ISSN 2080-2021 • e-ISSN 2449-9021

Medical Science Pulse 2017 (11) 1

Prace poglądowe | Reviews

DOI: 10.5604/01.3001.0009.9270

CREATION OF PRACTICE-BASED RESEARCH NETWORKS IN RURAL AREAS IN LOW-INCOME COUNTRIES: ADVANTAGES AND DISADVANTAGES

TWORZENIE SIECI BADAWCZYCH OPARTYCH NA PRAKTYCE NA OBSZARACH WIEJSKICH PAŃSTW O NISKIM DOCHODZIE: ZALETY I WADY

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A – przygotowanie projektu badania | study design, **B –** zbieranie danych | data collection, **C –** analiza statystyczna | statistical analysis, **D –** interpretacja danych | interpretation of data, **E –** przygotowanie maszynopisu | manuscript preparation, **F –** opracowanie piśmiennictwa | literature review, **G –** pozyskanie funduszy | sourcing of funding

SUMMARY

A Practice-Based Research Network (PBRN) consists of a group of clinicians, practices or institutions that are devoted primarily to the delivery of patient care and are associated with one another in order to answer community-based health care questions and translate research findings into practice.

The main goal of PBRNs is to involve busy community-based clinicians in studies conducted by investigators experienced in clinical and health service research. Doctors are drawn to take part in PBRNs in order to provide answers relevant to their practice, with the goal of improving the quality of practice and the health of their community.

PBRNs provide access to phenomena often neglected by researchers, but which are of great importance to those directly affected by the issues being studied.

Practice-based research in family medicine is an important way to acquire new knowledge by the means and outcomes of family medicine practice.

Although Practice-Based Research Networks (PBRNs) are useful tools for conducting practice-relevant research in the busy primary care setting, their existence is threatened by a range of challenges, e.g. the limited financial support that rural areas have been receiving over the last few years, especially during this period of austerity in many countries within the European zone.

Recruitment difficulties are a major impediment, fuelled by general practitioners' time constraints, lack of remuneration, non-recognition and workforce shortages.

In conclusion, despite the difficulties and challenges that PBRNs are facing, clinicians as individuals and organizations like EGPRN and EURIPA are trying to establish such types of networks, especially in low-income countries, in order to enhance the improvement and delivery of rural health care.

KEYWORDS: rural health research, community network, primary health care

STRESZCZENIE

Sieci badawcze oparte na praktyce (PBRN) składają się z grupy lekarzy, praktyk oraz instytucji, które są zaangażowane przede wszystkim w zapewnienie opieki pacjentom i powiązane ze sobą tak, aby wyjść naprzeciw potrzebom opieki zdrowotnej społeczności oraz przekształcić wyniki badań w praktykę kliniczną.

Głównym celem sieci badawczych opartych na praktyce jest zaangażowanie klinicystów pochłoniętych pracą na rzecz społeczności lokalnych w badania prowadzone przez badaczy, którzy mają doświadczenie w dziedzi-

nie badań klinicznych i usług zdrowotnych. Lekarze są zachęcani do wzięcia udziału w działaniach sieci badawczych opartych na praktyce po to, aby mogli udzielić odpowiedzi na pytania ważne dla swojej praktyki, a tym samym poprawić jakość praktyki i stan zdrowia społeczności.

Sieci badawcze oparte na praktyce zapewniają dostęp do zjawisk często pomijanych przez badaczy, ale bardzo istotnych dla osób bezpośrednio związanych z badanymi kwestiami.

Badania naukowe oparte na praktyce prowadzone w dziedzinie medycyny rodzinnej są ważnym sposobem zdobywania nowej wiedzy zarówno na podstawie stosowanych procedur, jak i rezultatów uzyskiwanych w praktyce medycyny rodzinnej.

Chociaż sieci badawcze oparte na praktyce są użytecznymi narzędziami w prowadzeniu badań istotnych dla praktyki w dziedzinie podstawowej opieki zdrowotnej, ich istnienie jest zagrożone przez szereg problemów, takich jak ograniczenie wsparcia finansowego na obszarach wiejskich w ostatnich kilku latach, szczególnie w trwającym w wielu krajach Unii Europejskiej okresie zaciskania pasa.

Trudności z rekrutacją są główną przeszkodą powodowaną ograniczeniami czasowymi, jakim podlegają lekarze rodzinni, brakiem wynagrodzenia, uznania oraz niedoborami kadrowymi.

Podsumowując, pomimo niedogodności i wyzwań, które stoją przed sieciami badawczymi opartymi na praktyce, sami klinicyści oraz organizacje, takie jak EGPRN (Europejska Sieć Naukowa Medycyny Rodzinnej) i EURIPA (Europejskie Stowarzyszenie Lekarzy z Terenów Wiejskich i Izolowanych) próbują tworzyć ten rodzaj sieci, zwłaszcza w krajach o niskim dochodzie, aby poprawić jakość i zapewnić jak najlepszy dostęp do opieki zdrowotnej na obszarach wiejskich.

SŁOWA KLUCZOWE: badania zdrowotne na terenach wiejskich, sieć społecznościowa, podstawowa opieka zdrowotna

INTRODUCTION

Practice-Based Research Networks are defined as a group of clinicians, practices or institutions that are devoted primarily to the delivery of patient care and are affiliated with one another in order to investigate questions related to community-based practice. These networks are usually formal collaborations between community-based physicians and academic institutions: the physicians collect research data, and academic institutions have the staff and facilities required to design research studies and analyze, interpret and publish the data [1].

PBRNs have already proved to be both a place and a concept. As a place, they are laboratories for quality surveillance and research by meeting the population health needs, which assists the family physicians in their responsibility to improve frontline clinical care. Therefore, PBRNs are essential for continuous quality improvement in primary care. Over the last few decades, family medicine research has made notable progress, focusing on different aspects of primary care, such as public health issues, quality and clinical topics [2].

Practice-Based Research Networks (PBRNs) in family medicine, according to the definition by the Agency for Healthcare Research and Quality, "are groups of primary care clinicians and practices working together to answer community-based health care questions and translate research findings into practice", while they "engage clinicians in quality improvement activities and an evidence-based culture in primary care practice to improve the health of populations" [3].

Practice-based research in family medicine is an important tool and vehicle to gain new knowledge by the means and outcomes of family medicine practice [2]. It offers essential information for evidence-based family medicine and as such represents the impetus for quality improvement.

HISTORICAL ROUTE

Practice-based research in family medicine began in the 1970s in Europe and Australia and provided evidence that family physicians could generate clinically significant and scientifically sound data [4]. In Europe, PBRNs in primary care emerged in the 1990s in Belgium and continued extensively in the United Kingdom and the Netherlands [5]. Moreover, there are primary care PBRNs that have been set up in other European countries. There are some positive examples of Practice-Based Research Networks in rural areas of select European countries. These enable the study of primary care problems, as well as the process of continuing quality improvement within primary care settings. This enables every family physician to take a proactive role in developing the overall discipline of family medicine [2].

ADVANTAGES

Residents of rural and remote areas experience several barriers to high-quality health care, such as geographical barriers - the need to travel greater distances to access different points of the health care delivery system. This can be a significant burden in terms of both time and money. Health care facilities in these areas are small and often provide limited services. Often, due to geographic distance, extreme weather conditions, environmental and climatic barriers, lack of public

transportation and challenging roads, rural residents may be limited/prohibited from accessing health care services. Other barriers include unemployment, lack of insurance and poverty, social stigma and privacy concerns, as well as low patient ability to understand health information and instructions from their health-care providers. General practitioners working in rural settings often encounter limited resources or equipment and lack of continuous training. Adaptation of evidence-based interventions that are easily accessible and cost effective is therefore crucial for promoting both population health and professional capacity in such areas.

The major goal of PBRNs is to involve busy community-based clinicians in studies directed by investigators experienced in clinical and health service research. Clinicians are drawn to participate in PBRNs in order to answer questions directly relevant to their practice, with the goals of improving the quality of practice and the health of their community [6,7].

In a time where evidence-based primary care is a high priority, and there are many unanswered questions relevant to the development of PBRNs, particularly within countries with limited resources and under financial crisis, primary-care research is needed to inform clinical practices and to develop the evidence base of primary care [4,8]. Primary care research seeks to answer questions of immediate relevance to the health of the community and has been described as "the missing link in the development of high-quality, evidence-based health care for populations" [5].

Despite most clinical health research being hospital-based, primary health care is the part of the health system patients use most often. International studies show that the strength of a country's primary health care system is associated with improved population health outcomes for all-cause mortality, all-cause premature mortality, premature mortality from major respiratory and cardiovascular diseases (including stroke), cancer mortality, infant mortality, low birth weight and self-rated health [10,11].

PBRNs provide access to phenomena often neglected by researchers, but which are of great importance to those directly affected by the issues being studied. Local and regional networks - especially in rural areas - often maintain close relationships with their members, which facilitates study recruitment and retention. Due to shorter travel distances, they are able to achieve tighter oversight during intervention and data collection and have a more visible presence within the community of practitioners. They are also more likely to be aware of the needs and interests of their members, to more effectively increase the readiness and capacity of practice sites to participate in research and to build viable learning communities for dissemination of knowledge [15].

The ability of PBRNs to involve "real-world" practices in clinical research provides new opportunities to engage understudied populations, to study a range of health problems and to accelerate community adoption of new knowledge and best practices. Research and needs assessments can help determine where and how resources may best be targeted, and program evaluations can indicate whether a particular intervention or approach works well in a rural context, especially in low-income countries. PBRNs can draw on the experience and insight of practicing clinicians to identify and frame research questions so that new findings can be applied directly to clinical practice. The role of PBRNs continues to evolve in the direction of a stronger focus on health improvement, primary care transitions and providing continuing education and maintenance of certification [16,17].

For better implementation, PBRNs should work more closely with their sponsoring or home institutions so that they can benefit from the research expertise and financial support they offer and facilitate mutually beneficial and respectful academic-practice partnerships. Networks that make more sophisticated use of Health Information Technology (HIT) can maximize their research capabilities in difficult economic times. The widespread use of electronic medical records (EMRs), coding systems and the ability to digitally extract anonymized data provides modern PBRNs with unparalleled research opportunities. Networks that employ a wide range of recruitment techniques and focus on clinically relevant research questions will engage and motivate their members. As a result of their close relationship with practitioners, PBRNs are in a unique position to create meaning with carefully selected projects that connect busy practitioners to the larger primary care research agenda. Lastly, established networks that join or create a consortium of PBRNs can build on local strengths while reducing the workload on any individual network member. In these ways, PBRNs can meet the challenging environment facing them today [9].

In Europe, there are two successful organizations (networks) which could take a leading role: EGPRN and EURIPA. Both are well positioned to establish such a network. Its purpose could be to share best practices, demonstrate the current state of the matter, improve rural health care equity between countries, standardize terminology and the use of common electronic platforms, etc. However, the establishment of such a network requires a great deal of preparation and careful consideration.

ONGOING DIFFICULTIES

Although Practice-Based Research Networks (PBRNs) are useful tools for conducting practice-relevant research in the busy primary care setting, their existence is threatened by a range of challenges.

Busy clinicians struggle with daily practice concerns, while practice-based research faces ever more stringent oversight and restrictions. Funding streams are tight, and many networks face a shortage of experienced prin-

cipal investigators. Health resource allocation in most countries still favors hospitals and specialist care [9,12]. This applies to clinical services as well as research.

A survey of public expenditure on primary care research in Australia, New Zealand, the United Kingdom and the Netherlands found that the average was less than $1.50 per capita per annum, in contrast to the international average expenditure on health and medical research of $28 per capita per annum [13]. This difference in funding can be more evident within countries under economic crisis.

Regardless the size and importance of general practice and primary health care in the health care system, the research output of these sectors has been low internationally [3]. Namely, rural areas have received limited financial support, which is further escalated by the current financial austerity that now more than ever has reduced research capacity in family practice and primary care [2]. The place of residence and geographical factors play a role in the assessment of health status, health care utilization and health service deficits, adequacy of health care and health-related behaviors. As expected, residents of rural areas are being increasingly identified as individuals at risk of health disparities.

In certain European low-income countries, including Greece, such networks are established with especially great difficulty [8].

Although improving patient care requires a sound evidence base, rigorously designed studies remain under-represented in primary care research. The pace of research activity in general practice and the rate and quality of publications do not match the pace of structural change or the level of funding provided. Recruitment difficulties are a major impediment, fuelled by general practitioners' time constraints, lack of remuneration, non-recognition and workforce shortages [14].

In addition, smaller numbers of practices available to participate can limit the types of study designs in which regional PBRNs can participate and may impact the generalizability of research findings to other regions of the country or to other practice types or patient populations, and as such, this may result in a competitive disadvantage when it comes to funding. To overcome this challenge, regional PBRNs working together can increase the generalizability of practice-based research by increasing the number and diversity of the participating practices [15].

CONCLUSIONS

The role of PBRNs continues to evolve in the direction of a stronger focus on health improvement, primary care transitions and providing continuing education and maintenance of certification. PBRNs are growing in experience and research capacity, and they are adopting more advanced study designs, disseminating and implementing practice change, participating in clinical trials and providing an essential component of a learning health system. This can be very important in low-income countries, where limited resources can be overcome by effective evidence-based primary care. Infrastructure funding, support and compensation strategies remain the biggest challenges. A better understanding of how challenges such as member compensation, provider training and community involvement affect the capacity of practices to participate would advance the ability of PBRNs to fulfill the promise of supporting better science in primary care.

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Word count: 2867 • Tables: – • Figures: – • References: 19

Sources of funding:
The review was funded by the author.

Conflicts of interests:
The author reports that there were no conflicts of interest.

Cite this article as:
Vasilopoulos T.
Creation of practice-based research networks in rural areas
in low-income countries: advantages and disadvantages.
MSP 2017; 11, 1: 19–23.

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Received: 23.02.2017
Reviewed: 08.03.2017
Accepted: 13.03.2017