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Reported barriers to evaluation in chronic care: Experiences in six European countries

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ABSTRACT

Introduction: The growing movement of innovative approaches to chronic disease management in Europe has not been matched by a corresponding effort to evaluate them. This paper discusses challenges to evaluation of chronic disease management as reported by experts in six European countries.
Methods: We conducted 42 semi-structured interviews with key informants from Austria, Denmark, France, Germany, The Netherlands and Spain involved in decision-making and implementation of chronic disease management approaches. Interviews were complemented by a survey on approaches to chronic disease management in each country. Finally two project teams (France and the Netherlands) conducted in-depth case studies on various aspects of chronic care evaluation.

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We identified three common challenges to evaluation of chronic disease management approaches: (1) a lack of evaluation culture and related shortage of capacity; (2) reluctance of payers or providers to engage in evaluation and (3) practical challenges around data and the heterogeity of IT infrastructure. The ability to evaluate chronic disease management interventions is influenced by contextual and cultural factors.

Conclusions: This study contributes to our understanding of some of the most common underlying barriers to chronic care evaluation by highlighting the views and experiences of stakeholders and experts in six European countries. Overcoming the cultural, political and structural barriers to evaluation should be driven by payers and providers, for example by building in incentives such as feedback on performance, aligning financial incentives with programme objectives, collectively participating in designing an appropriate framework for evaluation, and making data use and accessibility consistent with data protection policies.

1. Introduction

European countries are experimenting with a range of innovative approaches to better manage chronic disease [1–4]. Several have opted for structured disease management as a means to improve the quality and, potentially, reduce the cost of healthcare, and to improve health outcomes for those with chronic conditions. While intuitively appealing, the evidence that such approaches can in fact achieve these goals remains uncertain. Current evidence is largely based on small studies of high-risk patients, often undertaken in academic settings while systematic, scientifically robust evaluations of larger scale interventions and approaches remain scarce [5–7]. There is a comparatively large knowledge base on the methodological and practical challenges to evaluating disease management interventions [8–10] and more generally, complex interventions in healthcare [5,11–15]. The context for evaluation has been less extensively discussed, typically focusing on the setting within which evaluation takes place vis-à-vis the nature of the intervention to be evaluated [12]. There has been limited attention on unravelling the cultural, political and technological factors that may hinder systematic evaluation of complex healthcare interventions. Understanding these barriers is essential to encourage evaluation and in turn, generate evidence-based decision-making in chronic care.

This paper aims to contribute a better understanding of barriers to evaluation in chronic care. We examine in particular the broader perspective of key stakeholders on the evaluation of chronic disease management approaches as part of an overall assessment of health system performance.

2. Methods

This paper builds on work conducted by the European DISMEVAL project (Developing and validating DISease Management EVALuation methods for European healthcare systems), which sought to review current approaches to chronic care and their evaluations in EU Member States and to test and validate methods and metrics for their evaluation. We report on data collected from key informant interviews and a survey of chronic disease management approaches in the six partner countries, which informed this work. We complement these data with two in-depth case studies in France and The Netherlands.

2.1. Key informant interviews

We carried out semi-structured interviews with key informants from Austria, Denmark, France, Germany, The Netherlands, and Spain involved in the decision-making process as it relates to various aspects of chronic disease management in a given health system context.

The six countries were selected to capture the range of approaches to funding and governing healthcare across Europe: all six have a similar commitment to providing universal and reasonably equitable access to healthcare for their populations, but do so in different ways. Denmark and Spain operate primarily tax-funded systems, and the health systems in Austria, France, Germany and the Netherlands are primarily funded through statutory health insurance. Countries also represent different governance systems. France is characterised by structures that tend to be concentrated at the central (national) level, with decentralisation of some functions to regional agencies. In Denmark and Spain, administrative and political responsibility is partly or fully devolved to local or regional authorities; in Austria and Germany, it is devolved to state governments. Moreover, in Austria, Germany and The Netherlands, corporate actors (for example health insurance, providers) play an important role in healthcare governance [16]. It is our hypothesis that contextual, cultural, organisational and other features of the health system will influence the way chronic care initiatives are being implemented and, by extension, whether/how they are being evaluated.

We approached individuals in senior positions representing the decision-maker, payer, provider and/or patient perspective (Table 1). Study participants were identified through purposive and 'snowball' sampling, drawing from an established professional network of international contacts and through project partners based in the six countries.

Three researchers were present during each interview; one led the discussion (either CK or EN), a second person listened for key areas to explore further, and a third person took notes. Interviews were undertaken as telephone interviews between July and October 2010, using a semi-structured interview guide. The majority of interviews were held in English, with native language explanations