a path of stress (cf. fig. 2). These are: low earnings as the equivalent to hard and responsible job, the sense of destabilisation at work, which is caused by the reform in health care system and its consequences – domination of medical bureaucracy over factual contact with a patient, which causes dissatisfaction with medical staff among patients and their families. It results in dissatisfaction with work among medical employees and additional source of stress.

As FMH shows, to effectively fulfil the therapeutic role, medical employees need to strengthen their subjective resources, especially the sense of coherence, i.e. inclusiveness of emotional and cognitive factors. It lets a physician change from emotional attitude to cognitive one in greatly stressful situations. As a result, a physician may take up activities in favour of health of a patient and solve the problem and consequently reduce the stress, which is proven by the same values of path indicators (.63; –.63, cf. fig. 2). The emotional path in FMH is mainly contributed with material and social resources/deficits that are the source of positive emotions which result from proper functioning at work. However, the deficit may decrease the quality of life and become an additional source of stress. It requires continuous development of professional and social competences, ability to work in a medical team, but also an adequate compensation for hard and responsible work in money, i.e. adequate salary which is still a very sensitive point of social professions.

Author's Functional Model of Health of Helena Wrona-Polańska, based of holistic and functional approach to a man, as a creator of own health, shows multifaceted nature of the physician-nurse-patient contact and its psychological mechanisms. Its graphical representation with path indicators shows the way one's own health and the health of patients should be created.

The path of competences in FMH, i.e. the path of creative coping with stress, through the use of strategies of problem solving, positive redefinition, seeking for support, distraction from emotions or denying the disease, results in solving the problem and stress reduction. It confirms the universal nature if the path of competences and the path of stress in FMH. The path of emotions, which shows sources of good professional and social functioning, has specific nature as it defines the area of FMH used for social professions.

Summing up, the author's Functional Model of Health does not only indicate the necessity to include health psychology in education of the medical staff, but also precisely shows how it should be used in it. FMH should be a theoretical base for a innovation in education of medical staff aimed at increasing their knowledge, as well as social and psychological competences in such a way, they may meet needs and expectations of patients according to standards of 21st century and at the same time feel satisfaction with work, fulfilled obligation, and consequently the sense of good quality of life.

Conclusions

1. The author's Functional Model of Health, verified in the research on healthy people, who represented social professions, and sick people shows the functions of therapeutic contact: instrumental, cognitive and emotional which correspond to three paths of FMH – path of competence, stress and emotions, and thus is a base for an innovation in medical education aimed at health promotion and preparation to meet needs and expectations of patients at work.
2. The Functional Model of Health has a dynamic nature, points to specific psychological mechanisms of health and correlations between them represented by values of indicators in path analysis – subjective resources and the need to increase them to maintain health and good quality of life of medical staff and their patients.
3. The author's project shows a prospect of modern education of medical staff aimed at shaping social competences and effective strategies of coping with stress, including health promotion through pro-health education whose theoretical base is FMHI of Helena Wrona-Polańska.

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Are Online Forums a Useful Resource for the Study of Health Needs and Related Information Behaviour? Linguistic Analysis of Two Online Forums for People with Mental Disorders

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Abstract

Knowledge of people's health information needs and information behaviour can be used in planning health interventions in a way that they would meet people's needs as accurately as possible and reflect how health information is acquired and processed.

Aim. The aim of the study presented in this paper was to analyze the usefulness of online forums as a source of scientific knowledge about people's health needs and information behaviour, which could then be actively used in the area of public health.

Method. The content, a total of 1,575 entries, derived from two open forums devoted to depression in the years 2012–2015 was analysed using a set of mixed methods, including: a formal (quantitative) analysis of the material using the tools of computational linguistics (QDAMiner Simsat), inductive theme analysis EMIC, in the so-called hard variety, reinforced by elements of Awdiejew's conversational grammar, and comparative method.

Results. Both health information needs and behaviour can be identified on Internet forums dedicated to health problems. Linguistic analysis of online forums can give very interesting results and clues that cannot be obtained using questionnaires or personal interviews. It seems, however, that it should never be the only method used in investigating this matter. Since there are several intervening factors that may distort reliability of findings, determining whether we are dealing with real or created needs or behaviour requires confirming the results of the linguistic analysis of the forums using other methods.

Key words: **health information needs, health information behaviour, Internet, social media, depression, public health**

Słowa kluczowe: **zdrowotne potrzeby informacyjne, zdrowotne zachowania informacyjne, Internet, media społecznościowe, depresja, zdrowie publiczne**

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Introduction

Knowledge of people's health information needs and information behaviour can be used in planning health interventions in a way that they would meet people's needs as accurately as possible and reflect how health information is acquired and processed. It may also be helpful in creating resources and programs used to improve the level of health awareness, both very important from the public health perspective. Information needs and behaviour (terms explained below) are usually tested by asking questions to the representatives of the category of people that is of interest to the researcher. It is typically a poll conducted using questionnaires or individual or group in-

terviews, and so using data collection techniques where researchers cannot entirely avoid their impact on the subjects. Until the large-scale expansion of social media it was very difficult to study comments that would be spontaneous and completely independent of the investigators. Before, it was only possible to analyse texts/journals written in past or texts/journals written at the request of researchers, and therefore somehow stimulated [3, 6]. Only after the development of social media did the availability of natural expression – uninfluenced by researchers – change significantly. Posts published on the Internet on various forums, blogs, discussion lists, Twitter, have become a matter of interest to researchers [8, 9], also in the area of health [10–13]. Searching the Polish Medical Bibliography we found several research papers where contents of web forums or blogs were analyzed [14–17], and in the Medline database – a few dozen. While just a few, there are also papers whose authors seek to answer questions related to health information needs and information behaviours of the studied groups, more often than not, however, they refer to health needs [18–22]. Most commonly, these studies contain a quantitative text analysis, using programs such as NUD*IST or N-Vivo. Nevertheless, there is a small number of papers analyzing the fundamental issue; namely, whether the forums in general may be a credible and scientifically useful empirical resource [23]. In fact, this objection can be found in the literature [24].

By examining health-related information needs and behaviour as well as medical treatment or use of the health care system, one can learn about deficits within health competencies and health information competencies that are key to them, also about meeting medical care needs, as well as ways people deal with those deficits.

Aim and hypotheses

The aim of this pilot study was to analyze the usefulness of online forums as a source of scientific knowledge about health needs and information behaviour of people, which could then be actively used in the area of public health.

The analysis covered contents of only two online forums used by individuals with mental disorders. No generalizations should therefore be made based on analysis results; however, they allow for some initial identification of the research field. The choice of this particular kind of forums was dictated by the following rationale: 1) diseases and mental disorders are major public health problems. Nearly a quarter of the Polish population are affected by them [25]; 2) mental health disorders are a taboo subject. Therefore, it is likely that users can anonymously reveal needs and behaviour on online forums that they would not reveal elsewhere; 3) on Internet forums you can follow people's comments for a long time.

In the study described herein, the following research questions were asked:

1. Can specialist Internet health forums be a useful empirical resource for identifying information needs of their participants?
2. Can specialist Internet health forums be a useful empirical resource for identifying information behaviour of their participants?
3. Are there differences in the expression of needs and behaviours between forums moderated by health professionals and forums where there are no such moderators?

Three hypotheses were proposed:

1. Health information needs can be studied and identified on Internet forums.
2. Health information behaviour can be studied and identified on Internet forums.
3. There are differences in the expression of information needs and behaviours between forums moderated by health professionals and forums where there are no such moderators.

Explanation of terms

The terms presented in this paper are understood as follows:

Internet forum – Internet form of a discussion group, used to exchange information and ideas via a web browser (*Dictionary of Polish Language PWN*, http://sjp.pwn.pl)

Information – "any factor that reduces the degree of unawareness of the examined phenomenon, allowing a person (...) to expand the knowledge of the environment and carry out a deliberate action more efficiently [26]".

Health information is information that relates to person's health, treatment or the use of components of the health care system.

Information need – "recognition that their knowledge is inadequate to satisfy a goal, within the context/situation that they find themselves at a specific point in the time" [27]. It appears when a person carrying out some task, considering a possible action or solving a problem finds that a lack of knowledge prevents them from taking further, reasonable steps. Information needs related to health and treatment are called **health information needs**.

Information behaviours – "is the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use" [28]. This includes identifying information needs. When studying information behaviour, the following questions are asked: How does the user formulate their needs, how do they search for information; does anyone assist them in completing this task, and if so, who; how do they search through specific sources of information, and what internal and external factors affect these processes? Of interest are also factors motivating behaviour and the way they are affected by individual characteristics as well as the impact of the environment [29].

Health information competencies – "a set of skills needed to: accept the need for health information, identify possible sources of information and use them to download relevant information, assess the quality of acquired information and its application in a particular situation as

well as to analyze, understand and use this information to make decisions beneficial to health" [30].

Material and methods

***Material*:** The contents of all entries (posts) of two open Polish online forums dedicated to mental health disorders in the years 2012–2015. One of the forums – FORUM PRZECIWKO DEPRESJI, hereinafter referred to as FORUM AGAINST DEPRESSION (http://www.forumprzeciwdepresji.pl/forum/) – administered by Servier Polska as part of the project titled Forum Campaign against Depression is moderated by a psychiatrist. The other analyzed forum – DEPRESJA hereinafter referred to as DEPRESSION (www.gazeta.pl/forum/f,99,Depresja.html) – functioning on the Gazeta.pl portal, was not – in the period of the study – officially moderated by a specialist doctor. A total of 1,575 entries were analyzed (FORUM AGAINST DEPRESSION – 566, DEPRESSION – 1,009).

***Method*:** We studied the contents of two open forums devoted to depression, which topped the list of Google search results containing the words *forum, depression* (*forum, depresja*), and so at the start of the research project they were the best positioned Polish sites of their kind on the Internet. The material (the total of entries) from both forums was copied manually into the text editor, providing a body of text to be processed. The analysis of comments published by forum users was carried out using a set of mixed methods, including: a formal (quantitative) analysis of the material using the tools of computational linguistics (QDAMiner Simsat), inductive theme analysis EMIC, in the so-called hard variety, reinforced by elements of Awdiejew's conversational grammar, and comparative method [1,4]. Using the EMIC method combined with Awdiejew's elements of conversational grammar, was dictated by the intention to establish whether the forum participants articulate their information needs associated with the illness (their own or someone else's), and possibly to categorize these needs. It was also investigated whether the way forum participants get their information and what they do with it can be ascertained. We selected forums open to the public to bypass the procedure of obtaining approval for the analysis of comments, which could affect their content [31].

The study was conducted in several phases. Stages 1 and 2, realized using Simsat in tandem with QDAMiner, included a quantitative assessment of material aimed to determine whether it exhibits useful characteristics for the analysis of health needs and information behaviour. Stage 3 was to analyze the content of the collected material using QDAMiner functions. In stage 4, we compared the results obtained in the previous step for the material derived from the DEPRESSION and FORUM AGAINST DEPRESSION forums, respectively.

Stage 1. Formal parameters of the test material were determined with Simsat, a word frequency counter (a tool that automatically measures the frequency of preset words or phrases) in order to confirm that the extracted content of online forums coincides with the theme of mental health disorders. The verification was carried out as a precaution to make sure that the material does not demonstrate excessive theme scattering. The cut-off point was established at a frequency equal to or higher than 3,000 word occurrences. The analysis excluded conjunctions and particles. The resulting list of 11 words in polish (Depressi*, Doctor*, Medicine*, Mental*; Therap*, Antidepressant*, Anxiet*, Sleep, Disease*, Psycholog*, Mood*) was compared with the results obtained from the reference National Corpus of Polish (NKJP) (www.nkjp.pl), and we found that all the lexems are significantly overrepresented. It was thus demonstrated that the material analyzed clearly displays features of a thematic material (relating to mental problems) with a high degree of uniformity.

Stage 2. Again using the Simsat program and Aleksy Awdiejew's nomenclature, the density of operators realizing the functions of action was measured, in particular the operators of soliciting, readiness and resolution [1]. The analysis yielded frequency lists of individual operators, and comparing the data with the results obtained from the reference corpus of NKJP, it was found that words and syntactic structures used to express a request, solicitation, invitation, encouragement, or urging the recipient to do something that would be consistent with the intention of the addresser, were overrepresented in the material. A similar pattern was observed in previous studies of online forums devoted to depression, and it was interpreted as an indicator of a strong self-focus of addressers (autotelism), testifying to a high level of cognitive and affective uncertainty, which – in turn – through verbal activity in the forums translates into needs expression (in the ordinary sense of the word) and calls for support [32] that exceed the standard frequency.

Stage 3. The next step was to determine theme distribution in the content of the studied forums. To measure that, the EMIC method of content analysis was employed, assuming an inductive approach, and therefore categorizing the material solely on the basis of overt linguistic content of the comments posted by forum users, without applying any typological criteria imposed by the investigator.

Both forums were treated as living cultural environments created *ad hoc* by the varying, makeshift community of people who want to communicate about their mental well-being. This follows from the EMIC definition of thematic analysis: "An 'emic' account is a description of behaviour or a belief in terms meaningful (consciously or unconsciously) to the actor; that is, an emic account comes from a person within the culture" [7]. To reduce the degree of arbitrariness in extracting thematic categories from the material, which is inevitable in a study of discourse, the tools of conversational grammar by Aleksy Awdiejew were implemented. It was assumed that the material downloaded from the analyzed forums met the criteria for conversation, that is it constitutes "(...) a number of sequences of speech acts aimed to realize the strategic intentions of each of the interlocutors, who (...) seek to achieve their communication objectives" [1]. The basic units of a study of conversation that are also minimal sections of an interactive sequence

are adjacency pairs of two speech acts, where the first is a stimulus starting a dialogue, and the second is the response to this stimulus [1]. Conversational grammar serves to detect and describe the types of speech acts, as well as determine the overall goal of communication sought by the addresser, while this analysis is superficial and does not have the power to reach subjective intentions and motivations of the interlocutors, emerging in their mental sphere [2]. In practice, resorting to the tools of conversational grammar was based on the fact that the guiding principle of the material's theme categorization was assumed to be the presence of an adjacent pair of language exponents, the so-called action functions that according to Awdiejew: "have to rise to an executive commitment between the addresser and the addressee in relation to the implementation of a specific action that is beneficial to the addresser, addressee or all interlocutors. The condition of benefit is one of the typological elements that allows distinguishing different kinds of functions, because it concerns the addresser, addressee or persons associated with either of them" [5]. As a result, clear disjunctive thematic categories composed of statements were created, in which (at the language level) the addresser's intention of inducing the interlocutor to make a reciprocal language action, aimed to meet the need for gaining some benefit, was clearly set apart. At the same time, in view of the cognitive potential of conversational grammar and features of the tested information environment (open forums), it was stipulated that:

- intentions expressed in the language of the studied messages do not necessarily correspond with the profound subjective intentions understood as psychological facts,
- the need to obtain some benefit expressed in a given speech act does not necessarily correspond with the actual information need of the speaking subject, be it conscious or unconscious (e.g. the public question asked on the forum does not necessarily reflect the actual gap in the knowledge of the addresser or may even conceal it),
- regularities in the ways of communicating that may have been revealed in the material cannot be regarded as indicative of the verbal activity of people with depression, because it is unknown what percentage of users of both forums are patients with a clinical diagnosis of depressive disorders,
- despite the fact that – by mere analysis of the linguistic material – it is impossible to discover the deep intentions and actual information needs of the users of both forums, it should be assumed that the themes of the published posts are a sufficiently probable illustration of the users' deficiencies or other anomalies in the information economy regarding their own mental well-being; therefore, the speech acts realized by the participants, which – from a purely formal point of view – urge the other callers to respond verbally, and in many cases directly to provide specific information, they can be regarded as the expression of information needs, and as a manifestation of information behaviour.

Stage 4: In the last phase of the study the comparative method was used to verify whether based on the previously conducted analysis of the material, any differences can be identified in the expressed type of information needs and the course of users' information behaviour between the forum where there is no doctor fulfilling the role of the moderator and the forum moderated by a doctor.

Results and discussion

Forum entries have been unaltered but for typing errors, corrected in order to facilitate reading. Apart from that, the original entries have been preserved.

Information needs

It was found that the analyzed discussion forums devoted to mental health disorders are a place where health information needs are expressed. These needs can be extracted from descriptions of experiences/symptoms posted by the users, who involuntarily reveal those needs, or from descriptions of symptoms or experiences, where there is a tangible intention of obtaining a comment (response, advice) from the forum's co-users.

Below are categories of speech, selected in the course of the analysis and considered probable signs of the users' knowledge gaps, and so a likely reflection of their information needs. The different categories are ordered according to the frequency of their occurrence in the relevant material, but due to the limited range and distinctive nature of the test, this sequence must be regarded as conventional, not intended to address any proven regularity. Conversational exchanges between participants on both forums focused on the following themes:

- dosage and combination of drugs (example: *Hello, I have a question… Is it OK to combine these two drugs and are they used to cure the same disease? I'm also interested to find out their effect on a person that's mentally healthy, what damage can it do to the body? I am asking specifically about Rispolept [2 mg] and Zolafren [10 mg]*),
- pharmacokinetics and adverse drug reactions, among other weight-loss drugs, contraceptives and hormone therapy drugs taken posterior or prior to gender reassignment surgery (example: *After 8 months of taking the antidepressant, I have been down in the dumps for two or three weeks now. First I was OK taking it, but now I see I'm feeling worse and worse, and at a surprisingly fast pace. I do not sleep, and even if I manage to drop off, 3.30 a.m. is the "zero hour", and the morning is a nightmare, no need to write more, I think most of you know what I'm talking about. My question is: How is it possible that first it was OK and then I hit the bottom? Did the drug stop working so suddenly? Is that it? / Hello! For two years I've been taking Valsacor [320 mg], Amlozek [2 x 10 mg], Lokren [2 x 20 mg], Doxar [3 x 8 mg], Controloc [40 mg], Spamilan [3 x 5 mg] on a daily basis. For some time I have been feeling pain on the right side of*

the abdomen, under the ribs. Should I have my liver examined? Thanks in advance for your answer / just stopped taking androcur because of the hallucinations and depression that followed :(. I was giving my husb a hard time cos I didn't want to even leave the house. Today I didn't take any and it's a little better…),

- requests for recommending a specialist / facility (example: *Does anyone know a specialist centre for victims of violence in childhood?*),
- requests for assessing the relevance of a psychological and/or psychiatric consultation or other forms of diagnosis (example: *Is it possible to do other tests in addition to talking to your doctor or psychiatrist, which would confirm or deny the "pseudo" mental illness? / I get exhausted suffering in loneliness. How can I help myself, did you feel similar reservations, will the therapist even want and know how to cope with such a closed and distrustful person? / I turn to you for advice… It's been half a year now that I've been wondering whether I should see a psychologist or psychiatrist. What stops me is the thought that perhaps I'm overreacting, I don't want to take up anyone's time for nothing. The problem is that it is increasingly difficult for me to function*),
- requests for an opinion on the quality of work of a physician or psychologist (example: *Does anyone know anything about Dr* [surname]? / [answer] *Dr* [surname] *has her office in* [street name] *(right next to* [name of institution]*). She is mainly engaged in treatment addiction, but almost certainly treats other diseases. I especially recommend that young people go and see her (I mean people say between 20 and 40 years old). She is a great person, very friendly and genuinely cares about the patient. An appointment costs 80 zł*),
- users' own symptoms (example: *Hey, I have a little problem, recently I've been feeling weak, passive, dead-beat. In the morning I can't drag myself out of bed, but then time flies, at work I'm feeling OK and can stir up some enthusiasm :). After returning home, I feel deflated and don't feel like doing ANYTHING :(. Could it be weakness caused by some disease, or perhaps discouragement, me being bored with the monotony of everyday life? Have you ever felt like that? What did you do to fight it? Any sugg? :) / Doctor, for several years I've been struggling with derealisation and depersonalization. I had a depressive episode, I felt slightly better taking Venlafaxine, the antidepressant – it decreased derealisation a bit. I've recently had a lot of stress and derealisation greatly intensified. I feel as if I were daydreaming, I know what's going on but I'm kinda isolated, as if I were observing and not participating. How can I get rid of it completely? Are there any drugs to fight it? Please help. / Hello, in December due to dehydration I experienced nystagmus and dizziness. Since then I've been really scared of leaving the house. I focus all my attention on myself, on how I walk, the way I turn my head, I'm afraid of dizziness. This made me so hysterical that my neurologist prescribed me Bioxetin. I've been taking it for two weeks and I'm a little calmer, but I'm still not ready to leave the house on my own, all the time I'm thinking about what happened to me, I can't enjoy anything, I'm not interested in anything. The greatest fear of attacks occurs in shopping centres. I don't know what to do, maybe I should go and see a psychiatrist? I want to be like I was before, happy. / Good morning, for a long time I've been suspecting that there's something wrong with my behaviour, thinking and actions. More and more often I cry for no reason or for whatever reason. I get nervous easily, impulsively, I scream. […] These days I commute 40 km to work, crying, or I don't go there at all, it's often due to my reluctance, unwillingness, even though I need the money. My mother suffers from depression and anxiety, which used to impact me too and my brothers and sisters, before she underwent treatment. I'm overwhelmed by my parents' financial problems, me being unable to help them. I used to fulfil my mum's dreams and ambitions, ignoring my own aspirations, I felt that I was not good enough. I have no sense of self-worth in terms of being helpful to anyone, I feel hopeless, lonely, useless. I know how my mother's illness reflected on me, and I'm afraid that if there's something wrong with me and I don't treat it, it will affect my family*),
- mental disorders comorbid with other diseases – the sample material contains entries where depression is mentioned in the context of fibromyalgia, dementia, Hashimoto's disease, alcoholism, bipolar affective disorder, borderline personality disorders.
- mental health in the context of procreation (example: *During pregnancy I was prescribed Relanium [supposedly a safe drug]. I had strong contractions when I experienced the same attacks as the ones you describe [choking, numbness, shortness of breath]. Starting from the 25th week of gestation I was getting treatment to maintain my pregnancy because of intense panic attacks and anxiety. I tried to take Relanium as little as possible, but when it took hold of me, I didn't hesitate to take a dose. I didn't want to give birth at 25 weeks of gestation. / I have a question to the women who visit this forum and when pregnant had to take antidepressants – was the child born healthy? I'm asking, because my husband and I are trying to have a baby, so a few months ago I stopped taking ant. with the intention of becoming pregnant, unfortunately I had a relapse and returned to the medication which of course makes me feel good, but I don't know what can happen if I get pregnant – do I have to stop taking it or minimize the dose? What are your experiences in this matter?*),
- symptoms of withdrawal syndrome in pharmacological treatment of mental disorders (example: *How to discontinue treatment with Lorafen or change the medicine to another?* / [Answer] *I would recommend switching to Seroxat + Xanax the first 2 weeks of taking Seroxat. Take half a pill once a day for 7 days and then increase the dose to one pill and continue. Xanax should be taken in the evening before bedtime,*

start with 0.25 mg and if ineffective, increase the dose to 0.5 mg. Remember to take Xanax combined with Seroxat for only 2 weeks and then discontinue. / Does anyone know how long it takes to completely eliminate Mianserin from the body? I took it for almost six months, discontinued more than a week ago, nothing unusual was happening [tinnitus and dizziness, but only for two days], but at the moment my stomach aches and I'm not sure whether it's due to withdrawal systems after discontinuing Seroxat, which I've been taking for over 2 months, or maybe it's the same stomach discomfort I experienced six months ago, let me just say that while taking Lerivon it disappeared completely, in fact, I had a huge appetite and put on weight :(. I don't know what to think, maybe I should start taking it again, a minimal dose?),

- reliability of independently performed tests of mental health (e.g. Beck Depression Inventory) (example: *Is 27 points a high score? How reliable is the test? Since the symptoms of depression have been decreasing for two years now, is there a chance that I can handle it on my own? /* [Answer] *Yes, you could say that about anyone, but this is the BDI thread. But if you say that, you can't tell that the Beck scale assesses mood. It doesn't assess anything. On the Beck scale people have to tick off 21 or so sentences. And that's it. Recent studies have shown how idiotic that scale is, as I said before. I'm terrified that people get so 'thrilled' by the results. So what, if you got 20, 30, 40 pts. on the scale, even if you get 0, you are depressed, so there is nothing to get excited about*),
- requirements for incapacitation due to mental disorders (example: *My parents have died and I should receive inheritance. Unfortunately, not only me. My sister is mentally ill. For 9 years she has been treated for anxiety and depression, and f... knows what else. She doesn't work, doesn't do anything. Can I incapacitate her [she can't cope at all] and manage her assets as her next of kin? So that she wouldn't have a say. How can I do this, does anyone know?*),
- requirements for obtaining an order of compulsory psychiatric treatment (example: *Somewhere in the forum I read that it is possible to submit an application for involuntary treatment at the local mental health clinic. Apparently it can be submitted if the person's behaviour is a threat to their own life or health, or that of other people [family]. The application should include everything that worries us, and nothing should be omitted. Later the director of the clinic decides whether to take the matter to the courts, asking for compulsory treatment. Previously, however, the patient gets two registered letters from the clinic, asking them to show up for consultation. If they don't do it, they're taken there by the police. Perhaps someone knows if it's true that such an application can be submitted at the mental health clinic, and if so, how should it be formulated? Is there a model of the application form available?*),
- conditions for sick leave due to a depressive episode (example: *How long can you be on a sick leave due to endogenous depression or any other form of depression? mental illness?*),
- natural ways of combating insomnia (example: *For some time I've been unable to sleep, I fall asleep for 1–2 hours at 3 am. I'm at the end of my tether, both mentally and physically. The reason is stress [I'm going through a divorce]. I beg you to advise me, can I get something to help me sleep in the pharmacy, no prescription, what should I do?? Please help…*),
- general questions such as: "What should I do?", or requests for support (example: *I want to know if I can handle it on my own, and it will pass, or maybe I should ask the psychiatrist for help. Thank you in advance for any suggestions / My child, a young adult, has depression. I would like to help him without hurting him. I don't know how to act in spite of the many publications I read. I have no strength to fight for his health anymore, he doesn't trust me, I still know nothing about him. All of this is speculation based on my observations. He's undergoing treatment, goes to therapy, is making an effort to get better, but it is so hard to deal with all the problems. We're hardly coping, we are tired, sometimes we get irritated. We want it to be like in the past, we didn't realize he was ill, he has always been so, it was his nature, didn't admit he had such huge problems with himself and the environment. We need support, we can't cope anymore. I didn't find anything for families affected by depression that could help me in the exchange of experience, soon us ourselves will need therapy and a psychiatrist. Help families who have a sick family member. I would be happy to write to someone who has experience in this matter, who can advise how to go through this and not fall into depression*).

There are occasional entries where forum members ask for a recommendation accompanied with a brief justification (example: *Please recommend some psychotherapists, but do include some description.... Maybe I'm too demanding? I don't know, but I really have to do something, and I don't want to get discouraged again, nothing has changed for several years now. I will be very grateful!*).

There are also entries regarding difficulties in interpreting information and putting it to practical use. Patients sometimes report disappointment in specialists who – often as a result of their media appearances – enjoy the celebrity status. Although they seem to trust the recommendations obtained from experts, they use the forums to discuss it and obtain additional information, filtered by the experience of other patients and dependent *not* solely on the strength of professional authority. Here is an example: *Can you write more about Ms.* [surname]*? I was referred to her by two psychiatrists, independently of each other, I'm convinced she's good since she's recommended by the professional community. But you can never underestimate a patient's opinion. I got my fingers burnt – when I lived in Warsaw, I went to see a specialist, a very well-known media personality, and it was such a failure. She suggested getting onto first-name terms, she hugged me and gave good advice. Sorry, but it seems*

to me that this is not how a professional should behave. Regardless of how nice she is and her TV work, the therapy was ineffective. In addition, sometimes she was late, even 10–15 minutes, and at times she receives private calls during therapy. Later I came across some orthodox psychoanalyst whose face was like a mask, it seemed that I was being treated by a cyborg rather than a human being. Please write about Ms. M. Does she maintain boundaries, is she professional? Does she arrive for sessions on time etc.? Also, does she act like a human, or wears a mask? And – if you can – say how exactly she helped you, what changes you noticed and how long it took until you noticed them? I will appreciate an answer – I read this forum and I could see your comments, they're OK, so I believe you have experience in this area. Best regards.

These entries may indicate insufficient competence of their authors, but also awareness of their own limitations. Questions or requests are an often indirect expression of the need for authority, or the need to use a reliable source of information (example: *Warsaw – please help! i have read a lot of posts in this thread and I've had enough, I can't see who is truly recommended and who is self-advertising, I've googled several people and I'm still stuck. And I'm looking for a therapist! I've already had two failed therapies, I need someone specific – I don't know much about the different approaches – probably behavioural or short-term therapy would be best ... but I'm not sure / They have this beautiful advertisement on the main page of their service ... "Antidepressant Phone Forum Against Depression". Fat Thursday ... apparently too much of a Fat Thursday for them to pick up! If someone makes a bad first impression, I don't give second chances. I'll look for help elsewhere. Regards*).

Information behaviour

In the analyzed posts forum users report their information behaviour, that is, say how and where they search for the information they need, say that they evaluate it and that they have difficulty with this assessment.

Information behaviour on the DEPRESSION forum is more clearly presented than on the FORUM AGAINST DEPRESSION, because the list of topics in the former has – among other things – headers targeting users' statements, e.g. the headline: "White list of psychologists, therapists and psychiatrists", where its founder announces that *In this thread all information is included about verified and commendable therapy centres, psychiatrists and psychotherapists – collecting these data in one thread facilitates finding the right centre or doctor for those seeking psychiatric or psychological help*, and encourages other users to enter names of localities.

On the analyzed forums you can learn:

- to whom the participants turn for information / help and who they recommend. There are specific names of psychiatrists, sexologists, personal coaches, yogis, coaches and wellness trainers. On both forums more than 400 names of experts in these areas were mentioned. Forum users either have a general question, for instance *looking for a good specialist* [name of discipline] *in* [name of town] and wait for answers, or make a direct query about a particular person or facility (example: *Psychotherapy clinic – urgent! Maybe someone knows and can recommend a verified clinic where they offer temporary support for depressed people with low self-esteem. V. urgent, my friend needs immediate help!*),
- that the participants consult their family and friends about the problems. Sometimes, these people are presented – either with an explicit or implicit tone of complaint – as useless in resolving the problem (example: *I tried to talk about it with my best friend and my twin sister, terribly difficult for me to admit it, the more that they didn't seem to understand…*),
- how the participants seek information about specialists (e.g. using services of public and private health care institutions; recommendations given by doctors they already know, search engines such as Google; Internet forums) (example: *I'm looking for a good centre for treating depression... Maybe you could recommend something?* / [Answer] *Check out www.depresjastop.pl, I have a high regard for them, they may be unconventional, but I know many cases where long-term 'conventional' treatment turned out to be ineffective. Long-term psychotherapy often fills the therapist's pocket rather than doing good to the patient's health… I emphasize that I didn't take part in the workshops offered there, I only came across the portal and read their book, which is really OK. I wonder what others think about these coaches, maybe someone attended the workshops? / Check this link:* [address of the "White list psychologists ..." in the DEPRESSION forum of Gazeta.pl], *maybe this list will be of help. (It wasn't helpful for me, but maybe because I don't live in Suwałki or Białystok :). Regards / J ... N ... I recommend them. 100% certain. Their phone number can be found in local newspapers, where they advertise their services, or on the poster advertising their office at Giełdowa St. If necessary, I can give you the phone number*),
- where the participants seek knowledge about their health problems (example: *I've been reading a lot on the Internet about the symptoms of depressive disorders, and decided that I'm not quite all right / Unfortunately, only for those speaking English, there's no Polish translation: www.goodreads.com/book/show/2698726-how-sadness-survived. It's a popular science book about the evolutionary basis of depression – a very interesting read. But it has some therapeutic value too, because it helps to understand that in most cases depression is a natural and necessary process, allowing you to realize that you're going through a period in which it is worth slowing down the pace of life and examining yourself*),
- which medical and therapeutic centres the participants recommend and use (example: *The clinic for victims of violence B ... 4 is a very important place for people who are depressed due to past violence. There you can receive counselling, psychotherapy [also learn mental self-defence] and psychiatric help*

[as well as legal advice on social welfare]. The psychiatrist is very good [cannot remember the name, but there's only one], he really wants to help. There are also specialist psychotherapists treating victims of sexual violence, which is very important. Myself I've been seeing a specialist who has specialized in this field for more than 8 years. For victims of sexual violence; I also recommend this website: www ... pl, especially the support forum – it's helped me a lot and many other people in difficult times [what's important – it'll push you towards therapy, but not replace it]),

- about self-proclaimed 'healers', who express their own views on the etiology of depression, as well as propose remedies to the associated symptoms without quoting any sources (example: *Depression is caused by inhaling a VIRUS that impairs the immune system. This not only reduces the psychological resistance, causing depression, but also the resistance of the entire body. You can also develop allergies, infections, obesity, especially abdominal, visual impairment, diabetes, hypertension, heart problems, dizziness and fainting and even cancer. The virus can be easily removed from the body, and destroyed immune structures can be rebuilt, depression disappears COMPLETELY. If someone is having suicidal thoughts, call this* [number]).

Verbal exchanges between forums participants often have polemical overtones. Some utterances are accompanied by justification, other are not. While in the latter case, the entry only contains referral data, name, address, phone number, website address, and sometimes even an advertisement of the centre/specialist, in the former case, a deeper analysis of the exchange makes it possible to learn more about the beliefs, shared values, information competencies and health competencies, as well as behaviour of their authors.

Justified recommendations or opinions usually include:

- assessing the quality/price ratio of the consultation (example: *and so I lose a hundred zloty for each visit, even when I just need a prescription*),
- assessing the consultation cost and raising it in the course of treatment (example: *not recommended. She's a fraud – increases her rates in the course of treatment, when she sees the patient is well-off*),
- assessing treatment effectiveness (example: *I recommend her services, she's helped me a lot, helped me battle depression / she knew how to get to my children*),
- assessing pharmacotherapy treatment (example: *She's selected the right medicine / that lady knows nothing about pharmacotherapy*),
- assessing the education of the doctor/trainer (example: *A fraud, former drug addict, she's no psychologist, she's still studying, yet claiming to be a great psychologist / I was there, even their military chaplain studied psychology!*),
- comments on the diplomas, specializations and certificates (example: *Having seen a different therapist – a certified psychologist, rather than a person who's done some courses – there were some immediate effects / she practises psychodynamic therapy / specializes in addictions / treats couples*),
- assessing professionalism (example: *At every consultation, she has a different vision of treatment, lack of professionalism / she sets an aim and is working towards it, a kind of contract work / according to Ms. Izabela [...] for years I wasn't ready to end therapy. [...] Izabela wasn't able to determine what results would indicate the possibility of a gradual termination of therapy. Although the therapy didn't yield any tangible results, she didn't suggest trying to work with another professional. I think that it would have been fair*),
- comments on gender (example: *I need to find a good psychiatrist in Wrocław, preferably a woman*),
- assessing the attitude to the patient (example: *supportive / understanding / patient / can create an atmosphere of security, trust and mutual understanding*),
- assessing integrity (example: *A fraud [...], herself she writes the opinions about her work and posts them on the forums / luk123 recommends* [doctor's name], *supposedly she is the best psychiatrist in the world. However, if someone has a real problem with their mind, which impacts their everyday life, all the medicine prescribed by Ms.* [doctor's name] *doesn't help, and when it comes to the selection of drugs, the patient feels like a guinea pig serving someone who's totally incompetent. In such cases, it's not enough to talk, because it isn't a question of getting muddled thoughts, but a real mental problem, with which the 'wonderful Monika' can't cope. What she does cope with is getting more and more one hundred zloty notes – every subsequent consultation planned in order to change the medicine, is worth PLN 100 of forced tribute. Yes, forced tribute. I bet that she's not paying taxes*),
- assessing the availability, convenience and provision of services (example: *She sees her patients in a private consultation room three times a week / she consulted me in the hospital at Polna Street, and later in her private consultation room / even late in the evening / accepts National Health Fund patients, the queues are not so long / sessions via Skype, direct consultations and emails, none of my e-mails remained unanswered*),
- opinions presenting general assessment (example: *good / reliable / accurate / kind / zero panic / kindest woman / quack / this guy is hopeless / he is a therapist who's passionate about his work, a combination of a strict, logical and analytical mind with empathy, understanding and imagination*).

Forum members also discuss the need to verify the competence of professionals in the field of mental health (example: *Psychologists must be verified. it's a profession like any other, but since this person is entrusted with the most intimate details of our lives, they must be 100% competent and loyal / I'd like to encourage everyone to check the qualifications of therapists, especially if you suffer from some serious disorders, and to try to cooperate with other specialists if the treatment isn't bring-*

ing expected results! Good luck! :)). On the one hand, it demonstrates that the authors are critical and cautious, on the other hand, however, they do not provide rational guidelines on how to assess the expertise of specialists, limiting themselves to checking reviews on other forums. It should be added, though, that in the discussions on the criteria for the selection of specialists, the Gazeta.pl forum members repeatedly pasted a brief guide titled "What should you know about choosing a psychotherapist or psychologist? How to choose a good psychologist or psychotherapist? 20 things you should know (!!!)", published on the Facebook profile of the Association of Family Psychologists and Psychotherapists. Individual points of the guide, although in line with the standards of the sector-specific knowledge, were undermined by some of the participants (example: *Jola… part of what you write is harmful nonsense, especially the fourth point, but not only. The psychotherapist doesn't give opinions and diagnoses, and psychotherapeutic services can be provided not only by a psychologist, but a person with a higher humanities or medical diploma or one who's done a course in psychotherapy – a philosopher, sociologist, educator, doctor, etc. And how come there's no mention of compulsory clinical supervision, huh?*).

The authors of entries look for indications demonstrating that a doctor or other specialist advertises their services under cover of anonymity (example: *This is one big ADVERTISING THREAD! Real recommendations are few and far between, all the rest is written by paid canvassers. You should be ashamed to deceive people, write that you experienced depression, anxiety, and God knows what else. I wholeheartedly wish that all those hyenas experience mental illness and confusion firsthand when trying to find a specialist*). Public disclosure of such suspicions on the forum is aimed at reducing the risk of encountering manipulated information and can be considered an expression of concern for their own safety and that of others. Forum users also warn against the 'tricksters', who are commissioned to recommend the services of specialists, pretending to be patients (example: *What vested interest do the canvassers have in recommending a psychiatric office? Has anyone heard of leaving a psychiatric office without a prescription?*).

What is also investigated while analyzing people's information behaviour is what encourages them to search for and analyze information, and what motivates them to perform this kind of activity. These incentives are called mechanisms activating information behaviour [29]. Did the test material give insight into these stimulating factors? In the analyzed sequences of expression at least two driving forces can be seen, namely the desire to return to the former ("old") self, sometimes through a direct expression of guilt that the old 'former self' was lost (the desire to put an end to anhedonia, regain a sense of identity and control over their lives), and the desire to overcome indifference and skepticism of the people in their surroundings by showing that the disease is a real and debilitating affliction rather than a harmful whim, which the patient uses to mask their laziness and general awkwardness. In the latter case the point is to legitimize the disease, to be empowered first as a patient, and then as a patient with a right to receive treatment, even if social conditions are such that to be recognized, you have to scream very loudly, and perhaps even to self-annihilate. These two trends are illustrated by the following examples: 1) *(...) it's easy to get rid of friendships and expect God knows what on the forum; since I left the duplicate I've been trying not to wail too loud, I thought that being cocky on the internet would improve my well-being; the lesson I learnt is this: you have to wail as hard as you can – you need to wring your hands – stop leaving the house – gobble up medicine – use tonnes of tissues – lose your job – have a suicide attempt – and, what's best, break up into a million pieces; if you don't, there'll be people who want to prove that you're a bitch having fun on the forums at the expense of others. And others who will be surprised that you're not over the moon about what you have. At home they'll tell you that you're an antisocial outcast because of your pure malice and laziness; I'm not sick enough to satisfy you, or healthy enough to satisfy the people in the real world; at least my dog still likes me,* 2) *I have a wonderful husband who keeps me company, is close to me, supports me, helps me. But I have a great sense of guilt towards him and my son because they have to be part of what I'm going through. There are days when I think it will get better. But unfortunately there are also days when it seems to me that I can't make it anymore, that it's too much. Every morning fills me with horror, and I ask myself the question – what is today gonna be like? Will I make it through the day? Am I gonna hit the bottom again? I want to get well for my boys, I want to be like I was before. I don't know what happened to the old ME. Everything that's happening to me causes me great pain, depression, guilt – the fact that it can't be as it was. That I can't be as cheerful and full of energy as before. When I think of how I was a few months ago, I see a woman living life to the fullest. I miss her very much. And then come those thoughts about all these unsolved matters, things I haven't made. For me it is unthinkable. Thoughts are swarming in my head, sometimes I can't handle them. I feel like I'm losing control over everything. And there's chaos and fear. Sometimes I want to run away. But I have my boys, they pull me up, console me. I hope that I'll find a way out of this. I will, right? Regards. M.*

There is another motivation, namely the willingness to express views in a safe place – elsewhere they would put the authors at the risk of alienation, if not ostracism – and using the uncompromising language of emotions, metaphors that break social taboos. Here is an example: a woman writing about her feelings when pregnant: *I'm pregnant. Please don't refer me to the pregnancy and childbirth forum, or such like. I was there. I felt like an intruder among the expectant mothers getting excited about the ultrasound, dates, preparations. I'm not thrilled about the prospect, I'm not happy. One of my friends told me – you'll look beautiful, sexy. And I want to say: "F ..., first I'll look like a porker, and later as a suckler cow, completely asexual, chained to the trolley, waddling at a speed of 500m/h)". Others congratulate:*

"What a beautiful time of your life, a baby ... you have so much to be happy about". And I think: "The end of my life, the end of free choices, dedication, responsibility beyond my strength, fatigue, helplessness, dependency". Others say: "You need to see a doctor, go shopping, you need to have nice clothes, for yourself, for your child, redecorate the apartment, find a birthing school, and so on." And I'm just livid ... It all costs, why so much, why is it such a business – it doesn't serve anything, neither pleasure nor joy, nor health, and it costs. [...] Is it really going to be that way?

The impact of moderator on the comments posted on the forums

A comparative analysis of the contents of both forums showed that there are some differences between the forum moderated by a doctor and that without a moderator (**Table I**).

Both forums contained comments revealing all categories of needs, divulged both directly and in a camouflaged way. Therefore it seems as if the moderator did not affect the kind of expressed needs and described behaviours. The difference between the two forums is based on the intensity of responses to published statements. While on the unmoderated forum up to 64% posts were not commented upon, on the moderated forum, the users obtained an answer in 100% of cases (93% were answers to the implicit or explicit questions, 7% were statements about the inability to give a clear reply to the statement of the member due to absence of sufficient evidence). Questions were answered by both forum participants and the moderator. The following can be attributed to the presence of the moderator:

- lack of threads finished inconclusively, i.e. giving advice, expressing a professional opinion or any statement that – from a pragmatic point of view – indicates the exhaustion of the conversational exchange and its termination,
- lack of so-called incongruent interpolations, or explicitly nonsensical statements, deprived of a perceptible connection with the thread and previous comments, which can simulate or characterize an active cognitive impairment (obviously, this cannot be established in this study), e.g. *search for it PAYS VERY WELL make atonement even as someone described MENGELISM and are accounted for separately at the same time –silence who raped you soul never really pays off / peanut ... spilled! Everywhere I see pills, peanut, I'm scared now, everywhere I see those, AVE Caesar, what's gonna happen?*,
- greater detail and better logical organization of entries initiating the thread: linguistic analysis of posts published on the FORUM AGAINST DEPRESSION shows the prevalence of exponents of carefully composed written reports, which greatly facilitates the provision of substantive feedback for the doctor of psychiatry working on the forum.

Conclusions

1. Health information needs can be identified on Internet forums dedicated to health problems.
2. Health information behaviour can be identified on Internet forums dedicated to health problems.
3. With regard to the substantive content of statements, there is no significant difference between the moderated and unmoderated forum. The repertoire of threads and manner of verbalizing problems are very similar. From the point of view of a researcher of information needs and behaviour, and considering that the effects of verbal exchanges are unknown (not researched in this study), it cannot be established whether any of these sources is more reliable than the other.

Important concluding remarks

The pilot analysis of the content of the forums shows that this kind of spontaneous statements provides a very interesting, diverse and non-obvious knowledge about information needs and behaviours of their authors. Spontaneity, emotionality, but also anonymity of the posts enables us to get an insight into the area of needs and

Table I. *Comparison of formal characteristics of a moderated and unmoderated forum*

	DEPRESSION (Gazeta.pl) – no moderator	**FORUM AGAINST DEPRESSION – moderated by a psychiatrist**
Number of posts	566	1009
Average number of words in a post	28,9	88
Average number of sentences in a post	4,3	12,6
The percentage of posts remaining unanswered	64%	0%
Categories of statements	All	All
Needs revealed publicly / directly	Yes	Yes
Needs revealed indirectly	Yes	Yes
Reponse to the published post	77%	100%

Source: Own elaboration.

behaviours which probably would not be easily identified using a questionnaire or interview. We get a peek into the lives of the forum participants, their natural reactions, and often their intimate matters. They do not know that the researcher is observing them. They do not take the attitude of the study object 'posing' or 'teasing' the researcher. These emotions and anonymity that invites honesty make the picture richer, three-dimensional and variable. But does that mean we get to know the truth? Are the declared needs real needs? Certainly caution should be exercised.

First, the so-called sharp (pragmatic) variant of the EMIC method was used in the study, assuming that the tested language material is only an expression of what the participants say and how they say it, but it cannot testify to what they really think, and the intentions governing it, nor does it provide evidence that they actually take certain actions. This assumption stems from the cognitive, and consequently methodological, attitude inherent to pragmatic linguistics, which examines only the manifested content of the statement, without investigating the motivation, as well as without trying to predict the possible effects of these statements unless they are provided directly and can be explored. So the method itself limits us to the layer of verbal expression.

Second, the forum participants often have a problem with revealing their needs (example: *I feel awful and the worst is that I can't say that to anyone*). The difficulties are sometimes caused by:

- social anxiety (example: *... in addition my husband accuses me of something all the time, looks at me with condemning eyes. I don't feel like cleaning the house, our daughter has caries. [...] I am afraid of people, keep pretending someone else and that everything is okay. People don't like problematic people like me, they have enough problems of their own, and I'm not good enough for anyone – that's why I don't have any friends*),
- shame (example: *I'm going to see a specialist because I can't cope with my horrible state anymore [...]. The trouble is I'm anxious about the visit because I can't talk about myself and I'm ashamed of what happened, I'm ashamed to admit it to another person. I've never told anyone about my problem, I'm a secretive, shy person and it's hard for me to talk about some facts of my life. Starting this thread was a true act of bravery for me, I feel that I need to talk to someone ...*),
- low level of health competence (health knowledge) preventing the formulation of the problem, or leading to the denial of the disorder in such *a* way that any failure/problems are attributed – with clear signs of culpability (guilt), only to their own character traits (example: *The worst thing is that I'm not sick, just messed up, my character is so fucked up. I need to talk to someone, and I don't have anyone. / I've always been a little oversensitive about illnesses but now I'm obsessed. I look at my child and I want to scream because I keep telling myself that I have some form of cancer and will certainly die soon. If something hurts me a few days in a row, I do a search on the Internet and self-diagnose cancer, later it passes but then I find it in another part of the body. I'm mentally exhausted, have anger outbursts, I can't enjoy anything. Please help!!!!!*).

On the one hand, this observation (difficulty verbalizing needs) points to educational and psychological needs, but on the other, it can distort the picture of strictly informational needs. This conclusion can be drawn based on the statement: *... patients often prefer to swallow 10 tablets a day than to go to a psychologist for therapy. because, in my humble opinion, the problem is the man himself (and the way he's connected with his society and relatives), and of course sometimes drugs are recommended, but I think that Polish psychiatrists all too rarely talk of going to therapy. Myself I'm receiving pharmacological treatment, supported with therapy. and I find it more rewarding.*

The third reason for potential distortions of real needs and behaviours may be some other phenomenon. As we know from other studies, anonymous participants of online forums can create their personalities easily and without risk, wear a mask or adapt to the needs of others, especially those gaining the position of forum opinion leaders. Phenomena such as creationism and domination, cyberviolence or cyberbullying on online forums are well described in the literature [33]. It can be seen also on the forums analyzed in this study. Evidence was found for trolling/flaming, i.e. aggressive, unprovoked statements ridiculing the authors of posts. These statements demean others' statements or contain direct insults (example: *Why can't I go on the forum. Why has some lucynana.n blocked me? Interesting. What a scummy person? Kassssssaaaaaaa from the Schizophrenia forum on gazeta.pl, the same one. Jealous or what? About what? Some hag. / stop playing the f ... doctor! / get off, creep / but you're a crook – I didn't think you'd attack me that way. You know what? I'm not surprised that nobody wants to know you. goodnight! sure I insulted you, but I stopped and I apologized – now I'm p... off*). There are also statements by people that seem healthy, but pretending to be a person suffering from a mental disorder, who deliberately heat up the debate, lead it to a blind alley, and having done that, disappear from the forum or reveal the deception with derision (example: rzeznia_nr_5: *I'm taking the piss out of you. /* carlabruni: *And we're taking the piss out of you! you think we're on the receiving end, no way, sucker /* uri_ja: *you're taking the piss out of yourself, everyone can see you're just provoking others, and it's not f... hard provoking people, anyone can do it! I'm expert at that, talk to my husband! you're not a patch on me. you're an even bigger fraud!*). Statements of this kind can significantly affect others' response. Perhaps not all needs and behaviours disclosed by forum users are true. Some of them may be aimed at ingratiating themselves with the leaders, presenting themselves in a better light, awakening sympathy, hiding the real problems, etc. This assumption is the more legitimate – though not easy to prove unequivocally using the method adopted in this study – that in the content of the DEPRESSION forum on Gazeta.pl one can notice subtle signals of the existence of

local quasi-authorities, forged in the milieu, which could intimidate other users or otherwise modulate their verbal behaviour. The presence of these figures reveals itself only indirectly, and can be seen in that the user that has the supposed status of a quasi-authority – resulting from substantive reasons and seniority on the forum, or both – acts as follows:

- expresses spontaneous summary assessments, diagnoses individually noticed regularities, having granted themselves the right to do so. At the same time they allow themselves to bluntly invalidate the arguments put forward by other users who – by default – enjoy a lower status, for example: *It so happens that not every pregnancy is planned and sometimes it happens that a person that normally feels well experiences the first relapse when pregnant or relapse after years of remission. Then what, she should go and drown herself? Anyway, there's no point in writing with some stupid cow*;
- statements of this kind arouse applause from other members of the community who openly declare their adherence to the quasi-authority, for example: *Anyway, there's no point in writing with some stupid cow* / [comment on this statement:] *:DDDD Lucyna, I'm a big fan of your forum taglines :)) I have to start writing them down cos they're really good :) brief, concise and to the point :)) also funny :)) I love reading your texts :)*.

Assuming a different viewpoint, the same anonymity, the "security" of placing posts on the forum, may encourage honesty in revealing needs, even those considered to be shameful [34]. **Linguistic analysis of online forums can therefore give very interesting results and clues that cannot be obtained via questionnaires or personal interviews. It seems, however, that it should never be the only method used in the study of needs and behaviours. Determining whether we are dealing with real or created needs or behaviour requires confirming the results of the linguistic analysis of the forums using other methods**.

Can the analyses of posts published on mental health forums and described in this paper indicate that the knowledge derived from this kind of research could possibly be helpful in designing health interventions? The answer is yes. A linguistic analysis of statements provides insight not only into what people do and what they need (even assuming that it is all true and that not all speech acts formally expressing the information need faithfully reflect its essence), but also, and perhaps above all, into how they talk and conduct conversations. The language they use says a lot about their competencies, attitudes and beliefs regarding health or treatment, often very difficult to detect. Hence, it appears that the analysis of online forums can also provide valuable unobvious, often intuitive, knowledge of the target groups. In the present study, what certainly is of concern is that the forum participants do not seem to know reliable sources of information. They "google", ask people similar to themselves, have sketchy knowledge, coming from very diverse sources, they, most probably, do not ask themselves questions about its quality or credibility. This probably testifies to a low health information competence. Also for this reason, and the lack of knowledge and information skills, they feel helpless, alone in their problems with health, disappointed by lack of care.

Two forums analyzed here give insight into the narrow area of needs and information behaviour of Polish Internet users. A linguistic analysis of the comments on the forums related to other health problems, combined with other "checking" methods, would allow for a wider perspective on the deficiencies of knowledge and health competencies and a better understanding of the behaviour of people looking for a variety of health information. It could also be valuable knowledge as far as activities in the field of health education are concerned, as well as solutions in the area of information provision. In the context of online chatting analyzed here, it should be of serious concern to us that in Poland there is still no obvious, easy to find, credible health knowledge portal for citizens tailored to their needs.

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The Negative Consequences of Closed Access to Scientific Data and Other Barriers to Information Access – An Analysis of the Health Decisions of Parents Having Children with Autism Spectrum Disorder (ASD)

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Abstract

A diagnosis of autism can present a great challenge to the family with autistic children, especially to parents. Health information-seeking behaviour is described as one of many problem-solving and stress-coping strategies in literature. The information was found to have many important functions, e.g. it can contribute to the process of acceptance, it enables parents to access health care services, then to manage their child's difficult behaviour and it might help parents to respond more effectively to the range of life-changing events that may induce stress.

There are many barriers to meeting the information needs of parents having autistic children. Two different types of barriers to information access can be identified: "objective barriers" (problems communicating with health care professionals, healthcare professionals lack of skills and knowledge of managing children with autism, economic barriers to the access of information, information overload and a low level of health literacy) and "subjective barriers" (experience of social isolation and the parents' emotional state during diagnosis, which have the potential to make the families prone to misinformation).The main aim of this paper is to describe the negative consequences of barriers to the access of scientific research and evidence-based healthcare information (e.g.: spreading *anti-vaccine messages).* The problem will be discussed using the example of the information-seeking and health-related behaviour of parents with autistic children.

Key words: **Autism Spectrum Disorder, access to information, information dissemination, information seeking behavior**

Słowa kluczowe: **spektrum autystyczne, dostęp do informacji, upowszechnienie informacji, zachowania informacyjne**

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Introduction

According to the International Statistical Classification of Diseases and Related Health Problems, autism belongs to the group of pervasive developmental disorders (F.84). The most characteristic irregularities of this disorder appear predominantly in three areas: communication, social interactions and behaviour (a stereotype area of interest and activity). Data from the Centers for Disease Control and Prevention (2014) [1] indicate that nearly 1% of the world's population may suffer from autism; it is diagnosed in 1 out of 68 children in the United States. In Poland, the exact number of people suffering from autism is not known because there is no system for monitoring this disorder, especially in the adult population It has been estimated that there are 347 thousand people with a range of autism spectrum disorders and 64 thousand people with child autism [2]. Autism is a developmental

disorder of indeterminate aetiology, displaying a number of symptoms which may impede an early diagnosis. Although it is one of the most frequently recognised developmental disorders, an effective method of treating autism is still unknown and there is a lack of consensus in the scientific world of how to support families who are raising children with the symptoms of autism [3].

Receiving a diagnosis of their child's autism is a very stressful experience for parents, primarily because the specialists who provide it are not able to give clear information about the causes of their child's disability, nor about the course of its development and the treatment methods that should be adopted. The parental stress may be intensified by a long waiting time for the diagnosis, by the manner in which it is communicated by a specialist (frequently with little empathy but emphasising the negative aspects of the child's functioning) and by the lack of any guidelines for proceeding with further treatment or support for the child's development. It is the parents who have to take responsibility for finding the necessary information [3, 4].

It is worth indicating that the relevant literature considers searching for information to be one of active, problem-oriented stress coping strategies (Transactional Model of Stress and Coping by Lazarus & Folkman as quoted by Pain [5]). Accessing information about the child's disease may fulfil many important functions, firstly it can facilitate parents' ability to accept a new situation, to obtain health care and nursing appropriate for the health needs of their child, or it can ease the problems of dealing with child's difficult behaviours [5] and other everyday stressful situations [6].

However, the parents of children with autism encounter many barriers to information access, both objective (problems in communicating with professionals, the general practitioners' lack of knowledge of ASD, limitations and costs associated with the access to credible sources of information, information overload, a low level of health competence, existence of the closed model of scientific communication) and subjective (the feeling of isolation and high level of stress, which impedes finding, correctly interpreting and applying the health information).

The aim of the paper is to discuss, on the basis of an analysis of the literature concerning information needs, the satisfaction of the diagnosis, the health decisions undertaken by the parents of children with autism and the negative consequences of the various barriers to information access.

The following issues are analysed in this paper:

1. What barriers to information access are encountered by parents of children with autism at different stages of the diagnostic process of their child and after receiving the diagnosis?
2. To what extent are the decisions of parents of children with autism, regarding the choice of an adequate method of treatment, their mitigating decisions and health awareness formed by the results of current scientific research? What factors may influence their health decisions?

How to separate emotions from science – the barriers to information access encountered by the parents of children with autism

The literature indicates that there are at least four stages in the process of diagnosing children with Autism Spectrum Disorders: the period before receiving the diagnosis, receiving the diagnosis, the period after receiving the diagnosis and the period of accepting and adapting to the new situation [7]. To date, the research on health information needs and information behaviour of parents of children with autism was conducted during the last two stages of the diagnostic process, so there is limited information available about the process of searching for information before receiving the diagnosis. The research indicates that before receiving the diagnosis, parents have no prior knowledge of autism and their notion about this developmental disorder is frequently formed by the mass media or films like "Rain Man" directed by Berry Levinson [6]. Therefore, it would appear that the moment of the diagnosis should be the key moment for the health care provider to inform the parents about autism and the available support services for the child's development. This information should be suitably balanced between indicating the negative aspects of the developmental disorder (potential upbringing difficulties) and pointing to the programmes of early intervention [7], which may be of key significance for the further development of a child.

However, it is a primary health care provider who becomes the first barrier to information access for the parents of children with autism. Research, conducted with the participation of parents or carers of children with ASD, related to: the general difficulties associated with caring for autistic children [8], satisfaction with the diagnosis [7, 9] communication with doctors during the diagnosis [4], or the information needs of the carers of children with autism [6], indicates that parents are not satisfied with their interaction with the doctor giving the diagnosis. They are especially dissatisfied with the range and quality of the information obtained and the lack of the doctor's knowledge about autism [4, 9]. Parents report that physicians limit their role to disclosing the diagnosis, at best they give parents an information leaflet about autism without explaining the nature of this developmental disorder, or where, and how they can use the services of educational and therapeutic support for their child. They do not provide any guidelines for coping with child with ASD. This forces parents to take over the responsibility for finding the relevant information [4, 6]. The results of the survey conducted with 146 carers of children with autism in 2007 by Rhodes et al. [10] indicate that only in 40% of cases the specialist disclosing the diagnosis of autism gave additional information about the disorder. Only 6% of doctors referred carers to an autism specialist, 18% of doctors gave no further information about autism, or the availability of support services. Moreover, parents are usually dissatisfied with the mode of disclosing the diagnosis by doctors, who tend to visualise the child's future negatively by using technical and explicit language [7, 11].

Doctors inability to convey the information regarding the methods of treating autism and the available support services may result from the nature of the disorder itself, rather than from the doctors' lack of knowledge. The Autism Spectrum Disorder (ASD) is one of the most complex developmental disorders with unknown aetiology. There is currently no known 'cure' for autism, therefore and there is no-one who can ascertain parents about the future of their child, or advise them on what kind of therapy should be chosen [12]. According to Mansell and Morris [7], during the diagnosis parents are not given any information about the causes of autism because the answer to that question simply doesn't exist. The diagnosis of autism poses a great challenge for a family doctor, because the Autism Spectrum Disorder (ASD) have a very wide range of symptoms, from mild developmental anomalies to very serious behavioural disorders. Delays in speech development and behavioural disorders are frequently evident with small children between one and three years of age and are not necessarily the symptoms of autism. Therefore, physicians are wary of giving a wrong diagnosis and inducing unnecessary stress on parents whose children may just be developing more slowly [9]. The reasons for a delay in diagnosis may also be the physician's concern about the strong emotional reaction of parents on receiving the diagnosis of autism, or the hope that child's symptoms of autism may soon disappear [10].

However, parents of children with autism expect doctors and other specialists treating autism (special pedagogues, speech therapists, teachers) to be credible sources of information about the nature of this developmental disorder and the available support services of educational and health care [8]. The survey conducted by Derguy et al. [13] with a group of 141 parents (including 57 parents of children with autism), which aimed at investigating the priority needs of parents having children with ASD, indicated that information needs are the most important requirement (highlighted by 89.5% of parents having children with ASD). These needs were more important than psychological (73.5%), material (71.0%) or educational needs (58.8%).

The information needs, most frequently listed by parents as essential following the diagnosis, include information about the aetiology of autism, the available therapies, the possibilities of early support for the child's development, the systems of social support, guidelines for further action, the methods of coping with the diagnosis, the possibilities of financial support, the problems of parenting an autistic child, the child's future ("what will happen when we are not here") and explaining the children's problems to others [4, 6, 8]. The results of the research by Brogan and Knussen [14] indicated that parents' satisfaction with the diagnosis was increased by aspects such as, the way the diagnosis was communicated, the quality of the information received (parents were more satisfied if the information given orally by a doctor was reinforced with written information), the possibility of asking a specialist additional questions and a doctor's serious consideration of parents' early suspicion of their child's disability. The satisfaction with the diagnosis increased when it was presented in a more definite manner [14], it had a coherent structure and it was given relatively quickly by doctors having appropriate knowledge of autism and the appropriate interpersonal skills [4]. According to Abbot et al. the shock induced by hearing the diagnosis could make understanding of the information by parents very difficult, which is why they appreciated the doctors who devoted time to them, who understood their emotional state and enabled them to ask questions [15].The research by Osborne and Reed [4], who conducted 15 focus groups with parents of children with autism at various ages, indicated that the perceptions of the parents of what they feel would be of benefit to them changed with the passage of time after the diagnosis. The parents of younger children thought that they should be given the maximum possible amount of information about autism during the diagnosis, especially how the disorder may develop in their child, even though, at that moment, they were not able to absorb and remember this information. The parents of older, school-aged children thought that the information about the available support services should be given to them gradually and they wanted more specific information, e.g. about the programmes of early intervention.

The problems in communicating with doctors and other specialists working with children with ASD do not occur only during the diagnosis. Parents are relatively satisfied with the contacts with school teachers [4], however, they frequently indicate the lack of collaboration between the systems of health care, education services and social care following the diagnosis; they also mention the reluctance of these service providers to exchange information [4, 6]. According to parents, this problem could be solved by establishing a liaison service to forward information ("liaison worker", "key worker", "passer-on of information"), who would also act as a point of contact for the parents to guide them through the system supporting people with autism, simultaneously coordinating the work of the individual services [4].

The period after the autism diagnosis is the time when parents search most intensively for information [7, 16, 17]. Searching for information is recognised as one of active, problem-oriented stress coping strategies (Transactional Model of Stress and Coping by Lazarus & Folkman as quoted by Pain [5]). Acquiring information about children's diseases or disabilities by their parents may satisfy many significant requirements. Primarily, it may facilitate adapting to a new life situation and accepting the child's disability, access to health and nursing care appropriate for the child's wellbeing. Moreover, it may provide a sense of control, enable planning for the future, facilitate coping with various difficult everyday situations, e.g. educational problems and the child's difficult behaviour [5]. It could also enable parents to take an active role in making health decisions [6, 16]. Parents may be motivated to search for information in order to control the activities of professionals, or to acquire skills to communicate about the child's developmental disorder with others, including with the child [18]. The search

for information results from parents' dissatisfaction with the health service and other professionals specialising in autism therapy [6]. Furthermore, it results from the difficulty of accepting the diagnosis and the information about the impossibility of curing autism. Parents search for information in the hope of finding an effective method of treating autism, which will prove that "science is wrong" [8]. Although parents search enthusiastically and intensively for information about the problems of their child and frequently become experts in autism, knowing more about the developmental disorder than specialists in autism, they soon realise that finding valuable and credible information is not easy [6, 17]. The research relating to information needs and the behaviour of parents of children with ASD, or to their health decisions, reveals the difficulties which parents encounter in locating adequate information and putting it into practice in a manner which is beneficial for their child's current developmental situation [6]. Additionally, it emphasises the problems of information overload and the searching process itself, which overwhelms parents. Moreover, the barrier deterring the correct perception and interpretation of the information is the parents' emotional state immediately after the diagnosis [16], which may be compared to condition of grieving [19], increased by a feeling of helplessness, permanent stress and exhaustion.

The research by Pain [5] indicated that parents have mixed feelings about the benefits of searching for and finding information. The knowledge provides them with feeling of control of their own life by facilitating access to various health and educational services, or coping with the problems of bringing up their children. However, gaining knowledge may increase the fear, especially, if the sources of information used are contradictory and produce a dark vision of their child's future [4, 6].

Research [7, 12, 16, 17] indicated that parents of children with autism use many sources of information, including personal sources (doctors, teachers working with autistic children, speech therapists, special pedagogues, psychologists, physiotherapists, other parents with autistic children), written sources (books, magazines, newsletters about autism) and electronic sources (Internet, email letters, social networks). However, after a diagnosis, the predominant sources of information used by parents tend to be informal. The on-line survey conveyed by Mackintosh et al. [12] revealed, for example, that parents obtained their knowledge of autism from seven different information sources, 88% from books about autism, 86% from on-line sources, but only 44% from scientific journals. Of the personal sources of information, specialists in early intervention, psychologists, therapists and speech therapists were most appreciated by parents (57% of parents cited them as a source of information), 49% consulted with teachers, 48% with doctors and 17% with family members. Similar results were reported in the research undertaken by Rhodes et al. [10]]. The authors conducted an online survey in Virginia, USA, with 146 parents of children with autism. The parents indicated that the most frequently used sources of information after the diagnosis were the mass media (71–73% e.g. Internet), conferences/workshops (42%) and other parents (42%). Only 15–20% of the interviewed parents admitted receiving their information about autism from specialists. An important form of self-education for parents having autistic children is participating in conferences, seminars and support groups [17] as they provide an opportunity to meet with other parents [6]. It has been indicated that the parents of other autistic children and self-support groups become one of the most significant sources of information and social support [6, 8, 12, 16]. This may result from the fact that other parents of children with autism are most experienced in using the various support services and know their limitations [5]. In the face of professionals lacking adequate knowledge, the parents start acting as experts in autism. Parents can compare their feelings with the experience of other parents and learn from their failures and successes. They can be relieved and psychologically comforted by observing others in a similar, or even worse, situation [20]. This effect is called "walking in the same shoes factor" by Mackintosh et al. [12]. Although support groups and foundations may supply parents with much valuable information, it is assumed that this information may be largely shaped and distorted by the private perspective of people involved in the self-support groups, which may mean that this information is somewhat unbalanced [16].

The Internet is also an important source of information about autism for parents [10, 12, 16, 17]. However, the sources of information chosen by the parents frequently become the sources of disinformation. In 2012 Stephenson et al. [21] conducted research on the quality of information about educational and therapeutic interventions, which were available on-line in the services of the National Society for Autism. This information was compared with the ranking list prepared after a systematic survey of literature of the most effective interventions and therapies used in the treatment of autism. The research revealed that the institutions which were responsible for spreading the latest credible information about particular therapies and the educational interventions used to treat autism were ineffective. They frequently directed parents to methods which are unsupported by scientific evidence, or to commercial providers of health services. Frequently, contradictory information about the effectiveness of particular methods to treat autism was given within one service. In 2005 Metz et al. [22] conducted a very interesting experiment relating to on-line information about autism. After writing the key words "autism" and "treatment" into Google, the authors found over 65 recommended therapies as being effective for treating autism. They included: technology "ADAM" ("Aphysical Dimensional Access Manager"), which advocates unlocking autism by means of a technique similar to telepathy (using the Internet for this), stem cells of a sheep, fish oil, thyme and others.

There is another problem related to using the Internet as a source of information about health, which is the parents' vulnerability to various on-line fraudsters. This refers to web sites which exploit parents' gullibility and their desire to find 'a medicine for autism' as soon as

possible, and which try to sell them various products, by using the language of a religious or scientific discourse and quoting the opinions of pseudo-experts [6, 16]. Parents' vulnerability to disinformation was reported in the research on the information needs of parents with autistic children by O'Reilly et al. [16]. The research indicated that just after receiving a diagnosis, parents have a great need for information relevant to their child's disability. However, their emotional state frequently prevents them from "separating emotion from science" making them vulnerable to various sources of disinformation about autism. In consequence, they may take many wrong decisions, e.g. spending money participating in conferences of doubtful scientific quality. According to O'Reilly et al., this vulnerability of parents to disinformation is not solely conditioned by their emotional state after the diagnosis, or by the stress caused by the everyday care of their children. It may be significantly influenced by other factors, e.g. their low health literacy (inability to find appropriate health information, its evaluation and its practical application).

The research indicated that parents of children with autism may find it difficult to distinguish between the methods of treating autism, which are based on scientific evidence, and those which are potentially harmful to health [8]. This is because they do not fully understand what the 'effectiveness' of a treatment method means [16]. When choosing therapeutic or educational interventions, which are appropriate for their child, parents may consider a number of factors (e.g. cultural aspects, availability of services) rather than whether the effectiveness of a given method of treatment has been proven by scientific research [23]. The reason why parents do not use scientific sources of information may be the lack of time for studying them, their health competences [16, 21] or limited availability of such sources of information [12] resulting from the closed model of scientific communication prevalent in many countries.

The barriers to information access encountered by parents of children with autism may also depend on their social and economic situation. An on-line survey conducted by Mackintosh et al. [12] with a group of 498 parents of children with autism from many countries (USA, Canada, Australia, New Zealand, Ireland, England) revealed that parents with a lower income used personal sources of information (parents of other children with autism) and written sources of information (medical journals), much less than parents from more affluent classes. They had less opportunity to participate in group meetings (conferences, workshops), which the authors suggest, is related to the cost involved in accessing these sources of information (e.g. paying a conference fee, accommodation, travel costs). According to the authors, single parents also were in a more difficult situation because they could not participate in meetings with other parents (even free meetings), being constrained by family limitations and the high cost of caring for children.

The vaccine which reputedly induced autism – the influence of the media in forming health awareness in the parents of autistic children

There has not been enough research conducted which would address the link between the barriers to information access encountered by parents of children with autism and the decisions made by them about the choice of the most suitable treatment method for their child or the parents' preventive behaviour. However, reports about health or prevention choices, which are most frequently made by parents of children with autism, conclude that their decisions are little influenced by the results of current scientific research.

One of the most illogical scientifically examples, which could bring catastrophic results of health choices taken by parents of children with autism, is the decision to stop or delay vaccine for children with autism or their younger siblings. In 2002 Bazzano et al. [24] conducted a cross-sectional telephone survey with 197 parents or legal guardians of children with autism spectrum disorder, who used the services offered by Westside Regional Centre (WRC) in Los Angeles. More than half of those surveyed decided to change or discontinue their child's vaccine schedule after receiving the diagnosis of autism. Similar conclusions were presented in the research paper by Abu Kuwaik et al. [25]. These authors investigated the vaccination history of the younger siblings of autistic children who were treated in three health centres in Canada. The research group consisted of 261 parents: 98 of their children were the younger siblings of children with ASD, 98 were older siblings of autistic children, while 65 children did not have siblings with autism and constituted the control group. It was revealed that in the group of 'younger siblings', the use of vaccines was delayed for 48% of the children, and vaccines were not used at all for 12.2% of the children; in the group of 'older siblings', vaccines use was delayed in 16.3% and only one child was not vaccinated at all. However, in the control group all children were fully vaccinated, with vaccines being delayed for only 9.2%. Additionally, the on-line survey, conducted by Rebecca Rosenberg et al. [26], with almost 500 parents of children with autism, indicated that almost 20% of respondents delayed or resigned from vaccinating their younger children because they were convinced that the vaccine played a significant role in the appearance of autism in their older children.

The 'anti-vaccination' behaviour of parents having children with autism results from the fear of the combined vaccine against measles, mumps and rubella (MMR), which spread in UK after the publication of an article by Wakefield et al. [27]. In the article, which was published in the prestigious "The Lancet" medical journal, Wakefield et al. described cases of 12 children with the symptoms of bowel inflammation and developmental regression, whose parents had consulted a gastroenterology specialist in London. In two thirds of the cases the parents of these children were convinced that their children's developmental regression occurred soon after their

inoculation with the MMR vaccine. This was used by the authors to hypothesise that there may be a relationship between the use of the MMR vaccine and the increase in children developing autism. The article by Wakefield et al. proposed only a hypothesis arising from the research, however, it caused great interest in the British press. Many press articles were published about "the research that proved the relationship between the use of vaccines and autism". The spread of the gossip about the MMR vaccine causing autism was intensified by the transmission of a CBS programme called "60 Minutes", in which Wakefield stated, that if he had to vaccine his children, he would not use the combined vaccine, but would use separate vaccines against measles, mumps and rubella. It has been estimated that the media publicity caused a reduction in the use of the preventative vaccination in Great Britain from 94% to 75%, with a simultaneous increase in children contracting mumps [28].

The scientific limitations of Wakefield et al.'s publication were soon discovered by other scientists (the small number of cases, the lack of a control group and relying on parents' memories and convictions). Moreover, the whole series of reliable scientific research conducted in the following period did not identify any relationship between MMR vaccine and autism (information about them is included in the publication of Offit and Coffin [28]). The investigation conducted by a British journalist, Brian Deer, proved that Wakefield committed scientific fraud (including: falsifying patients' history, treating children unethically, having a conflict of interests and cooperating with other vaccine producing pharmaceutical companies), which led to the trial of the scientist and later being struck off the medical register by the General Medical Council [29]. In 2010 the publication of Wakefield et al. was retracted by "The Lancet". The official reason for withdrawing the publication was the lack of an agreement to conduct the research by a local bioethical commission and falsification of the research results [30]. Despite all the measures taken, the vaccination panic was impossible to control. This was confirmed by many studies undertaken with parents of children with autism who frequently claimed that the MMR vaccine was one of the causes of their children's disability (as quoted by Hebert & Koulougliot [31]).

Further evidence for the influence of the media on the development of health awareness, not only with parents of autistic children, but also with doctors, is the use of secretin, the hormone released by the glands of the duodenum mucous membrane and small intestine, as a method of treating autism. Using secretin as a medicine for autism became popular after the publication of an article by Horvath et al. [32], which described three cases of autistic children having disorders in their digestive system. As a result of applying an injection of secretin for diagnostic purposes (endoscopy), the symptoms of gastric disorders were abated as were the symptoms of autism in the sphere of social-communication. After the mass media publicity about Horvath's discovery, thousands of children with autism received injections of secretin, which led to major problems in purchasing the hormone. From the scientific point of view, Horvath et al.'s article is of little value (the case study is at the bottom of the hierarchy of scientific proof). Moreover, the whole series of well-designed clinical research (presented in the articles by Levy and Hyman [33] and Metz et al. [22], Matson et al. [23]) and a systematic review of the research undertaken by Cochrane Collaboration [34] revealed that secretin is not effective in treating the autistic symptoms such as problems with social interaction, communication, or for the reduction of compulsive and routine behaviour. However, in practice doctors still prescribe secretin following a clear demand by the parents of children with autism [22].

"When there is no cure, there are 1000 treatments"

'When there is no cure, there are 1000 treatments' (Daniel Cohen) – it is not surprising, that this quotation is placed at the beginning of an article by Goin-Kochel et al. [35] about the treatments which the parents choose for their children with ASD. Autism belongs to the group of developmental disorders for which, to date, no effective medicines have been found. For the various people suffering from this disorder, autism may have a different course and degree of intensity. However, cases of total "recovery from the disease" have very rarely been reported [31].

The research has shown that the most effective methods for supporting children with autism are: methods combining special pedagogy and educational support programmes, communication training (speech therapy), early intensive behavioural therapy and social skills training [23, 36]. There is no scientific evidence for the effectiveness of alternative medicine in the treatment of autism [22, 37, 38]. However, according to some studies, the parents of children with autism frequently choose non-conventional medicine as a treatment for their children [37–42]. It has been estimated that from 32% to 92% of parents of children with autism choose to use non-conventional methods of treatment [23]. The most important reasons for using alternative medicine are: the parents' dissatisfaction with conventional methods of treatment, or their ineffectiveness; the lack of consensus about the most effective method of treatment; the lack of access to physiotherapy programme; a preference for non-invasive treatments [23, 37]; the fear of side-effects caused by traditional treatments and the parents' personal health convictions [36], e.g. about the aetiology of the disease [43]. Choosing non-conventional treatments may also be related to the willingness of alternative medicine specialists to devote more time to parents comparing to the traditional medical specialists [36, 37]. Hanson et al. [41] indicate that the use of alternative medicine may be related to parents' preference for treating their children with natural methods rather than "artificial" or "industrial" products for fear of the safety of pharmaceutical treatment, the low cost of non-conventional treatments (e.g. vitamins) and their availability without a prescription. Additionally, Hanson et al. indicate that the choice of these treatments may relate to the parents' system of

values, because the research results reveal that people with a higher level of spirituality, or are more religious, tend to select non-conventional treatments.

The survey conducted by Miller et al. [44] with 400 parents of children with autism in the USA shows that these parents tend to use untested, pseudo-scientific methods to support their children's development regardless of their education level, wealth and the time of the diagnosis. When taking health decisions, parents rely on recommendations and word-of-mouth (e.g. information heard during workshops, or from other parents of children with autism) more frequently than the information from scientific sources. Although in the cited research, parents indicated that autism specialists (such as psychologists, speech therapists, physiotherapists, doctors, special pedagogues) are a valuable source of information, the research results revealed that those specialists frequently recommended parents to use scientifically unjustified treatments. Physiotherapists, speech therapists and occupational therapist especially recommended parents to use treatments not supported scientifically. Five treatments are most frequently recommended by these specialists, which include for e.g. Auditory Integration Training or the Tomatis method, although research indicates that these methods may be potentially harmful for children and sensory integration therapy, for which there is limited or mixed evidence of its effectiveness.

Another study, showing that the results of scientific research are not necessarily a decisive factor for the health choices of parents of children with ASD, was an on-line survey to investigate the treatments currently used by families of children with the autism spectrum disorder [40]. The survey, which was distributed by means of web sites devoted to autism and distribution lists in Canada and the USA, was answered by 970 parents of children with autism. 63% of those parents did not use the Applied Behaviour Analysis treatment (ABA), which according to the authors is the best supported scientifically method and 23% did not use any treatment for their children. However, among the methods most frequently chosen by parents were scientifically unsupported treatment methods, such as pharmaceuticals, alternative diets and psychological treatment. According to the authors, the parents' health care decisions are influenced by many factors, such as their conviction about the aetiology of the disease, their parenting style, their lifestyle, the mass media and information from other parents. The choice of treatment may also be influenced by the availability of health care and the educational services (parents frequently have a limited choice of treatments, so they choose those which are currently available), their social-economic status or how they perceive the effectiveness of a given treatment. Parents' opinions on the effectiveness of a given method are formed by their perception of the child's progress after the application of a given intervention, not by the scientific results presented in literature.

An interesting insight into the factors motivating parents of children with autism to choose pseudo-scientific or esoteric treatments, called by the authors "fad treatments", is given in an article by Metz et al. [22]. The first group of reasons for choosing fad treatments may be the lack of access to programmes providing early support for child development, the need to find prompt help for the child, the desire to be free from the feeling of guilt for not taking appropriate action. These may force parents to choose treatments which look reliable (although they may not necessarily be so) and give them hope. The second group includes the parents' lack of knowledge about autism, understanding the concept of evidence based medicine, the lack of appropriate scientific competence, or the ability to evaluate the quality of the various sources of information. The parents of children with autism tend to learn as much as possible about the disability of their children and the availability of possible therapies. However, it is not known if the parents' process of acquiring knowledge is systematic and whether they have the ability to understand it. The parents of children with autism frequently rely on secondary sources of information, which tend to have a summary character, but they do not provide parents with the insight to the process of reaching scientific conclusions. Finally, parental choices of fad treatments may be ascribed to the health care system. Doctors have little knowledge of autism and may frequently communicate contradictory information about the developmental disorder, which may often result from their financial relationships with commercial institutions.

Metz's hypothesis that medical doctors could be the potential source of disinformation on the effectiveness of autism treatments is supported by research conducted by Rahbar et al. [45] on 348 general practitioners in Karachi, Pakistan. The aim of the cross-sectional survey was to investigate knowledge and attitude of GPs in Karachi regarding autism. The survey revealed that less than half of the physicians interviewed (44.6%) had heard of autism, 53.4% had learnt about autism from the media and less than 20% had encountered the problem during their clinical practice. Moreover, even those doctors who had heard about autism had false concepts about its aetiology and symptoms. They marked the wrong statements in the survey e.g. the cause of autism is parents' emotional frigidity (theory from 1943), autism is a prediction of schizophrenia, the occurrence of autism may be prevented. The survey showed that doctors less than thirty years of age, who had graduated from medical studies within the previous five years, had a better knowledge of autism. In the group of doctors who had knowledge of autism, only 45.5% declared that their medical school was their source of information about this developmental disorder, 12.8% declared that their source of information was participation in symposia and seminars. Another survey conducted with 191 doctors in New South Wales in Australia [46] also revealed that family doctors may lack sufficient knowledge about autism. However, almost 60% of the surveyed doctors were correct in knowing that the programmes of early developmental support are based on scientific evidence. Nevertheless, 8% of doctors indicated that children with a suspicion of autism should not be vaccinated with the combined MMR vaccine. The analysis of doctors' comments displayed that their sources of knowledge about autism were primarily through

their interactions with the parents of children with autism and members of diagnostic teams, basic health care articles on autism, participation in special courses, and even web sites about autism prepared by schools, or for programmes offering early support interventions for children with ASD.

Reaching for untested and scientifically unsupported methods of treating autism by family doctors and other autism treatment professionals may be caused by various factors. These may include: a low level of social awareness of autism; gaps in the system of medical education [45, 47]; the low level of research infrastructure in many centres; the lack of knowledge of current research on autism, or effective interventions in the treatment of the disability [21]; reliance on clinical practice experience and interactions with patients, rather than medical literature, when taking decisions about treatments for patients. Another factor accounting for physicians' lack of knowledge about autism may be the closed system of scientific communication existing in many countries, however, this relationship has not yet been studied. As stated by Emanuel Kulczycki [48], in the closed model of scientific communication, access to knowledge and scientific materials is possible only by paid subscriptions. This model doubly enforces the limitations. To get access to a given journal, academic institutions (libraries) must pay for access to the publisher's database. The chosen licence enforces additional limitations, e.g. allowing access to the data base only from licensed computers on the premises of the institution which purchased the subscription. In this manner, only students and researchers employed by the institution have access to the scientific material [48]. When free access to scientific knowledge is the privilege of the very few clinical doctors who work in large academic centres, it is not surprising that the primary health care physicians working in hospitals and clinics, far away from universities or centres specialising in autism treatment, may have problems recognising the symptoms of autism, making the appropriate diagnosis and supporting parents in selecting a suitable method of treatment. As stated earlier, the lack of appropriate knowledge of autism, especially among primary health care physicians, may have many negative consequences. Primarily, it may impede the early diagnosis of autism and the introduction of early educational interventions, which are key matters in treating a developmental disorder such as autism. As a result, parents searching for various possible treatments frequently choose non-conventional treatment methods, not scientifically supported, which may have negative effects on the health and development of the child.

Conclusions

The decisions taken by parents of children with autism about the methods of treatment, which are most suitable for their children, may be influenced by various factors. However, the significance of the access to adequate, current and reliable information about autism in health decisions must be remembered. The parents of children with autism face many barriers in accessing information at every stage of the diagnosing process and following the diagnosis. These barriers range from the professional incompetence of the primary health care providers, limitations resulting from the degree of the parents' health literacy (including health information literacy), their emotional state and stress, especially after receiving their child's diagnosis, to accessing various, frequently contradictory, sources of information about autism (Internet, mass media, word of mouth, the opinions of other parents of children with autism). Another set of barriers to information are limitations of a social and economic nature such as low income, single parenthood or geographical constraints by living far away from specialist centres of scientific knowledge.

It is very important that, during and after the process of diagnosis, doctors and other professionals specialising in autism provide parents with current, scientifically supported information about the suspected aetiology of autism, the available and effective treatments and indicate the other forms of support available for the children and their parents. The lack of access to reliable information, as discussed in the paper, may result in parents taking risky health decisions, such as resigning from further vaccinations for their children, choosing ineffective, expensive and harmful methods of treatment, or applying various treatments at the same time, which in some cases may lead to the regression of autism. Searching for information is one of the important strategies of coping with stress during the diagnostic process, and subsequently coping with the problems of raising a child with autism. However, during the process of information seeking, parents should be provided with appropriate support by the specialists. As proposed in the publication by: Osborne and Reed [4] this may be done by establishing a service of "a liaison worker" for information, which would facilitate the mutual exchange of information between the various centres specialising in autism treatment and provide information support for parents. This function could be partially undertaken by libraries and information centres, especially those located in the medical and educational centres. It is equally important to disseminate current scientific achievements adequately through the mass media; e.g. the research proving the lack of a relationship between the combined MMR vaccine and autism; in a form which is fully understandable by an average user of health care.

Equally important is the appropriate education of doctors and other specialists. They should be provided with evidence-based information related to autism treatment. This may be achieved by introducing appropriate changes into educational programmes (medical studies, pedagogy, speech therapy, physiotherapy studies and others). Doctors' knowledge may also be improved by expanding the concept of "Open Access", which is an open model of scientific communication enabling free access to the most current and credible research papers on the subject of autism.

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History and Characteristics of Direct-to-Consumer Advertising in the United States

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Abstract

Direct-to-consumer advertising (DTCA) in which pharmaceutical companies market prescription drugs directly to consumers is legal in only two countries – the USA and New Zealand. This article describes legislative milestones of DTCA development in the USA which have given rise to the current legal framework.

The article shows the cultural background for DTCA expansion, outlining the fight of patients' associations for better access to information about therapy and drugs and change in perceiving the role of the patient in the health care professional-patient relations. It presents arguments supporting the producers' right to advertise their products.

Direct-to-consumer advertising in the USA is a controversial subject. Although based on only limited data, the existing research gives arguments both in favor and against direct-to-customer advertising. The article also presents the EU policy towards DTCA, considering the consequences of the existing DTCA ban in the EU.

Key words: **drug advertisements, DTCA, patients, pharmaceutical marketing**

Słowa kluczowe: **reklama leków, leki na receptę, pacjenci, marketing farmaceutyczny**

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Introduction

Only in two countries in the world, the USA and New Zealand, the law authorizes direct advertising of prescription drugs to consumers (DTCA – direct-to-consumer advertising) [1]. Such advertising entails that prescription drugs can be promoted in popular media, such as television, radio, newspapers and magazines as well as on billboards, via mail or leaflets [2].

The definition of DTCA does not include ads published on drug manufacturers' websites because such information is searched independently by consumers. Nor does it subsume materials that patients receive from the company e.g. by calling their hotline or by post. The concept of DTCA does not cover promotional information published in medical journals because there the target group are healthcare professionals [2].[1]

It is on an everyday basis that American citizens are 'bombarded' with advertisements of prescription drugs that are to cure their high cholesterol, diabetes, depression, pain and many other conditions [3]. The development of this form of advertising has been made possible, among other things, due to the establishment of patients and consumers associations demanding that patients be allowed active participation in making health decisions and that there be improved communication between the patient and medical staff [3]. This evolution supported the arguments of DTCA proponents as advertising was to provide patients with information about diseases and their treatment [1]. Although it has been over thirty years since the publication of first advertisements, this issue remains controversial. Advantages and disadvantages of DTCA are widely discussed in the literature [4, 5].

One can only speculate to what extent DTCA contributes to the fact that the drug market in the United States is the largest in the world – 41.8% of the world's drugs are purchased there. It is also worth noting that as many

as 56% of new drugs (launched between 2006 and 2010) were sold in the US [6].

The aim of this article is to present and explain how public-directed prescription drugs advertising became legally binding in the United States, and the characteristics of this form of marketing. An analysis of the literature and the milestones leading to the current legislation will be presented, as well as the cultural conditions that enabled DTCA. Both positive and negative aspects of this solution will be shown. Finally, the EU approach on the introduction of such advertising in Europe will be demonstrated.

1. History of prescription drugs advertising

In the early twentieth century there were only a few effective drugs on the US market and the patients themselves opted for one or the other [7]. At that time the roles of the doctor who prescribed medication and the pharmacist who dispensed it were not so strictly separated, and virtually all the drugs could be obtained both by prescription and without it.

In 1905, the American Medical Association (AMA) appointed the Council on Pharmacy and Chemistry, which established standards for drugs and evaluated them [3]. The aim of the council was to advocate the use doctor-prescribed drugs, avoiding ineffective self-prescribed medication. The AMA encouraged medical journals not to publish drug ads aimed at laymen, and doctors not to prescribe medicine whose advertising is addressed to the public. Self-treatment was perceived as a threat to the medical profession. The AMA's guidance led to the fact that over the years the only 'ethical' advertising was considered to be that addressed directly to physicians [3].

The aim of the first federal drug regulation in 1906 was to discourage people from self-medicating, but at the same time to encourage drug manufacturers to give consumers accurate drug information (e.g. medicines could not be marked in a confusing or misleading way, the presence and quantity of dangerous substances was to be indicated) [3].

In 1938, the Food, Drug and Cosmetic Act (FDCA) was introduced, which gave the federal Food and Drug Administration (FDA) the right to exercise supervision over food, drugs and cosmetics [2]. The Act was the result of over a hundred deaths caused by the drug called Elixir sulfanilamide. Since then the consent of the FDA had to be obtained before placing the medicament on the market. Also, the scope of information to be included in the drug leaflet was extended. In addition to the drug name and composition, they were to include directions for use [3].

Before 1951 whether the drug was sold without a prescription (such drugs in the US were called OTC – 'over the counter') or by prescription (RX – 'prescription only') depended on the drug manufacturer. Only sometimes did the FDA indicate medications which should be issued only on prescription, when they were considered potentially dangerous. The lack of clear rules gave rise to confusion among both patients and pharmacists. In 1951, the FDCA was amended and a definition of RX drugs was created. Medicines that were potentially toxic, had harmful actions, complicated dosing, or were dangerous if taken without medical supervision, were to be issued only by prescription. The introduction of this distinction has significantly increased the number of prescription drugs. This move has strengthened the position of the AMA that it be qualified medical personnel that keep watch over what drugs the Americans are taking. Pharmaceutical companies ceased to direct their ads to ordinary people, focusing mostly on physicians [8].

In 1952, further amendments were introduced to the FDCA. It was required that the manufacturer of the drug provide evidence of the safety and efficiency of the drug – only then could it be promoted. Ads were to inform about both risks and gains from taking the medication. The FDA was also given the possibility of jurisdiction over drug advertising [8].

In the 1960s, 90% of marketing expenses were allocated to the promotion addressed to doctors – the remaining 10% on advertising in hospitals and directed to pharmacists. This move was in direct opposition to that of thirty years earlier, when the companies incurred heavy investments in advertising addressed to the public [3].

In subsequent years, the significance and prestige of the medical profession were increasing. Doctors were becoming better educated and specialized. There was a growing disparity between their knowledge and that possessed by the average patient. At that time it was common practice not to inform patients about the diagnosis and treatment. In the late 1960s, spending on prescription drugs amounted to 83% of all drugs spending incurred by the Americans [3].

In 1969, the FDA determined the final regulation on prescription drugs ads. They were: 1) not to be false or misleading, 2) to maintain the correct balance between medication risk and gains (*fair balance*), 3) to contain facts that are significant from the point of view of using the advertised product, 4) to contain information about the most common risks of taking the drug (*brief summary*) [9]. These regulations did not affect public-addressed prescription drugs advertising, but only that directed to healthcare professionals.

Until the mid-1980s US pharmaceutical companies focused mainly on doctors as their core customers, and trained armies of medical sales representatives that would offer them mugs, notepads, conference fees and other things [10]. In the 80s, the policy changed favourably for pharmaceutical companies [2]. At the time, the idea of 'managed care' was being developed, aimed at reducing costs and increasing the efficiency of care. The patient was to take a greater part in the decision-making process regarding their treatment, also have an impact on the drugs they were prescribed, which were to be more modern, newer, better functioning rather than simply the ones chosen by their doctor after they had dinner with a pharmaceutical representative [10]. Organizations of patients and consumers were being formed, demanding better information about treatment. They became the driving force of DTCA. In order for such advertising to take effect, pharmaceutical companies had to properly educate patients and prepare them to talk with the medical staff, the same aim – better education – had the patient's organisations [3]. While the companies tried to give patients

only the amount of knowledge sufficient for them to influence the doctor to prescribe a particular product, the associations aimed at developing the patient's capability of establishing an equal dialogue with health professionals.

In the early 1980s, some drug manufacturers started to change their marketing approach, directing their attention towards ordinary citizens. At the beginning it was not so much advertising as social campaigns. For example, Pfizer began the 'Partners in Health Care' campaign, which drew attention to the consequences of untreated diabetes, tonsillitis, hypertension or arthritis. However, no drugs were mentioned. Only the name of the company was visible, with the hope that patients would ask about the company's drugs at their local clinic [3]. In 1981, the Reader's Digest published an advertisement of Merck's pneumococcal vaccine, Pneumovax [8]. The advertising machine started rolling.

When advertising of prescription drugs was being regulated in 1969, there was still no advertising for prescription drugs directed to the public, and so the first marketing campaigns were not subject to any restrictions. Initially, the legislators favoured DTCA and hoped that the regulations they created within advertising aimed at medical professionals would be sufficient to protect ordinary consumers. However, in 1983 the FDA heard some criticism – it was feared that DTCA would cause, among other things, the patients to exert influence on the authorized professionals to write out prescriptions for unnecessary drugs, causing an increase in drug prices [3]. In 1985, after conducting a survey among patients and a public debate, in which lobbying pharmaceutical companies pointed to the educational importance of these ads, the FDA published the Federal Register, where it declared that the 1969 regulations are sufficient to protect consumers. This greatly popularized the printed advertising of prescription drugs directed to ordinary people [2].

Still, in the early 1980s, most companies avoided DTCA. According to the 1984 survey, a large part of company managers felt that such advertising would harm the doctor–patient relations, confuse the minds of ordinary people and lead to an increase in drug prices. Also, associations of doctors and consumers did not support this form of advertising. Between 1985 and 1990, at least twenty-four products were promoted in this way [3].

2. Development of DTCA

In the late 1980s and early 90s, the pharmaceutical industry adopted more aggressive marketing and began increasing investments in DTCA. This change was caused i.a. by the economic recession and changes in the health care system. Moreover, American doctors were losing public trust [3]. Patients wanted to be better informed about their treatment and its possibilities, and the development of technology, also the Internet, meant that it was becoming increasingly easy. DTCA spending in the mass media grew rapidly, in 1991 amounting to USD 55 million, in 1995 to the staggering 363 million [3].

In 1997, after several years of discussions with the pharmaceutical industry and a public debate, the FDA issued guidance for the industry (Draft Guidance for Industry: Consumer-Directed Broadcast Advertisements) [2]. Changes were introduced which somewhat loosened the restrictions imposed on the pharmaceutical companies advertising prescription drugs. The new regulations allowed that in selected types of advertising (e.g. TV commercials where only the name of the drug was presented) be included only the main risks associated with the drug (*major statement*), rather than its common risks (*brief summary*), which was previously required. However, the ads needed to present information about where full information of these risks were to be found (*adequate provision*) – e.g. telephone hotline, fax number, website [2]. The pharmaceutical companies responded with a dynamic growth of investment in TV advertising, and a lowered interest in print advertising [8].

Along with changes in the law, pharmaceutical companies were increasing their spending on prescription drugs advertising in the media. In 1996, it amounted to 0.7 billion USD, in 2006 reaching the record 5.41 billion USD – since then the expenditure has been steadily falling, in 2012 reaching 4.16 billion USD [11].

Since 1999, the FDA began to examine the impact of DTCA by conducting large surveys among physicians and patients. In a report published in 2004, the FDA states that the ads seem to increase treatment awareness, motivate to ask questions to health workers and to ask better-informed questions. However, the studies also pointed to a poor understanding of the risks associated with the use of the drug. The final conclusions of the FDA pointed to both good and bad aspects of advertising directed to the public [1]. In 2004, 2009 and 2012 the FDA came up with additional guidelines on DTCA, addressed to the industry [12].

In the United States there are occasional calls to ban DTCA. However, the most simple argument that manufacturers should not be prohibited from advertising their own product, is sufficient to silence such appeals [5].

Currently, there are three categories of DTCA ads. These are: defining advertising product (*product claim ad*), advertising reminding of the product (*reminder ad*) and advertising for seeking help (*help-seeking ad*) [5].

Ads defining the product include the product name, indicate its application and report safety and performance. When considering regulations for these cases of DTCA, two forms of communication should be distinguished. The first type being the ads printed in newspapers, magazines and periodicals, and the second – ads broadcast in mass media, via radio, television and telephone communication systems [13]. Internet-based ads are yet another category. Researchers point to the need for additional regulation on prescription drugs advertised on the Internet [5].

Printed ads must include information about the most common risks of taking the drug (*brief summary*), i.e. all side effects, contraindications, warnings, precautions and side effects. In their 2004 guidelines, the FDA encourages companies that they avoid using difficult, medical language, as it was often practiced before, but consumer-friendly vocabulary, so that the warnings and the most important dangers and side effects of the drug could be easily understood. The printed ads must also contain the

statement: "You are encouraged to report negative side effects of prescription drugs to the FDA. Visit MedWatch or call 1-800-FDA-1088" [13].

Broadcast advertising must include a statement about the key risks (*major statement*), presented in a clear, understandable and neutral form [13]. It is therefore more constrained than printed advertisements. This entails that broadcast advertising must refer the patient to the relevant source (*adequate provision*), where they can find at least the most common risks of taking the drug (*brief summary*) – e.g. printed advertising, the Internet, doctor or pharmacist.

Reminder ads include the name of the drug, but not its application. It is assumed that the patient knows what the drug is and does not need to be repeated that information. This type of advertising cannot be used for drugs that have warnings on the package [14].

These advertisements describe the disease or condition but do not mention a specific drug which can be applied to a given ailment. For example: 1) people are shown who constitute the group, which might take a given drug; 2) some symptoms are shown, e.g. a runny nose, sneezing, red or watery eyes; 3) individuals with such symptoms are encouraged to talk with their doctor; 4) information about the drug manufacturer and its website are provided [14].

Although not as popular as in the case of other goods, product placement in popular TV series and films is another form of drug promotion [15]. Since it is increasingly popular, the need to regulate such advertising is being pointed out [16].

An example of a drug product placement is the film titled *The Sixth Sense*, where Zoloft by Phizer is presented. Also, in the *Scrubs* TV series, the NuvaRing by Organon was shown. Sometimes a famous person suffering from an illness speaks favourably in the popular media about a drug they use [15].

A regulation of the placement of pharmaceutical products is a challenge currently faced by the FDA. The applicable law does not solve the problems arising in this sphere, which can lead to many abuses. [15]

3. DTCA – advantages and drawbacks

Prescription drugs advertising directed to the public raises many dilemmas. Allowing such advertising certainly affects the patient-doctor relations. Researchers suggest both positive and negative effects of such advertising.

DTCA proponents are of the opinion that these ads help educate patients, give them control over their own health and help maintain it [4, 5]. Thanks to providing the patient with knowledge about their disease and its treatment, they **facilitate discussion between the medical staff and the patient**. Patients may engage in discussions regarding the treatment of their disease, ask for a particular drug and find out whether it is suitable for them.

Most physicians (53%) agree that DTCA advertising is useful because it facilitates discussion with the patient. Seventy-three percent of respondents said that it allows patients to ask more informed questions [17]. Doctors believe that patients' questions about a certain drug have a positive or neutral impact on the visit. One-third of American adults has discussed some drug with a doctor, and 10% of them received the drug they asked for [18]. As many as 63% of oncology nurses believe that DTCA promotes dialogue with the patient [2].

Ads encourage patients to contact the medical personnel. If patients experience any symptoms mentioned in the advertisement, or think they are at a risk of developing an illness, they can go and see their doctor or nurse, which could save their lives. This is particularly important in diseases such as hypertension or elevated cholesterol, which are slow and 'silent' killers.

In the years 1998–1999, drugs for allergies were actively promoted. At this time, there was an increase in related visits, from 13–14 million to 18 million [19]. The 2004 FDA survey also indicated that 27% of Americans were attracted by the ad and consequently arranged an appointment with their doctor to talk about the disorder, which they had never discussed before [5]. Ads can help diagnose diseases whose symptoms the doctor has not noticed, and the patient – alarmed by advertising – informs the doctor.

Ads make it **more likely that patients take their prescribed medications**. Studies consistently show a small but statistically significant improvement in the use of drugs by those 'exposed' to DTCA. This is because the ads remind us of taking the medicine [5]. There are also studies indicating that patients watching DTCA play a more active role in caring for their health and follow the rules of medication more conscientiously. One of them, conducted by pharmaceutical companies, indicated that patients with diabetes, depression, increased cholesterol, arthritis or allergy were more likely to continue treatment after 6 months if themselves they asked the doctor about the drug after seeing the ad, than if the drug was prescribed by the physician [4].

DTCA **remove the stigma of people suffering from a medical condition**. There are certain diseases that seem shameful to people – e.g. depression or erection problems. Ads make us familiar with these topics, showing that others also have such problems. A 1997 survey among people calling the number shown in television advertising on genital herpes showed that after seeing the ad 45% of these people decided to go to the clinic in the next three months [5].

The negative consequences of DTCA are also extensively presented in the literature. Usually, when considering the considerable **increase in drug prices** in the United States, two reasons are mentioned. The first is the possibility of prescription drugs advertising directed to the public. The second is the lack of a formal policy of controlling drug prices in the United States. Pharmaceutical companies typically advertise the most expensive drugs and most do not mention their cheaper counterparts [19].

Advertising creators are accused of **misleading consumers, inventing new diseases and exaggerating the benefits related to the use of drugs**. A common accusation is that relevant information is omitted [5, 20]. An analysis of television commercials of Frosch's drugs and those of other companies seems to suggest that despite

the claim that drug advertising serves an educational function, it provides a very limited amount of information about the causes of disease and groups of people at risk. People who have lost control over their emotional, social and physical life as a result of not taking any medication are usually depicted. The importance of a healthy lifestyle is minimised [20]. It is often suggested that health improvement is the result of taking the drug, or at most, a combination of taking the medication and lifestyle changes, not the lifestyle change only [21].

Prescription drugs advertising directed to the public **leads to an improper prescription of drugs**. It may happen that the patient really wants to get the advertised drug, and the practising professional is unable to convince them that it is inappropriate for them, and gives out the desired prescription under pressure, which can lead to extremely negative consequences. There are also patients who, thanks to advertising, learn to mimic the symptoms so as they are issued a prescription for the drug they need. [5]

In the opinion of some, DTCA is also a threat to doctor-patient relations. Ads for prescription drugs can cause a loss of confidence in the medical personnel. In one of the studies cited by Ventola, more than half of the patients were disappointed when they did not get the drug they requested [5].

Visits at the clinic have specific time frames. Discussing advertised drugs is a waste of time. They can stop the doctor from asking the patient some relevant questions about their health and informing them about important preventive behaviours. The medical staff lose time to explain the patient why the touted drug may not be best for them [22]. Some patients may also self-diagnose the disease, which they in fact do not suffer from, and may unnecessarily come to visit.

The above-mentioned negative and positive effects of prescription drugs advertising leave considerable room for doubt. Undoubtedly, DTCA contributed to the increase in the value of the pharmaceutical market in the United States and a growth in sales of innovative, modern drugs. But its good and bad aspects for the patient are still widely discussed in the literature, making it a field for further research.

4. EU approach to DTCA

The EU law prohibits public advertising of prescription drugs [23]. Obviously the large pharmaceutical companies are lobbying to make DTCA advertising legal [24]. They repeat the argument used in the US, arguing that such advertising has a very important role in education regarding the disease and appropriate treatment. So far, however, European leaders have been effectively resisting those pressures. In 2002, during the European Parliament's vote on the admission of DTCA, as many as 494 MPs voted against it, only 42 saying 'yes' [3].

All drug advertising (both OTC and RX addressed to doctors) are subject to various kinds of EU regulations. Drugs are specific products – not only our health, but even our life depends on them, hence the justification to give their advertising more attention. Member states differ in terms of how strictly they approach pharmaceutical marketing. [25]

For example, in Poland, advertising drugs was prohibited [26] until 1993, when public advertising of OTC drugs was allowed [27]. Advertising of OTC drugs caused that there was a fourfold increase in sales in 1994–2001 [28]. In accordance with the European Union law, public advertising of prescription drugs is currently prohibited in Poland [29]. Poland has quite strict regulations regarding pharmaceutical marketing, physicians cannot be visited by medical representatives during their working hours, doctors cannot accept gifts worth over 100 PLN or unrelated to the practice of medicine [25].

Does the ban on advertising prescription drugs mean that the Europeans, including Poles, are less informed about them than the Americans? Pharmaceutical companies will of course argue that it is so. However, despite the ban on advertising prescription drugs, it is required in the EU to provide accurate information about drug products. On the Internet you can find i.a. product characteristics and leaflets, which are attached to the packaging. Therefore, a patient who wants to become acquainted with the possibilities of therapy for some diseases, will have to put more effort into seeking information than the average American but will not be deprived of such a possibility. And the information, thus obtained, will not be in any way considered advertising.

It is worth noting that we are not quite defended against DTCA in the European Union. All fans of the popular *Dr. House* series must recognize the Vicodin brand (Abbott Laboratories) – a popular painkiller prescribed in the USA.

Summary

The aim of the article was to present and explain how it happened that advertising of prescription drugs directed to the public became legal in the United States, and the characteristics of this form of marketing. It is worth quoting a few significant facts related to DTCA. Firstly, it is the cultural factors – the organizations and associations of patients demanding better access to information about treatments and medication; change in the perception of the role of the patient in doctor-patient relations, and in a sense defending freedom, that is, the rights of producers to market their products – all of these factors have aided the development of this form of advertising.

Secondly, this form of advertising has developed in the last three decades. In the last two there has been a very dynamic investment in this form of advertising, and pharmaceutical companies strongly increased their spending on this type of promotion.

Thirdly, advertising of prescription drugs addressed to the public, even though legal in the United States raises a lot of controversy there. Various studies are underway that indicate both positive and negative effects of such a solution. Certainly, the possibility of such advertising affects the entire health care system in the USA – drug prices, choice of prescribed drugs by authorized professionals, and use of drugs by patients.

Fourthly, in the United States there are still unresolved legal issues related to DTCA advertising on the Internet and drug product placement in TV series, films, etc. It is a challenge faced by legislators.

Fifthly, advertising products that may affect human health is a very complex issue, which presents a number of ethical and legal challenges both to manufacturers wishing to sell their products with the help of marketing and to state authorities and consumer organizations wanting to defend the best interests of citizens. Despite pressure from various groups, at the moment it is little probable that a ban on DTCA in the US be introduced. Also the EU politicians do not seem to be inclined to revoke the prohibition of this type of advertising.

Note

[1] In the US, medication can be prescribed by physicians, dentists, optometrists, qualified nurses and veterinarians.

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Implementation of the IHE XDS in Electronic Medical Data Interchange

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Abstract

A new integrated information system, based on electronic document, is to be implemented in the Polish Health Care System in 2017. Electronic medical records are the obligatory form of medical documentation in this system. Two crucial elements of this system are: EHR (Electronic Health Record), i.e. defining criteria and standards of electronic medical documentation and constructing a communication system allowing exchange of data and information between various institutions – stakeholders functioning in the healthcare system. IHE XDS (Integrating of Health Enterprise Cross Enterprise Document Sharing), developed specially for usage in healthcare systems, should be implemented in the Polish healthcare information system as both a local and global solution. European Union regulations dealing with electronic public service, openness and interoperability of information systems are important requirements and standards.

Key words: **medical data, IHE XDS, electronic public service, interoperability, openness**

Słowa kluczowe: **dane medyczne, IHE XDS, elektroniczna usługa publiczna, interoperacyjność, otwartość**

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Effective implementation and smooth functioning of the electronic workflow of medical records is crucial for the digitalization of healthcare in Poland. The transition to a higher level of information processing enabled by the use of digital data resources regarding medical events is dictated firstly by the need to adapt the current model of providing healthcare services to the needs of the aging population, and new organizational conditions where this care is provided. Secondly, as a member state of the European Union, Poland is committed to the consistent implementation of Community guidelines in the field of integrated healthcare system based on modern information and communications technologies [1]. The implementation of the Electronic Health Record and the construction of an integrated information system of healthcare based on electronic documentation and teletransmission has been underway in Poland for several years now, and according to the already modified guidelines should start functioning in 2017. One of the basic elements of this system is the efficient exchange of data and information between the vast number of diverse companies operating in the healthcare system.

The solution enabling efficient digital data exchange also in the information system of healthcare are data transfer buses. The integration of electronically supplied services, in particular access to the data collected, for example, in data warehouses or in cloud computing, is enabled by data transfer buses. In this paper we present the concept of using IHE XDS (Integrating Healthcare Enterprise Cross Enterprise Document Sharing) telecommunications paths in the information system of healthcare being constructed. The possibility of processing

electronic medical records (or, speaking more broadly, digital medical data concerning the patient) in the information system of healthcare has many benefits, which include [2]:

- improving the availability of medical services for patients (equal access for eligible beneficiaries, shortening the waiting time, rationalization of resource use);
- supporting the continuity of care (by improving the coordination of actions and information processing by medical entities);
- improving the safety of treatment (rationalization of clinical decisions, the emphasis on reducing the health risks associated with study drug);
- improvement of quality of care as perceived by the patient (in the context of the level of satisfaction, effectiveness and efficiency of healthcare provision).

Electronic public service

Modern IT solutions are becoming increasingly popular tools to support the provision of medical services in EU countries. Regulations contained in the European directives and introduced into the national legal system contribute to the formulation of the concept of 'electronic public service', meaning public service provided electronically [3]. The definition of electronic services included in the EU 'services' directive (77/388 / EEC), and implemented in the Polish act on electronic services, specifies that the service "is provided only using ICT, via the Internet or another digital network" [4, 5]. In force since January 2012, the Act on the information system in healthcare includes many advanced solutions and new medical functionalities of information systems that change the current model of health services [6]. Its aim is a multidimensional application of ICT and telecommunications integrating the processes of providing medical services in the healthcare system. Efforts in this area contribute at the same time to the development of information society, where a prompt and efficient processing of reliable information is becoming increasingly important [1].

On the other hand, transfer processes affecting such vast amounts of health data in a digital format (the so-called sensitive data) with an extremely broad semantic range and a diverse and intricate structure, is an extremely difficult organizational challenge for the present national information infrastructure understood as a series of complex, connected resources and information systems determining the functioning of the state as a whole, such as standards of information, information resources, information systems, information institutions as well as organizational structures and technical equipment used to support the collection, storage, processing and transmission of information in information processes and systems [3]. These difficulties are further complicated by the strategic importance of the healthcare information system as one of the key domain information systems of the state. According to the adopted premises of the healthcare information system in Poland, it fulfils the following roles:

1. shaping the information conditions for making long-term, optimal decisions in health policy regardless of the adopted organizational model of healthcare and the principles of its financing;
2. ensuring a stable information system, which, on the one hand, has a flexible approach to the organization of the system of healthcare (including the model of financing public funds benefits), on the other hand, remains resistant to disruptions in the collection and archiving of data due to system changes in healthcare, as well as
3. organizing the information infrastructure of the healthcare system by integrating all existing systems and registers and ensuring convenient exchange and analysis of collected data, based on the principles of openness and interoperability [7].

Openness and interoperability

In the context of the exchange of electronic medical data, the function of 'organization through integration' seems to be of key importance for the currently executed stage of computerization of the healthcare system. However, in order for the organizational function of the healthcare information system to be effectively put in practice, exchange and analysis of collected data should be based on the criteria of *openness* and *interoperability*. The importance of the first term refers to the definition of the so-called open standard, which – in order to gain the status of 'openness' – must meet the following conditions: (1) provide the opportunity to participate in the development of specifications for any person concerned (2) the standard itself is subject to public verification, (3) standard specification is available for free for everyone, and (4) the specification can be implemented using a variety of software development models [2].

The use of open standards is characterized by a large measure of discretion for the user – as a rule, their use cannot be subject to any legal or technical restrictions. The attribute of 'open' standards is consistent with the growing popularity of the so-called 'technological neutrality' principle, under which open standards should be used wherever available [8]. On the other hand, the use of open standards in the exchange of electronic medical data is held within the framework of the so-called 'interoperability principles' – the second element which determines efficient processing of information in the information system of healthcare. In the literature, interoperability has acquired different definitions, whose form and scope vary depending on the adopted perspective of the user. According to standardizing organizations dealing with the unification of standards and protocols used in the exchange and processing of information, this term means "the ability of two or more systems or components to exchange information and to use it" [9] or "the capacity of various functional elements of information systems to communicate, run programmes, or transfer data between one another in a manner not requiring any knowledge of the user, or requiring minimal knowledge of the unique properties of these elements" [10].

A slightly different interpretation of interoperability is assumed by the companies and market organizations

working in the field of information and communication technologies. For those entities, it mainly means "the ability of two or more entities to exchange information and to use the information exchanged between one another. Interoperability includes in particular interconnectedness (the capacity of two or more computer systems to exchange data and to use the data exchanged between one another – authors' note)" [11] or "the possibility of an efficient, effective and consistent communication and information exchange between different systems, applications, and computer networks, and the use of the resulting information" [12]. Some sources, apart from defining interoperability, also distinguish the levels at which the capability of exchanging information may be implemented [13, 14]. In the four-level model of interoperability, the first one provides the integration of the application using technical specifications, making possible the application-to-application integration type. The second level is conditioned by the possibility of accessing information and replacing it using the technical specifications for the exchange of files, character sets, encoding, etc. The third tier allowing the exchange of information using interoperability principles are the technical specifications ensuring safety of the transfer of the information exchanged.

The fourth level of interoperability is assumed to be the capability of communicating (within the afore-mentioned interconnectedness) using technical specifications for communication between the systems [13].

Some authors distinguish a three-level model of interoperability, where the capability of effective mutual co-operation covers three areas, i.e. business processes, information exchange and technical capacity to ensure safe and effective co-operation of different systems [14]. The above illustrated distinctive definitions and interpretations of the concept of interoperability by various entities and organizations, share a common definition proposed by the European Commission, where interoperability is "the capacity of fundamentally disparate, diverse organizations to interact in order to achieve mutually beneficial and agreed objectives, including the sharing of information and knowledge between organizations as part of business processes they realize, implemented through the exchange of data using these organizations' IT systems" [15]. An almost identical wording of the definition of interoperability could be found in the Polish act on the computerization of activities of public entities[1] [16]. Standardization and adaptation of the European legislative framework in the area of interoperability norms to the dynamic development of the information and communication technologies market is a necessity, indicated, among others, by the Digital Agenda for Europe [17]. This document prepared by the European Commission is one of the most important pillars of the Europe 2020 Strategy, aiming to define a way out of the European economic crisis and programming EU growth in the coming decades [18]. As a necessary condition for building a fully digital society, the Digital Agenda for Europe mentions, i.a. effective interoperability between IT products and services, including those operating in the health sector, enabling a secure storage of data on the health status of patients in the healthcare system available online [17]. These criteria are met by the XML format, which is already used in recording systems, especially in the exchange of electronic documents based on the HL7 standard. The implementation of the principles of interoperability at the European level and their adaptation by healthcare service providers representing diverse profiles and scopes of activity brings many practical challenges which make such an undertaking considerably difficult. These include: (1) different legal environments in individual member states, which often makes it difficult or even impossible to cross-border exchange of information between public organizations, (2) problems with adapting different types of business processes realized by various public organizations, (3) lack of agreements and guidelines concerning the meaning and the format of information exchanged between member states, (4) the need to support multilingual communication, and (5) problems with the provision of uniform technical guidelines to support the exchange of medical records in an electronic form [14]. However, for each member state the primary problem is the efficient running of the process of development and harmonization of rules of interoperability between systems of domestic medical institutions. The effectiveness of the mutual co-operation of information systems regarding the exchange of electronic medical data throughout the Community depends on the results obtained at the level of individual member states.

The results to date of the implementation work related to the development and introduction of unified standards for interoperability in the Polish healthcare information system can raise a lot of doubts. This fact was noted in the report of the Supreme Chamber of Control (in Polish abbreviated to NIK) from the controls carried out in 2012 checking the degree of preparation of service providers for the implementation of the Medical Information System and the actions of government related to the construction of healthcare information system as part of the 'Healthcare Computerization Programme' [19]. Among the weaknesses identified in its implementation were problems with ensuring interoperability in the exchange of medical data between the surveyed institutions. The results of the study showed i.a. that approximately a third of them have distributed ICT systems, which not only *do not* provide interoperable collaboration in the area of data exchange with other health entities, but only slightly facilitate communication between patients and the healthcare provider. The NIK audit confirmed that even if a selected region (hypothetically) established cooperation between the institutions with regard to the required interoperability principles, this fact would most probably be omitted by the Ministry of Health. According to NIK controllers, the Minister of Health did not have the full knowledge about the state of computerization of healthcare units in different voivodeships, in particular in the area of interoperability of the implemented solutions with the central project coordinated by the Centre for Health Information Systems (Polish: CSIOZ). Until the completion of the audit there was also a failed attempt to develop and implements solutions aimed at ensuring interopera-

bility across borders, especially in the area of the planned integration with the epSOS project (European Patients Smart Open Services; this project will launch initiatives to develop modern communication technologies and integrated electronic services in the field of health in European Union countries, especially in terms of ensuring secure access to patient health information and electronic prescriptions available between the health systems of the member states – authors' note). Due to lack of national legislation sanctioning interoperability as a standard for data exchange in healthcare, it was not possible to implement policies ensuring consistency between medical information systems developed in different regions and those realized by CSIOZ. Delays and difficulties in the implementation of interoperability standards, required by the information system of the Polish healthcare, are above all due to there not being an agreed, responsible approach both of the decision-makers and suppliers of IT solutions that would enable the electronic exchange of medical data within and between computerized healthcare entities.

This problem requires particular attention as the system of electronic medical records is planned to have been implemented by 2017, allowing a full-range exchange of digital medical data in the Polish healthcare facilities for the first time on such a large scale and enabling efficient and secure cooperation of many different institutions for the optimal coordination of patient care. It will only be possible, however, if healthcare entities meet the deadline for launching the digital documentation system based on the framework principles of interoperability of computerized healthcare systems. They are to be implemented using the so-called profiles of integration describing the collection of necessary clinical information or data flows and the use of standards for the exchange of information in order to ensure interoperability of information systems functioning in healthcare [20].

The IHE XDS Model

Implemented on the basis of integration profiles, the interoperability model, rather than created in our country for the purpose of the computerization of the Polish healthcare system, is a concept developed by the international organization called IHE (*Integrating of Healthcare Enterprise*), representing an initiative to develop global standards for interoperability in the health sector [21]. Its national adaptation includes i.a. the use of IHE XDS profiles (*Cross Enterprise Document Sharing*) as an open standard for communication between service-oriented applications and their user. The concept of profile integration can be understood as a coherent mechanism for effective communication (and, more broadly, interoperability) between digital systems of healthcare providers, where the primary carrier of information about medical events related to the patient are electronic medical records providing current knowledge about the patient, available at the right time and for the right addresser [21]. A block diagram presenting the exchange of information between two medical entities (hospitals) using IHE XDS is shown in **Figure 1**. Taking into account the process of communication between healthcare entities based on the model of IHE XDS, the primary task of a system of electronic medical data exchange thus organized, is maintaining the central register of documents and central management of permissions for their users. The medical facility included in the system, by creating and storing the medical records of the patient becomes responsible for the repository of documents, registering documents, accepting requests and sharing documents, keeping the history of document releases and further development of central dictionaries. The interoperability framework for the efficient transfer of data between institutions is determined, in turn, by the regional system of hospital network, which keeps the database of regional users, enables the integration of information systems, can maintain regional data repositories and on the basis of separate agreements operate entities outside the home network of hospitals (e.g. county hospitals, individual medical offices, etc.) [20].

So that all of the above utilities could become a functional part of the exchange of data in the electronic format, it is necessary to ensure compatibility (consistency) of the IHE XDS profile with existing standards of medical records workflow, especially in terms of the content of medical documents (e.g. HL7 CDA4 / CRS5, DICOM, PDF+) and the infrastructure of sharing medical records (including registries and repositories of electronic medical records) [21]. An additional potential of practical applications of the IHE XDS profile is also due to its participation in the representation of other profiles developed by the IHE organization, with which it forms a coherent whole (see **Figure 2**). The resulting family groups profiles into two main categories relating to semantics and content of medical records and the integration of their exchange. A detailed specification of this issue is as follows [21]:

1. The areas of semantics and content of medical records:

1.1. XDS-SD (*Scanned Documents*) – profile that describes the mechanisms of storing and sharing documents in the scanned form;

1.2. BPPC (*Basic Patient Privacy Consents*) – profile that describes the mechanisms of storing and sharing documents on the patient's consent;

1.3. EDR (*Emergency Department Referral*) – profile that describes the mechanisms of referrals relating to emergency departments;

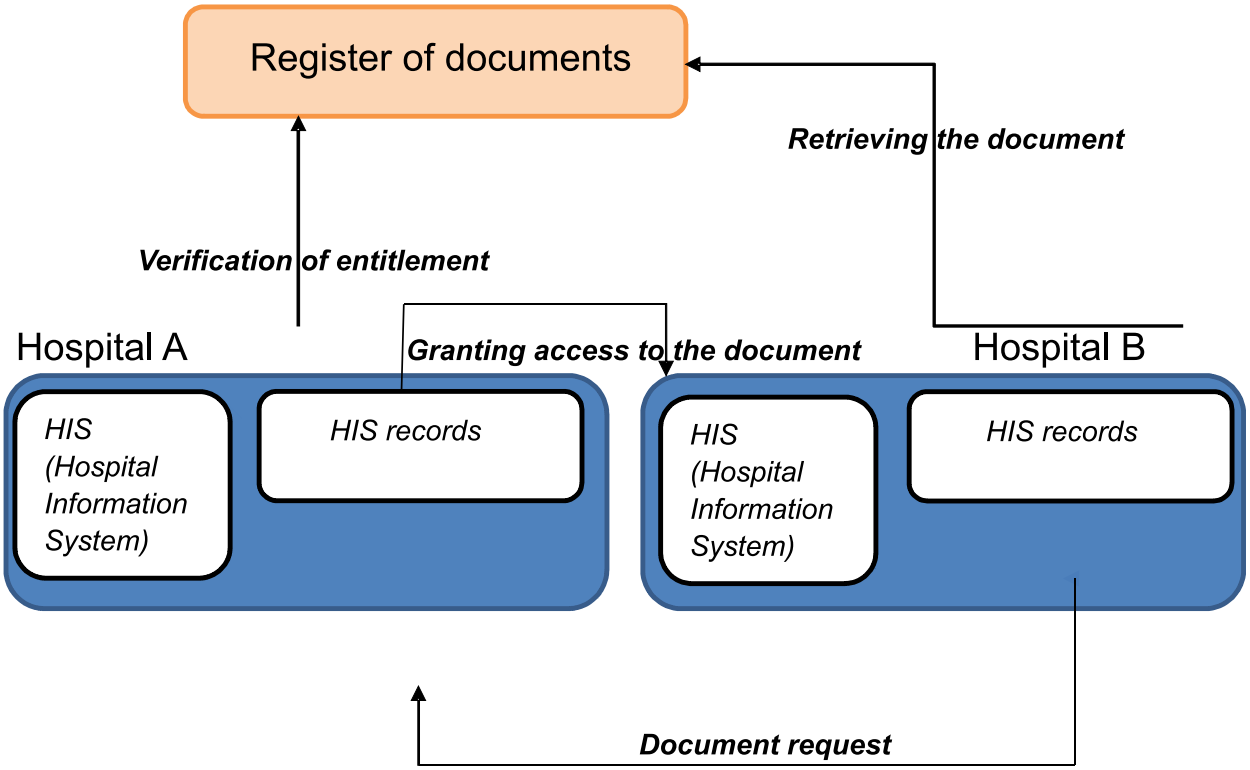
1.4. PPHP (*Pre-procedure History and Physical*) – profile that contains information about the patient relating to surgical and invasive treatment;

1.5. XDS-I (*Cross Enterprise Document Sharing for Imaging*) – profile that describes the mechanisms of distribution of diagnostic images and reports, and contains information associated with them;

1.6. XD-LAB (*Sharing Laboratory Reports*) – profile that describes the mechanisms of exchange of laboratory test results between shareholders of the IHE XDS profile;

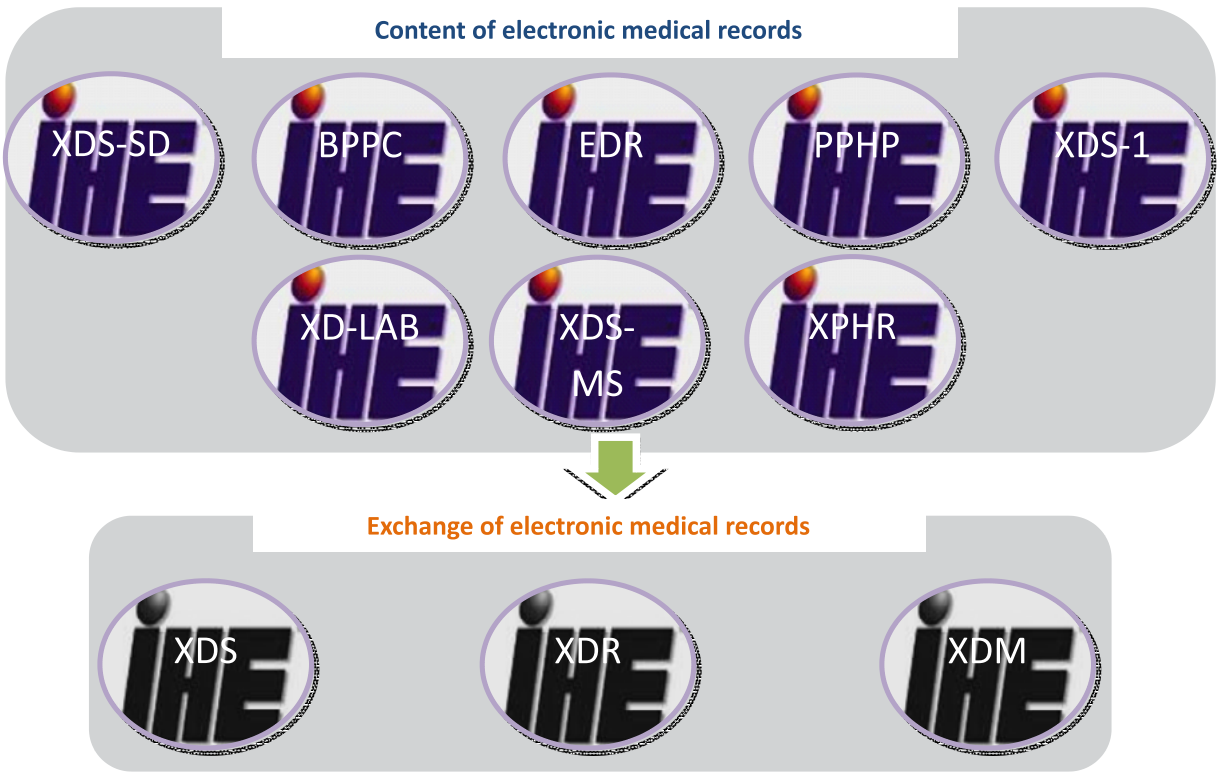
1.7. XDS-MS (*Cross-Enterprise Sharing of Medical Summaries*) – profile that describes the mechanisms of exchanging medical history reports and extracts;

Figure 1. *General IHE XDS model in the exchange of data between medical institutions*



Source: Kulesza K., Sokołowski M., Pośpiech A., Elektroniczna dokumentacja medyczna – doświadczenia światowe a polska rzeczywistość, Oracle Polska, http://www.slideshare.net/wydzial_ds_ezdrowia/elektroniczna-dokumentacja-medyczna-krzysztof-kulesza-marek-sokoowski-adam-popiech; accessed: 08.06.2015 [20].

Figure 2. *Position of IHE XDS in the representation of IHE profiles*



Source: Bliźniuk G., Profile IHE XDS i IHE XDW w zapewnieniu współdziałania instytucji medycznych, "Collegium of Economic Analysis" 2014; 35: 9–23 [21].

1.8. XPHR (*Exchange of Personal Health Record Content*) – profile that describes the content and format of the two-way exchange of patient medical data between systems of healthcare entities.

2. The area of medical records integration:
2.1. XDS – profile that describes the mechanisms of integrating the exchange of data stored in electronic health records;
2.2. XDR (*Cross-enterprise Reliable Document Interchange*) – profile that describes the optimization mechanisms in the exchange of medical records, i.a. when there is no access to the registry of XDS documents and repository;
2.3. XDM (*Cross-enterprise Document Media Interchange*) – profile describing the mechanism of exchanging data containing media content by way of sharing files and catalogues.

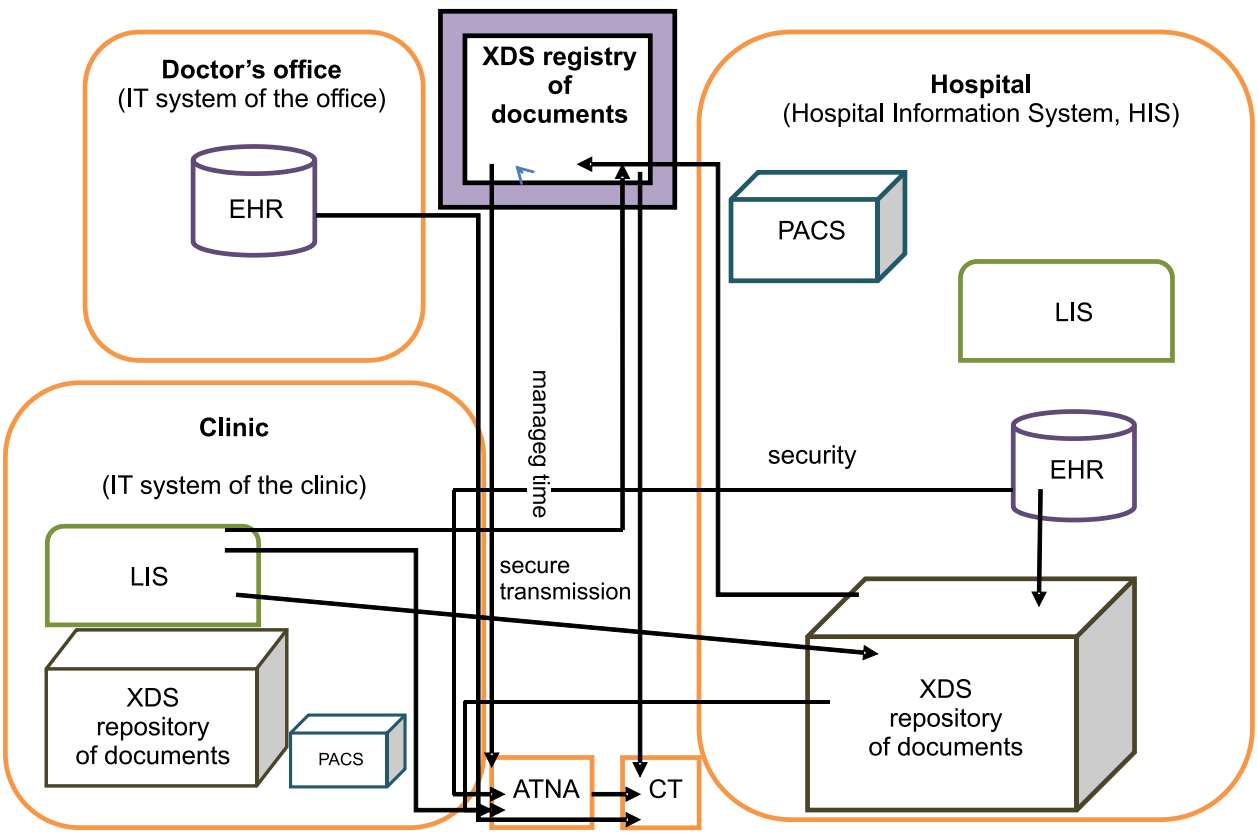
The data flow may be more complex in the process of communication between the patient and healthcare facility using the IHE XDS profile (see **Figure 3**). In the example below, the beneficiary of the patient's medical data is the hospital. As an institution where the patient is currently receiving treatment, it can access data from the computer systems of the doctor's office and the clinic. Exchange of hospital data with other profile users is carried out with the use of data repository, maintained by every institution, and the central register of documents XDS.

The following example shows that when exchanging certain types of medical data, you can skip the repository and registry nodes, e.g. the laboratory system used at the clinic can exchange data containing patient's laboratory results with the hospital without the mediation of the repository and the registry of documents. All profile stakeholders use the time server, which ensures that operations are performed in a unified real-time.

Enterprise Service Bus (ESB) and integration platform

The target model of integrating central ICT platforms with systems of healthcare facilities in accordance with the rules of interoperability is to be consistent with the requirements of the so-called *Service-Oriented Architecture*

Figure 3. *A possible scheme of communication between users of the IHE XDS profile regarding patient data*



EHR – Electronic Healthcare Records
PACS – Picture Archiving and Communication System
LIS – Laboratory Information System
ATNA – Audit Trail and Node Authentication
CT – Coordinated Time
XDS – Repository of Documents

Source: Kulesza K., Sokołowski M., Pośpiech A., Elektroniczna dokumentacja medyczna – doświadczenia światowe a polska rzeczywistość, Oracle Polska, http://www.slideshare.net/wydzial_ds_ezdrowia/elektroniczna-dokumentacja-medyczna-krzysztof-kulesza-marek-sokoowski-adam-popiech; accessed: 08.06.2015 [20].

(SOA). Its basic idea boils down to designing a system depending on the way the services to be performed by it are defined [22]. A key component for the realization of the SOA concept is the so-called *Enterprise Service Bus* (ESB) or specialized software performing a fundamental role in the attribution characteristics of efficiency and standardization of electronic exchange of medical data among cooperating IT systems.

The component of the enterprise service bus along with the IT systems of individual users connected to it forms the so-called integration platform. ESB enables integrated information exchange between applications based on different technologies and IT platforms using integration services, thus providing a secure, unified, fully flexible and collision-free (with respect to the information flow processes implemented earlier) configuration of the application, e.g. its expanding, moving or replacing [21]. An example of such a solution can be found in the Estonian EHR system, which uses a similar solution called X-ROAD. An additional functionality of the bus service is the management of information processes important from the perspective of continuity and monitoring of implemented information exchange. Although according to the accepted guidelines in healthcare computerization, the enterprise service bus will not be used as a direct provider of functionality for the end user, it will be critical to ensure interoperability and scalability. Only in rare cases will there be a possibility of direct links between some IT systems and specific resources and data registers without ESB [23]. The architectural design for ESB contained specific requirements for such a solution, which are given below. According to them, ESB must (1) carry out the translation (transposition) of communication, (2) enable integration of data registers implemented in a variety of different technologies, (3) implement redirection of communication depending on the context and content of the message, (4) have load-balancing mechanisms of communication between the nodes, (5) enable integration of applications and services implemented in different technologies, (6) ensure integrity, non-repudiation and confidentiality of communication, and (7) provide mechanisms for filtering and validating messages [23]. The expected functionalities of ESB include the capacity to connect old IT healthcare systems with implemented ICT platforms, supporting standards of cooperation and communication between IT systems, ease of configuration, and enabling mass flow data [24]. The balance of benefits and results of the implementation of the ESB architecture in the healthcare information system is shown in **Table I**.

Table I. *ESB – balance of selected benefits and results of implementation*

Benefits	Results
faster and cheaper connection of information systems	enabling online registration for medical consultations
enabling easy communication and exchange of data between systems	providing patients with electronic medical history, performed services, referrals, prescriptions, vaccination plans, recommendations
minimizing data redundancy (possibility of transmitting certain data between systems)	enabling electronic implementation of prescriptions
flexibility and scalability of architecture	allowing electronic handling of sick leave
allowing for an easy expansion of information systems with additional modules and integration of the existing ones thanks to the relative independence of the technologies used, among other things	providing the medical staff with electronic health data of patients
ensuring communication security between systems	providing fast access to electronic medical records in an emergency
	providing information on health (prevention)
	allowing ongoing analysis of data on medical events
	enabling electronic invoicing
	improving electronic billing of medical services
	improving electronic handling of drug refunds
	providing information enabling ongoing monitoring and responding to threats
	ensuring homogenous and uniform rules for the collection of sharing of digital resources on medical events
	ensuring interoperability
	access to reliable data on medical events

Source: Elektroniczna Platforma Gromadzenia, Analizy i Udostępniania Zasobów Cyfrowych o Zdarzeniach Medycznych – studium wykonalności, Centrum Systemów Informacyjnych Ochrony Zdrowia, 2009, http://konfederacjalewiatan.pl/upload/File/2009_06/Studium.pdf; accessed: 11.06.2015 [24].

Conclusions

In 2017 an integrated IT system based on electronic documentation is to be introduced in the Polish healthcare. An electronic document is to be a valid form of documentation. The two key elements of the system are: EHR (*Electronic Health Record*), i.e. defining the criteria and standards for electronic medical records system and the construction of an efficient exchange of data and information between a large number of various entities operating in the healthcare system. Data transfer buses are a solution enabling an efficient exchange of digital data also in the healthcare information system. IHE XDS data transfer buses (*Integrating Healthcare Enterprise Cross Enterprise Document Sharing*), specially developed for use in healthcare, systems should be introduced as a both local and global solution. The construction of the system should include European Union regulations for electronic public service, openness and interoperability. The component of ESB along with IT systems of individual users connected to it creates the so-called integration platform. The solution using data transfer buses enables an exchange of information between applications based on different technologies and computing platforms.

Note

[1] Note, however, that the provisions of the said act do not apply to state-owned companies, commercial companies or special services in the meaning of Art. 11 of the Act of 24 May 2002 on the Agency of Internal Security and Intelligence Agency (Journal of Laws, no. 74, item 676, as amended), The Sejm Chancellery, the Senate Chancellery, Office of the President of the Republic of Poland and the Polish National Bank except in cases where in connection with the execution of tasks by these entities there is an obligation to provide information to and from entities other than government administration.

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Implementation of Health Maps in Poland

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Abstract

In April 2015 came to force a new regulation of The Ministry of Health regarding healthcare maps and preparation of the General Polish Healthcare Map. During implementation process of this regulation several questions and problems about practical solutions in preparing of healthcare maps were raised. Collection of the required data, their analysis and presentation in current healthcare information system is difficult. Healthcare maps will require further regular current data supply and updates. Without unified system of data collection, required standards of data format and models of analysis and presentation, preparation and use of such maps may not be possible.

Key words: **maps, healthcare maps, regional healthcare maps, General Polish Healthcare Map, GIS, HL7**

Słowa kluczowe: **mapy, mapy potrzeb zdrowotnych, regionalne mapy potrzeb zdrowotnych, Ogólnopolska Mapa Potrzeb Zdrowotnych, GIS, HL7**

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On 14th of April 2015, a regulation of Ministry of Health of 26th of March 2015 came into force, which concerned the scope of content of health maps. Voivodes became responsible for development of both Regional Health Maps and the General Health Map of Poland. The maps will be a base for a purchase plan of medical services which will be used to define the type and number of purchased medical services. Thanks to the development of maps and chosen priorities, voivodes may not only hand down an administrative decision including an opinion concerning the reasonability of creating a new health facility on a given area, but also their further units. Health maps concern health services in both hospital and ambulatory treatment.

Conditions for development of health maps

In the law, the legislator mentions the expenses, mainly investments, that are related to submission of voivodes. Thus, a voivode will be able to change a decision ex officio "in the case of change in circumstances that influence its issuance" [3]. A healthcare provider, who will not get a positive opinion, will not be allowed to take part in call of proposals of National Health Fund (NFZ). It should be emphasised that a positive opinion does not guarantee a contract to a health facility.

According to the regulation, Regional Health Maps and the General Polish Health Map should consist of: demographic and epidemiological analysis, stock and the use of resources as well as forecasts for demand for health services. Regional Health Maps should include annual data from 2 years before the current year. According to the regulation, a part of maps which concerns demographic and epidemiological analysis includes the analysis of:

- number of people in a voivodeship with a division into counties;
- structure of counties in comparison to structure of population in a voivodeship and whole country. The structure should include sex and age divides;
- average further continuance of life in a voivodeship;
- birth rate and coefficient of fertility in a voivodeship and counties based on 3-year data;
- density of population in a voivodeship and counties;

- deaths according to causes important from the perspective of public health in a voivodeship on the basis of the absolute number of deaths and death rate for 100 000 of people from 3 years in particular age groups;
- value of standardized mortality rate;
- value of prevalence rate in hospitals for 100 000 of people and incidence rate in particular voivodeships and counties;
- perinatal mortality in voivodeship.

The part concerning the analysis of stock and use of resources should include the following:

- number of providers;
- number of hospital beds in particular wards;
- number of hospital beds in the ratio to 100 000 people;
- bed occupancy rate and occupancy rate of medical apparatus;
- provided health services according to the International Statistical Classification of Diseases and Related Health Problems ICD-10 (triple character codification will be demanded) [1, 2];
- average stay of a beneficiaries at units providing services and the average wait for providing a service

The part of a map that concerns a forecast for demand for health services should include:

- forecasted populacy in a voivodeship and its counties;
- forecasted structure of populacy in particular counties in relation to the structure of populacy in a voivodeship and the whole country with sex and age divide;
- forecasted birth rate;
- forecasted death rate;
- forecasted demand for .

The data mentioned in the regulation is a closed list, which means that, for example, data for demographic analyses included in health maps can be based only on mortality rates, and not on morbidity or incidence rate. Another question, which was not really discussed before, is the use of information technologies to develop such maps and the question of technical and economic potentials that will let voivodes realize the postulates of the act and the regulation. What is more, some discrepancies in ways that several rates were calculated by authors of already released maps are also worth taking into consideration. The data concerning a forecast of morbidity for breast cancer include a statement: '(…) in 2009 there will be over 22,9 thousand new cases of malignant breast tumours in Poland' [8]. On the other hand, the data presented in National Cancer Registry shows that the forecasted number of new cases of the disease will be lower [9]. A similar situation may be observed in the case of uterine cancer [8, 9].

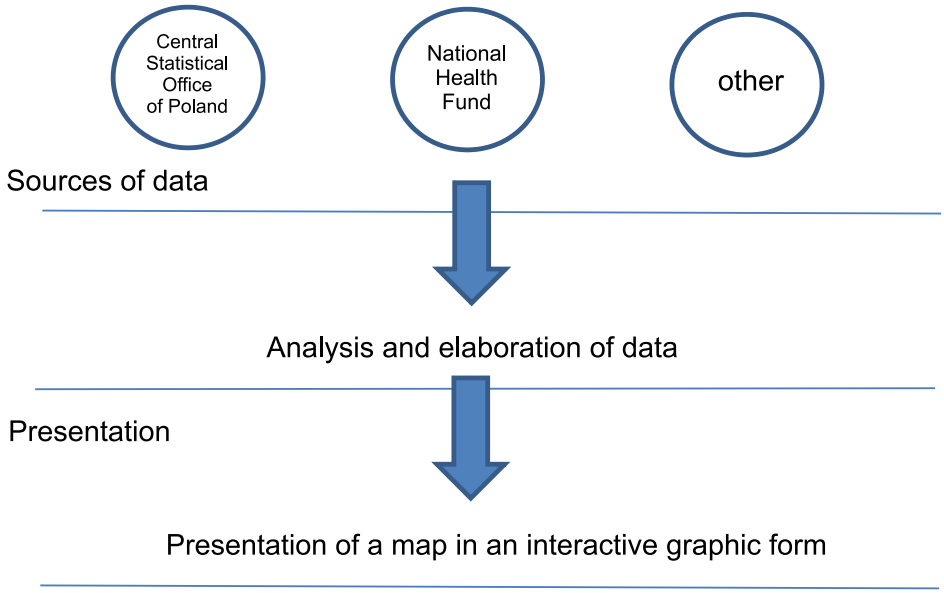
Practical implementation of health maps

Epidemiological rules and methods are one of the most important tasks for public health and prophylaxis. Development of health maps, both regional ones and the Polish General Health Map, is a complex process. First of all, the data necessary for the analysis need to be collected. The main provider of data is NFZ, but demographic data comes from Central Statistical Office of Poland. Other data, e.g.: morbidity, PYLL (potential years of life lost) or forecasts need to be calculated separately. Such rates as: Age-Period-Cohort (estimation of demographic and epidemiological rates) or PREDAAAP model and PREDMAP model (a forecasting model used to predict the occurrence of new cases of cancer, and other non-infectious diseases) are based on the algorithm developed by T. Hakulinen and T. Dyba. The method was proposed for calculation of estimated prognosis of demanded factors, with the assumption that morbidity has Poisson's or extra-Poisson's distribution in age brackets. Since the next group of data involves the analysis of the use of resources (according with regulation [3]), i.e. what is the possibility of signing a contract for both equipment and localisation, it may be assumed that the aim of the activity is to show the number of providers who realize signed health services. The number of health service providers may not be sufficient from the perspective of the various services. As a result, health maps should involve not only the information about the type of health service, but also the volume of contracts in relation to the potential of a provider, length of queues for services (the latter is obligatory according to the regulation). Except for the theoretical part, health maps must also include graphic representation of the data. So far, the institutions that developed regional maps (mainly the Ministry of Health), have not implemented a presentation of the data. The interactive features of such maps could be also significant. Such a form of presentation may also concern demographic, epidemiological and statistical data, e.g. forecasted birth rate in a particular area. The model of development of maps is presented in **Figure 1**.

One of solutions that may be used to present a health map is GIS (Graphic Information System) [5]. These systems are a result of work in geography and informatics which involved, among others, a territorial division of a particular geographical area (e.g. area of a commune, a county or a voivodeship). The use of graphical representation of the data on a map allows for clear presentation of big amount of data. Implementation of GIS may also involve presentation of objects (e.g. hospitals) and the distance from them to a given point or between the points themselves.

Plotting some information, for example demographic data, on a map without the knowledge about functioning of health care system may lead users to false conclusions [7]. Thus, the use of GIS requires understanding of the rules and methods, especially in the context of a query, testing hypotheses, cause-and-effect relationships, but also a critical assessment of such data, i.e. its quality and confounders. As a result, practical implementation of maps without the knowledge from such areas as: informatics, epidemiology or public health, seems to be a difficult challenge. It may be said that the minimum required for proper functioning of Regional Health Maps is: data, program and equipment. Obtaining the data mentioned in the regulation is not as easy as it seems to be. Collection of raw data from, for example, the Central Statistical Office of Poland and plotting it on a map (GIS)

Figure 1. The model of preparation of a health map



Source: Own elaboration.

is not a sufficient condition for the proper realization of postulates of regional health maps.

Regarding programs that may be used for graphical presentation of health maps, some factors are worth mentioning, and these are:

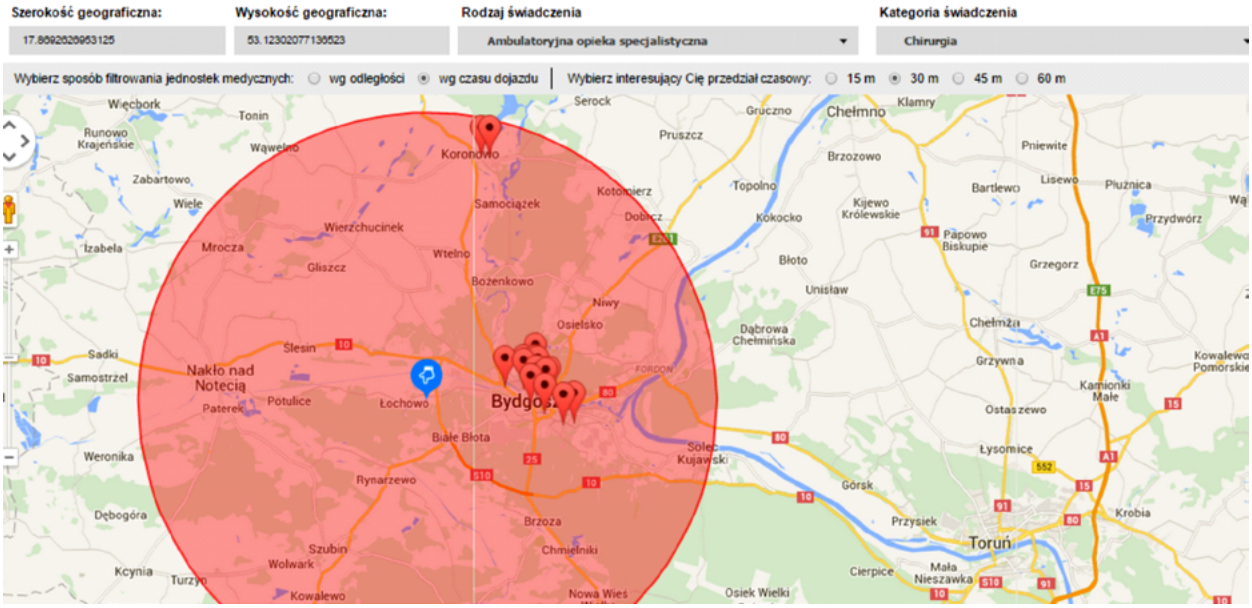
- data bases which include digital data (also data mentioned in the regulation);
- digital maps equipped with borders of counties and voivodeships, which allow for implementation of such data as: a distance in time from a particular specialist to a given point – **Figure 2** presents an example of 30-minute distance approach to a surgeon in Łochowo);
- information system which, for example, automatically connects data with maps keeping a distance on a set level. **Figure 3** presents the possibility of setting a type and category of service (here: a night shift within maximum 20 km form the defined point);
- possibility to implement *i-frame,* to externally implemented systems, which allow for presenting maps in other information systems, for example on portals of institutions from the health care sector.

Figure 2 presents a potential time of approach to a given health care institution. A user may choose coordinates of his current position or his house. If he does not know the coordinates, he may choose the position with a computer mouse. Afterwards, it is possible to set the time of approach, kind and category of the service, e.g. usual care, spa treatment or hospitalisation. For a chosen kind of a service, it is also possible to choose its category. For example, in the case of usual care, the available categories are: a family doctor, sanitary transport, a health nurse, etc. Figure 3 presents a similar interactive map which includes similar data, i.e. kind of a service, category, current position (in this case Łochowo). However, in this case, a user chooses the distance from the current position to an institution that he is looking for. The distance equates to the radius of a circle in which a given health care institution may be found.

The efficient functioning of health maps, especially regional ones, is ensured by their systematic update. Epidemiological data, forecasts and analysis of medical resources are variable and, according to the act [3], each institution which issues health maps must update them at least once a year. Thus, without an efficient updating system, the update may be relatively high-maintenance for an institution, both from the perspective of organizational and economic aspects. It is also significant that the data collected in various institutions (National Health Fund, Central Statistical Office of Poland, Ministry of Health) are saved in various formats. What is even worse, the bases in which the data is integrated have different structures. The lack of standardised format and transfer of medical data (for example HL7) inhibits efficient and bona fide implementation of health maps in Polish system of health care. As a result, there is an urgent need for implementation of the Electronic Health Record (EHR). Due to the Record, the data will be digital and uniform.

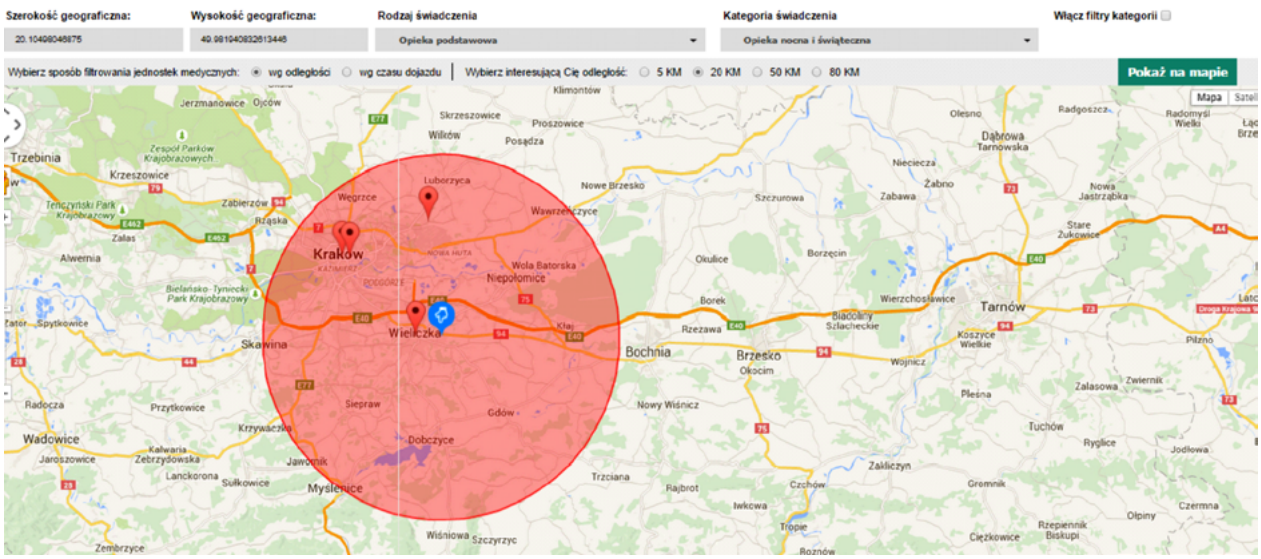
Maps including information about occupancy of medical equipment in particular voivodeships and counties are another element of the system of health maps. It is not only a question of the number and type of the equipment, but also the frequency of use and the queues of beneficiaries who wait for examinations carried out on them. This element of health care system is also important for estimations of health needs and should be included in maps.

Figure 2. *An example of setting the time of approach according to the kind and category of a service*



Source: S.E. Thrall, Geographic information system (GIS) hardware and software, "J. Public Health Manage Pract." 1999; 5 (2): 82–90 [4].

Figure 3. *An example of setting a distance according to a type and category of a service*



Source: S.E. Thrall, Geographic information system (GIS) hardware and software, "J. Public Health Manage Pract." 1999; 5 (2): 82–90 [4].

Independently of problems with data analysis and defined postulates, health maps may strongly influence the market of health care. They may be at the same time a significant help for some health care institutions, and a cause of many problems for others. The process of creating health maps is steady and continuously improved. It should be emphasised that without the maps, it will be hard to win funds for hospitals (77 billion euro will be allocated until 2020). The maps are a fundamental tool that may help allocate the money according to real and accurate needs of voivodes. Until now, funds from European Union were mainly voted for purchasing medical

apparatus in regions without any analysis of needs in this range in relation to hospitals.

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