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Shared decision making in the UK: Moving towards wider uptake

Partizipative Entscheidungsfindung in Großbritannien: auf dem Weg zu einer stärkeren Verbreitung

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ABSTRACT

Shared decision making (SDM) is firmly on the policy agenda in the UK and a recent legal ruling has confirmed its importance. Policymakers, ethicists, professional regulators and societies, patient organisations and now the courts are committed to ensuring that SDM becomes the norm throughout the NHS, but an unfavourable economic climate makes this especially challenging. Considerable progress has been made over the last few years, with new learning from demonstration sites, various initiatives in capacity building and training, wider availability of patient decision aids, and important leadership initiatives. Enthusiasm for this way of working is growing among clinicians, patients and managers, but it could be undermined if SDM comes to be seen primarily as a means of cost control.

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ZUSAMMENFASSUNG

Partizipative Entscheidungsfindung (PEF) hat in Großbritannien einen festen Platz auf der politischen Agenda gefunden, und eine kürzlich getroffene gerichtliche Entscheidung hat die Bedeutung von PEF bestätigt. Entscheidungsträger, Ethiker, Regulierungsbehörden und Fachgesellschaften, Patientenorganisationen und nun auch die Gerichte setzen sich dafür ein, dass PEF im gesamten *National Health Service* (NHS) zur Norm erhoben wird; allerdings macht ein ungünstiges ökonomisches Klima diese Aufgabe zu einer besonderen Herausforderung. Dabei konnten in den letzten paar Jahren beträchtliche Fortschritte erzielt werden; dazu zählen das Lernen von Vorzeigeeinrichtungen, verschiedene Initiativen zum Aufbau von Kompetenzen und Schulungsmaßnahmen, eine höhere Verfügbarkeit von Entscheidungshilfen für Patienten und wichtige Initiativen von Meinungsführern. Unter Ärzten, Patienten und Managern nimmt die Begeisterung für diese Art zu arbeiten zu, doch könnte sie auch schnell wieder nachlassen, wenn partizipative Entscheidungsfindung in erster Linie als Kostendämpfungsinstrument wahrgenommen würde.

Introduction

There has been considerable progress towards wider implementation of shared decision making (SDM) in the UK since we last reported on this in 2011 [1]. We describe these developments

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below, but first we will briefly outline the context in which they have been achieved.

Most UK citizens depend on the *National Health Service* (NHS) for almost all their healthcare needs. Funded out of taxation, the NHS covers primary care, hospital care (inpatients and outpatients), community care (including home nursing and other out-of-hospital services), and mental health care. These services are free at the point of use.

The NHS was established in 1948 and run centrally for the whole of the UK by the *Department of Health* in London until 1999, when responsibility for healthcare was devolved to the four nations of England, Scotland, Wales and Northern Ireland. Since then health policy has developed on somewhat different trajectories in the four nations. However, funding is still largely determined centrally and the NHS has been subject to significant financial pressures following the 2008 banking crisis and changes in government. These resource constraints, coupled with increased demand due to an ageing population, multi-morbidity and widening health inequalities, have placed the system under severe strain. However, the NHS still commands strong public support and the national health administrations have been making strenuous efforts to secure more patient-centred services and improved health outcomes while containing costs.

Policy priorities

SDM has been a policy priority for the NHS for several years. Patient organisations have been demanding a greater say in decisions about their care [2], and the NHS Constitution for England tells patients that they have the right to be involved in planning and making decisions about their health and care and to be given information and support to enable this [3]. NHS England's strategic plan states that *"when people do need health services, patients will gain far greater control of their own care"*[4]. This is mirrored in Scotland, where the Chief Medical Officer has told patients:

> *"You should expect the doctor (or other health professional) to explore and understand what matters to you personally and what your goals are, to explain to you the possible treatments or interventions available with a realistic explanation of their potential benefits and risks for you as an individual, and to discuss the option and implications of doing nothing. You should expect to be given enough information and time to make up your mind. You should consider carefully the value to you of anything that is being proposed whether it be a treatment, consultation or diagnostic investigation and be prepared to offer challenge if you feel it appropriate."* [5]

SDM is also seen as an ethical imperative by the UK's professional regulators. The *General Medical Council's* (GMC) statement of professional standards says that doctors should work in partnership with patients, sharing with them the information they need to make decisions about their care [6]. Other regulators, including the *Nursing and Midwifery Council*, have espoused similar principles and these are reinforced in quality standards published by the *National Institute for Health and Clinical Excellence* (NICE)[7]. In 2015 the government made it clear that they expected the NHS in England to become '*dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment*' [8].

Following a landmark ruling in 2015 by the *Supreme Court*, SDM became a legal imperative throughout the UK [9]. The practical effect of this decision is that people with full mental capacity must be properly advised about their treatment options and the risks associated with each option so that they can make informed decisions when giving or withholding consent to treatment. In other words, the courts have now caught up with the policymakers, ethicists, professional and patient organisations in stating that the principles of SDM must become the norm.

The case for providing treatment, care and support that informed patients actually want, not just what professionals think they should have, is now more widely acknowledged. A growing professional movement is beginning to embrace SDM, recognising that population-based evidence, as enshrined in guidelines and frameworks, should be tempered by a more personalised approach, where clinicians and patients make decisions together, based on mutual review of the evidence but also on an understanding of the individual's personal circumstances and preferences [10].

Despite this, progress in implementing SDM across the NHS has been slow. Many health professionals still fail to comply with the requirement to inform and involve patients in all the decisions that affect them. However, there are signs that the tide is beginning to turn. Recent results from the large-scale annual national inpatient surveys for the NHS in England show an encouraging upward trend in the proportion saying they were involved in decisions about their care (Figure 1).

Proof of concept

A number of demonstration projects have taken place in various parts of the UK, exploring the feasibility of embedding SDM in routine clinical care. The *Health Foundation*, a London-based charity, provided funding and support for sites in the north east of England and in Wales through its *MAGIC (Making Good Decisions in Collaboration) programme* (http://www.health.org.uk/programmes/magic-shared-decision-making) [11]. These projects explored how to overcome the barriers to change, focusing on a multifaceted approach incorporating clinical skills development and training, patient decision aids, patient activation, clinical and organisational leadership, and support for commissioning across a range of primary and secondary care settings and specific clinical decisions (for example in benign prostate conditions, breast cancer surgery, head and neck cancer, antibiotic prescribing, cholesterol-lowering treatments, pregnancy and childbirth).

Another project, the *Year of Care programme*, is examining how to provide better support for people with long-term conditions by engaging them in developing personalised care and support plans [12]. Demonstration sites are using a model known as the House of Care to help primary care teams adapt their services to the needs of these patients (Figure 2). This focuses attention on the support and resources needed to enable personalised care planning based on SDM principles, which has been shown to improve health outcomes [13]. The model has proven useful for supporting self-management in people with single conditions and with multi-morbidities. *NHS England* and the *Royal College of General Practitioners* have adopted this approach in their drive to improve services for people with long-term conditions [14].

Meanwhile, the *Scottish Government* has introduced a national *Health Literacy Action Plan* and is supporting various initiatives to ensure health service organisations and staff work in ways that make it easy for everyone to engage in SDM and more generally live well, on their own terms, with their health conditions [15]. Importantly a movement of '*Realistic Medicine*' is building in Scotland, a heavy focus of which is around SDM. Realistic Medicine is now a key part of Scotland's national clinical strategy [5].

Building capacity and skills

SDM theory, skills and competencies (listening, information sharing, risk communication, options appraisal, preference diagnosis, goal setting, care planning and outcomes assessment) should