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# In search of patient-centred care in middle income countries: The experience of diabetes care in the former Soviet Union

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ABSTRACT

In this study we apply the principles of patient-centred care to assess how health systems in middle income countries shape the experiences of patients with a common chronic disease and their care providers. We conducted semi-structured interviews with patients with diabetes, health professionals and key informants. We selected interviewees by purposive and snowball sampling. In total 340 respondents were interviewed in five countries: Armenia, Belarus, Moldova, Russia and Ukraine. Data were analysed according to a coding framework that was developed by three researchers, who then uncovered salient themes, similarities and differences between the five countries. Access to and consistent use of services was hampered by the lack of coordination and the financial weaknesses in the health systems. In many cases, lack of external support for individual patients left friends and family as the main providers of support. Patients were not expected to have a say or challenge the decisions concerning their treatment. Our study suggests the need for a radically different way of delivering care for people with diabetes and, by extension, other chronic diseases. Reforms should focus on improving self-management, the coordination of care, involving patients in decisions about their care, and providing emotional and practical support for patients.



## 1. Introduction

What exactly is "patient-centred" care? As Stewart has noted, "it may be most commonly understood for what it is not—technology centred, doctor centred, hospital centred, disease centred" [1]. It is concerned with the patient as a whole person, instead of viewing her in terms of current disease status. This means taking into account personal

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history, preferences and values, instead of merely fulfilling treatment protocols. Patient-centred care is as much about enabling a system that can cater to patient needs, as it is about the personal 'healing relationship' between the patient and the physician [2].

There is now widespread acceptance, at least in political and policy declarations that the patient should be at the heart of the health system and that a response to the global rise in non-communicable diseases such as diabetes should be "patient driven" [3–6]. The resulting model of patient-centred care [2,7–9] has been advocated on moral, ethical and instrumental grounds and is seen to benefit patients, health professionals and policy makers alike [2]. At international level, patient-centred care received added impetus from the inclusion in the seminal 2000 World Health Report of responsiveness to patients' legitimate expectations as a core goal of health systems [10]. The WHO expanded this concept, differentiating "people-centred [primary] care" from traditional disease control programmes and conventional ambulatory medical care in clinics or outpatient departments [11]. These and other reports reflected ideas that had taken root in some countries since the 1960s, where they were contrasted with the previously dominant illness-centred model of health care that typically defined patients in terms of their diseases rather than as individuals with a complex mix of symptoms, fears, and expectations. There were many reasons for its emergence, including a societal retreat from deference to professional judgement, a recognition that the patient is usually best equipped to determine his or her interests, and growing evidence that it achieved better outcomes at lower cost [12–18] and more equitable care [19,20].

Research has tended to focus on the micro-level, concentrating on the quest to create informed patients, responsive physicians and an optimal patient–physician interaction. Yet these interactions take place within and are influenced by health systems, whose governance, financing and delivery arrangements manifestly shape the patient experience but are rarely explored. It has been argued that in highly constrained health systems patients' ability to influence their care through cooperative behaviour and negotiation may be very limited [21]. Finally, most existing research on patient-centred care has been conducted in high income countries.

There is no reason why patient-centred care should be the prerogative of high income countries. The evidence that it enables better outcomes at low cost makes it even more appropriate for low and middle income countries [22,23]. But how can patient-centred care be achieved in middle and low income countries, where health care budgets are often constrained and where there are shortages of health workers, medicines and much else? In this paper we analyse macro and meso-level barriers and incentives for patient-centred care at the health system level in three lower (Armenia, Moldova, Ukraine) and two upper middle income countries (Belarus and Russia) [24] in the former Soviet Union. The countries of the former Soviet Union share several characteristics that make an assessment of patient-centred care especially relevant. They have reasonably well resourced health systems and a large health workforce [25] (although many have low skill levels and substitute for other health workers, such as nurses and technical staff [26]). The five countries studied inherited the Soviet system, which aimed at universal coverage of basic health care. They also inherited adequate (although unequally distributed) health care coverage, dominated by poorly equipped public hospitals at the expense of primary care. However, the countries have taken different political paths in the two decades since the collapse of the USSR and have met with differing degrees of economic success (or failure) (Table 1). All countries apart from Belarus followed a path of rapid decentralisation during the 1990s, which has resulted in uneven local budgets and often fragmentation of the health system.

The successes of the Soviet health system in terms of access were achieved by focusing on the collective good with little attention to individual needs. Mechanisms that can make health services more responsive, such as exit and voice [27], were not available to the average Soviet patient. This reflected an underlying lack of democratic representation and public participation. As a result, patients often resorted to what has been termed "inxit", or informal exit, using informal payments to influence preferences; this served to maintain rather than change the system [28]. Today, the USSR has been replaced by 15 independent states, all of which have, to varying degrees, introduced aspects of the market economy. People who once queued for basic provisions are now consumers who can choose where and what they purchase from providers who compete for custom. At least in urban centres, if suppliers do not respond to patients' needs, they can go elsewhere (exit) or complain (voice). Yet, while these changes have transformed the retail sector, it is less clear whether health services have also become more responsive. Health

**Table 1**
Characteristics of the five study countries.

| | Armenia | Belarus | Moldova | Russia | Ukraine |
|---|---|---|---|---|---|
| GDP in US$ per capita (2011) | 3305.49 | 5820.35 | 1966.93 | 13,089.3 | 3615.38 |
| Real gross domestic product, PPP$ per capita (2011) | 5829.04 | 15,040.3 | 3391.89 | 21,358.3 | 7250.51 |
| Life expectancy at birth (2009) | 73.85 | 70.62 | 70.97* | 69.03† | 71.12* |
| Age standardised death rate from diabetes/100,000 (2009) | 14.75 | 1.78 | 4.76 | 2.74 | 2.93 |
| Reported diabetes prevalence in (%) 2009 | 1.45 | 2.08 | 1.54 | 2.24 | 2.58 |
| Expenditure on health as (%) of GDP (2010) | 4.4 | 5.62 | 11.68 | 5.08 | 7.72 |
| Physicians/100,000 population (2011) | 269.85 | 379.01 | 282.59 | 431.04‡ | 349.14 |
| Nurses/100,000 population (2011) | 466.33 | 1062.46 | 646.77 | 806.22‡ | 635.84 |
| Hospital beds per 100,000 (2011) | 374.36 | 1125.12 | 618.85 | 965.85‡ | 865.8◦ |

* In 2011 † in 2010 ‡ in 2006◦ in 2009.
Source: World Health Organisation Health for All and Mortality databases.