Universidade de Lisboa

Faculdade de Medicina de Lisboa

Person-centered care

and health information technology in Portugal

Implications for chronic care and health quality improvement

Liliana Catarina Cândida Laranjo Silva

Tese orientada pelo Doutor Armando Brito de Sá

e co-orientada pelos Doutores

Constantino Theodor Sakellarides e Kenneth Mandl

Tese especialmente elaborada para obtenção do grau de Doutora

Programa Doutoral em Doenças Metabólicas e Comportamento Alimentar, ramo Medicina e especialidade Epidemiologia

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Abstract

Person-centered care and health information technology in Portugal

- Implications for chronic care and health quality improvement -

Background

There is overwhelming evidence of the importance of person-centered care in achieving desirable health outcomes. Putting patients in control of their health, and facilitating easy access to health information, are increasingly recognized as crucial aspects of quality health care. One of the areas where patient participation in care is especially important is chronic disease management.

Chronic diseases such as diabetes mellitus (DM) present some of the most challenging health problems nowadays. The prevalence of DM continues to increase, and its management is complex, greatly relying on patients' behavioral change.

Little is known about the facilitators, barriers and expectations of Portuguese patients with DM in the self-management of their disease. Furthermore, greater use of patient-reported measures is needed, so that person-centered care may be improved in type 2 DM. One questionnaire that has been gaining increasing attention in the literature is the Patient Activation Measure 13 (PAM13), which measures a person's knowledge, skills, and confidence in managing their health.

Another crucial area in the fields of quality improvement and chronic care is health information technology (HIT). Despite concerns about the digital divide, HIT has huge potential to improve person-centered care. Three particular HIT tools reveal growing potential: Personal Health Records (PHRs), Social Networking Sites (SNSs), and Electronic Health Records (EHRs).

Aims

The main aims of this project were to: I) Revise the literature regarding patient access to their medical records; II) Translate, culturally adapt and validate the PAM13 to Portuguese, in patients with type 2 diabetes mellitus; III) Assess the facilitators, barriers and expectations in the self-management of type 2 diabetes mellitus; IV) Evaluate current access to health information technology by Portuguese type 2 diabetes patients;

V) Evaluate the adoption and use of a PHR by the Portuguese population; VI) Evaluate the use and effectiveness of interventions using SNSs to change health behaviors; and VII) Evaluate the feasibility of using EHRs and geographic information systems for public health surveillance of type 2 diabetes.

Methods

Several data collection and data analysis methods were applied in the seven studies that compose the present thesis, of which the most relevant were: narrative and systematic reviewing of the literature, qualitative methods (e.g. focus groups, e-Delphi panels, cognitive debriefing interviews, content analysis), survey research methods, data collection from existing electronic databases, meta-analysis, Rasch modeling, logistic regression, and geographic information system analysis.

Results

Paper I - Patients' access to their medical records

Despite the potential benefits of sharing medical records with patients, this is still far from being common practice. In Portugal, although the legal framework favors patients' access to their medical records, several barriers (e.g. cultural, organizational, administrative) are still in place.

Paper II - Translation, cultural adaptation and validation of the Patient Activation Measure 13 in a population of Portuguese type 2 diabetes patients

The PAM13 was translated to Portuguese and applied to a sample of 193 patients with type 2 diabetes. Respondents had a mean age of 67.1 years [Standard Deviation (SD) 10.1], 42.7% were women, and mean PAM score (0-100) was 58.5 (SD 10.1). All items in the instrument had good fit and the response categories were well adjusted to the Rasch Model. Item reliability was 0.97, and person reliability was between 0.77 (real) and 0.83 (model).

Paper III - Facilitators, barriers and expectations in the self-management of type 2 diabetes – a qualitative study from Portugal

The exploration of facilitators, barriers, and expectations in the self-management of type 2 diabetes revealed three major themes: diet, physical exercise, and glycemic control.

Information and knowledge translation, as well as family and social ties were commonly explored aspects across the three themes.

Paper IV - Internet use by Portuguese patients with type 2 diabetes mellitus – association with demographic and clinical characteristics

A total of 205 patients with type 2 diabetes responded to the questionnaire (response rate: 83%). Mean age was 67 years (SD 10); 42.7% of respondents had a computer at home, and 47% had Internet available at home. Additionally, 63.5% reported that they used the Internet less than once monthly. Less frequent users of the Internet were older and had a lower level of education.

Paper V - Adoption of a national integrated Personal Health Record in Portugal – Who are the early adopters?

A total of 110,529 people were registered in the PHR (mean age: 44.7 years, SD 18.1; 60.5% women). Approximately 17% of registered people were considered users of the system. People engaging in comprehensive use of the PHR totaled 12,549. People with two or more health problems, and taking one or more medications, had higher odds of engaging in comprehensive use of the system.

Paper VI - The influence of social networking sites on health behavior change – a systematic review and meta-analysis

In the systematic review of SNS interventions, twelve studies (7411 participants) met the inclusion criteria. Facebook was the most utilized SNS, followed by health-specific SNSs, and Twitter. Eight randomized controlled trials were combined in a meta-analysis. A positive effect of SNS interventions on health behavior outcomes was found [Hedges' g 0.24; 95% confidence interval (CI) 0.04 - 0.43].

Paper VII - Use of electronic health records and geographic information systems in public health surveillance of type 2 diabetes

Using data from electronic health records we identified 205,068 individuals with the diagnosis of type 2 diabetes. The mean age was 67.5 years, and hypertension was present in 71% of all individuals. There was considerable variation in diagnosed comorbidities across parishes. Diabetes patients with concomitant hypertension or dyslipidemia showed higher odds of having been diagnosed with cardiovascular complications, when adjusting for age and gender [(hypertension odds ratio (OR) 2.16, CI 2.10-2.22; dyslipidemia OR 1.57, CI 1.54-1.60)].

Conclusion

Promoting person-centered care can be pursued at several levels, namely by facilitating patients' access to their medical records, increasing the use of patient-reported measures, and exploring patients' needs and perspectives regarding health care, as well as their limitations in an increasingly digital world. Furthermore, HIT has huge a role to play in improving health care, both at the individual and population-levels, through the meaningful use of PHRs, SNSs, and EHRs.

Key Words

Patient Participation [MeSH]; Patient Activation; Health Records, Personal [MeSH]; Diabetes Mellitus [MeSH]; Health Information Technology.

Resumo em português

Cuidados centrados na pessoa e tecnologias de informação na saúde em Portugal
- Implicações nos cuidados à doença crónica e na melhoria da qualidade em saúde -

Introdução

Cuidados de saúde centrados na pessoa são essenciais para atingir bons resultados em saúde, de acordo com a atual evidência científica. Facilitar aos doentes o controlo da sua saúde, nomeadamente através da promoção do acesso à informação dos processos clínicos, tem vindo a ser reconhecido como crucial para esse objectivo. Uma das áreas em que a participação do doente se torna cada vez mais necessária é no tratamento de doenças crónicas.

Doenças como a diabetes melitos tipo 2 (DM2) são atualmente alguns dos maiores desafios em saúde. A prevalência da DM2 tem vindo a aumentar e a sua gestão é complexa, estando muito dependente da mudança de comportamentos.

Pouco se sabe sobre os fatores facilitadores, barreiras e expectativas dos doentes portugueses com DM2 no controlo da doença. Além disso, uma maior utilização de indicadores reportados pelo doente é necessária, para que se possa melhorar a qualidade dos cuidados centrados na pessoa, nomeadamente na DM2.

Um dos questionários que tem vindo a ganhar relevância nesse sentido é o '*Patient Activation Measure 13*' (PAM13), que mede o conhecimento, a capacidade técnica e a confiança dos pacientes na autogestão da saúde.

Outra área de crescente relevância, tanto na melhoria da qualidade em saúde como nos cuidados à doença crónica, é a das tecnologias de informação em saúde (*health information technology, HIT*). Apesar da preocupação acerca das desigualdades no acesso a tecnologia, a HIT apresenta um enorme potencial na melhoria dos cuidados centrados na pessoa. Atualmente, três ferramentas em HIT estão a revelar-se particularmente promissoras: o Sistema Personalizado de Informação de Saúde (*Personal Health Record, PHR*), as Redes Sociais (*Social Networking Sites, SNS*) e o Registo Electrónico Médico (*Electronic Health Record, EHR*).

Objetivos

Este projeto teve como principais objetivos: 1) Rever a literatura acerca do acesso dos pacientes aos seus processos clínicos; 2) Traduzir para Português, adaptar culturalmente e validar o PAM13 em doentes Portugueses com DM2; 3) Identificar os elementos facilitadores, as barreiras e expectativas dos doentes na autogestão da DM2; 4) Avaliar o atual acesso a tecnologias de informação e comunicação por doentes portugueses com DM2; 5) Avaliar a adoção e uso de um Sistema Personalizado de Informação de Saúde pela população portuguesa; 6) Avaliar a eficácia de intervenções utilizando redes sociais electrónicas na mudança de comportamentos de saúde; e 7) Avaliar a exequibilidade do uso de Registos Electrónicos Médicos e Sistemas de Informação Geográfica na vigilância epidemiológica da DM2.

Métodos

Foram utilizados diversos métodos na recolha e análise de dados nos sete estudos que compõem a presente tese, dos quais se destacam os seguintes: revisão sistemática e narrativa da literatura, meta-análise, métodos qualitativos (ex.: grupos de foco, painel e-Delphi, entrevista, análise de conteúdo), recolha de dados armazenados em bases electrónicas, questionário, modelo Rasch, regressão logística e análise com Sistemas de Informação Geográfica.

Resultados

Artigo I - O acesso dos pacientes aos seus processos clínicos

Apesar dos potenciais benefícios da partilha de registos clínicos, esta está ainda longe de ser uma prática comum. Em Portugal, apesar do enquadramento legal claramente favorecer o acesso dos doentes aos seus processos clínicos, existem ainda várias barreiras a serem ultrapassadas (ex.: barreiras de origem cultural, organizacional e administrativa).

Artigo II – Tradução, adaptação cultural e validação do questionário PAM 13 (Patient Activation Measure 13) numa população portuguesa de doentes com DM2

O PAM 13 foi traduzido para Português e aplicado a uma amostra de 193 pacientes com DM2. Os participantes tinham uma média de idades de 67.1 anos [Desvio padrão (DP) 10.1], 42.7% eram mulheres, e a média do score do PAM (0-100) foi de 58.5 (DP 10.1). Todos os itens do instrumento revelaram boa adaptação e as categorias de resposta mostraram estar bem ajustadas ao Modelo Rasch. A fiabilidade do instrumento foi de 0.97, e a fiabilidade dos participantes foi de 0.77 (real) e 0.83 (modelo).

Artigo III – Elementos facilitadores, barreiras e expectativas da autogestão da Diabetes tipo 2 – um estudo qualitativo em Portugal

A exploração dos elementos facilitadores, das barreiras e das expectativas na autogestão da DM2 revelaram três temas principais: a dieta, o exercício físico e o controlo glicémico. Informação e transferência de conhecimento, assim como redes sociais e familiares foram aspectos mencionados frequentemente e explorados de forma transversal nos 3 temas.

Artigo IV – Utilização da Internet por doentes Portugueses com Diabetes melitos tipo 2 - associação com características demográficas e clínicas

Um total de 205 doentes com DM2 responderam ao questionário (taxa de resposta: 83%). A média de idades foi de 67 anos (DP 10); 42.7% dos participantes tinha um computador em casa, e destes, 47% tinha internet disponível em casa. Adicionalmente, 63.5% reportaram utilizar a internet menos de uma vez por mês. Os utilizadores da internet menos frequentes tinham idade mais avançada, bem como um nível de escolaridade inferior.

Artigo V – Adoção de um Sistema Personalizado de Informação de Saúde (Personal Health Record) em Portugal – Quem são os 'early adopters'?

Na altura do estudo estavam registadas no Sistema Personalizado de Informação de Saúde 110,529 pessoas (média de idades: 44.7 anos, DP 18.1; 60.5% mulheres). Aproximadamente 17% das pessoas registadas foram consideradas 'utilizadoras' do sistema. Foram ainda identificadas 12,549 pessoas com 'utilização extensa' do sistema.

Pessoas com um ou mais problemas de saúde e medicadas cronicamente com pelo menos um fármaco foram as que apresentaram uma maior probabilidade de terem uma 'utilização extensa' do sistema.

Artigo VI – A influência das redes sociais electrónicas (*social networking sites*) *na modificação de comportamentos de saúde – revisão sistemática e meta-análise*

Foram encontrados 12 estudos (7411 participantes) que preencheram os critérios de inclusão. O Facebook foi a plataforma mais utilizada, imediatamente seguido por redes sociais especificamente relacionadas com a saúde, e pelo Twitter. Oito ensaios clínicos aleatorizados foram combinados numa meta-análise. Encontrou-se um efeito benéfico de intervenções envolvendo redes sociais electrónicas na modificação de comportamentos de saúde [Hedges' g 0.24; intervalo de confiança 95% (CI) 0.04 – 0.43].

Artigo VII – Utilização de Registos Electrónicos Médicos (Electronic Health Recods, EHR) e de Sistemas de Informação Geográfica na vigilância epidemiológica da diabetes tipo 2

Utilizando dados colhidos de EHRs da zona de Lisboa foram identificados 205,069 indivíduos com o diagnóstico de DM2. A média de idades foi de 67.5 anos e o diagnóstico de hipertensão estava presente em cerca de 71% de todos os indivíduos. Verificou-se uma variação considerável na proporção de comorbilidades entre freguesias. Doentes com DM2 e hipertensão ou dislipidemia concomitantes revelaram maior probabilidade de terem complicações cardiovasculares diagnosticadas, ajustando para a idade e género [(odds ratio (OR) hipertensão 2.16, CI 2.10-2.22; OR dislipidemia 1.57, CI 1.54-1.60)].

Conclusão

A promoção dos cuidados de saúde centrados na pessoa pode ser realizada a vários níveis, nomeadamente através da facilitação do acesso do paciente ao seu processo clínico, da maior utilização de indicadores reportados pelos pacientes, e da identificação das necessidades e perspectivas do doente nos cuidados de saúde, bem como das suas limitações num mundo cada vez mais digital. As tecnologias de informação e comunicação em saúde apresentam um enorme potencial na melhoria da qualidade dos

cuidados, tanto ao nível individual como ao nível populacional, através da utilização estratégica de Sistemas Personalizados de Informação de Saúde (*Personal Health Records*), Redes Sociais electrónicas (*Social Networking Sites*) e Registos Electrónicos Médicos (*Electronic Health Records*).

Palavras-chave

Participação dos pacientes; Ativação; Sistema Personalizado de Informação de Saúde; Diabetes Mellitus; Tecnologias de Informação na Saúde.

Só se nos detivermos a pensar nas pequenas coisas

chegaremos a compreender as grandes.

José Saramago

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Preface

This journey began in October 2009, when I initiated the curricular component of the Doctoral program. The first three lectures, taught by Professor Sakellarides, mark the moment I began seeing health care through different lenses, from a quality improvement perspective. It was also during those lectures that I first heard the term "Personal Health Record", and became fascinated by the idea of putting patients in control of their own health.

In early 2011, I was selected for a Junior Clinical Research Award, from the Harvard Medical School-Portugal Program. This award gave me the perfect opportunity to enhance my clinical research skills and benefit from the stimulating environment of the Harvard School of Public Health, while collaborating on several projects at the Portuguese School of Public Health, and further developing my PhD studies.

In October 2011, approval was granted by the Scientific Committee of Lisbon's Medical School, for research development of my PhD project. While initially being focused on the development, implementation and evaluation of a Personal Health Record, it gradually evolved to contemplate a broader perspective of person-centered care and health information technology - two important elements in the fields of quality improvement and chronic disease management. Type 2 diabetes mellitus, one of the most burdening chronic diseases in Portugal and worldwide, became the logic background on which part of the research presented in this thesis was conducted.

The evolution of this project into a broader and more comprehensive framework was deeply influenced by my concomitant clinical activity in Family Medicine (as a resident until November 2014 and since then as a specialist), as well as by the knowledge gained while attending the Master of Public Health program, at the Harvard School of Public Health (completed in November 2013). Both Primary Care and Public Health have the advantage of enabling a whole-system view of health care, which allowed me to integrate the technological perspective with the - so often forgotten - person-centered approach to care.

During the last four years I collaborated with several institutions to develop the different studies that compose this thesis. Specifically, collaboration protocols were signed with the Portuguese School of Public Health, Portugal Telecom, APDP – Associação Protetora dos Diabéticos de Portugal, and SPMS – Serviços Partilhados do Ministério da Saúde. Moreover, I was lucky enough to visit two research centers of excellence in the field of Medical Informatics: the Intelligent Health Laboratory in Boston, directed by Professor Kenneth Mandl, and the Centre for Health Informatics in Sydney, directed by Professor Enrico Coiera.

The main outputs of this PhD are the seven papers presented in the 'Results' section of this thesis, of which three are already published (Appendices 1, 2 and 3). Additionally, a systematic review was conducted in 2011 - "The use of patient-centered health information systems in type 2 diabetes mellitus – which is presented in Appendix 4. Several oral presentations were also performed during the last five years, nationally and internationally, of which the most relevant are openly accessible online (http://pt.slideshare.net/LilianaLaranjo1). The abstracts for some of these presentations are included in Appendices 5, 6 and 7. In Appendices 8 and 9, two conference papers conducted in co-authorship are presented, regarding a design proposal for the national Personal Health Record 'Portal do Utente'. The final report for the funding agency (Fundação para a Ciência e Tecnologia – Programa Harvard Medical School Portugal) is shown in Appendix 10.

Lisboa, 24 de Julho de 2015

Liliana Laranjo

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À Vera Dias, a minha primeira mestranda, por ter acreditado em mim, e pela imensa dedicação que tornou possível transformar a visão de um projeto em realidade.

Aos pacientes, que tanto me têm ensinado, e cujas histórias me foram relembrando constantemente o porquê deste doutoramento.

A todos os amigos e familiares, a quem dediquei menos tempo do que desejava ao longo dos últimos anos.

A todos com quem tive oportunidade de trabalhar (e aprender) ao longo deste percurso.

I cannot thank enough to Professors Kenneth Mandl and David Bates, who welcomed me into the Harvard world. They were (and are) an enormous source of inspiration to me.
Many thanks to Annie Lau, who welcomed me in Sydney and has been teaching me so much since then.

I would also like to thank the Faculty of the Harvard School of Public Health, for taking teaching to a whole different level - one I did not know was possible.

Finalmente, agradeço à Escola Nacional de Saúde Pública, Associação Protetora dos Diabéticos de Portugal, Fundação para a Ciência e Tecnologia, Portugal Telecom e Serviços Partilhados do Ministério da Saúde a contribuição dada para o sucesso deste projeto.

Funding: Junior Clinical Research award - Harvard Medical School-Portugal program (HMSP-ICJ/0005/2010; Fundação para a Ciência e Tecnologia).

Introduction

Health care quality improvement

The landmark report "Crossing the quality chasm", issued by the Institute of Medicine, set forth a vision for a higher quality health care system[1]. In this vision, there would be a shift from physician-centered care to a patient-centered approach, where citizens would have as much control over their health care as they desired[1] (Table I). In this transition, a health system would go through four stages of evolution, where the patient would be progressively at the center of care, and health information technology would become more efficient, facilitating care delivery, learning, knowledge translation, performance tracking, and population health monitoring[1] (Table II).

Table I | Vision for the 21st-century health care system

Current approach	New approach
Care is based primarily on visits	Care is based on continuous healing relationships, where communication happens through several means (e.g. face-to-face, telephone, internet)
Professional autonomy drives variability	Care is customized according to patient needs and values
Professionals control care	The patient is the source of control
Information is in siloes and not easily accessible	Knowledge is shared and information flows freely
Decision-making is based on training and experience	Decision-making is evidence-based
"Do no harm" is an individual responsibility	Safety is a system property
Secrecy is normal	Transparency is the norm
The system reacts to needs	Needs are anticipated
Cost reduction is sought	Waste is continuously decreased
Hierarchies and professional roles hamper cooperation	Cooperation among clinicians is a priority

(Adapted from "Crossing the Quality Chasm", Institute of Medicine, 2001)

Table II | Stages of evolution in health systems design

Stage	Patient experience	Knowledge and skills management	Care delivery
1	• The physician determines what is in the best interest of the patient • Patients have a passive role • Physician/institution-centered care	• Heavy reliance on memory and knowledge • No significant real-time aids and tools • Information technology is almost entirely absent	• Physicians mostly work individually; very little team work
2	• Physician autonomy predominates • Informal mechanisms for patient input • Care is organized for the benefit of professionals and/or institutions	• Clinicians still rely on memory, but there is more knowledge assistance (e.g. journals, conferences) • Patients receive some information from clinicians (mostly verbal) • Very little information technology is in use	• Traditional professional roles define working relationships • Informal sharing of control between health professionals
3	• Formal mechanisms for patient input exist • Care is organized for the benefit of the professional and/or the institution, but there is some movement toward a patient-centered system	• Clinicians and patients have access to clinical knowledge, in varying degrees • Significant reliance on best practices and guidelines • Real-time decision-support tools are available, but information technology capability is modest	• The physician is the leader • Formal sharing of roles and tasks between health professionals, but little integration of care • Several vertical programs for disease management exist
4	• Care processes are based on the need for quality improvement • Care is patient-centered • Patients and families are part of the care team • Patients have access to as much information as they wish to have • Patients have opportunity to exercise as much control over their care as they desire	• Clinical information is abundant and easily accessible for patients and clinicians • Skill development, training, and leadership support the multidisciplinary character of clinical practice • Automated decision-support systems incorporating patient-specific data are used at the point of care	• The delivery of services is coordinated over time across practices, settings, and conditions • Information technology facilitates care delivery, learning, knowledge translation, performance tracking, and population health monitoring • The health workforce is used efficiently and flexibly to implement change

(Adapted from "Crossing the Quality Chasm", Institute of Medicine, 2001)

In “Crossing the quality chasm”, the Institute of Medicine listed ten main areas for improvement, six imperatives for system redesign, and six desirable outcomes: effectiveness, safety, patient-centeredness, efficiency, timeliness and equity[1] (Figure 1).

Similarly, in the United Kingdom (UK), the National Health Service (NHS) has established the vision for a transformed, patient-oriented health service, with “The NHS Plan” in 2000[2]. More recently, in 2008, three important domains for health care quality have been highlighted: clinical effectiveness, patient safety, and the patient experience[3]. Also, in Australia, the first of fifteen Principles for Australia’s Health System includes ‘people and family centeredness’[4].

It is now widely recognized that care should be customized based on patient needs and values, and that patients should have easy access to their health information, so that they are able to exercise the degree of control they wish over health care decisions[1,5]. In January 2015, the importance of patient-centered care was also highlighted by President Barack Obama when launching the ‘Precision Medicine Initiative’, with the aim of promoting research to advance personalized Medicine and to “provide every patient access to the personalized information necessary to keep themselves and their families healthier”[6].

One important reason to promote patient-centeredness is the current crisis in patient safety[1,7,8]. Iatrogenic causes are known to be responsible for a great number of deaths every year[9] and medical harm has been estimated to be one of the top three killers in the United States (US)[10,11]. It has been advocated that Medicine needs a cultural shift to promote safety in every aspect of care, but improvements in the system have been slow to occur[12,13]. Eric Topol recently suggested the “creative destruction of Medicine” as a way to transform health care and improve its quality, namely through radical innovation and active participation of patients and their families in health care[14]. Patient safety can be greatly enhanced if patients are involved in their care[15]. Indeed, an informed patient is a safer patient[1].

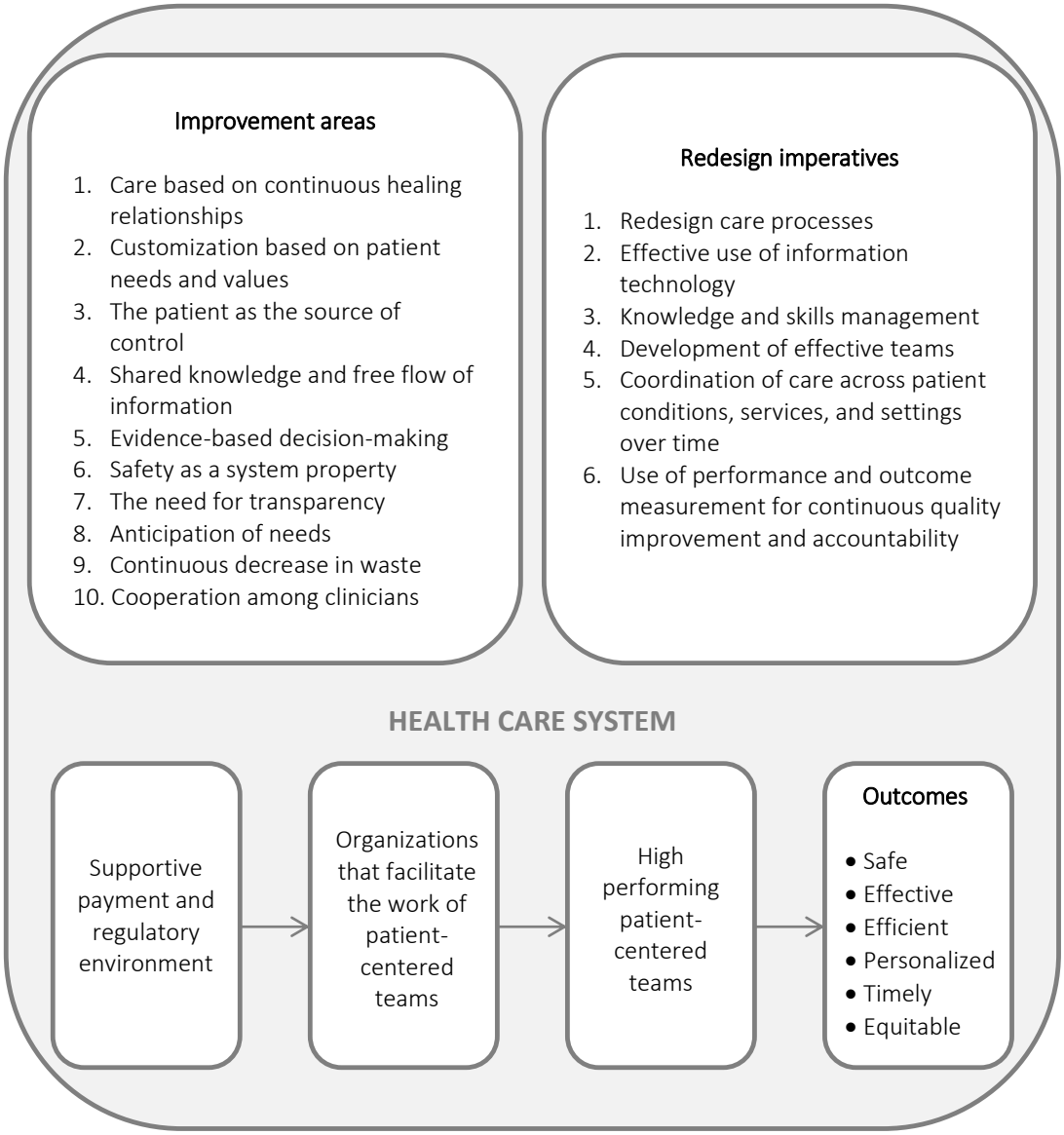

Figure 1 | Ten areas for improvement, six redesign challenges and six aims for the 21st century health care system

(Adapted from "Crossing the Quality Chasm", Institute of Medicine, 2001)

Patient, person, citizen, consumer – terminology clarification

Controversy remains regarding what to call individuals who utilize health services[16]. Terms like 'patient', 'service user', 'consumer', 'client', 'citizen', and 'person' (among others) are frequently applied in the health care literature, but none seems to be completely satisfactory[16].

The term 'user' is becoming popular in the UK[15] but has been pointed out to be frequently associated with drug dependency[17]. In Australia, the term 'consumer' is preferred, having a sociopolitical meaning that implies involvement and participation in health care[18]. However, in many other countries, 'consumer' is seen less favorably, denoting a consumerist and market-oriented approach to health care[15].

'Patient' has been defined as a "person receiving or registered to receive medical care" and derives from the Greek, originally meaning 'one who suffers'[10]. Some have argued that the term 'patient' suggests a predominantly passive role[15,19,20] and the term 'individual, active participant' has recently been suggested as an alternative[10].

In this thesis, all these terms will be recognized as similar in their essence and will be used interchangeably to address the 'recipients of health care'. Nevertheless, 'patient' will be frequently used, since it is the most widely understood term. Another commonly used term in this thesis will be 'person', lending a more holistic connotation to the concept of health care delivery.

Person-centered care

> "Every patient is an expert in their own chosen field,
> namely themselves and their own life."
> Emma Hill, The Lancet [10]

Meaning and importance

Person-centered care, also known as patient-centered care[17], has been defined as "respecting and responding to patients' wants, needs and preferences, so that they can make choices in their care that best fit their individual circumstances"[1].

The term "person-centered" was first applied in 1957 by Carl Rogers, in the context of psychotherapy[17], and later by Michael and Enid Balint, who developed the notion that care could be 'patient-centered' (concerning the whole person, mind and body) or 'illness-centered' (focused on the illness or disease)[21,22]. Later, this concept was adopted as the core principle of the "biopsychosocial" model of medicine[23,24].
Person-centered care can be distinguished from disease-centered care by being congruent with and responsive to the needs and preferences of the whole person, in a timely manner, over time, and independent of care for particular diseases[15,25,26] (Table III). Another common view of patient-centeredness involves "learning with, from, and about patients" in order to democratize medical practice[17].

Several dimensions of patient-centered care have been described in the literature, such as: respecting patient's values, preferences, and needs; affording people dignity, compassion and respect; providing information and education; involving the patient in care decisions (promoting shared decision-making); involving family, friends and caregivers; providing personalized, accessible, timely, safe, and appropriate care; facilitating care continuity, coordination and secure transition between health care settings; providing physical comfort and emotional support; and supporting people to recognize and develop their own strengths and abilities to enable them to live an independent and fulfilling life[1,15,22,27–34].

Table III | Differences between disease-centered care and person-centered care

Disease-centered care	Person-centered care
Generally focuses on interactions during consultations	Refers to interrelationships over time
May be episode-oriented	Considers episodes of illness as part of life-course experiences with health
Generally centered around the management of diseases	Views diseases as interrelated phenomena
Generally views comorbidity as the number of chronic diseases	Often considers morbidity as combinations of types of illnesses (multimorbidity)
Generally views body systems separately	Views body systems as interrelated
Uses coding systems that reflect professionally defined conditions (e.g. International Classification of Diseases)	Uses coding systems that also allow for specification of people´s health concerns (e.g. International Classification of Primary Care)
Is concerned primarily with the evolution of patients' diseases	Is concerned with the evolution of people´s experienced health problems as well as with their diseases

(Adapted from "Is Patient-Centered Care the Same As Person-Focused Care?", Starfield B., 2011)

Patient-centered care is a crucial element in quality improvement efforts[1] and chronic care[35], having been identified by the Institute of Medicine as one of the six domains of quality[1].

Shared decision-making

Historically, medicine has been largely physician-centered, and paternalism was in fact seen as an example of "patient-centeredness", where the doctor, in good faith, acted in patients' supposed best interests, and whose expertise was seen as justifying the display of power and authority[10,17,36]. Hippocrates, the "father of medicine", was also the "father of medical paternalism" and advocated "concealing most things from the patient while (…) attending to him (…) revealing nothing of the patient's future or present condition"[10,26,37]. Considerable evidence shows that paternalism still lingers today, compromising patient autonomy[17,38]. However, shared decision-making is increasingly considered an ethical imperative[22]. After all, health care is intended primarily for the benefit of patients[26], and no one has a bigger interest in their health

than patients themselves[10].

Shared decision-making involves a partnership where two types of equally important expertise are involved: the clinical knowledge provided by the clinician, and the individual information provided by the patient (e.g. needs, priorities, attitudes regarding risk, values, preferences, habits, experience, social circumstances, skills, resilience)[1,15,39–45]. Similar expressions found in the literature include 'collaborative management', 'patient involvement' and 'patient participation', among others[38].

Whilst physicians are experts in medicine, patients are experts in living with their own conditions, and both are important stakeholders in health care, having an equal role in determining the course of action[18,46,47]. Therefore, the quality of clinical communication is key, having the potential to influence outcomes[15,18,48–51]. Ultimately, the goal of evidence-based health care is to "optimize decision-making by integrating clinical expertise and patients' values with the best available evidence"[46].

The availability of reliable and clear evidence-based information is fundamental for shared decision-making, and an essential component of a patient-centered health care system[15,38,52–55]. However, evidence suggests there is a lack of high quality patient information materials[15,16]. In fact, it has been suggested that some of the problems that are commonly described as 'health literacy problems' are often 'health clarity problems' instead[7]. Therefore, availability and easy access to knowledge translation tools[18,46,56–60] and patient decision aids[15,18,46,53,61] is essential to facilitate decision-making and patient participation in care[15,38,46].

Nevertheless, patients differ in regards to how active they wish to be in health care and decision-making – some may want more autonomy, others may prefer to delegate most decisions to a clinician[1,62]. Shared decision-making implies involving the patient to the extent that they desire[46]. The goal of patient-centered care is to accommodate the needs and preferences of individual patients, adapting the provision of care, and allowing patients to exercise the degree of control they wish[1,63,64]. Indeed, the "right not to know" is an important part of patient-centered care[26], as is the right to choose

a more passive role in decision-making[15]. People's preferences regarding decision-making vary throughout their lives, as well as according to the severity and course of disease episodes[15,46]. Therefore, it is crucial to find out in each particular circumstance what is the role that the patient wants to play in their care and how much they want to be involved in decision-making[15].

There is now a huge body of evidence showing that patient-centered care and shared decision-making lead to better health outcomes, efficiency, and satisfaction with care[17,18,25,35,39,55,65–80]. For instance, it is known that patients who receive patient-centered care are more likely to trust their clinicians[81] and follow treatment recommendations[82], as well as less likely to die following a major event such as an acute myocardial infarction[22,83]. Moreover, higher levels of involvement are associated with better quality of care, increased satisfaction (for both patients and clinical staff), and improved self-esteem for patients[46,84].

Empowerment, activation, engagement, enablement

Research on patient-centered care has been growing rapidly, and there is wide variation regarding the terms used in the literature to describe patient participation in their care (e.g. empowerment, activation, engagement, involvement, adherence, or compliance)[85,86].

Patient 'compliance' is one of the oldest terms in the literature[85], reflecting a paternalistic model where the patient is seen as a passive receiver of health care[87,88]. The ongoing transition to patient-centered care has led to a marked increase in the use of other terms, such as 'engagement', 'activation' and 'empowerment'[85,86,89]. This is not surprising, given that patient engagement has even been described as the blockbuster drug of the century[90].

Nevertheless, there is not yet consensus on the definitions for most of those terms. One of the perspectives is that both 'empowerment' and 'activation' are related with increases in *ability* and *motivation*[86,90], and that enablement is associated with the *ability* to understand and manage a health condition, while 'engagement' relates to the gain of *motivation*[86] (Figure 2). Furthermore, 'empowerment' is considered to be

dependent on the existence of opportunities in the health care system for power to be gained, which differentiates it from 'activation'[86] (Figure 2).

A wide number of questionnaires are available to measure most of these constructs, with varying degrees of validity. Their importance is increasingly being recognized in quality measurement and research, as a way to promote and evaluate patient-centered improvement efforts[91–94].

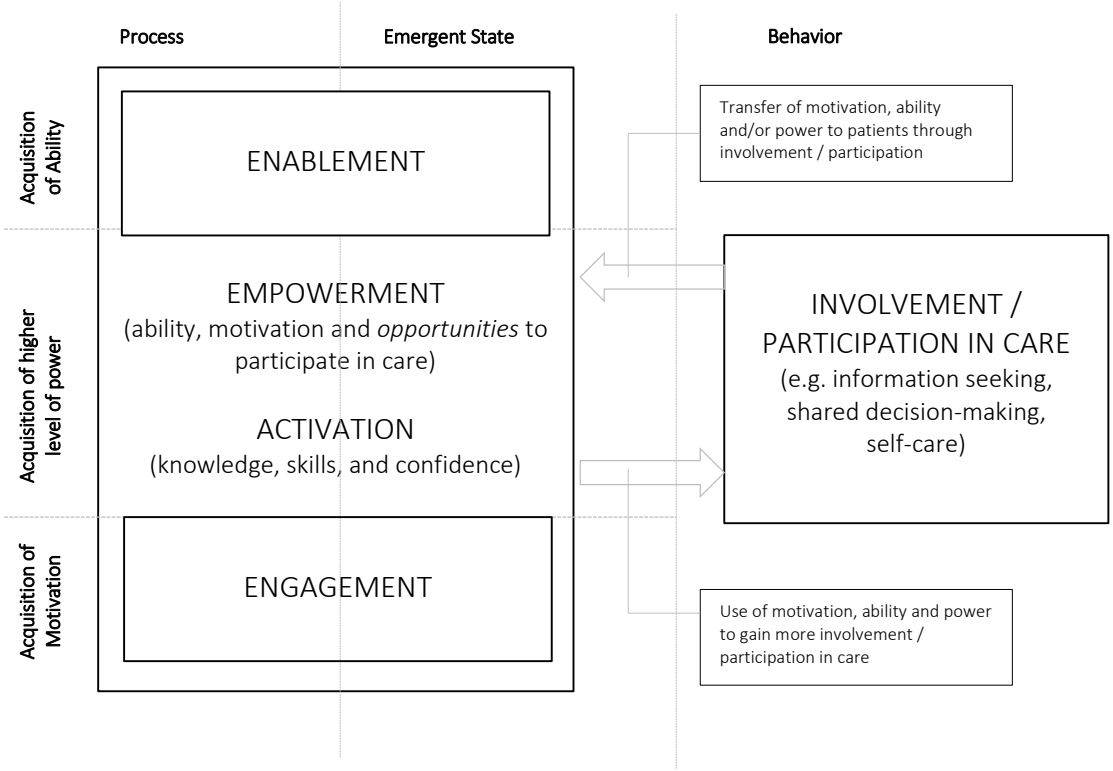

Figure 2 | Interrelation between empowerment, activation, enablement, engagement, and involvement/participation in care

(Adapted from *Fumagalli LP et al. Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships; 2014*)

Patient-centered quality measurement

Definition and importance

The first step in increasing patient-centered care is having reliable and valid measures to assess quality improvement efforts, as well as to use in research studies[25,92,94–96]. There is still no 'gold-standard' measure to evaluate 'patient-centeredness'[18] but several methods can be used to collect patient-relevant data, namely qualitative approaches (e.g. ethnography, focus groups, storytelling, interviews) and quantitative methods (e.g. patient surveys, patient-reported experience measures, patient reported outcome measures)[22].

Donabedian's typology for health care quality measurement usually focuses around three types of measures: structure, process, and outcome[26,97,98].

Structure measures are related to the characteristics of the institutions and resources that are available to provide care, as well as the organizational context that may facilitate or hamper the provision of optimal care. One example of a structure measure to evaluate patient-centeredness could be whether the institution is using survey data to improve quality[99].

On the other hand, process measures focus on what is done by health care providers when providing care to patients[99]. Examples of process measures to assess patient-centeredness include patient-reported experience measures (PREMs) like the Patient Assessment of Chronic Illness Care[100], the Ambulatory Care Experiences survey[101], or the Consumer Assessment of Health Plans[102].

Traditionally, patients' perspective on health care performance has been assessed through the measurement of patient satisfaction, either as a process measure (i.e. satisfaction with the way in which care was delivered) or as an outcome measure (i.e. satisfaction with health status following treatment)[15]. However, satisfaction measures are influenced by prior expectations, personal preferences, and reporting biases[15], and provide little information for quality improvement. Indeed, "knowing that a patient was dissatisfied suggests a need for improvement, but provides no information on why that patient was dissatisfied or how this could be addressed"[22]. Consequently, a new approach to patient feedback consists of focusing on reports of experiences rather than

satisfaction. Patient experience surveys ask patients to report in detail their experiences when receiving care, namely what happened to them and whether or not certain processes and events occurred during an episode of care[15]. PREMs originate from extensive qualitative research on which specific aspects of care are of value to most patients. Therefore, these instruments allow for a relatively objective assessment of whether care was provided in a way consistent with what is most important to patients.

Finally, **outcome measures** focus on changes in health status that are attributable to health care[99]. These include mortality, morbidity, and **patient-reported outcome measures** (PROMs). PROMs aim to capture patients' perspectives of health, illness, and health care interventions in a valid and feasible way[103], and are now seen as crucial to provide patient-centered care[22]. The inclusion of PROMs in clinical care has the potential to improve communication and promote shared decision-making and patient participation in care, by introducing a discussion about patients' priorities in their care[93,104,105].

PROMs are questionnaires designed to assess aspects of self-reported health, health status, and quality of life[22]. PROMs put patients at the center of the health care system, by recognizing the importance of their perspectives in health care improvement. PROM data can be collected using either condition-specific instruments or generic measures[22].

Several research and policy initiatives have been developed in the past years which reflect this new approach to measurement, namely the 'Patient-Centered Outcomes Research Institute' (PCORI)[44,106], the 'Patient-Reported Outcome Measurements Information System' (PROMIS)[38], the 'Patient-Centered Outcomes Research Network' (PCORnet)[107], and the Picker/Commonwealth Patient-Centered Care Program[22,108]. One of their common aims is to encourage the use of similar and validated measures that are relevant to patients. Additionally, some tools have been developed to facilitate the selection of PROMs, like COSMIN (COnsensus-based checklist for the Selection of health status Measurement INstruments), a checklist to assess the quality of data provided in studies evaluating PROMs[22,109], and EMPRO (Evaluating the Measurement of Patient Reported Outcomes)[110].

Patient activation measure

One questionnaire that has been gaining increasing attention in the literature is the Patient Activation Measure 13 (PAM13), which measures a person's knowledge, skills, and confidence in managing their health[96]. This questionnaire has strong psychometric properties[92,96,111–113] and has already been translated and validated in several countries and specific populations[112,114–119].

PAM13 items are statements about various aspects of managing one's health, which respondents classify with degrees of agreement or disagreement. The PAM13 classifies patients into one of four stages of activation: 1) the patient is not prepared to play an active role in their own health; 2) the patient believes he or she plays an important role in managing his or her care, but lacks the confidence and/or knowledge to take action; 3) the patient is beginning to take action, but may still lack confidence; and 4) the patient has adopted many self-management behaviors, but may not be able to maintain actions over time or during times of stress[96]. These stages present some similarities with Prochaska's Transtheoretical Model[120] (precontemplation, contemplation, preparation, action and maintenance) and indeed both models advocate the tailoring of interventions to each patient's specific level[92,121]. However, in addition to motivation and readiness, the PAM13 also includes aspects of skill and knowledge acquisition[92,96]. Not only that, but activation is also a more global construct, not focusing on just one specific behavior but on the whole concept of managing health and health care[122].

Prior studies have shown that the PAM is stable across differing health status and across gender and age groups, and that higher PAM scores are associated with better process and outcome measures, including healthier behaviors, better utilization of health care services, and performance of recommended self-management care [123–142]. Furthermore, activated people are more likely to seek health information, use it more often, and understand it better[132,143,144].

Activated patients with diabetes have been shown to be more likely to perform feet

checks, receive eye examinations, and exercise regularly, as well as to have better metabolic control and report less difficulty in managing diabetes care[75,96,145–153]. On the contrary, type 2 DM patients with low levels of activation seem to have greater tendency to be hospitalized[154,155].

An interesting feature of the PAM questionnaire is that it can be used both at the individual patient level (for physicians to evaluate their patients' activation level and target therapeutic options accordingly), and at a group level, as an indicator of the effectiveness of health interventions[123,124,127,150,156–159].

Chronic care

The global burden of chronic disease

Chronic diseases are the leading cause of mortality and morbidity worldwide[1,10,160–164]. It is known that effective management of chronic conditions is greatly dependent on the personal, clinical, social, economical, and environmental factors surrounding the patient[88,165–167]. Therefore, the challenges posed by chronic diseases seem to require an integrated patient-centered approach with a combination of individual and population-level interventions, involving environmental, public health, clinical, and behavioral aspects[161,166,168,169].

Chronic care model

The Chronic Care Model (CCM) is a primary care-based approach to improve the quality of care for chronic conditions[1,168]. According to the CCM, informed, activated patients interact with prepared, proactive practice teams, resulting in high-quality care and improved outcomes [170,171] (Figure 3).

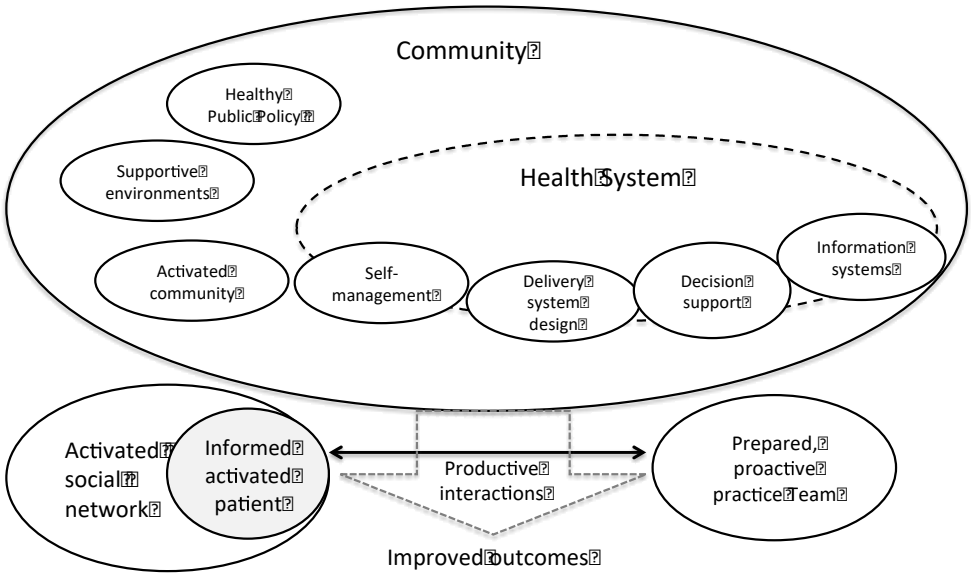

Figure 3 | Wagner's Chronic Care Model

(Adapted from *Institute of Medicine. Living Well with Chronic Illness: A Call for Public Health Action. 2012)*

The CCM is based where the care provision for the majority of chronic illness occurs – the primary care setting[170]. It focuses on six interrelated components: community resources and policies; health care organization; self-management support; delivery system design; decision support; and clinical information systems [170,171] (Figure 3).

Nowadays, the most common chronic condition is multimorbidity, defined as the coexistence of multiple chronic diseases[18,172,173]. Care for patients with multimorbidity, namely the elderly, is very demanding, as it poses challenges for care coordination and adequate management of the various health problems[174]. People with multimorbidity tend to have worse quality of life and poorer health outcomes than the rest of the population, including premature death, higher rates of hospitalization, and adverse events[175,176].

Unfortunately, clinical guidelines rarely address comorbidity, and often lead to polypharmacy and to contradictory and complex therapeutic regimes in these patients[18,25,175,177–179]. Additionally, guidelines often do not account for the fact that patients vary greatly regarding the value they place on different health outcomes (e.g. longer survival, prevention of specific disease events, physical and cognitive functioning) and the amount of inconvenience and risk they are willing to tolerate[25,172,178].

Given the complexity of multimorbidity, vertical disease-oriented programs have a tendency to fragment care, leading to inefficient use of resources[1,180–182]. Horizontal primary care-based models tend to be better at providing coordinated care in an efficient manner, allowing the focus on chronic conditions while still managing a myriad of other health problems, thereby putting people at the center of care, rather than specific diseases[1,18,176,180,181,183–185].

The CCM, with its focus on primary care, favors longitudinal person-centered care, and goes beyond the disease-oriented approaches commonly offered by vertical programs[25]. Redesigning care using the CCM has been shown to improve processes of care and multiple health outcomes for patients with chronic illnesses[170,171,186–189].

Self-management

An essential element of the chronic care model is the activated patient, with the knowledge, skills, and confidence to participate in the management of their disease[1,123,132]. Patients with chronic conditions spend on average one hour per year with their physician, leaving around 10000 hours where they have to manage their health and illnesses by themselves.

Self-management activities involve managing symptoms, doing the necessary treatments, making lifestyle changes and coping with the physical and psychosocial consequences of the disease, with the aim of minimizing its impact on health[167]. Consequently, self-management programs aim at improving the knowledge, skills, and confidence necessary to manage care, in order to increase activation and participation in care[72,94,168,190–193].

Elements that are commonly involved in successful self-management and behavioral change programs include: education; collaborative problem definition; self-management training and support; targeting, goal setting, planning, skill development, problem solving; and follow-up[167,168,194–197]. Programs involving motivational interviewing and focusing on patients values and needs are known to be particularly effective[198].

Research has shown that self-management support programs tend to be effective in improving knowledge, symptom management, self-management behaviors, self-efficacy, and a variety of clinical outcomes[80,167,192,196,199,200].

Type 2 diabetes as a study model

Diabetes Mellitus (DM) is a highly prevalent chronic disease worldwide and one of the most challenging health problems in the 21st century[201–204]. It is estimated that the world prevalence of diabetes will rise from 6.4% in 2010 (285 million adults) to 7.7% in 2030 (439 million)[205]. In Portugal, the prevalence of diabetes has been rapidly increasing[206].

Diabetes is commonly associated with several co-morbidities[207–209], as well as with an increased risk of cardiovascular events[210]. Furthermore, the burden of diabetes and its economic impact on healthcare systems have become reasons for increasing concern with the disease[211,212].

Evidence suggests that self-management and behavioral change programs are effective in improving clinical outcomes for patients with diabetes[35,72,168,213–218]. In fact, there is now overwhelming evidence that optimizing lifestyle behaviors is a key factor in both the prevention and management of chronic illness[185]. However, the best approach to promote sustained behavior change remains to be identified[213].

Interest in the use of information and communication technology (ICT) to facilitate self-management and promote patient empowerment is rapidly increasing[52,219–223]. Not surprisingly, diabetes is the most common disease targeted in ICT implementation studies[224]. Literature on web-based interventions for diabetes self-management is promising, showing improvements in patient activation, health care utilization, self-care behaviors, self-efficacy, health status, and hemoglobin A1c, among others[190,225–235].

Health information technology

"Medicine has built on a long history of innovation, from the stethoscope and roentgenogram to magnetic resonance imaging and robotics.
Doctors have embraced each new technology to advance patient care.
But nothing has changed clinical practice more fundamentally than one recent innovation:
the Internet."
Hartzband P et al., New England Journal of Medicine [236]

Health Information technology (HIT) has enormous potential to promote patient-centeredness and quality improvement in health care[1]. This potential has recently given rise to the fields of ehealth and Medicine 2.0.

Although the definition of ehealth is not consensual[237], it can be considered "an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies" and "involving a new way of working, an attitude, and a commitment for networked, global thinking, to improve healthcare"[18,238,239].

More recently, ehealth started to adopt some features of Web 2.0 technologies, and the concept of Medicine 2.0 emerged[240]. Medicine 2.0 can be defined as "Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and/or semantic web and virtual reality approaches to enable and facilitate social networking, participation, apomediation, openness, and collaboration within and between these user groups".

Role of HIT in patient-centered care and quality improvement

The main HIT tool used by health care providers in their daily practice is the computer-based patient medical record, traditionally designated 'Electronic Medical Record' (EMR)[18,185]. Nowadays, the term Electronic Health Record (EHR) is more commonly used, representing an EMR with interoperability.

There are several benefits associated with the use of HIT by health care providers, namely in terms of medication safety[241,242], compliance with clinical practice

guidelines[243–245], and improvements in various process and outcome measures[246–249]. Furthermore, information technology (IT) offers great potential in chronic care, as it may facilitate the provision of evidence-based medicine, allow physicians to evaluate and improve their performance, enable surveillance of risk factors and health conditions, and facilitate implementation of population-based interventions[1,170].

At the same time, HIT is increasingly being used to facilitate timely access of patients to the care they need, namely through telehealth and secure messaging with physicians, therefore complementing face-to-face consultations in the provision of care[1,250–255]. Moreover, due to the shortage of doctors worldwide and the lack of access to medical care in certain regions, connecting patients to physicians online is becoming increasingly important[256].

In line with these benefits and promising capabilities, the 'meaningful use' initiative was created in the US, as part of a set of regulations to promote a private and secure 21st-century electronic health information system[257]. The main purpose of this initiative is to facilitate the meaningful use of EHRs, defined as their use by providers in a way that enhances safety, quality, and efficiency of care, namely through the utilization of several software applications (e.g. electronic prescription, decision support tools)[257]. Another interesting 'meaningful use' objective includes promoting patient access to the health information contained in the EHR[257], as well as to self-management tools[185].

Interest in the use of information technology (IT) to facilitate self-care and promote patient empowerment is also growing[52,219–222,258], as is the use of web-based self-management interventions to improve care for specific diseases or chronic conditions[190,259–261]. The internet offers several advantages as a tool to deliver health interventions to patients: it provides convenient and easy access to real-time information; allows the tailoring of educational programs to patients' needs; and has the ability to reach distant and large audiences, using fewer human resources than traditional interventions[190].

e-Patients

Patients are increasingly able to use the Internet and other IT to help them make informed decisions about health care[1,89]. The term '**e-patients**' describes "empowered, engaged, equipped, and enabled" patients, who are able to use modern electronic tools to actively participate in care, and to be heard by other patients, physicians, and policy makers[7,43,256,262].

An interesting distinction can be made between e-patients and individuals who have been termed 'googlers'[262]: although both use digital technologies in their health management, e-patients tend to use them with strategy, and are better able to deal with the huge amount of online information, therefore having more fruitful and less frustrating relationships with their doctors.

One of the first white papers about e-patients was published in 2007 and, shortly after, the Society for Participatory Medicine was created[8]. The Society for Participatory Medicine is an "organization devoted to promoting the concept of participatory medicine, a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners"[262].

The number of e-patients is rapidly increasing[262]. Three factors have been identified as contributing to this growth: the common use of the internet to search for health information; the popularity of social media and its use for health purposes; and the increased availability of biosensors and self-trackers (e.g. sleep/activity trackers), which led to the development of the quantified self movement ("the movement of making lifestyle-related decisions based on everyday measurements of health parameters")[7,10,14,256].

Patient access to their health information

Putting patients in control of their health information has been advocated as an important step in improving the quality of health care[1,263,264].

For many years, medical records were seen as the property of the clinician, rather than the patient[15]. One of the first papers regarding patient access to medical records was published in 1973 in the New England Journal of Medicine[265], and the first interventions

to show benefits date back to 1985[266]. There is now a growing body of evidence showing the advantages of patient access to medical records, namely in improving patient empowerment, health literacy, patient–provider communication, patient safety, medication adherence, and in decreasing the fragmentation of health care[10,14,267–270].

With the growing availability and use of HIT, a new tool is showing increasing potential to provide patients with access to their medical records – Personal Health Records.

Personal Health Records

Personal Health Records (PHRs) are electronic applications that enable individuals to access, manage and share their health information in a private, secure and confidential environment[271,272]. They are increasingly seen as a promising tool in the promotion of patient empowerment, activation, knowledge translation and health literacy[272].

Three main types of PHRs are generally considered in the literature[185,271,273–278]: 1) stand-alone, in which content is solely uploaded by the user; 2) tethered, which are 'patient portals' based on the health care provider's Electronic Health Record; and 3) integrated, which are patient-controlled electronic health records where content may be uploaded from multiple caregivers and different sources.

Evidence regarding the effectiveness of PHRs in improving the quality of health care is increasing[261,274,279–297]. Published literature suggests PHRs may lead to improvements in patient activation[298], communication with health care providers[282–284], medication safety[284–286], medication adherence[287–289], satisfaction with care[274,282,298], and also in several processes of care[290–294,298], among other benefits. Furthermore, PHRs are increasingly being used in chronic disease management, showing promising results[274,295], namely in diabetes care[296].

Despite their huge potential for health quality improvement, adoption of PHRs has been slower than expected[299–306], due to a myriad of factors[271,307–311]. One important aspect influencing the adoption of a PHR is its usefulness, which seems to be directly related with the ability to easily populate the data fields in the record[14]. In fact, lack of

integration with EHRs has been one of the reasons appointed to the failure of the stand-alone PHR from Google (GoogleHealth) in 2011[14].

Integrated PHRs potentially provide the greatest value to patients, as they allow them to import, export and manage health information from different sources (e.g. EHRs, monitoring devices), as well share it with whom they wish to[271,273,312]. However, the potential of integrated PHRs to reduce the current fragmentation of health information[258,313] has been greatly limited by the lack of interoperability – the capacity to share, integrate, and apply health information from disparate sources[185,258].

Another aspect that contributes to the usefulness of a PHR is the inclusion of features valued by patients, such as communication with providers, health education, tailored support, health maintenance reminders, and administrative functionalities like ordering prescription refills or booking appointments[281,299,314–320]. These functionalities are becoming increasingly common in integrated PHRs, and are core features of two of the most successfully adopted PHRs described in the literature – the ones from Kaiser Permanente and the Veterans Administration[307,315,316,321].

In May 2010, the first freely available web-based PHR was launched in Portugal, by Portugal Telecom (Appendix 7). Despite initial interest of the public in this platform, a combination of factors was probably responsible for its abandonment after a few years: lack of usefulness (this stand-alone PHR had no integration with digital devices or mobile health applications, which meant that any data in the PHR had to be self-entered manually by users); lack of usability (several usability problems were detected after implementation); and decreased investment from Portugal Telecom in the project, due to political and economic reasons.

In July 2012, a different web-based PHR was launched in Portugal, provided freely by the Ministry of Health. During the first year of deployment, 'Portal do Utente' evolved from being a stand-alone platform to becoming an integrated PHR, with connection to a national data-sharing platform that aggregates patient data from different health providers throughout the country.

PHRs and data-sharing platforms are now common components in many e-health reform strategies worldwide. However, many issues in their implementation and dissemination have been described[320,322]. Indeed, the implementation of a data-sharing platform in the UK has been criticized for being "strongly top-down and milestone-heavy", for having "no official independent evaluation", and for privileging 'hard' management aspects (e.g. technology, milestones) over 'soft' aspects (e.g. informing and engaging citizens and health care providers, managing concerns about privacy and data protection, getting buy-in from all stakeholders, supporting the needs of frontline staff)[303,323]. Multidisciplinary project management seems essential for successful HIT implementation[18][207], and is especially important in the case of shared electronic patient records[303,310].

Other countries, like Australia, implemented a national PHR that is not based on a data sharing platform[311]. Rather, the Australian PHR is a collection of summary documents and data uploaded from several primary sources, in different points in time[311]. Two disadvantages that have been pointed out to this system are the difficulty in maintaining the record up-to-date and the burden in reconciling the information from different documents and sources[311].

In Portugal, the national data-sharing platform has been criticized for operating in an opt-out model, given that most people are not aware of its existence and that there are no easy mechanisms in place to allow the least advantaged to opt-out without using the Internet.

Social Networking Sites

Social media may be defined as "a group of internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user-generated content"[262]. Use of social media for health purposes is gaining interest, namely the use of blogs, discussion boards, wikis and, especially, Social Networking Sites (SNSs) [325–327].

SNSs[328] are now a global phenomenon. As of September 2013, 73% of online adults

were using a SNS of some kind and 42% were using more than one[329,330]. Facebook is the most popular platform (with more than 1.19 billion monthly active users[331]), followed by Twitter (500 million users worldwide[332]).

In parallel to general-purpose SNSs like Facebook and Twitter, health-specific SNSs are also emerging[333,334]. Some are oriented towards patients with a specific chronic condition (e.g. TuDiabetes[335,336]), others are more general and designed for patients with any chronic condition (e.g. PatientsLikeMe[337,338]), and a few others target people wanting to change a particular health-risk behavior (e.g. smoking cessation[339]), or other health-related lifestyle factors.

The application of SNSs in the health domain shows tremendous potential[89,340]. At the population level, they are currently being used for public health surveillance[341], both for communicable[341,342] and non-communicable diseases[336,343]. At the individual level, they are able to facilitate access to health-related information[344–347] and social support[339,348], promoting better-informed treatment decisions[337,338].

Given that lifestyle behaviors are nowadays responsible for the global burden of noncommunicable diseases[161], interest has been growing on how to use SNSs to fight this trend and promote health behavior change[349,350].

Clinical data as a public good

Tremendous amounts of data are currently generated in the course of care, and they offer a unique opportunity for quality improvement[1,41], as well as for the monitoring of acute and chronic health conditions in real-time[1,160,351–353]. Consequently, EHRs have the potential to become a cost-efficient, feasible and sustainable source of de-identified data for continuous population health management[352,354–356].

Currently, estimates indicate that less than 5 percent of clinical data collected are analyzed[10,357]. Secondary use of clinical data for health monitoring, planning and research has the potential to accelerate knowledge[185], as it may enable weak signals to be detected and distinguished from noise[358].

Undeniably, the opportunity for big data analytics in healthcare is increasing[359]. From tracking diseases and evaluating their burden, to clinical prediction, clinical

effectiveness research, monitoring of treatment side effects, and quality improvement[89].

Nevertheless, multiple ethical and technical challenges must be considered, namely regarding privacy and security[10,18,360,361]. In the end, the decision to become data altruists[362] should be left to patients themselves, who must be able to opt-out of data sharing if and when they wish to do so.

Aims and conceptual framework

The main aims of this project were to:

I. Review the literature regarding patient access to their medical records, namely advantages, disadvantages, and current legislation in Portugal and internationally.
II. Translate, culturally adapt, and validate the PAM13 to Portuguese, in patients with type 2 diabetes mellitus.
III. Assess the facilitators, barriers and expectations in the self-management of type 2 diabetes mellitus.
IV. Evaluate current access to health information technology by elderly patients with type 2 diabetes.
V. Evaluate the adoption and use of a national integrated Personal Health Record by the Portuguese population.
VI. Evaluate the use and effectiveness of interventions using Social Networking Sites to change health behaviors.
VII. Evaluate the feasibility of using electronic health records and geographic information systems for public health surveillance of type 2 diabetes.

The conceptual model for this project is presented in Figure 4, including the main themes of the seven papers presented in the thesis, as well as the four major areas constituting its background. The epicenter of the project, connecting all these topics, is patient-centered care.

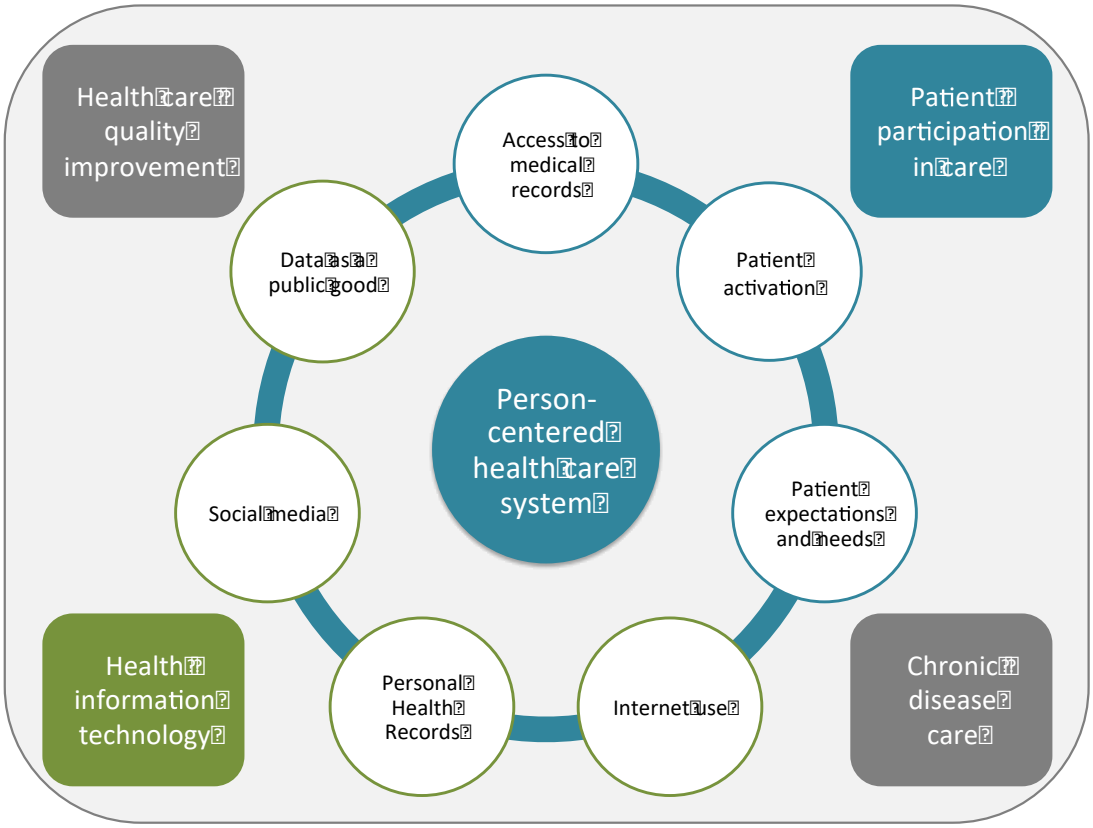

Figure 4 | Conceptual model of the thesis

Methods

Several research methods were applied in the seven studies that constitute the present thesis:

- Paper I - Patients' Access to their Medical Records – comprised a narrative review of the literature and qualitative synthesis of the findings.
- Paper II - Translation, cultural adaptation and validation of the 'Patient Activation Measure' to Portuguese patients with type 2 diabetes – involved a qualitative component where an e-Delphi and cognitive debriefing interviews, and a quantitative component using Rasch model analysis.
- Paper III - Facilitators, barriers and expectations in the self-management of type 2 diabetes - a qualitative study from Portugal – was conducted using Focus Groups as data collection method, and the constant comparative method for data analysis.
- Paper IV - Internet use by Portuguese elderly patients with type 2 diabetes – was a cross-sectional study using logistic regression for data analysis.
- Paper V - Adoption and use of a national integrated Personal Health Record – was a cross-sectional study using logistic regression as data analysis method.
- Paper VI - The influence of social networking sites on health behavior change – was a systematic review and meta-analysis.
- Paper VII - Use of electronic health records and geographic information systems in public health surveillance of type 2 diabetes – was a cross-sectional study, using geographic information systems and logistic regression for data analysis.

Results

Overview of the results

All seven papers in this thesis are related with a specific aspect of person-centered care. Paper I described the potential benefits of sharing medical records with patients, and analyzed the adoption of this practice in several countries. Additionally, it showed that despite the legal framework in Portugal favoring patients' access to medical records, several barriers (e.g. cultural, organizational, administrative) seem to be still in place.

Paper II intended to translate one important patient-reported measure to Portuguese, as well as validate it for use in type 2 DM. The Patient Activation Measure 13 was translated to Portuguese and applied to a convenience sample of 193 patients with type 2 DM. Respondents had a mean age of 67.1 (SD 10.1) years, 42.7% were women, and the mean PAM score (0-100) in the sample was 58.5 (SD 10.1). All items in the instrument had good fit and ten of the thirteen items had near perfect fit. The response categories were well adjusted to the Rasch Model. Item reliability was 0.97 (both real and model), and person reliability was between 0.77 (real) and 0.83 (model).

Paper III explored patients' facilitators, barriers, and expectations in the self-management of type 2 diabetes, revealing three major themes: diet, physical exercise, and glycemic control. Information and knowledge translation, as well as family and social ties were commonly explored aspects across the three themes, and were regarded as facilitators in some situations and as barriers in others.

Paper IV characterized Internet access and use by Portuguese patients with type 2 diabetes mellitus, through a questionnaire that was applied to 205 respondents, with a response rate of 83%. The mean age was 67 years (±10), 42.5% of respondents were female, and mean PAM score (0-100) was 58.5 (± 10.1). In this sample, 42.7% of respondents had a computer at home, and 47% had Internet available at home. Additionally, 63.5% (n=127) reported that they used the Internet less than once

monthly; 36.5% (n=73) used it one or more times per month. Less frequent users of the Internet were older and had a lower level of education.

Paper V evaluated the adoption of a recently deployed PHR in Portugal, by analyzing the number of registrations in the platform, and the frequency of its use to input health information. A total of 110,529 people were registered in the Portuguese PHR at the time of the study (mean age: 44.7 ± 18.1 years; 60.5% women). Approximately 17% of registered people were considered users of the system. There were a total of 45,039 entries for height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol, triglycerides, allergies and emergency contacts. People engaging in comprehensive use of the PHR totalled 12,549. Those with two or more health problems, and taking one or more medications, had higher odds of engaging in comprehensive use of the PHR.

Paper VI was a systematic review of the effectiveness of SNS interventions for health behavior change. Twelve studies (7411 participants) met the inclusion criteria. Facebook was the most utilized SNS, followed by health-specific SNSs, and Twitter. Eight randomized controlled trials were combined in a meta-analysis. A positive effect of SNS interventions on health behavior outcomes was found [Hedges' g 0.24; 95% confidence interval (CI) 0.04 - 0.43]. There was considerable heterogeneity (I2=84.0%; T2=0.058) and no evidence of publication bias.

Paper VII was a feasibility study exploring the use of EHR data as a public good, for chronic disease surveillance. In total, 205,068 individuals with the diagnosis of type 2 diabetes were identified from primary care EHR data in the region of Lisbon. The mean age of these patients was 67.5 years, and hypertension was present in 71% of all individuals. There was considerable variation in diagnosed comorbidities across parishes. Diabetes patients with concomitant hypertension or dyslipidemia showed higher odds of having been diagnosed with cardiovascular complications, when adjusting for age and gender [(hypertension OR 2.16, CI 2.10-2.22; dyslipidemia OR 1.57, CI 1.54-1.60)].

Paper I

Patients' access to their medical records

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Acta Médica Portuguesa

All the authors contributed substantially to the design of the study and the acquisition, analysis and/or interpretation of data. The paper was drafted by the first author and critically reviewed by all the remaining authors.

Acesso dos pacientes aos seus processos clínicos

Resumo

Até muito recentemente, o processo clínico era visto exclusivamente como propriedade das instituições de saúde ou dos médicos que o elaboravam. A sua grande componente técnica e científica, bem como com o forte cunho pessoal por parte do médico, têm sido as razões invocadas para esse controlo. Atualmente, um pouco por todo o mundo, assiste-se a uma mudança neste campo.

Em Portugal, desde 2007 que os pacientes podem aceder diretamente à totalidade dos seus processos clínicos. No entanto, o Código Deontológico da Ordem dos Médicos (2009) defende que o acesso dos pacientes aos seus processos clínicos deverá ser feito através de um médico e que este último "é o detentor da propriedade intelectual dos registos que elabora". Além disso, muitos médicos e instituições de saúde confrontados com os pedidos de acesso dos pacientes aos seus processos clínicos acabam por solicitar o parecer da Comissão de Acesso aos Documentos Administrativos. Esse parecer vai, invariavelmente, no sentido do acesso total e direto.

A partilha dos processos clínicos com os pacientes parece fulcral e inevitável num modelo de medicina centrada na pessoa, tendo o potencial de melhorar a capacitação, a literacia em saúde, a autonomia, a autoeficácia e a satisfação dos pacientes.

Com os progressivos avanços tecnológicos e a crescente disseminação dos Sistemas Personalizados de Informação de Saúde, é previsível que cada vez mais pacientes desejem aceder aos seus processos clínicos. Assim, a consciencialização sobre esta matéria é essencial, por forma a que seja possível promover o debate informado entre as várias partes envolvidas.

Abstract

Until recently, the medical record was seen exclusively as being the property of health institutions and doctors. Its great technical and scientific components, as well as the personal characteristics attributed by each doctor, have been the reasons appointed for that control. However, nowadays throughout the world that paradigm has been changing.

In Portugal, since 2007 patients are allowed full and direct access to their medical records. Nevertheless, the Deontological Code of the Portuguese Medical Council (2009) explicitly states that patients' access to their medical records should have a doctor as intermediary and that the records are each physician's intellectual property. Furthermore, several doctors and health institutions, receiving requests from patients to access their medical records, end up requesting the legal opinion of the "Commission for access to administrative documents". Each and every time, that opinion goes in line with the notion of full and direct patient access.

Sharing medical records with patients seems crucial and inevitable in the current patient-centred care model, having the potential to improve patient empowerment, health literacy, autonomy, self-efficacy and satisfaction with care.

With the recent technological developments and the fast dissemination of Personal Health Records, it is foreseeable that a growing number of patients will want to access their medical records. Therefore, promoting awareness on this topic is essential, in order to allow an informed debate between all the stakeholders.

Introdução

Em 1973 foi publicado, no *New England Journal of Medicine*, um dos primeiros artigos acerca da partilha dos processos clínicos com os pacientes, onde foram apontadas as várias vantagens e possíveis objeções a esta prática[1].

No entanto, até muito recentemente, o processo clínico continuou a ser visto exclusivamente como propriedade das instituições de saúde ou dos médicos que o elaboravam. Atualmente, um pouco por todo o mundo, assiste-se à mudança desta visão.

O surgimento e a disseminação dos Sistemas Personalizados de Informação de Saúde (em inglês, *Personal Health Records* / *Personally Controlled Electronic Health Records / Personal Health Information Systems*) tem desempenhado um papel importante nesta mudança de atitude, facilitando o controlo progressivo dos processos clínicos por parte dos doentes[2,3].

Cada vez mais médicos defendem que o controlo dos processos clínicos pelos pacientes é um direito humano básico, além de ser um passo essencial na organização dos

cuidados de saúde em torno das pessoas, e não das instituições[4]. É impossível ter cuidados centrados nos pacientes quando a informação de saúde dos mesmos está espalhada por várias instituições e fora do seu controlo[5].

Também a Comissão Europeia afirmou em 2010, no documento "*A digital agenda for Europe"*, que o acesso dos pacientes à sua informação pessoal de saúde, através de sistemas online seguros, é um "direito" dos mesmos, tendo consequentemente oferecido apoio a diversos projetos-piloto para o desenvolvimento desse tipo de plataformas.

Em 2012, o *Department of Health* do Serviço de Saúde do Reino Unido lançou o documento "*The power of information: putting all of us in control of the health and care information we need*", o qual lança uma estratégia para os próximos 10 anos focada na mudança de cultura das instituições e profissionais de saúde, de modo a que passe a ser natural que os pacientes acedam à sua informação de saúde facilmente, num ambiente de total transparência.
Além disso, no Reino Unido, o que se discute agora já não é a simples consulta do processo clínico, mas sim o próprio controlo do processo por parte dos pacientes (que passariam a poder inserir as suas próprias anotações e seriam, assim, responsáveis por decidir quais os profissionais de saúde que poderiam aceder ao processo)[6].

Vantagens e desvantagens da partilha do processo clínico

O processo clínico surge, primariamente, da obrigação dos médicos em proceder à documentação e registo da sua atividade clínica. No entanto, atualmente, outro objectivo tem sido progressivamente invocado: informar os pacientes acerca da sua saúde e processo de cuidados[7].
Existem potenciais vantagens e desvantagens na partilha dos processos clínicos com os pacientes, a qual pode ter efeitos a três níveis principais: no paciente, na relação médico-doente e na prática clínica (Quadro I) [1,6,8–17].
É interessante notar que, nos estudos realizados, têm sido mais frequentemente verificadas as vantagens desta partilha, sendo geralmente reportado um impacto mínimo no trabalho dos médicos. Especificamente, os resultados mais consistentes

têm sido a melhoria da comunicação entre o médico e o paciente e o aumento da adesão à terapêutica[9,18].

Quadro I: Potenciais vantagens e desvantagens da partilha dos processos clínicos com os pacientes

Vantagens	Desvantagens
Ao nível do paciente	
• Promoção da capacitação, literacia em saúde, autonomia, autoeficácia e satisfação com os cuidados; • Maior compreensão e interesse sobre o próprio estado de saúde/doença e sobre as decisões terapêuticas; • Facilitação da pesquisa de informação adicional sobre os problemas de saúde escritos no processo; • Maior aceitação e melhor gestão de determinadas doenças crónicas; • Reforço da memorização do plano de cuidados; • Maior participação no plano de cuidados e adesão à terapêutica; • Maior motivação para a mudança de comportamentos e maior responsabilização; • Maior autonomia na gestão da própria saúde; • Maior adesão aos cuidados preventivos recomendados por profissionais de saúde; • Facilitação da partilha das notas clínicas com outras pessoas, nomeadamente outros profissionais de saúde; • Facilitação da participação da família nos cuidados; • Menor ansiedade graças a uma maior sensação de controlo.	• Confusão e dificuldade na interpretação da terminologia médica; • Maior ansiedade dos doentes na exposição de eventuais situações do foro da saúde mental ou perante hipóteses de diagnóstico como cancro; • Desconforto ao ler registos de algumas informações mais sensíveis; • Possível coerção por parte de companhias de seguros de saúde ou dos empregadores para obtenção de informação clínica; • Agudização de ansiedade em doentes hipocondríacos.
Ao nível da relação médico-doente	
• Maior transparência;	• Potencial ofensa ou desagrado em relação a alguns dos registos feitos ou

• Maior confiança no médico, bem como compreensão e apreciação pelo seu trabalho; • Partilha de responsabilidade nos cuidados; • Melhoria da comunicação médico-doente.	a termos utilizados ("obeso", "hipocondríaco"…); • Relação médico-doente prejudicada se o médico sentir que o seu trabalho está a ser posto em causa; • Descontentamento com a versão da história clínica registada pelo médico (ex.: omissão de informação que seja considerada importante pelo doente).
Ao nível da prática clínica	
• Menor duração das consultas se muitas das perguntas dos pacientes ficarem respondidas com a leitura dos registos; • Melhor preparação dos pacientes para as consultas (consultas mais eficientes); • Registos clínicos mais completos e de melhor qualidade; • Diminuição da repetição desnecessária de exames complementares de diagnóstico; • Mais pessoas a ver o registo, possivelmente evitando ou corrigindo erros médicos; • Decisões clínicas baseadas em informação clínica mais completa; • Melhoria da coordenação de cuidados entre várias especialidades e/ou profissionais de saúde; • Melhoria da continuidade de cuidados. A longo prazo: • Diminuição do número de consultas; • Aumento da qualidade e eficiência na prestação de cuidados; • Melhoria de indicadores de saúde.	• Maior duração da consulta se for necessário explicar alguns dos registos e/ou esclarecer eventuais mal-entendidos; • Modificação da dinâmica da consulta por aumento do enfoque nos registos; • Necessidade de alteração dos registos para se tornarem mais compreensíveis pelos doentes, com palavras mais fáceis e menos abreviaturas; • Possível cuidado dos médicos em evitar escrever hipóteses de diagnóstico que possam preocupar o doente; • Pedidos de correção (por vezes fúteis) quando o doente não concordar com a versão da sua história clínica que foi registada; • Desconforto ou embaraço dos médicos pela forma como escrevem ou pelos erros que inadvertidamente possam constar nos registos; • Aumento das situações de âmbito legal (negligência, má-prática...).

Considerações éticas

No que se refere às considerações éticas implicadas no acesso do paciente à sua própria informação médica, são importantes dois princípios: autonomia e beneficência.

Os possíveis **conflitos entre os princípios de autonomia e beneficência** têm por base referências culturais, uma vez que o dever primário do médico, historicamente e na linha da tradição hipocrática, era o de agir em benefício do paciente e não o de promover a sua capacidade de decidir autonomamente[19].
Em 1988, o bioeticista Edmund Pellegrino defendia que a autonomia do paciente tinha limites e salientava que nem sempre o interesse do mesmo é benéfico para ele próprio, quer pelo desconhecimento da sua própria fragilidade em situações patológicas, quer pela incapacidade de plena compreensão da informação técnica que lhe é facultada. Assim, o autor defendia um modelo de beneficência fiduciária ou "beneficência em confiança", que respeita a autonomia dos doentes e a necessidade de obtenção de um consentimento informado antes de qualquer ato médico, mas também reconhece e valoriza a autonomia do médico[20]. Este modelo reconhece a vulnerabilidade do paciente face aos avanços científicos e tecnológicos da medicina e procura promover a confiança entre médico e doente, distinguindo-se do princípio da beneficência hipocrático, que se caracterizava por um paternalismo praticamente absoluto.

A elaboração da Declaração Universal de Direitos Humanos e as posteriores normativas relacionadas com os direitos dos pacientes têm vindo a transformar profundamente a prática clínica. Deste modo, o paternalismo médico e o modelo biomédico têm sido progressivamente substituídos por uma abordagem centrada no paciente com maior valorização da sua autonomia[21]. Um exemplo interessante desta mudança de paradigma é a substituição do nome do processo clínico, no Brasil, de "prontuário médico" para "prontuário do paciente"[22].

Perspectiva internacional

Europa

O direito de consulta do processo clínico por parte do paciente é abordada, na Europa, de duas maneiras distintas[23]:

- A posição tradicional, mais restritiva, é o "Acesso indireto", em que o acesso ao processo clínico é concedido, mas apenas mediante um médico nomeado pelo paciente.
- Outro modelo de acesso à informação de saúde – o "Acesso direto" – é mais liberal, estando em vigor atualmente na maioria dos países europeus. As diferenças entre os vários países a este respeito resultam, apenas, das exceções existentes a esse acesso direto (doença psiquiátrica, menores, dados subjetivos do médico e direitos de terceiros).

Em Espanha, segundo a "*Ley de Autonomía del Paciente 41/2002"*, os profissionais participantes na elaboração dos processos clínicos podem-se opor ao acesso dos pacientes às suas anotações subjetivas. Segundo a "*Ley Foral 17/2010"*, entendem-se por anotações subjetivas as impressões ou valorizações pessoais dos profissionais de saúde, incluindo hipóteses diagnósticas não confirmadas e situações de incumprimento terapêutico, de tratamentos não declarados ou de hábitos nocivos não reconhecidos.

No Reino Unido, os pacientes têm o direito de aceder diretamente aos seus processos clínicos desde 1998 sob o "*Data Protection Act*". Além disso, de acordo com a estratégia do Governo para o Serviço de Saúde Britânico, publicada em Maio de 2012, todos os centros de cuidados de saúde primários terão de oferecer acesso *online* aos seus pacientes até 2015. Atualmente apenas 1% o fazem[4].

Austrália

A *Australian Medical Association* disponibilizou em 1997 o documento "*Guidelines for doctors on providing patient access to medical records*", o qual foi revisto em 2002. Nesse documento, é especificado que os pacientes podem aceder diretamente à totalidade do seu processo clínico, excepto em situações de "privilégio terapêutico", ou seja, situações em que seja comprovadamente prejudicial para os pacientes esse acesso.

Estados Unidos da América

Nos Estados Unidos da América o direito de acesso ao processo clínico electrónico foi reconhecido legalmente em 1996, após aprovação da "*Health Insurance Portability and Accountability Act*" (HIPAA). Sob esta lei, a única exceção ao direito de acesso são os casos de doença mental em que tiver sido determinado por um especialista em Saúde Mental que esse acesso pode ser prejudicial ao estado de saúde do doente.

No entanto, poucos pacientes terão, até à data, visto os seus processos clínicos[7,24]. Podem ser enunciados como obstáculos a taxa cobrada para fazer uma cópia dos mesmos, a dificuldade na interpretação dos registos sem a presença de um médico e os atrasos frequentes no processamento dos pedidos. Além disso, a visão defensiva da prática da Medicina por alguns profissionais de saúde, poderá também desempenhar um papel no desencorajar desse acesso por parte dos pacientes. Ainda hoje, das primeiras coisas em que um médico pensa quando um paciente pede para aceder ao seu processo clínico, é num processo judicial[24].

O contexto Português

Perspectiva histórica

A **Carta dos Direitos e Deveres dos Doentes**, publicada em 1997 pela Direcção-Geral da Saúde, foi dos primeiros documentos a afirmar que "o doente tem direito de acesso aos dados registados no seu processo clínico". Esclarece ainda que "o doente tem o direito de tomar conhecimento dos dados registados no seu processo" e que "a omissão de alguns desses dados apenas é justificável se a sua revelação for considerada prejudicial para o doente ou se contiverem informações sobre terceiras pessoas".

No mesmo sentido, pode-se ler no artigo 35º da **Constituição da República Portuguesa** que "Todos os cidadãos têm o direito de acesso aos dados informatizados que lhes digam respeito, podendo exigir a sua rectificação e atualização, e o direito de conhecer a finalidade a que se destinam"[25].

O **acesso indireto** aos dados de saúde era o previsto na Lei de Proteção dos Dados Pessoais (art.11º, n.º5 da Lei n.º 67/98, de 26 de Outubro), na Lei de Acesso aos

Documentos Administrativos (LADA, 1999) e na Lei da Informação genética pessoal e informação de saúde (2005). Segundo esta última, o titular da informação de saúde tinha o "direito de, querendo, tomar conhecimento de todo o processo clínico que lhe diga respeito, salvo circunstâncias excepcionais devidamente justificadas e em que seja inequivocamente demonstrado que isso lhe possa ser prejudicial" (o que tem sido denominado de privilégio terapêutico). No entanto, esse acesso deveria ser "feito através de médico, com habilitação própria, escolhido pelo titular da informação". Era, assim, um pouco paradoxal que a mesma lei que afirmava que "a informação de saúde, incluindo os dados clínicos registados (...), é propriedade da pessoa, sendo as unidades do sistema de saúde [meros] depositários da informação", seguisse depois o modelo conservador e paternalista do acesso indireto ao processo clínico.

Atualidade

Desde 2007, a Lei de Acesso aos Documentos de Administração (LADA, 2007) reconhece o acesso direto dos pacientes aos seus dados de saúde: "a comunicação de dados de saúde é feita por intermédio de médico se o requerente o solicitar", afirmando também que "todos, sem necessidade de enunciar qualquer interesse, têm direito de acesso aos documentos administrativos, o qual compreende os direitos de consulta, de reprodução e de informação sobre a sua existência e conteúdo".

O Relatório do Grupo de Trabalho ad hoc sobre o Direito de Acesso à Informação de Saúde (ARS Norte, 2008), reflete já estas prerrogativas.

No entanto, o Código Deontológico da Ordem dos Médicos (2009), no seu capítulo XIV (Processos Clínicos), artigo 100º, mantém a premissa do acesso indireto:

"3. O médico é o detentor da propriedade intelectual dos registos que elabora (...); 4. O doente tem direito a conhecer a informação registada no seu processo clínico, a qual lhe será transmitida, se requerida, pelo próprio médico assistente ou, no caso de instituição de saúde, por médico designado pelo doente para este efeito."

Ora, a Comissão de Acesso aos Documentos Administrativos (CADA), emitiu já vários pareceres sobre este assunto:

- "Os titulares têm direito de acesso a toda a informação que lhes diga respeito e conste do respectivo processo. (...) O titular da informação de saúde tem o

direito de acesso (...) a toda a informação que lhe diga respeito (escolhendo a forma de acesso), sem necessidade de indicar a finalidade do mesmo, podendo utilizá-la como bem entenda" (parecer da CADA n.º294/2007);

- "Nos termos [da LADA, 2007] 'a comunicação de dados de saúde é feita por intermédio de médico se o requerente o solicitar'. Esta norma revoga o disposto no artigo 3º, nº 3 da Lei nº 12/2005 (...) bem como o artigo 8º, nº 3 da antiga LADA (revogada em bloco pela [LADA, 2007])." (parecer da CADA n.º229/2007).
- "A intermediação médica para acesso a dados de saúde deixou de ser obrigatória"(parecer da CADA n.º274/2007).

Outro aspecto interessante, diz respeito à interpretação da lei no que concerne ao acesso às anotações dos médicos. Por um lado, parece claro na lei (LADA, 2007) que o paciente tem o "direito de, querendo, tomar conhecimento de todo o processo clínico". Inclusivamente, num dos pareceres da CADA (n.º274/2008), é afirmado o seguinte: "No que respeita ao acesso pelo próprio titular, não há lugar ao expurgo de informação de saúde (...). E, assim sendo, não pode ser restringido o acesso àquela informação por parte do seu titular. (...) Só não serão acessíveis anotações que nada tenham a ver com questões clínicas respeitantes ao paciente, que, eventualmente de forma inadvertida, constem do processo."

No entanto, outras interpretações mais restritivas têm sido publicadas. Em Fevereiro de 2012 na Revista da Ordem dos Médicos, foi veiculada a seguinte informação, pelo seu Departamento Jurídico[26]:

"A regra geral é do acesso imediato ao processo. Só não será assim se o requerente solicitar a intermediação de um médico. Consideramos, contudo, que neste sistema de acesso direto, estão ressalvadas exceções, como é o caso do "privilégio terapêutico", do acesso a anotações subjetivas dos médicos (notas pessoais, apontamentos ou outros registos de natureza semelhante); e outras que contendam com direitos ou interesses de terceiros, podendo estes dados ser excluídos de informações escritas para efeitos de comunicação e acesso por parte dos doentes ou interessados."

Mesmo em 2011, o Conselho Nacional de Ética para as Ciências da Vida afirma no seu parecer nº60 que as "aplicações [informáticas] devem ter um campo, associado ao

registo clínico de cada titular, de acesso exclusivo ao profissional de saúde, isto é, onde só o seu autor possa aceder, destinado a anotações de carácter pessoal".

Assim, parece impor-se a necessidade de um debate informado acerca deste tema entre todas as partes envolvidas, incluindo os próprios pacientes. Só assim poderão ser esclarecidas todas as interpretações contraditórias que têm sido apresentadas, de forma a que se torne consensual o modo de atuação perante estes pedidos, cada vez mais frequentes, por parte dos pacientes.

Discussão

A substituição progressiva do modelo centrado no médico por um modelo centrado na pessoa, tem sido responsável pelo surgimento de uma nova visão sobre o processo clínico. Um pouco por todo o mundo, este documento deixou de pertencer aos médicos e às instituições de saúde, que passam agora a ser os meros depositários dessa informação. Cada vez mais, é reconhecido o direito das pessoas à sua informação de saúde, e vários modelos de partilha do processo clínico têm surgido.

Apesar das leis existentes em cada país sobre a partilha do processo clínico, subsistem conflitos entre as várias partes envolvidas nesta questão, nomeadamente os pacientes, os seus familiares, os profissionais de saúde e as instituições de saúde.

Em Portugal, atualmente, os pacientes têm consagrado na lei o direito de aceder diretamente à totalidade dos seus processos clínicos (exceptuando-se as situações de privilégio terapêutico), sem ser necessária a mediação por um médico, ou qualquer justificação para o pedido de acesso.
No entanto, opiniões discordantes têm sido publicadas sobre este assunto, nomeadamente no que diz respeito à propriedade intelectual dos registos dos médicos. O dilema é que, ao ser defendido o direito à privacidade das anotações subjetivas dos médicos, está-se também a privar os doentes de informações relevantes sobre o seu estado de saúde.

Por outro lado, se a vontade de acesso à totalidade dos processos clínicos por parte dos pacientes se generalizar, poderemos assistir à transformação dos registos clínicos em documentos desprovidos de comentários subjetivos ou termos que possam desagradar ao doente, os quais são por vezes úteis na prática clínica.
Uma possível solução para este problema seria a separação das anotações subjetivas dos médicos, do restante processo clínico. Assim, as notas de seguimento, que contêm obviamente informação útil para os pacientes, poderiam ser partilhadas com menos receio, caso estivessem isentas dos comentários subjetivos dos médicos.
Outro aspecto a ter em consideração refere-se às notas de seguimento antigas, escritas numa altura em que a partilha com os pacientes não era uma realidade. Uma possibilidade, não prevista no atual panorama legal, seria a interdição de acesso a esses registos, sendo a partilha com os pacientes feita apenas prospectivamente.

É, ainda, importante considerar a facilidade ou dificuldade dos pacientes em compreender a informação registada no processo clínico, uma vez que os benefícios da sua partilha apenas serão maximizados no caso das pessoas conseguirem perceber aquilo que foi escrito sobre elas. Duas soluções são possíveis na abordagem a esta questão. Por um lado, os médicos poderão aprender a fazer os registos clínicos de uma forma mais facilmente compreensível pelo doente, nomeadamente com menos abreviaturas. Por outro lado, o acesso a um glossário de termos médicos poderá ser facilitado. Idealmente, ambas as soluções poderiam ser implementadas em simultâneo.

Atualmente, nem os pacientes acedem habitualmente à sua informação de saúde, nem os profissionais de saúde conseguem observar toda a informação clínica de um determinado paciente, a qual se encontra muitas vezes dispersa por diversas instituições de saúde. A partilha dos processos clínicos com os pacientes seria uma forma de obviar esta grande limitação na atual prestação de cuidados de saúde.
Além disso, a partilha do processo clínico tem o potencial de promover a transparência nos cuidados de saúde, tendo sido já identificadas inúmeras vantagens associadas a ela, tanto ao nível do paciente, como da relação médico-paciente e ao nível da própria prática clínica.

Não seria desejável que os nossos pacientes estivessem bem informados sobre a sua saúde? E que conseguissem detectar erros nos seus processos clínicos, perceber os seus diagnósticos, entender o efeito das medicações e ser capazes de discutir os seus problemas de saúde com os vários profissionais?

Tornar a informação disponível não significa que os pacientes sejam forçados a olhar para ela, mas permite estimular a responsabilização, tanto dos pacientes como dos médicos, acerca do plano de cuidados que é estabelecido em cada contacto.

Conclusão

A partilha dos processos clínicos com os pacientes parece fulcral e inevitável num modelo de medicina centrada na pessoa. Assim, os esforços de oposição a esta realidade deviam, pelo contrário, ser concentrados na procura de soluções para os eventuais problemas que com ela vão surgindo. A partilha dos processos clínicos deveria, inclusivamente, ser estimulada, tendo em conta o potencial de melhoria da capacitação, da literacia em saúde, da autonomia, da autoeficácia e da satisfação dos pacientes. Para esta mudança de atitude irão certamente contribuir os progressivos avanços tecnológicos e a crescente disseminação dos Sistemas Personalizados de Informação de Saúde.

Referências

1. Shenkin BN, Warner DC. Sounding board. Giving the patient his medical record: a proposal to improve the system. N Engl J Med. 1973;289(13):688–92.
2. Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: A systematic review of controlled trials. Journal of Medical Internet Research. 2012. p. e162.
3. Mandl KD, Kohane IS. Tectonic shifts in the health information economy. N Engl J Med. 2008 Apr;358(16):1732–7.
4. Davies P. Should patients be able to control their own records? BMJ. 2012. p. e4905–e4905.
5. Al-Ubaydli M. Patients must have control of their medical records. BMJ. 2012. p. e5575–e5575.

6. Pyper C, Amery J, Watson M, Crook C. Patients' experiences when accessing their on-line electronic patient records in primary care. Br J Gen Pract. 2004 Jan;54(498):38–43.

7. Delbanco T, Walker J, Darer JD, Elmore JG, Feldman HJ, Leveille SG, et al. Open notes: Doctors and patients signing on. Annals of Internal Medicine. 2010. p. 121–5.

8. Walker J, Leveille SG, Ngo L, Vodicka E, Darer JD, Dhanireddy S, et al. Inviting patients to read their doctors' notes: Patients and doctors look ahead patient and physician surveys. Ann Intern Med. 2011;155(12):811–9.

9. Ross SE, Lin CT. The effects of promoting patient access to medical records: A review. Journal of the American Medical Informatics Association. 2003. p. 129–38.

10. Bernstein RA, Andrews EM, Weaver LA. Physician attitudes toward patients' requests to read their hospital records. Med Care. 1981;19(1):118–21.

11. Ferreira A, Correia A, Silva A, Corte A, Pinto A, Saavedra A, et al. Why facilitate patient access to medical records. Stud Health Technol Inform. 2007 Jan;127:77–90.

12. Wiljer D, Urowitz S, Apatu E, DeLenardo C, Eysenbach G, Harth T, et al. Patient accessible electronic health records: Exploring recommendations for successful implementation strategies. J Med Internet Res. 2008 Jan;10(4):e34.

13. Britten N, Bartholomew J, Morris R, Zander L. Consultants' and patients' views about patient access to their general practice records. J R Soc Med. 1991 May;84(5):284–7.

14. Liaw ST. Patient and general practitioner perceptions of patient-held health records. Fam Pract. 1993 Dec;10(4):406–15.

15. Ross a P. The case against showing patients their records. BMJ. 1986 Mar 1;292(6520):578–578.

16. Fairweather NB, Rogerson S. A moral approach to electronic patient records. Med Inform Internet Med. 2001;26(3):219–34.

17. Meltsner M. A patient's view of opennotes. Annals of Internal Medicine. 2012;157(7):523–4.

18. Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, et al. Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead. Ann Intern Med. 2012 Oct 2;157(7):461.

19. TL Beauchamp; JF Childress. Principles of biomedical ethics. 6th ed. New York: Oxford University Press; 2008.

20. Pellegrino, ED; Thomasma D. For the patient's good: Toward the restoration of beneficence in health care. New York: Oxford University Press; 1988.

21. Gracia D. Pensar a bioética – metas e desafios. São Paulo: Loyola; 2001.

22. Galvão, M; Ricarte I. Prontuário do paciente. Rio de Janeiro: Grupo-Gen: Guanabara Koogan; 2012.

23. Dever de documentação, acesso ao processo clínico e sua propriedade - uma perspectiva europeia. Rev Port do dano Corpor. 2006;2005(12):9–24.

24. Topol E. The creative destruction of Medicine. New York: Basic Books; 2013. 336 p.

25. Miranda, J; Pereira da Silva J. Constituição da República Portuguesa. 2nd ed. Cascais: Principia; 2000.

26. Sancho P. Segredo médico: limites e requisitos. ROM.

Paper II

Translation, cultural adaptation and validation of the Patient Activation Measure 13 in a population of Portuguese type 2 diabetes patients

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All the authors contributed substantially to the design of the study and the acquisition, analysis and/or interpretation of data. Liliana Laranjo and Vera Dias both contributed as first authors. The paper was drafted by the first authors and critically reviewed by all the remaining authors. Bill Mahoney is the co-developer of the Patient Activation Measure (PAM).

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Translation, cultural adaptation and validation of the Patient Activation Measure in a population of Portuguese type 2 diabetes patients

Abstract

Background

Type 2 diabetes mellitus (DM) has now reached an unprecedented prevalence all over the world. Management of DM is complex, and is largely dependent on patients' active participation in care. The Patient Activation Measure 13 (PAM13) is currently the only questionnaire that assesses the knowledge, skills, and confidence in self-managing a chronic condition. We aimed to translate, culturally adapt, and validate the PAM13 to Portuguese, in patients with type 2 DM.

Material and Methods

The translation and cultural adaptation occurred in 6 phases: 1)Forward-translation; 2)Back-translation; 3)Harmonization; 4)e-Delphi; 5)Cognitive debriefing; 6)Appraisal and consensus. A convenience sample of people with type 2 DM was recruited from an outpatient clinic in Lisbon. The questionnaire was self-administered; medical records were reviewed to obtain A1C levels. Main statistical analyses were based on the Rasch rating scale model.

Results

Rasch analysis was conducted on 193 respondents. Respondents had a mean age of 67.1 (SD 10.1) years, 42.7% were women, and the mean PAM score (0-100) in the sample was 58.5 (SD 10.1). The sample was low to moderate in terms of activation: 40.4% were low in activation (levels 1 and 2), 49.7% were in level 3, and 9.8% were in level 4, the highest level of activation. All items had good fit and the response categories were well adjusted to the Rasch Model. Item reliability was 0.97 and person reliability was between 0.77 (real) and 0.83 (model).

Conclusion

The PAM13 was translated and culturally adapted to European Portuguese and validated in patients with DM, showing good psychometric properties.

Background

Type 2 diabetes mellitus (DM) is a challenging health problem worldwide, with a rapidly increasing prevalence. In 2013, 382 million people had diabetes; that number is estimated to rise to 592 million in 2035[1]. It is known that compliance with medication and with healthy lifestyle behaviors can significantly reduce the morbidity and mortality associated with the disease[2,3]. In fact, interventions aimed at promoting disease self-management are amongst the most effective in improving metabolic control[4]. However, engaging patients in effective self-management remains a challenge[5]. Existing literature suggests that self-management behaviors may be substantially influenced by the level of patient participation in care[6], as well as by the type of diabetes education provided[7], and by patients' perceived obstacles [8,9]. Additionally, the Chronic Care Model stresses the importance of an activated patient in achieving improved outcomes[10].

The concept of activation involves having the skills, knowledge, and confidence to participate in care, and may be assessed by the Patient Activation Measure (PAM)[11]. This questionnaire has been shown to perform well in patients with chronic conditions, and it classifies them as being in one of four stages: 1) the person is not prepared to play an active role in their own health; 2) the individual believes he or she plays an important role in managing his or her care, but lacks the confidence and/or knowledge to take action; 3) the individual is beginning to take action, but may still lack confidence; and 4) the individual has adopted many self-management behaviors, but may not be able to maintain actions over time or during times of stress[11].

Prior studies have shown that the PAM is stable across differing health status and across gender and age groups, and that higher PAM scores are associated with better process and outcome measures, including healthier behaviors, better utilization of health care services, and performance of recommended self-management care[12–30]. Furthermore, activated diabetic patients have been shown to be more likely to perform feet checks, receive eye examinations, and exercise regularly, as well as to have better metabolic control and report less difficulty in managing diabetes [11,31–40]. On the contrary, type 2 DM patients with low levels of activation seem to have greater tendency to be hospitalized[41,42].

An interesting feature of the PAM questionnaire is that it can be used both at the individual patient level (for physicians to evaluate their patients' activation level and target therapeutic options accordingly), and at a group level, as an indicator of the effectiveness of health interventions[12,13,16,36,43,44].

The PAM questionnaire has strong psychometric properties[11,45–48] and has already been translated and validated in several countries and specific populations[44,46,49–54].

Considering the high prevalence and economic burden of diabetes in Portugal[55], the PAM questionnaire appears to be a valuable tool in this population to guide and measure quality improvement efforts, as well as to facilitate the individualization of care[56].

The main objective of this study was to translate and culturally adapt the short-version of the PAM (PAM13) to European Portuguese, as well as to validate and test the psychometric properties of the Portuguese PAM13 (PAM13-P) in type 2 diabetes patients.

Methods

Participants and setting

We followed a pre-defined protocol for the translation, cultural adaptation, and validation of the questionnaire, based on guidelines from the World Health Organization[57] and other published recommendations[58–61].

Participants were recruited from the waiting rooms of the Portuguese Diabetes Association's outpatient clinic (APDP-Diabetes), in Lisbon. Eligible patients had been diagnosed with type 2 DM, were registered at the clinic, fluent in Portuguese, and 18 years of age or older. Patients with dementia, blindness, deafness or inability to give informed consent were excluded.

Patients were recruited between March and April 2014 for the several phases of the study: cognitive debriefing sessions, pre-testing, and final questionnaire application. All participants gave written informed consent for participating in the study. No incentives were given to the participants. Ethical approval of the study was granted by the Ethics Committee of APDP-Diabetes.

Translation and cultural adaptation

The process of translation and cultural adaptation of the original version of the PAM13 (Figure 1) involved six phases[57–60] (Figure 2): 1) Forward-translation; 2) Back-translation; 3) Harmonization; 4) e-Delphi; 5) Cognitive debriefing; 6) Appraisal and consensus.

The *forward translation* to Portuguese was carried out independently by two bilingual translators (one with a medical background and one lay translator). The two versions of the forward translation were compared, and differences were discussed by the research team until a single reconciled version was reached. The *back-translation* to English was done independently by two bilingual translators (one with a medical background and one lay translator), based on the reconciled translation resulting from the previous stage. The two back-translations were then compared by the research team to resolve discrepancies and reach a single back-translation. None of the four translators was previously familiarized with the PAM or the concepts being explored by the questionnaire.

During the *harmonization* stage, the final back-translation was compared with the source questionnaire, so that differences could be highlighted and discussed. Additionally, the research team reconciled the translation and back-translation of the PAM, focusing on cultural adaptation and readability.

An *e-Delphi panel* (n=21) constituted by health researchers, health professionals, lay people, and DM patients, analyzed the questionnaire in an iterative process. This phase was conducted by email, in several rounds, until consensus was reached. After each round, comments and suggestions were analyzed, and the questionnaire was modified by the research team based on feedback. Equivalence between the source and pre-final versions was sought in five main areas: semantic, idiomatic, experiential, conceptual and cultural.

Two *cognitive debriefing* sessions were conducted to assess the general comprehension of the instrument by the target population. Each session was conducted with a convenience sample of patients with type 2 diabetes (n=12 and n=10), who were individually asked to complete the PAM13-P, think out loud, and discuss the meaning, interpretation, and phrasing of each item of the questionnaire.

A! report! was! written! for! each! stage! of! the! translation! and! cultural! adaptation! process.!All!the!reports!and!versions!of!the!PAM!were!finally!analyzed!and!*appraised*! by! the! research! team,! before! the! resulting! version! of! the! PAM13H-P! was! deemed! ready!for!preHtesting.!

'

PreHtesting!and!final!questionnaire!

PreHtesting!of!the!PAM13H-P!was!conducted!with!type!2!DM!patients,!some!of!which! had! already! participated! in! the! cognitive! debriefing! sessions.! For! the! final! testing! only!patients!who!had!not!had!any!previous!contact!with!the!PAM!were!recruited.! The!final!questionnaire!was!applied!in!the!waiting!rooms!of!APDPHDiabetes!during!6! working!days!in!March!and!April!2014,!as!a!selfHadministered!paper!questionnaire! including! the! PAM! and! demographic,! diseaseHspecific,! and! validation! questions! (Supplement).!

Demographic! questions! were! used! to! assess! age,! gender,! educational! level! and! current!occupation.!Educational!level!was!assessed!using!multiple!categories,!which! were!later!grouped!into!the!variable!'schooling!years',!with!four!categories!(≤4;!]4H9];!]9H12];! >12).! Current! occupation! was! grouped! into! three! categories! ('retired',! 'employed',! or! 'unemployed'),! considering! the! observed! frequencies.! DiseaseH specific! questions! evaluated! diabetes! duration! (in! years)! and! current! medication! (none,! oral! antidiabetics! and/or! insulin).! The! most! recent! result! of! glycated! hemoglobin!(A1C)!was!collected!from!the!electronic!health!record!of!each!patient,! by!a!physician!blinded!to!the!results!of!the!questionnaire.!

!

Construct!validity!

Seven! questions! were! developed! and! preHtested! by! the! research! team! with! the! purpose!of!assessing!construct!and!criterion!validity.!These!questions!were!believed! to!be!conceptually!related!to!activation!in!this!population[11],!and!evaluated!selfH management! attitudes! and! behaviors,! mostly! related! to! diet! and! participation! in! care!(Supplement!–!Part!I).!The!same!response!categories!of!the!PAM13!were!used! (i.e.!disagree!strongly,!disagree,!agree,!agree!strongly,!not!applicable).!

!

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Psychometric analysis

Psychometric analysis of the PAM13-P was conducted with the Rasch rating scale measurement model[62] via Winsteps v3.8.1® (Rasch Measurement Software, Chicago, IL, USA). The analysis involved evaluating the fit of the data to the measurement model by examining the quality control fit statistics for response categories, items, and respondents. Infit is a statistic that is most sensitive when the person and item are close together on the scale (e.g. a person with low activation answering an easy question); outfit is most sensitive when person and item are far apart[11,62]. Fit values of 1 represent a perfect fit to the model, and fit values between 0.5 and 1.5 are considered to indicate sufficient unidimensionality and construct validity[11,62].

When the data fit the model the result is a true equal interval measurement scale of activation. The final score of the PAM varies from 0 to 100, where 0 is the lowest possible score, and 100 is the highest (scoring instructions available from Insignia Health). This 0-100 score corresponds to a level of activation, varying from 1 (lowest activation) to 4 (highest level of activation), using previously defined cut-offs (level 1, ≤47; level 2, 47.1-55.1; level 3, 55.2-67; level 4, ≥67.1) [48,63].

The reliability of item calibrations and generated activation scores of respondents was evaluated by item and person reliability statistics. Rasch person reliability is the proportion of the total variability in measured activation that is not measurement error, and provides upper and lower bounds to the estimate of the 'true' reliability of the measure. The lower bound is represented by the 'real person reliability', which is calculated under the assumption that misfit in responses is due to deviation from the model's expectations. The upper bound is indicated by the 'model person reliability', which is based on the assumption that the data fit the model (i.e. any misfits are due to the probabilistic nature of the model).

Analyses and statistical methods

Free-Marginal Multirater Kappa[64] was used to evaluate agreement in the e-Delphi process. Response rates were calculated using the number of completed

questionnaires!in!the!numerator!and!the!number!of!people!invited!to!participate!as!the!denominator.!

Data!quality!was!assessed!using!means,!medians,!percentage!of!missing!data,!and!number!of!'not!applicable'!answers.!!

Pearson's!correlation!coefficient!was!used!to!assess!correlation!between!continuous!variables;! Chi-square! tests! were! used! to! study! associations! between! categorical! variables,! and! ANOVA! to! test! associations! between! categorical! and! continuous! variables.!

Rasch! analyses! were! conducted! in! Winsteps.! All! other! analyzes! were! performed! using! Statistical! Package! for! the! Social! Sciences! v21®.! Results! were! considered! statistically!significant!if!*p*!was!equal!or!inferior!to!0.05.'

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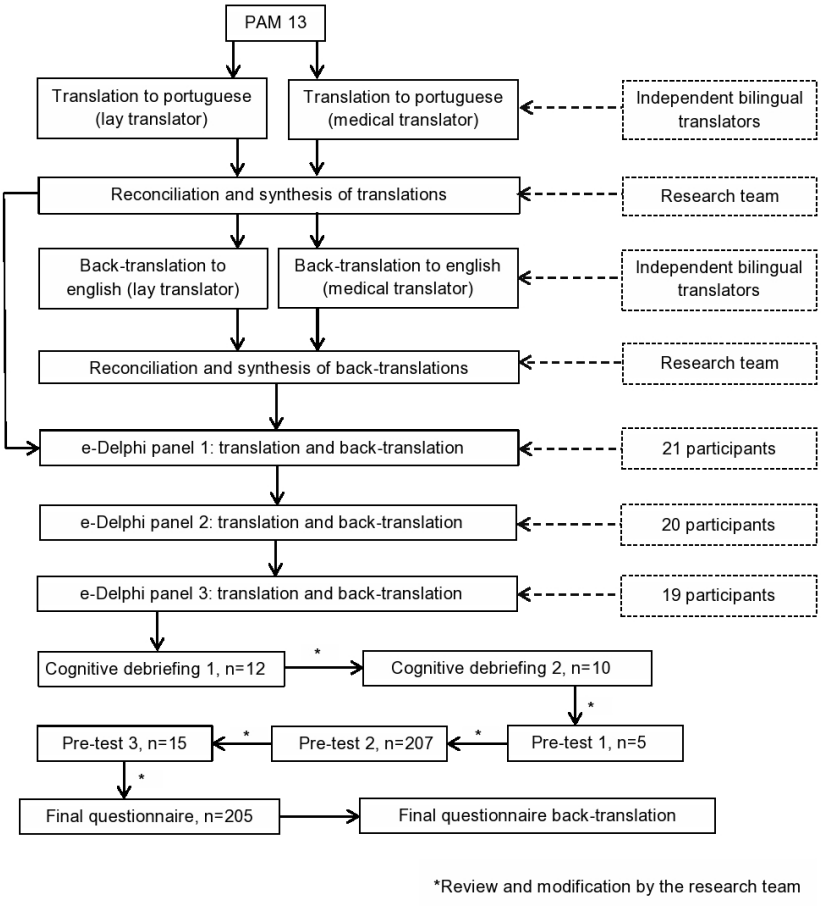
1	When all is said and done, I am the person who is responsible for managing my health condition
2	Taking an active role in my own health care is the most important factor in determining my health and ability to function
3	I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition
4	I know what each of my prescribed medications do
5	I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself
6	I am confident I can tell my health care provider concerns I have even when he or she does not ask
7	I am confident that I can follow through on medical treatments I need to do at home
8	I understand the nature and causes of my health condition(s)
9	I know the different medical treatment options available for my health condition
10	I have been able to maintain the lifestyle changes for my health that I have made
11	I know how to prevent further problems with my health condition
12	I am confident I can figure out solutions when new situations or problems arise with my health condition
13	I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress

Figure!1:!Original!version!of!the!Patient!Activation!Measure!13!!



Figure!2:!Flow!diagram!of!the!translation,!cultural!adaptation!and!validation!of!the!PAM13HP!

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Results+

Translation!and!cultural!adaptation!

The!two!translations!and!backHtranslations!were!concordant!on!most!items,!except!for!minor!differences!in!wording.!For!the!reconciliation!in!a!single!translation,!preference!was!given!to!less!complex!and!semantically!equivalent!words!and!expressions.!!

The!analysis!of!the!harmonized!translation!and!backHtranslation!of!the!PAMH13!by!the!eHDelphi!was!done!in!three!rounds!(Figure!2),!until!consensus!was!reached!(round!1:!n=21,!kappa=0.63;!round!2:!n=20,!kappa=0.80;!round!3:!n=19,!kappa=0.96).!The!most!problematic!expressions!in!the!source!version!were:!'when!all!is!said!and!done',!'taking!an!active!role',!'I!am!confident',!'I!can!help!prevent!or!reduce!problems!associated!with!my!health',!'I!can!tell!a!doctor!concerns!I!have',!

'follow!through!on!medical!treatments',!and!'I!have!been!able!to!maintain!(keep!up!with)!lifestyle!changes,!like!eating!right!or!exercising'.!!

During!cognitive!debriefing!sessions!the!most!mentioned!comprehension!difficulty!was!related!to!the!response!categories,!which!were!modified!accordingly!(e.g.!'not!applicable'! was! substituted! by! 'I! don't! know/not! applicable',! a! more! common! response!category!in!Portuguese!questionnaires).!The!two!items!that!posed!more! comprehension! issues! were! number! 10! and! 13,! which! had! to! be! significantly! simplified!to!improve!readability.!!

Three!pre-tests!were!conducted!(n=5,!n=207,!n=15)!(Figure!2);!a!few!corrections! were! deemed! necessary! after! the! first! two! pre-tests,! mostly! related! with! the! formatting!of!the!questionnaire!(e.g.!increasing!the!font!size!and!spacing),!in!order!to! decrease!respondent!burden.!

! !

<u>Characteristics!of!the!study!population</u>!

The!response!rate!for!the!final!questionnaire!was!83%!(205!respondents).!The!63! individuals!who!declined!the!invitation!to!participate!were!found!to!be!similar!to!the! respondents!in!terms!of!gender!(*p*=1.00)!and!age!(*p*=0.876).!Four!questionnaires! were!excluded!before!analysis:!two!individuals!who!were!not!able!to!complete!the! questionnaire!due!to!poor!vision,!and!two!others!that!left!the!questionnaire!blank! after!agreeing!to!participate.!!

Of!the!201!respondents,!eight!had!'perfect!scores',!meaning!that!they!had!replied! 'totally! agree'! to! all! 13! questions.! These! 8! respondents! had! fit! statistics! that! suggested! response! set,! indicating! that! they! did! not! participate! in! the! effort! to! measure!activation,!and!were!deleted.!!

Rasch!analysis!was!conducted!on!193!respondents.!Respondents!had!a!mean!age!of! 67.1!(SD!10.1)!years,!42.7%!were!women,!and!the!mean!PAM!score!in!the!sample! was!58.5!(SD!10.1)!(Table!1).!PAM!scores!varied!from!41.8!to!90.5!(Figure!3).!The! sample!was!low!to!moderate!in!terms!of!activation:!40.4%!were!in!levels!1!or!2,! 49.7%!in!level!3,!and!the!remaining!in!level!4!(≈9.8%).!!

Mean!age!differed!significantly!by!PAM!level:!patients!in!level!4!were!older!(mean! age!72.3!years)!than!those!in!level!1!(mean!age!63.5;!F=2.75;!*p*=0.044).!There!was!a! trend!towards!lower!A1c!values!in!patients!with!higher!activation:!mean!A1c!in!level!

1! was! 8.5%! and! in! level! 4! was! 7.4%! (F=1.59;! *p*>0.05).! There! was! no! significant! association!between!measured!activation!and!gender,!schooling,!occupation,!mean! diabetes!duration,!or!type!of!medication.!

!

Table!1:!Characteristics!of!the!sample!

		Mean (±sd)	n (%)[a]		PAM score (mean)[b]
Gender	Female		82	(42.7)	
Age (years)		67.1 (±10.1)	193[d]		
Schooling years	≤ 4		84	(43.5)	58.6
	]4; 9]		49	(25.3)	57.9
	]9; 12]		31	(16.1)	55.9
	>12		29	(15.0)	61.6
Occupation	Retired		146	(75.6)	59.2
	Employed		27	(14.0)	56.1
	Unemployed		20	(10.4)	56.3
A1c (%) [c]		7.9 (±1.6)			
	< 8		97	(58.4)	59.6
	≥ 8		69	(41.6)	56.9
Diabetes duration (years)		17.3 (±10.2)	193[d]		
Oral diabetes medication	Yes		150	(77.7)	
Insulin use	Yes		115	(59.6)	

Abbreviations: A1c, glycated hemoglobin

[a] Sums may not add up to 100% due to rounding; [b] Mean PAM scores are presented for relevant variables; [c] A1c results were from the last two years (approximately two thirds from the previous 3 months). [d] Represents the total number of individuals for which there were valid data concerning each continuous variable

!

Data!quality!and!Rasch!analysis!

Item!response!was!high,!with!missing!answers!varying!between!0!and!7.8%!(Table!2).! The!PAM-13!items!with!a!higher!percentage!of!missing!answers!were!numbers!3,!8,! and!9.!

The!Rasch!analysis!showed!that!the!PAM13-P!could!be!considered!a!unidimensional! set!of!items.!Item!infit!and!outfit!statistics!ranged!from!0.78!to!1.32!(Table!2).!All! items!had!good!fit!and!ten!of!the!thirteen!items!had!near!perfect!fit.!Item!difficulty! was!smallest!for!item!4!(38.5),!and!highest!for!items!13!(56.1),!8!(55.4),!and!10! (53.4).!

!

Table 2: Data quality, item difficulty, and fit statistics for the validation of the Portuguese PAM13

Item	Total number of responses	Missing values n (%)	'Not applicable' responses n (%)	Item difficulty	Infit	Outfit
1	193	0 (0.0)	0 (0.0)	43.6	1.12	1.17
2	191	2 (1.0)	1 (0.5)	41.3	.78	.79
3	180	13 (6.7)	9 (4.7)	42.9	.87	.84
4	186	7 (3.6)	5 (2.6)	38.5	.96	.93
5	188	5 (2.6)	4 (2.1)	45.0	.97	.97
6	188	5 (2.6)	4 (2.1)	40.4	.94	.93
7	193	0 (0.0)	0 (0.0)	41.0	.87	.82
8	178	15 (7.8)	14 (7.3)	55.4	1.17	1.24
9	179	14 (7.3)	13 (6.7)	51.4	.95	.98
10	188	5 (2.6)	3 (1.6)	53.4	1.18	1.32
11	184	9 (4.7)	7 (3.6)	50.9	1.00	1.04
12	181	12 (6.2)	12 (6.2)	50.3	.98	1.00
13	183	10 (5.2)	9 (4.7)	56.1	1.11	1.28

Item difficulty is its location on the 0-100 activation scale (higher being more difficult); Infit and outfit: fit statistics assessing item dimensionality; Infit is most sensitive when the person and item are close together on the scale; outfit is most sensitive to item dimensionality when the item scale location is distant from the person scale location.

The response categories had a good fit to the Rasch rating scale model; all categories except 'disagree strongly' (which was infrequently used) had fit values very close to 1.0 (Table 3).

Table 3: Response category fit statistics

Response category	Total times used		Infit	Outfit
	n	(%)		
Disagree strongly	40	(2)	1.42	1.79
Disagree	321	(13)	.98	.98
Agree	1495	(62)	.92	.91
Agree strongly	556	(23)	.93	.93

Infit and outfit: fit statistics assessing item dimensionality.

Item reliability was 0.97 (both real and model), and person reliability was between 0.77 (real) and 0.83 (model).

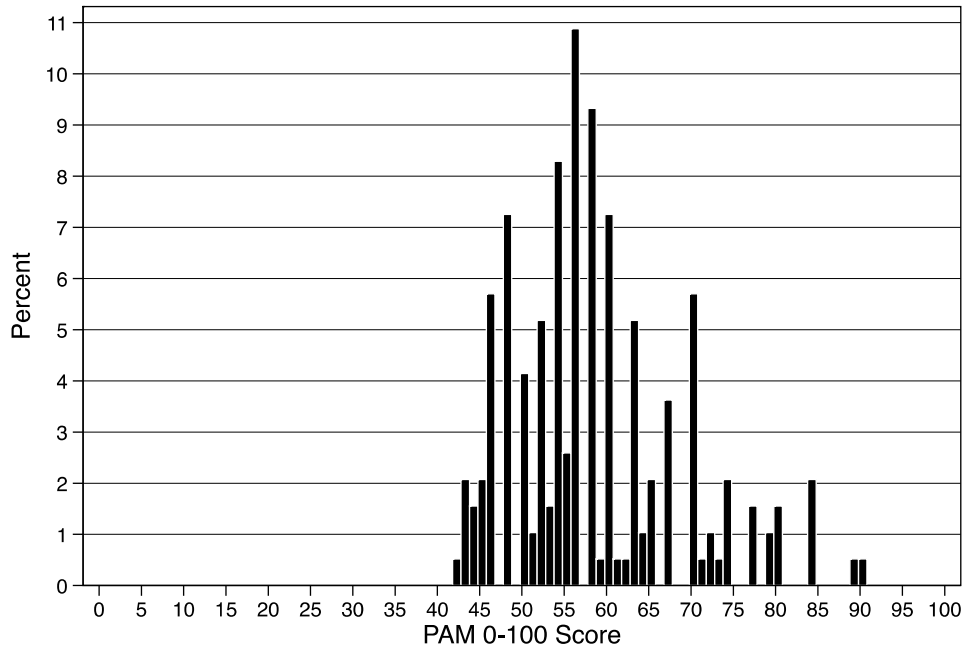

Figure 3: Distribution of PAM scores in the sample of 193 patients with type 2 diabetes (Winsteps)

Validation questions

PAM 0-100 score was significantly different between response categories in 6 of the 7 validation items (item 6 was the exception)(Table 4). The seven items together explained 51% of the variance in PAM 0-100 score (multivariate ANOVA with 173 people who responded to all seven validation questions). Three items had a significant independent association with the PAM score in the multivariate ANOVA: item 2 (p<.001), item 4 (p=.0054) and item 7 (p<.001).

Table 4: Analysis of Variance for mean PAM score by validation items' response categories[a]

Validation items	F	*p*-value
.. I am the main responsible for the management of my diabetes	15.15	<.00001
:. I know what I need to do on a daily basis to manage my diabetes	26.18	<.00001
;. Most of the times I am capable of self-managing my diabetes on a daily basis	17.93	<.00001
<. I know what I should or should not eat, in order to manage my diabetes	14.13	<.00001
=. Most of the times, I am capable of eating right, in order to manage my diabetes	13.43	<.00001
>. Most of the times, the doctor and/or nurse are the ones who make decisions regarding my health	5.11	.007
?. Most of the times I am capable of managing the stress related to my diabetes	29.25	<.00001

Due to the low number of responses in the "disagree strongly" category, the two disagree categories ("disagree strongly" and "disagree") were combined, resulting in a total of three categories: any disagree, "agree", and "agree strongly".

Discussion

The PAM13 was successfully translated and culturally adapted to European Portuguese, and validated in a population of patients with DM2. To the best of our knowledge, this is the first study in Portugal measuring activation in patients with a chronic condition, and the first to validate the PAM-13 in the Portuguese population.

In our study, some expressions posed equivalence challenges and had to be adapted to the Portuguese context (e.g. 'when all is said and done', 'I am confident'). Additionally, cognitive debriefing sessions identified a small number of comprehension issues regarding the response categories, as well some items (mostly items 10 and 13), which were therefore modified accordingly. The final version of the PAM13-P was applied with a good response rate. Rasch analysis on 193 patients revealed good fit statistics, both for items and response categories, as well as good people reliability (between 0.77 and 0.83), and excellent item reliability (0.97).

Comparison with other studies

Other validation studies of the PAM13 have been conducted, with comparable results[46,49–54].

Study population

The mean PAM score in our sample was 58.5, a value that is similar to what has been found in other validation studies with chronic disease patients[46,48,51,53], namely in patients with type 2 diabetes[18,31,33,65].

There was a trend towards lower A1c values in patients with higher activation, although this was not statistically significant. This association of activation with metabolic control has been previously described in the literature[31,34].

In contrast with other studies[17,48,54,66,67] no association between education/schooling and PAM scores was found. This finding should be further analyzed in future studies using the PAM13-P.

Rasch model

All **infit and outfit statistics** for the 13 items were within the 0.5-1.5 acceptable range, and most were close to 1, indicating an excellent fit of the items in the PAM13-P to the measurement model, and reflecting its unidimensionality[11,62]. Response categories had a good fit to the Rasch rating scale model. However, the "disagree strongly" category was less frequently used, which is a common pattern[46,48,54].

As in other studies, **item difficulty** followed a different order than observed in the original PAM-13[46,53,54]. Nevertheless, in general, there was a gradient of increasing difficulty from the first items to the last ones in the scale, reflecting the developmental model of activation suggested by the authors of the PAM[11]. In this model, basic knowledge about one's condition, and beliefs about the patient role, are seen in early stages of activation, followed by skills and confidence in managing care, and ability to implement and maintain lifestyle changes[11]. In this continuum, small amounts of activation are needed to endorse items that appear first on the scale, and higher amounts of activation are required for items that measure later developmental steps[11].

The calibrated scale varied from 38.5 to 53.4 (on a theoretical 0–100 point scale), which is a range similar to the one found in the original PAM13 (38.6-53.0)[48].

The measurement had good person **reliability**, between 0.77 (real) and 0.83 (model), which is comparable with the original PAM13 (0.81-0.85; 0.79-0.83 in diabetes patients)[48], and other PAM validations[46]. **Item reliability** was excellent (0.97), similarly to the original questionnaire[48].

Finally, the fact that the validation questions explained 51% of the variance in PAM 0-100 score is in line with what would be expected, given that they were not meant to cover the whole spectrum of the activation concept in just seven items, and that only a few components of diabetes self-care were included. Nevertheless, we believe that a good degree of criterion validity has been demonstrated.

Strengths and limitations

Our study incorporated many quality control steps in the process of translation and cultural adaptation, with a focus on achieving equivalence between the original PAM13 and the PAM13-P, in five major categories: semantic, idiomatic, experiential, conceptual and cultural. In order to make sure the PAM13-P was adapted to people with low reading levels, our e-Delphi process included lay people, and several cognitive debriefing sessions and pre-testing rounds were conducted.

There was a good response rate and no age and gender differences were found between respondents and non-respondents, minimizing the impact of selection bias.

On the other hand, some caveats should be considered. Firstly, although our sample size was big enough to ensure the adequacy of the Rasch analysis and the validation process, our conclusions could have been strengthened by a larger and more diverse sample of the target population. Secondly, some items and response categories (e.g. 'not applicable') had to be substantially modified to allow understanding by the target population. Although we believe conceptual equivalence was maintained, this should be given further consideration, especially when considering the application of the PAM13-P in other populations of chronic disease patients.

Lastly, our study was conducted in one outpatient diabetes clinic, and our sample may not be representative of the population of type 2 diabetes patients in Portugal, as it may have a higher proportion of patients with diabetes complications. Future studies should be conducted in other settings (e.g. primary care) to ensure validity is maintained.

Implications for research, clinical practice, and health policy

The validation of the PAM13-P in type 2 DM is an important step in enhancing the use of patient-reported outcome measures in diabetes research. Future research should aim at the refinement of the PAM13-P, evaluate test-retest reliability, and explore its ability to measure changes in activation over time, which could turn it into a useful tool to measure the effectiveness of patient-centered interventions.

In clinical practice, the PAM13-P can be a rapid and reliable way of assessing aspects of activation and assess in what area each specific patient is experiencing more difficulties, enabling the personalization of health care.

Finally, the PAM13-P has a great potential use in health policy, to identify patients at risk for poorer health outcomes, guide resource allocation, and facilitate the planning and evaluation of public health interventions.

Conclusion

The PAM13 is now translated and culturally adapted to European Portuguese, and has been validated in a population of patients with type 2 DM. The PAM13-P formed a unidimensional scale with good psychometric properties, and should now be further tested in different settings and chronic disease populations.

References

1. Guariguata L, Whiting DR, Hambleton I, Beagley J, Linnenkamp U, Shaw JE. Global estimates of diabetes prevalence for 2013 and projections for 2035. Diabetes Res Clin Pract. Elsevier Ireland Ltd; 2014;103(2):137–49.

2. UK Prospective Diabetes Study Group. Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. BMJ. 1998;317(7160):703–13.

3. Haas L, Maryniuk M, Beck J, Cox C, Duker P, Edwards L. National Standards for Diabetes Self-Management Education and Support. Diabetes Care. 2012;36(Supplement 1):S100–8.

4. Tricco A, Ivers N, Grimshaw J, Moher D, Turner L, Galipeau J. Effectiveness of quality improvement strategies on the management of diabetes: a systematic review and meta-analysis. Lancet. 2012;379(9833):2252–62.

5. Norris S, Engelgau M, Narayan K. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. Diabetes Care. 2001;24(3):561–87.

6. Golin C, DiMatteo M, Gelberg L. The role of patient participation in the doctor visit. Implications for adherence to diabetes care. Diabetes Care. 1996;19(10):1153–64.

7. Davies M, Heller S, Skinner T, Campbell M, Carey M, Cradock S. Effectiveness of the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed type 2 diabetes: cluster randomised controlled trial. BMJ. 2008;336(7642):491–5.

8. Vermeire E, Hearnshaw H, Rätsep A, Levasseur G, Petek D, van Dam H. Obstacles to adherence in living with type-2 diabetes: An international qualitative study using meta-ethnography (EUROBSTACLE). Prim Care Diabetes. 2007;1(1):25–33.

9. Vermeire E, van Royen P, Coenen S, Wens J, Denekens J. The adherence of type 2 diabetes patients to their therapeutic regimens: a qualitative study from the patient's perspective. Pract Diabetes Int. 2003;20(6):209–14.

10. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient Self-management of Chronic Disease in Primary Care. JAMA. 2002 Nov 20;288(19):2469–75.

11. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004 Aug;39(4 Pt 1):1005–26.

12. Hibbard JH, Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? Health Serv Res. 2007 Aug;42(4):1443–63.

13. Hibbard JH, Greene J, Tusler M. Improving the Outcomes of Disease Management by Tailoring Care to the Patient's Level of Activation. Am J Manag Care. 15(6):353–60.

14. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Med. 2012 May;27(5):520–6.

15. Frosch D, Rincon D, Ochoa S, Mangione C. Activating Seniors to Improve Chronic Disease Care: results from a pilot intervention study. J Am Geriatr Soc. 2010;58(8):1496–503.

16. Shively MJ, Gardetto NJ, Kodiath MF, Kelly A, Smith TL, Stepnowsky C, et al. Effect of patient activation on self-management in patients with heart failure. J Cardiovasc Nurs. 2013;28(1):20–34.

17. Marshall R, Beach MC, Saha S, Mori T, Loveless MO, Hibbard JH, et al. Patient activation and improved outcomes in HIV-infected patients. J Gen Intern Med. 2013 May;28(5):668–74.

18. Rask KJ, Ziemer DC, Kohler S a, Hawley JN, Arinde FJ, Barnes CS. Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population. Diabetes Educ. 2009;35(4):622–30.

19. Mosen DM, Schmittdiel J, Hibbard J, Sobel D, Remmers C, Bellows J. Is patient activation associated with outcomes of care for adults with chronic conditions? J Ambul Care Manage. 2007;30(1):21–9.

20. Hibbard JH, Tusler M. Assessing activation stage and employing a “next steps” approach to supporting patient self-management. J Ambul Care Manage. 2007;30(1):2–8.

21. Aung E, Donald M, Coll JR, Williams GM, Doi S a. R. Association between patient activation and patient-assessed quality of care in type 2 diabetes: results of a longitudinal study. Heal Expect. 2015;n/a – n/a.

22. Sacks RM, Greene J, Hibbard JH, Overton V. How well do patient activation scores predict depression outcomes one year later? J Affect Disord. Elsevier; 2014;169:1–6.

23. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When Patient Activation Levels Change, Health Outcomes And Costs Change, Too. Health Aff. 2015;34(3):431–7.

24. Katz ML, Fisher JL, Fleming K, Paskett ED. Patient activation increases colorectal cancer screening rates: A randomized trial among low-income minority patients. Cancer Epidemiol Biomarkers Prev. 2012;21(1):45–52.

25. Magnezi R, Glasser S, Shalev H, Sheiber A, Reuveni H. Patient activation, depression and quality of life. Patient Educ Couns. Elsevier Ireland Ltd; 2014;94(3):432–7.

26. Hibbard JH, Greene J, Shi Y, Mittler J, Scanlon D. Taking the Long View: How Well Do Patient Activation Scores Predict Outcomes Four Years Later? Med Care Res Rev. 2015;2015.

27. Smith SG, Pandit A, Rush SR, Wolf MS, Simon C. The association between patient activation and accessing online health information: results from a national survey of US adults. Heal Expect. 2014;n/a – n/a.

28. Donald M, Ware RS, Ozolins IZ, Begum N, Crowther R, Bain C. The role of patient activation in frequent attendance at primary care: a population-based study of people with chronic disease. Patient Educ Couns. Elsevier Ireland Ltd; 2011 May;83(2):217–21.

29. Salyers MP, Matthias MS, Spann CL, Lydick JM, Rollins AL, Frankel RM. The role of patient activation in psychiatric visits. Psychiatr Serv. 2009;60(11):1535–9.

30. Alegría M, Sribney W, Perez D, Laderman M, Keefe K. The role of patient activation on patient-provider communication and quality of care for US and foreign born Latino patients. J Gen Intern Med. 2009 Nov;24 Suppl 3:534–41.

31. Remmers C, Hibbard J, Mosen D, Wagenfield M, Hoye R, Jones C. Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? J Ambul Care Manage. 2009;32(4):320–7.

32. Rost KM, Flavin KS, Cole K, McGill JB. Change in metabolic control and functional status after hospitalization. Impact of patient activation intervention in diabetic patients. Diabetes Care. 1991;

33. Rygg LØ, Rise MB, Grønning K, Steinsbekk A. Efficacy of ongoing group based diabetes self-management education for patients with type 2 diabetes mellitus. A randomised controlled trial. Patient Educ Couns. 2012 Jan;86(1):98–105.

34. Rogvi S, Tapager I, Almdal TP, Schiøtz ML, Willaing I. Patient factors and glycaemic control--associations and explanatory power. Diabet Med. 2012 Oct;29(10):e382–9.

35. Bolen SD, Chandar A, Falck-Ytter C, Tyler C, Perzynski AT, Gertz AM, et al. Effectiveness and safety of patient activation interventions for adults with type 2 diabetes: Systematic review, meta-analysis, and meta-regression. J Gen Intern Med. 2014;29(8):1166–76.

36. Wolever RQ, Dreusicke M, Fikkan J, Hawkins T V, Yeung S, Wakefield J, et al. Integrative health coaching for patients with type 2 diabetes: a randomized clinical trial. Diabetes Educ. 36(4):629–39.

37. Parchman ML, Zeber JE, Palmer RF. Participatory decision making, patient activation, medication adherence, and intermediate clinical outcomes in type 2 diabetes: A starnet study. Ann Fam Med. 2010;8(5):410–7.

38. Williams GC, McGregor H, Zeldman A, Freedman ZR, Deci EL, Elder D. Promoting glycemic control through diabetes self-management: Evaluating a patient activation intervention. Patient Educ Couns. 2005;56(1):28–34.

39. Willaing I, Rogvi S a., Bøgelund M, Almdal T, Schiøtz M. Recall of HbA1c and self-management behaviours, patient activation, perception of care and diabetes distress in Type 2 diabetes. Diabet Med. 2013;30(4):139–42.

40. Hendriks M, Rademakers J. Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. BMC Health Serv Res. 2014;14(1):393.

41. Begum N, Donald M, Ozolins IZ, Dower J. Hospital admissions, emergency department utilisation and patient activation for self-management among people with diabetes. Diabetes Res Clin Pract. Elsevier Ireland Ltd; 2011 Aug;93(2):260–7.

42. Kinney RL, Lemon SC, Person SD, Pagoto SL, Saczynski JS. The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: A systematic review. Patient Educ Couns. Elsevier Ireland Ltd; 2015;98(5):545–52.

43. Alegría M, Polo A, Gao S, Santana L. Evaluation of a patient activation and empowerment intervention in mental health care. Med Care. 2008;46(3):247–56.

44. Green C a, Perrin N a, Polen MR, Leo MC, Hibbard JH, Tusler M. Development of the Patient Activation Measure for mental health. Adm Policy Ment Health. 2010 Jul;37(4):327–33.

45. Hung M, Carter M, Hayden C, Dzierzon R, Morales J, Snow L, et al. Psychometric assessment of the patient activation measure short form (PAM-13) in rural settings. Qual Life Res. 2013 Apr;22(3):521–9.

46. Maindal HT, Sokolowski I, Vedsted P. Translation, adaptation and validation of the American short form Patient Activation Measure (PAM13) in a Danish version. BMC Public Health. 2009 Jan;9:209.

47. Skolasky RL, Green AF, Scharfstein D, Boult C, Reider L, Wegener ST. Psychometric properties of the patient activation measure among multimorbid older adults. Health Serv Res. 2011 Apr;46(2):457–78.

48. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res. 2005 Dec;40(6 Pt 1):1918–30.

49. Magnezi R, Glasser S. Psychometric Properties of the Hebrew Translation of the Patient Activation Measure (PAM-13). PLoS One. 2014;9(11):e113391.

50. Stepleman L, Rutter M-C, Hibbard J, Johns L, Wright D, Hughes M. Validation of the patient activation measure in a multiple sclerosis clinic sample and implications for care. Disabil Rehabil. 2010;32(19):1558–67.

51. Brenk-Franz K, Hibbard JH, Herrmann WJ, Freund T, Szecsenyi J, Djalali S, et al. Validation of the German version of the patient activation measure 13 (PAM13-D) in an international multicentre study of primary care patients. PLoS One. 2013 Jan;8(9):e74786.

52. Packer TL, Kephart G, Ghahari S, Audulv Å, Versnel J, Warner G. The Patient Activation Measure: a validation study in a neurological population. Qual Life Res. 2015;n/a(n/a):n/a.

53. Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). BMC Public Health. 2012 Jan;12(1):577.

54. Zill JM, Dwinger S, Kriston L, Rohenkohl A, Härter M, Dirmaier J. Psychometric evaluation of the German version of the patient activation measure (PAM13). BMC Public Health. 2013;13:1027.

55. Gardete-Correia L, Boavida JM, Raposo JF, Mesquita a C, Fona C, Carvalho R, et al. First diabetes prevalence study in Portugal: PREVADIAB study. Diabet Med. 2010 Aug;27(8):879–81.

56. Hibbard JH. Moving toward a more patient-centered health care delivery system. Health Aff (Millwood). 2004 Jan;Suppl Vari:VAR133–5.

57. World Health Organization. Process of translation and adaptation of instruments [Internet]. 2007. Available from: http://www.who.int/substance abuse/research tools/translation/

58. Streiner DL, Norman GR. Health Measurement Scales. 4th ed. 2008.

59. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. Value Health. 2005;8(2):94–104.

60. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine (Phila Pa 1976). 2000 Dec 15;25(24):3186–91.

61. Breugelmans R. Dangers in using translated medical questionnaires: The importance of conceptual equivalence across languages and cultures in patient-reported outcome measures. Chest. 2009. p. 1175–7.

62. Bond T, Fox C. Applying the Rasch model. Fundamental measurement in the human sciences. 2001.

63. Dixon A, Hibbard J, Tusler M. How do people with different levels of activation self-manage their chronic conditions? Patient. 2009;2(4):257–68.

64. Randolph JJ. Free-Marginal Multirater Kappa (multirater κfree): An Alternative to Fleiss ' Fixed- Marginal Multirater Kappa. Joensuu Learning and Instruction Symposium; 2005. p. 20.

65. Otero-Sabogal R, Arretz D, Siebold S, Hallen E, Lee R, Ketchel A, et al. Physician-community health worker partnering to support diabetes self-management in primary care. Qual Prim Care. 2010 Jan;18(6):363–72.

66. Lubetkin EI, Lu W-H, Gold MR. Levels and correlates of patient activation in health center settings: building strategies for improving health outcomes. J Health Care Poor Underserved. 2010 Aug;21(3):796–808.

67. Bos-Touwen I, Schuurmans M, Monninkhof EM, Korpershoek Y, Spruit-Bentvelzen L, Ertugrul-van der Graaf I, et al. Patient and Disease Characteristics Associated with Activation for Self-Management in Patients with Diabetes, Chronic Obstructive Pulmonary Disease, Chronic Heart Failure and Chronic Renal Disease: A Cross-Sectional Survey Study. PLoS One. 2015;10(5):e0126400.

Supplement

Translation, cultural adaptation and validation of the Patient Activation Measure in a population of Portuguese type 2 diabetes patients

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PART I

Por favor, indique a sua resposta com **uma cruz (X)**. **Responda o que é verdade na sua situação e não aquilo que gostava que fosse verdade.**

	Não concordo nada	Não concordo	Concordo	Concordo totalmente	Não sei / Não se aplica
1. Eu sou o principal responsável no tratamento da minha diabetes					
2. Eu sei os cuidados que tenho que ter com a minha diabetes, no dia-a-dia					
3. A maioria das vezes, eu consigo ter os cuidados necessários para o controlo da minha diabetes, no dia-a-dia					
4. Eu sei qual é a dieta que devo fazer para controlar a minha diabetes					
5. A maioria das vezes, eu consigo fazer a dieta necessária para controlar a minha diabetes					
6. Quase sempre, o médico e/ou o enfermeiro é que tomam as decisões em relação à minha saúde					
7. Quase sempre, eu consigo controlar o nervosismo relacionado com a minha diabetes					

PART II - Patient Activation Measure 13 - Portuguese Version (PAM13-P)

Em baixo encontrará frases que as pessoas costumam dizer quando falam sobre a sua saúde. Por favor indique com **uma cruz (X)** até que ponto concorda ou não concorda com cada afirmação em relação a si mesmo(a). **Responda o que é verdade na sua situação e não aquilo que gostava que fosse verdade.**
Caso alguma afirmação não se aplique na sua situação, escolha por favor a opção "Não sei / Não se aplica".

	Não concordo nada	Não concordo	Concordo	Concordo totalmente	Não sei / Não se aplica
1. Eu sou o principal responsável por cuidar da minha saúde					
2. Aquilo que é mais importante para a minha saúde é eu participar nos meus cuidados de saúde					
3. Eu sei que posso evitar ou diminuir problemas da minha saúde					
4. Eu sei para que servem os medicamentos que me foram receitados					
5. Eu consigo perceber quando sou capaz resolver um problema de saúde ou quando preciso da ajuda do médico					
6. Eu sou capaz de dizer a um médico as preocupações que tenho, mesmo se ele não me pergunta					
7. Eu sou capaz de cumprir os tratamentos médicos que tenho de fazer em casa					
8. Eu percebo os meus problemas de saúde e porque é que eles aparecem					
9. Eu sei quais são os tratamentos que existem para os meus problemas de saúde					
10. Eu tenho conseguido manter hábitos de vida saudáveis					
11. Eu sei como evitar problemas relacionados com a minha saúde					
12. Eu sou capaz de procurar soluções quando me aparecem novos problemas de saúde					
13. Mesmo quando estou mais nervoso, sei que consigo manter hábitos de vida saudáveis					

PART III

Por favor, indique a(s) sua(s) resposta(s) com **uma cruz (X), ou com o número respetivo**.

1. Sexo:
   a. Feminino ☐
   b. Masculino ☐

2. Idade: _____ anos

3. Habilitações Literárias (anos completos de escolaridade):
   a. Sem escolaridade ☐
   b. 1ª ou 2ª Anos, 1.º Ciclo (antiga 1ª ou 2ª Classe)☐
   c. 3ª ou 4ª Anos, 1.º Ciclo (antiga 3ª ou 4ª Classe)☐
   d. 2.º Ciclo (antigo 2.º ano do ciclo preparatório) ☐
   e. 3.º Ciclo (antigo 5º ano do liceu) ☐
   f. Secundário (antigo 7º ano do liceu) ☐
   g. Curso Profissional ☐
   h. Bacharelato ☐
   i. Licenciatura ☐
   j. Mestrado ☐
   k. Doutoramento ☐

4. Situação Profissional:
   a. Reformado ou Pensionista ☐
   b. Doméstica ☐
   c. Empregado ☐
   d. Desempregado ☐
   e. Estudante ☐

5. Há quantos anos tem diabetes? _____ anos

6. Faz medicação para a diabetes?
   a. Não ☐
   b. Sim ☐

6.1. Se sim, de que tipo?
   a. Comprimidos para a diabetes ☐
   b. Insulina ☐

7. Tem computador em casa?
   a. Sim
   b. Não

8. Tem internet em casa?
   a. Sim
   b. Não

9. Com que frequência utiliza a internet? (em casa ou noutro local)
   a. Nunca
   b. Raramente
   c. Uma vez por mês
   d. Entre duas e quatro vezes por mês
   e. Mais do que uma vez por semana
   f. Diariamente

Muito obrigado pela sua participação!

Paper III

Facilitators, barriers and expectations in the self-management of type 2 diabetes – a qualitative study from Portugal

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European Journal of General Practice

All the authors contributed substantially to the design of the study and the acquisition, analysis and/or interpretation of data. The paper was drafted by the first author and critically reviewed by all the remaining authors.

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Facilitators, barriers and expectations in the self-management of type 2 diabetes

A qualitative study from Portugal

Abstract

Background: Patients with type 2 Diabetes Mellitus (DM) have a central role in managing their disease, but the effective adoption of self-management behaviours is often challenging.

Objectives: The main objective of this study was to assess the facilitators, barriers and expectations in the self-management of type 2 DM, as perceived by patients.

Methods: Patients with type 2 DM were recruited at the Association for the Protection of Portuguese Diabetics outpatient clinic, using a convenient sampling technique. Qualitative data were obtained using video-recorded focus groups. Each session had a moderator and an observer, and followed a pre-tested questioning route. Focus group data were transcribed and analysed by two independent researchers.

Results: Three major themes were identified: diet, physical exercise, and glycaemic control. Difficulties in changing dietary habits were grouped in four main categories: decisional, food quality, food quantity, and dietary schedule. Barriers related to physical exercise also included decisional aspects, as well as fatigue, muscle and joint pain, and other co-morbidities. Information and knowledge translation, as well as family and social ties were commonly explored aspects across the three themes, and were regarded as facilitators in some situations and as barriers in others.

Conclusions: This study provided new insight on the barriers, facilitators and expectations of in type 2 DM self-management, pointing out the importance of tailored guidance. Future research should explore interventions designed to promote and facilitate behaviour change in this population.

Introduction+

Diabetes!Mellitus!(DM)!is!a!highly!prevalent!chronic!disease!worldwide!and!one!of!the!most!challenging!health!problems!in!the!21st!century[1].!In!Portugal,!the!prevalence!of!diabetes!is!estimated!to!be!12.9%[2],!of!which!approximately!half!the!patients!do!not!reach!the!recommended!treatment!goals!for!glycated!haemoglobin[3].!

Type!2!DM!comprises!90%!of!people!with!diabetes!worldwide,!and!is!largely!due!to!excess!body!weight!and!physical!inactivity[4].!It!is!known!that!adherence!to!medication!and!lifestyle!recommendations!can!significantly!reduce!the!morbidity!and!mortality!associated!with!the!disease[5].!In!fact,!a!recent!metaAanalysis!showed!that!interventions!aimed!at!promoting!selfAmanagement!were!amongst!the!most!effective!in!decreasing!glycated!haemoglobin[6].!However,!diabetes!selfAmanagement!relies!greatly!on!health!behaviour!change,!which!represents!a!difficult!endeavour!for!most!people,!remaining!one!of!the!biggest!challenges!in!modern!day!life[7,8].!!

Several!theories!and!models!can!provide!insight!on!the!process!of!behaviour!change[7].!However,!the!successful!application!of!these!models!in!clinical!practice!and!public!health!is!greatly!dependent!on!the!specificities!of!the!context,!as!well!as!on!the!expectations!and!characteristics!the!target!population.!!In!diabetes,!despite!the!existence!of!general!recommendations!for!selfAmanagement!education!and!support[9],!the!best!intervention!to!engage!patients!in!selfAmanagement!and!health!behaviour!change!remains!to!be!identified[10].!Given!that!a!'oneAsizeAfitAall'!kind!of!strategy!is!unlikely!to!be!found,!it!is!important!to!assess!local!needs,!barriers,!and!facilitators!to!selfAmanagement,!so!that!we!can!better!fit!existent!scientific!knowledge!to!each!particular!population.!

Some!studies!have!suggested!that!selfAmanagement!behaviours!are!greatly!influenced!by!the!level!of!patient!participation!in!care[11],!their!perceived!obstacles!to!adherence[12,13],!and!type!of!diabetes!education!they!receive[14].!!

Therefore,!a!better!understanding!of!facilitators!and!barriers!to!selfAmanagement!in!DM!is!essential!to!prioritise!targets!for!intervention!and!provide!appropriate!educational!tools.!Several!facilitators!of!diabetes!selfAmanagement!behaviours!have!

been suggested, including diabetes self-management education, social support, problem-solving skills, and self-efficacy[15–20]. Care provider communication also seems to be associated with a better performance regarding both diabetes self-management and glycemic control[21,22].

Regarding the barriers in the self-management of type 2 diabetes, Booth AO et al proposed that they can be divided into six main categories: difficulty changing well-established habits, negative perception of the 'new' or recommended regimen, barriers relating to social circumstances, lack of knowledge and understanding, lack of motivation, and barriers relating to the practicalities of making lifestyle changes[23].

In Portugal, care of people with diabetes occurs mainly within the primary care system, but also in specialized clinics such as the Association for the Protection of Portuguese Diabetics (APDP-Diabetes), and to a lesser degree, in secondary care. The population of patients in APDP-Diabetes is heterogeneous – while some patients are referred to this outpatient clinic for complication management, several receive their primary care for diabetes there, for lack of an available Family Physician in their area of residence.

Regarding the characteristics of the care provided, a recent report by ERS, the Portuguese Health Regulation Authority, states that there has been a disproportionate emphasis on the control of glycemic values at the primary care level, without the necessary investment in patient education and self-management promotion[24]. Indeed, to the best of our knowledge, no studies have been published or conducted evaluating the facilitators, barriers and expectations regarding diabetes self-management. Furthermore, although there are some instruments to assess the needs and obstacles to diabetes self-management[25], none of them is validated to the Portuguese population.

The main aim of this study was to qualitatively assess the facilitators, barriers and expectations in the self-management of type 2 DM, as perceived by Portuguese patients.

Methods

Study Design

A qualitative descriptive approach was taken using focus groups as the data collection method. Focus groups were chosen as the data collection method due to their ability to elicit unique perspectives on the study subject, originating from interactions between participants within each group[26,27]. We planned on conducting focus groups until data saturation, within the limits of our budget.

Three focus groups (n=6, n=6 and n=4) were conducted in June 2013 and lasted between 45 and 60 minutes. A trained moderator with familiarity with diabetes care facilitated each session. An independent observer was also present, being responsible for videotaping the group discussions and taking notes during the focus groups. Videotaping was performed as it eases the process of identifying who is speaking, and also provides access to subtle nuances of the discussion (e.g. body language). Neither the facilitator nor the observer had provided health care to the participants in the past.

A topic guide with open-ended questions was pre-tested with four persons similar to the target population, and was then used to focus the discussion and cover all of the relevant topics during focus groups (Figure 1). Probes for each question were also used as necessary, to elicit further comments. At the end of each session the moderator summarized the main points and participants were asked if they wanted to modify or add any information. Refreshments were provided at the end of each session.

Data analysis

After each session the moderator and assistant debriefed and analysed the notes taken during the focus group. Focus group videotapes were transcribed verbatim by one of the authors. Content analysis of the qualitative information gathered was done using NVivo® 7 (NVivo, Melbourne, Australia). Two independent researchers systematically reviewed the transcripts, following the constant-comparative method. This method involves breaking down the data into discrete 'units' and coding them to categories[28]. According to Taylor and Bogdan, in the constant comparative method

the researcher simultaneously codes and analyses data in order to develop concepts; by continually comparing specific incidents in the data, the concepts and their properties are defined and their relationships explored[29]. Analysis began with open coding of transcripts to identify areas of relevance emerging from the data, which formed the basic themes, which were later clustered to form categories. Discrepancies in coding between the two investigators were resolved through consensus. Statements that typified each content area were identified in the transcripts.

In writing this paper we followed the appraisal checklist for focus group research, published by the European Journal of General Practice[30].

Participants

Patients with type 2 DM were recruited at the outpatient clinic of APDP–Diabetes, a Portuguese Diabetes Association in Portugal, using convenience sampling. Inclusion criteria included: having the diagnosis of type 2 DM at the electronic medical record and being over 18 years old. Exclusion criteria included: not speaking Portuguese, having diabetes for less than one year or having a cognitive disability. We contacted by phone prospective participants that had a diabetes consultation scheduled for the following day (after consulting physicians' electronic medical record to check inclusion and exclusion criteria), and assessed their availability to participate in the study before their clinical visit.

For descriptive purposes, all participants were asked to complete a pre-session survey to gather the following information: age, gender, number of years of education and diabetes duration.

Written informed consent was obtained from each participant. All the participants consented to being video-recorded, and the information they provided was kept confidential. The Ethics Committee of APDP Diabetes approved this study, and no financial benefits were given to the participants.

Results

Demographic and disease-related characteristics of the participants are presented in Table 1. The major themes identified were: diet, physical exercise and glycaemic control (Figure 2). Aspects regarding Information and knowledge translation, as well as family and social ties, were mentioned both as barriers in some situations and as facilitators and expectations in others, being common to all three themes. At the third session there were no new perspectives being elicited on the subject, so additional focus groups were not conducted.

Barriers

Diet. Diet was the most problematic self-management behaviour, as referred by the majority of participants (Table 2).

Several aspects were mentioned as barriers in changing dietary habits, which were grouped in four main categories: decisional, food quality, food quantity, and dietary schedule (Figure 2).Decisional aspects (such as lack of motivation, self-control, and willpower) were mentioned by the majority of participants as a huge barrier to implementing behaviour changes.

> *"I don't stick to a healthy diet, I don't really care about it" (female, FG2)*
> *"I really think that the problem is not having enough motivation to follow a healthy diet" (female, FG1)*

Also, cravings for particular types of foods (e.g. chocolate, desserts) made it difficult for several patients to avoid their consumption.

> *"Sometimes I eat too many sweets. I feel that I crave more for cakes now" (male, FG2)*

In terms of quality, the cost of healthy foods and having to learn how to cook healthy recipes were mentioned as common barriers to improving the quality of the diet.

Quantity-related comments regarding diet were also prominent. Several participants said it was difficult to limit the portion sizes at each meal, and some mentioned it was hard to decrease their overall food consumption in order to try to lose weight.

In terms of knowledge and information, we identified several myths, doubts and knowledge gaps regarding specific types of foods. It was common for participants to correctly identify general aspects of a healthy diet, but also to reveal confusion and lack of understanding about how to implement it on a daily basis when making their food choices and when preparing their meals. A common myth was the belief that some foods were 'forbidden' for people with diabetes (e.g. potatoes, banana, bread, cherries, grapes, green peas, beans).

Finally, participants mentioned some barriers related to family and social aspects. The most commonly mentioned one was the difficulty in maintaining a healthy diet during holidays and social events.

> *"For me, the most difficult moments are the birthdays and family parties. We go and start eating a little bit of this and that… it's also a social thing." (female, FG3)*

Some patients also mentioned the lack of support by family members, sometimes even resembling sabotage of their efforts. Female participants frequently said it was hard to have to cook for others in the household who were not motivated to eat the meals they had to prepare for themselves.

Physical exercise. Decisional aspects related to physical exercise, such as lack of motivation and willpower, and not having created the habit of exercising, were the most frequently mentioned difficulties regarding maintaining regular physical activity (Table 2). Other barriers referred less often by participants were fatigue, muscle and joint pain and additional co-morbidities that made exercising hard (e.g. heart problems, diabetic foot) (Figure 2).

"I'm not walking that much nowadays because my legs ache too much." (female, FG2)

"I don't have the will to exercise; I end up sitting on the couch. I prefer being at home than going outside to walk."(male, FG3)

Participants also mentioned lack of information regarding the specific types of physical activities that were adequate for them, as well as lack of knowledge about how often they should exercise, or how to implement a plan for regular physical activity.

In addition, lack of family or friend support was also brought up by patients as a barrier to engage in physical exercise.

Glycaemic control. Aspects regarding glycaemic control were often indicated as barriers to self-management (Table 2). The most frequently mentioned barrier was stress (Figure 2). The majority of participants felt that their anxiety about the disease made it difficult for them to achieve glycaemic control. Additionally, it was very common for patients to express confusion and lack of understanding regarding sudden blood sugar rises (that they could not explain based on their diet), which made it frequent for them to blame stress. This apparently unexplainable lack of control often made them feel frustrated and less motivated to adhere to recommended behaviours

"Today I ate the right foods, I walked, I did everything right, why did the blood sugar rise so much? Is it the stress, is it the nervous system? Then, I get that feeling that I'm not in control of the disease, it's frustrating" (female, FG1)

Seldom mentioned aspects were the discomfort involved in measuring their blood sugar and also the lack of family or friend support in certain aspects of self-management.

Facilitators and expectations

Participants' comments regarding facilitators and expectations were common for all three themes, and concerned two major topics: information and knowledge translation, as well as family and social ties (Table 3).

Knowledge/information. In general, participants expressed the need for more information about type 2 DM. Some expressed concern that such a prevalent disease was not well-known by the majority of people, and others said they wanted to learn more about how to self-manage their disease, but it was hard for them to find that information.

> *"There is not enough information – there should be more, it's a disease that affects so many people." (female, FG1)*

> *"Lots of people watch television or listen to the radio so there should be more information about diabetes in those means of communication" (male, FG3)*

Some sources of information regarded by patients as facilitators were: family members, friends or acquaintances with diabetes; healthcare professionals; their own experience in dealing with the disease; the media (e.g., television, magazines); and the booklets and magazines offered by the APDP-Diabetes.

Family and social ties. Family and social connections were seen either as facilitators in certain situations, or as barriers in others.

> *"The family can either help or make things more difficult. My daughter is always worried with me and might call me five times a day saying "eat this, don't eat that". My husband is the opposite, always telling me to taste this and that." (female, FG2)*

In general, participants who had a friend or family member that helped them with some aspect of self-management considered them as facilitators.

> *[about a healthy diet] "it is not too difficult because my wife and my kids help me with that at home" (male, FG2)*

> *"Sometimes I go for a walk because my wife suggests so, and there we go together. Otherwise, I wouldn't go…"(male, FG2)*

1. Please say your first name and what diabetes means to you in a single word.
2. What do you know about the treatment of type 2 diabetes?
3. What do you know about the complications of diabetes?
4. What do you think is your role in the treatment of diabetes?
5. What do you think is your family's role in the treatment of diabetes?
6. Do you have problems or difficulties in the management of diabetes? Like what?
7. How do you think these problems / difficulties could be eliminated or overcome? Can you anticipate any possible solutions?
8. Is there anything that makes the management of diabetes easier for you?
9. In what areas of diabetes and diabetes management do you feel you need more information?
10. How would you like to learn more about diabetes?
11. What do you do when you have questions about diabetes?
12. Is there anything else you want to add or feel that we should have spoken about?

Figure 1: Interview guide for the Focus Groups.

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Table 1: Demographic and disease-related characteristics of the participants.

Gender (n)	
Female	9
Male	7
Age, mean ± SD	64.3 ± 11.8
Years of schooling (n)	
4 years	11
6 years	2
12 years	1
Missing	2
Duration of DM, mean ± SD	17.0 ± 10.0

Abbreviations: SD – standard deviation, DM – diabetes mellitus

Table 2: Identified barriers concerning diet, physical exercise and glycaemic control, as perceived by participants of the focus groups

Theme	Quotes
Diet	· "My biggest struggle is the diet because I enjoy eating." · "I try to have a healthy diet – but sometimes is difficult. Sometimes is really very difficult, in social dinners or lunches. One cannot manage it. (…) Trying to have a healthy diet was the most difficult thing, the hardest thing." · "I think that the biggest problem is not having the motivation to have a healthy diet." · "The family can either help or make things more difficult. My daughter is always worried with me and might call me five times a day saying "eat this, don't eat that". My husband is the opposite, always telling me to taste this and that."
Physical exercise	· "I don't like walking. I prefer sleeping; I know it's a mistake." · "I don't have the will to exercise; I end up sitting on the couch. I prefer being at home than going outside to walk." · "The doctor told me I should walk everyday after lunch but it's not practical and I don't feel like it, so I don't go." · "I'm not walking that much nowadays because my legs ache too much."
Glycaemic control	· "[one day] I had a coffee and then I came home. All didn't have anything to eat. And when I checked by blood glucose it was extremely high. I think it's the stress because I didn't have anything to eat" · "What really messes my diabetes control is the stress" · "Today I ate the right foods, I walked, I did everything right, why did the blood sugar rise so much? Is it the stress, is it the nervous system? Then, I get that feeling that I'm not in control of the disease, it's frustrating."

+

Table!3:!Identified!facilitators!and!expectations!in!the!selfAmanagement!of!type!2!diabetes,!as!stated!by!participants!of!the!focus!groups!

Subject+	Quotes+
Information! needs!	· "There!is!not!enough!information!–!there!should!be!more,! it's!a!disease!that!affects!so!many!people."! · "Lots!of!people!watch!television!or!listen!to!the!radio!so! there!should!be!more!information!about!diabetes!in!those! means!of!communication"! · "When!I!hear!something!new!about!how!to!manage!my! disease!I!try!to!take!notes.!Sometimes!I!learn!new!things! watching!a!television!show!or!talking!to!a!friend!with! diabetes."!! · "I!think!I!have!some!knowledge!about!the!disease!but!I! could!use!some!tricks!to!help!me!maintain!a!healthy!diet,! resist!temptations,!and!exercise!more."!
Family!and! social!ties!	· [about!a!healthy!diet]!"it!is!not!too!difficult!because!my!wife! and!my!kids!help!me!with!that!at!home"! · "If!it!wasn't!for!the!friend!that!goes!walking!with!me,!I! wouldn't!go.!But!then!she!motivates!me!and!I!end!up! going."!

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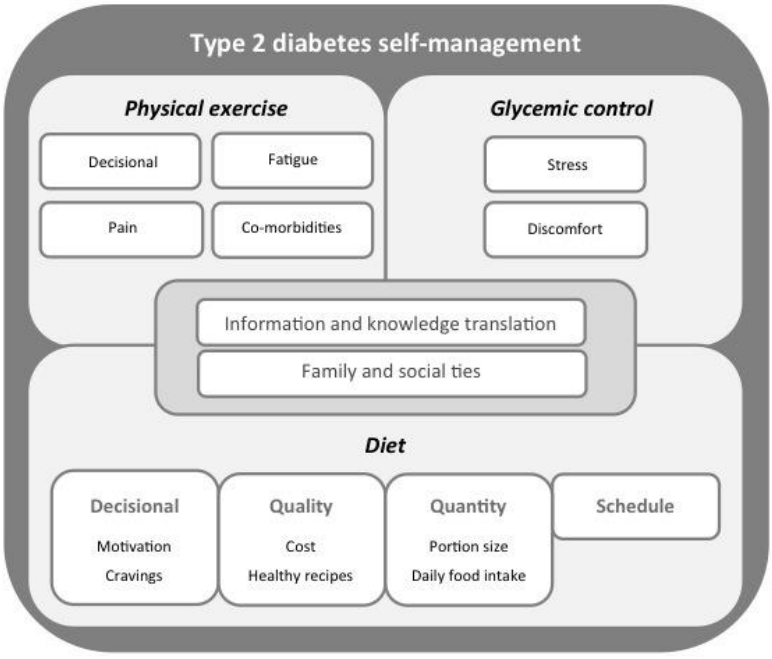

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Figure!2:!Major!themes!identified!in!the!analysis!of!the!focus!groups.!

Discussion

Main findings

To the best of our knowledge, this is the first study evaluating the facilitators, barriers and expectations of Portuguese type 2 diabetes patients, regarding the self-management of their disease. Three major themes were identified: diet, physical exercise, and glycaemic control. Information and knowledge translation, as well as family and social ties, were commonly mentioned aspects across the three themes, and were regarded as facilitators in some situations and as barriers in others.

Strengths and limitations

This study has several strengths: the use of a pre-tested interview guide, where the questions were first tested for comprehension with some patients of the target population; the fact that each session was videotaped, which enabled a richer interpretation of the results; the data analysis method, that was conducted by two independent researchers, to ensure reliability; and the fact that we addressed a previously unevaluated population in terms of their perspectives on self-management.

The results from this study need to be interpreted in the context of its study design. One can argue that the number of participants and sessions was not high or extensive enough. However, it is important to bear in mind that generalizability is not a goal of qualitative research. Rather, its objectives are to enable an in-depth exploration of the main subject, as well as to generate hypothesis, both of which we were able to achieve in this study. The fact that by the third session no new information was being collected suggests data saturation, but results should be interpreted with caution.

Another possible limitation concerns the context where the focus group sessions took place – the patients' usual place of care. Although this choice could have hampered participants' ability to speak freely, efforts were made to guarantee confidentiality and no concerns were brought up by any of the subjects interviewed.

Literature

In this study, lifestyle behaviour change appeared to be the hardest part of self-management, for the majority of participants. Specifically, diet was the richest theme in our study, an aspect that has been previously documented in the literature[31,32]. Participants seemed to lack specific information about diet and exercise that could help them implement strategies for behaviour change. Although it seemed that they had general knowledge about the importance of diet and exercise in DM management, they appeared to be missing specific guidance to actually change habits and follow self-care recommendations. In other studies, knowledge by itself has been inconsistently associated with behaviour change and health outcomes[33,34], but tailored advice and individual guidance have previously shown effectiveness and are generally valued by patients[7].

Family and social ties were viewed by the participants in this study either as barriers or as facilitators in diabetes management, depending on the circumstances. Patients described situations where they received social support in specific aspects of self-management, but also other occurrences where some family members or friends diverted them from their goals regarding diet or exercise. The importance of social contacts as either facilitators or barriers has been previously recognized[12,35,36]. Additionally, studies have demonstrated that certain behaviours have the ability to actually spread between individuals in a social network[37,38]. Therefore, understanding the social influences that are at play in each particular situation seems paramount in self-management improvement.

Participants also shared thoughts regarding the effect of stress on blood sugar control, as well as a sense of frustration and lack of control when blood sugar levels rose unexplainably. Stress and glycemic control-related aspects appear to be an important cause of concern among patients with type 2 diabetes, a fact that has been previously reported[39].

Finally, one commonly mentioned aspect was the cost of a healthy diet, which has been previously addressed in the literature[32]. The current economic and social crisis in Portugal may be exacerbating this barrier, and should be studied further.

Implications

The results from this study are important for healthcare providers, as they can be used to help them be more effective in addressing the common barriers to diabetes self-management. Tailored guidance and specific information about diet and physical exercise seem to be important in goal setting and habit modification, and should be provided regularly[40].

The primary care setting may be a successful place for the implementation of behavioural counselling interventions to promote patients' engagement with self-management behaviours, due to its proximity to the patients, easier accessibility, and continuity of care[14,41,42] . Additionally, consultations involving not only the patient with diabetes but also close family members, friends, and/or other patients, might be helpful in creating a social support network that can act as a facilitator in self-management.

Considerations for Policy Makers include the need to facilitate access to healthy foods and safe settings for exercise. Supportive environments are essential for individual-level behaviour changes(7), so public health action has a crucial role in promoting healthy lifestyles.

Future research should focus on further identifying characteristics of patients that may affect or be associated with self-management, in order to improve the tailoring of interventions. Concerning the participants' perception of lack of information and their expressed will to learn more about how to self-manage their disease, specific measures of health literacy and patient activation are now being translated, culturally adapted, and validated to this population of Portuguese patients.

Finally, we believe our results may be important in other contexts, populations, and countries, to raise awareness regarding the importance of a "needs assessment" approach preceding and accompanying every health intervention. Patient-centered care should become the focus of health care systems worldwide. The first step in that

direction is by actively listening to patients' voices, eliciting their perspectives, and engaging them in the process of continuous health care improvement.

Conclusion

To the best of our knowledge, this is the first study evaluating the facilitators, barriers and needs of Portuguese type 2 diabetes patients, regarding the self-management of their disease. While revealing similar barriers and facilitators to those encountered in the international literature, this study has also highlighted the need for a more robust support of diabetes education and self-management, while identifying the priority areas of attention to do so.

References

1. Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes - estimates for the year 2000 and projections for 2030. Diabetes Care. 2004;27(5):1047–53.
2. Observatório Nacional da Diabetes. Diabetes: Factos e Números 2013 - Relatório Anual do Observatório Nacional da Diabetes. Sociedade Portuguesa de Diabetologia; 2014.
3. Cortez-Dias N, Martins S, Belo A, Fiuza M. Prevalence, management and control of diabetes mellitus and associated risk factors in primary health care in Portugal. Rev Port Cardiol. 2010;29(4):509–37.
4. Alberti K, Zimmet P. Definition, diagnosis and classification of diabetes mellitus and its complications. Part 1: diagnosis and classification of diabetes mellitus provisional report of a WHO consultation. Diabet Med. 1998;15(7):539–53.
5. UK Prospective Diabetes Study Group. Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. BMJ. 1998;317(7160):703–13.
6. Tricco A, Ivers N, Grimshaw J, Moher D, Turner L, Galipeau J. Effectiveness of quality improvement strategies on the management of diabetes: a systematic review and meta-analysis. Lancet. 2012;379(9833):2252–62.
7. Glanz K, Rimer B, Viswanath K. Health Behavior and Health Education. 4th ed. San Francisco: John Wiley & Sons; 2008.
8. Narayan KMV, Ali MK, Koplan JP. Global noncommunicable diseases-where worlds meet. N Engl J Med. 2010 Sep 23;363(13):1196–11988.
9. Haas L, Maryniuk M, Beck J, Cox C, Duker P, Edwards L. National Standards for Diabetes Self-Management Education and Support. Diabetes Care. 2012;36(Supplement 1):S100–8.
10. Norris S, Engelgau M, Narayan K. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. Diabetes Care. 2001;24(3):561–87.
11. Golin C, DiMatteo M, Gelberg L. The role of patient participation in the doctor visit. Implications for adherence to diabetes care. Diabetes Care. 1996;19(10):1153–64.

12. Vermeire E, Hearnshaw H, Rätsep A, Levasseur G, Petek D, van Dam H. Obstacles to adherence in living with type-2 diabetes: An international qualitative study using meta-ethnography (EUROBSTACLE). Prim Care Diabetes. 2007;1(1):25–33.

13. Vermeire E, van Royen P, Coenen S, Wens J, Denekens J. The adherence of type 2 diabetes patients to their therapeutic regimens: a qualitative study from the patient's perspective. Pract Diabetes Int. 2003;20(6):209–14.

14. Davies M, Heller S, Skinner T, Campbell M, Carey M, Cradock S. Effectiveness of the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed type 2 diabetes: cluster randomised controlled trial. BMJ. 2008;336(7642):491–5.

15. Fisher E, Boothroyd R, Coufal M, Baumann L, Mbanya J. Peer support for self-management of diabetes improved outcomes in international settings. Health Aff. 2012;31(1):130–9.

16. Glasgow R, Fisher L, Skaff M, Mullan J, Toobert D. Problem solving and diabetes self-management: Investigation in a large, multiracial sample. Diabetes Care. 2007;30(1):33–7.

17. Hill-Briggs F. Problem solving in diabetes self-management: A model of chronic illness self-management behavior. Ann Behav Med. 2003;25(3):182–93.

18. King D, Glasgow R, Toobert D, Strycker L, Estabrooks P, Osuna D, et al. Self-Efficacy, problem solving, and social-environmental support are associated with diabetes self-management behaviors. Diabetes Care. 2010;33(4):751–3.

19. Raffle H, Ware L, Ruhil A, Hamel-Lambert J, Denham S. Predictors of daily blood glucose monitoring in Appalachian Ohio. Am J Health Behav. 2012;36(2):193–202.

20. Skelly A, Arcury T, Snively B, Bell R, Smith S, Wetmore L, et al. Self-monitoring of blood glucose in a multiethnic population of rural older adults with diabetes. Diabetes Educ. 2005;31(1):84–90.

21. Gao J, Wang J, Zheng P, Haardörfer R, Kegler M, Zhu Y, et al. Effects of self-care, self-efficacy, social support on glycemic control in adults with Type 2 diabetes. BMC Fam Pract. 2013;14(66).

22. Nagelkerk J, Reick K, Meengs L. Perceived barriers and effective strategies to diabetes self-management. J Adv Nurs. 2006;54(2):151–8.

23. Booth A, Lowis C, Dean M, Hunter S, McKinley M. Diet and physical activity in the self-management of type 2 diabetes: barriers and facilitators identified by patients and health professionals. Prim Heal Care Res Dev. 2013;14(3):293–306.

24. Entidade Reguladora da Saúde. Cuidados de Saúde a Portadores de Diabetes Mellitus. Lisboa; 2011.

25. Hearnshaw H, Wright K, Dale J, Sturt J, Vermeire E, van Royen P. Development and validation of the Diabetes Obstacles Questionnaire (DOQ) to assess obstacles in living with Type 2 diabetes. Diabet Med. 2007;24(8):878–82.

26. Morgan D. Focus Groups as Qualitative Research. 2nd ed. Thousand Oaks California: SAGE Publications, Inc; 1997.

27. Krueger R, Casey M. Focus Groups: A Practical Guide for Applied Research. 4th ed. Thousand Oaks California: SAGE Publications, Inc; 2000.

28. Lincoln Y, Guba E. Naturalistic Inquiry. Beverly Hills, CA: SAGE Publications, Inc; 1985.

29. Taylor S, Bogdan R. Introduction to Qualitative Research Methods: The Search for Meanings. New York: Wiley; 1984.

30. Vermeire E, van Royen P, Griffiths F. The critical appraisal of focus group research articles. Eur J Gen Pract. 2002;8(3):104–8.

31. Hill-Briggs F, Cooper D, Loman K, Brancati F, Cooper L. Qualitative Study of Problem Solving and Diabetes Control in Type 2 Diabetes Self-Management. Diabetes Educ. 2003;29(6):1018–28.

32. Vijan S, Stuart N, Fitzgerald J, Ronis D, Hayward R, Slater S. Barriers to following dietary recommendations in Type 2 diabetes. Diabet Med. 2005;22(1):32–8.

33. Heisler M, Piette J, Spencer M, Kieffer E, Vijan S. The relationship between knowledge of recent HbA(1c) values and diabetes care understanding and self-management. Diabetes Care. 2005;28(4):816–22.

34. Persell S, Keating N, Landrum M, Landon B, Ayanian J, Borbas C. Relationship of diabetes-specific knowledge to self-management activities, ambulatory preventive care, and metabolic outcomes. Prev Med. 2004;39(4):746–52.

35. Mayberry L, Osborn C. Family support, medication adherence, and glycemic control among adults with type 2 diabetes. Diabetes Care. 2012;35(6):1239–45.

36. Dye C, Haley-Zitlin V, Willoughby D. Insights From Older Adults With Type 2 Diabetes: Making Dietary and Exercise Changes. Diabetes Educ. 2003;29(1):116–27.

37. Christakis N a, Fowler JH. The spread of obesity in a large social network over 32 years. N Engl J Med. 2007 Jul 26;357(4):370–9.

38. Rosenquist J, Murabito J, Fowler J, Christakis N. The Spread of Alcohol Consumption Behavior in a Large Social Network. Ann Intern Med. 2010;152:426–33.

39. Furler J, Walker C, Blackberry I, Dunning T, Sulaiman N, Dunbar J. The emotional context of self-management in chronic illness: A qualitative study of the role of health professional support in the self-management of type 2 diabetes. BMC Heal Serv Res. 2008;8:214.

40. Norris S, Lau J, Smith S, Schmid C, Engelgau M. Self-management education for adults with type 2 diabetes: a meta-analysis of the effect on glycemic control. Diabetes Care. 2002;25(7):1159–71.

41. Whitlock E, Orleans C, Pender N, Allan J. Evaluating primary care behavioral counseling interventions: an evidence-based approach. Am J Prev Med. 2002;22(4):267–84.

42. Renders C, Valk G, Griffin S, Wagner E, Eijk Van J, Assendelft W. Interventions to improve the management of diabetes in primary care, outpatient, and community settings: a systematic review. Diabetes Care. 2001;24(10):1821–33.

Paper IV

Internet use by Portuguese patients with type 2 diabetes mellitus – association with demographic and clinical characteristics

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All the authors contributed substantially to the design of the study and the acquisition, analysis and/or interpretation of data. The paper was drafted by the first author and critically reviewed by all the remaining authors.

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Internet use by Portuguese patients with type 2 diabetes mellitus – association with demographic and clinical characteristics

Abstract

Background and aim

Web-based interventions for diabetes self-management have been shown to contribute to improved outcomes at many levels. However, a digital divide exists, which may be responsible for increased disparities between those who have access to information technology, and those who do not.

We aimed to evaluate current access and use of information technology by patients with type 2 diabetes, as well as analyze possible characteristics associated with increased frequency of Internet use.

Methods

Cross-sectional study using a pre-tested questionnaire in a sample of patients with type 2 diabetes. The most recent result of glycated hemoglobin (A1C) was collected from electronic health records. Activation level was measured by the Portuguese version of the Patient Activation Measure-13.

Results

There were 205 respondents and the response rate was 83%. The mean age was 67.0 (±10.0), 42.5% of respondents were female, and mean PAM score (0-100) was 58.5 (± 10.1). In this sample, 42.7% of respondents had a computer at home, and 47% had Internet available at home. Additionally, 63.5% (n=127) reported that they used the Internet less than once monthly; 36.5% (n=73) used it one or more times per month. Less frequent users of the Internet were older and had a lower level of education.

Conclusion

There appears to exist a digital divide in patients with type 2 diabetes, especially amongst elderly and less educated individuals. Policy makers should be mindful of gaps in IT accessibility, in order to prevent the exacerbation of health disparities in this population.

Background

Diabetes Mellitus (DM) is a highly prevalent chronic disease worldwide and one of the most challenging health problems in the 21st century[1]. In Portugal, the prevalence of diabetes has been rapidly increasing[2]. It is known that adherence to medication and lifestyle recommendations can significantly reduce the morbidity and mortality associated with the disease[3]. Interventions aimed at promoting self-management are known to be amongst the most effective in improving metabolic control[4].

Interest in the use of information technology (IT) to facilitate self-management and promote patient empowerment is rapidly increasing[5–10]. Its advantages include convenient and easy access to real-time information and education, as well as the ability to reach distant and large audiences, using fewer human resources than traditional interventions[11].

Literature on web-based interventions for diabetes self-management is promising, showing improvements in patient activation, health care utilization, self-care behaviors, self-efficacy, health status, and hemoglobin A1c, among others[11–20].

However, the internet also brings the danger of widening health disparities, due to the digital divide (the gap that exists between people who do and those who do not have access to modern information technology)[21–24].

Although reports indicate that access to information technology is steadily rising in Portugal, it is also known that adoption of these tools remains much lower among the elderly[25]. Furthermore, research shows that use of the internet for health purposes is much lower amongst the less educated, in Portugal[26,27].

This study aimed to evaluate current access and use of information technology by patients with type 2 diabetes, as well as analyze possible characteristics associated with increased frequency of Internet use in this population.

Methods

Participants and setting

Participants were recruited from the waiting rooms of the Portuguese Diabetes Association (APDP-Diabetes) outpatient clinic, in Lisbon, between March and April 2014.

This study was conducted as part of a larger project aiming at validating the Patient Activation Measure-13 (PAM-13)[28,29] in Portuguese patients with type 2 DM.

Eligibility criteria included being diagnosed with type 2 DM, registered at the clinic, fluent in Portuguese, and 18 years of age or older. Patients with dementia, blindness, deafness or inability to give informed consent were excluded. Patients who refused to participate were characterized in terms of gender and age group.

All participants gave written informed consent for participating in the study. No incentives were given to the participants. Ethical approval of the study was granted by the Ethics Committee of APDP-Diabetes.

Study design

A paper questionnaire was developed for self-administration, including demographic and disease-specific questions, the Portuguese PAM-13 (PAM13-P), and questions to determine participants' access and use of computers and the Internet.

Demographic questions were used to assess age, gender, educational level and current occupation. Educational level was assessed using multiple categories, which were later grouped into the variable 'schooling years', with four categories (≤4;]4-9];]9-12]; >12). Current occupation was grouped into three categories ('retired', 'employed', or 'unemployed'), for simplicity. Disease-specific questions evaluated diabetes duration (in years) and current medication (none, oral antidiabetics and/or insulin). Having a computer and/or Internet available at home were assessed by 'yes or no' questions. Use of the Internet was assessed using ordinal response categories that varied between never and everyday; these categories were then collapsed into a binary variable for the purpose of analyses (frequency of internet use: 'less than one time per month' and 'at least once monthly'). The 0-100 PAM score corresponds to a level of activation, from 1 to 4 (stage 1: ≤47; stage 2: 47.1 to 55.1; stage 3: 55.2 to 67; stage 4: ≥67.1)[28].

Cognitive debriefing interviews were conducted to assess the general comprehension of the instrument by the target population. Three pre-tests were conducted (n=5, n=207, n=15); differences between versions were mostly related with the formatting

of the questionnaire (e.g. increasing the font size and spacing), to decrease respondent burden.

The final questionnaire was applied in the waiting rooms of APDP-Diabetes during 6 working days in March and April 2014. The most recent result of glycated hemoglobin (A1C) was collected from the electronic health record for each patient, by a physician blinded to the results of the questionnaire.

Analyses and statistical methods

Continuous variables were evaluated for normality by observing their distribution, means, medians, skewness, kurtosis, and Wilk-Shapiro test.

T-tests were used to compare the means of continuous variables between the two groups of Internet use. Chi-square tests were used to test the association between dependent categorical variables and Internet use.

Respondents with 'perfect scores' in the PAM (people who replied 'totally agree' to all 13 questions) were analyzed to distinguish between ceiling effects and 'response set' (automated responses). In case 'response set' was thought to be present, their PAM scores were not considered valid, which was the case for eight respondents.

Rasch analyses were conducted in Winsteps v3.8.1® (Rasch Measurement Software, Chicago, IL, USA). All other analyzes were performed using Statistical Package for the Social Sciences v21®. An alpha level of $p \leq 0.05$ was used for tests of statistical significance.

Results

There were 205 respondents; the response rate was 83%. The 63 individuals who declined the invitation to participate were found to be similar to the respondents in terms of gender (p=1.00) and age group (p=0.88). Four questionnaires were excluded before analysis: two individuals who were not able to complete the questionnaire due to poor vision, and two others that left the questionnaire blank after agreeing to participate. Therefore, the final number of respondents in the analyses was 201.

Characteristics of the study population

The characteristics of the study population are summarized in Table 1. The mean age was 67.0 (±10.0) and 42.5% of respondents were female. In terms of occupation, 75.5% were retired; 43.5% had 4 years of schooling or less. Mean A1c value was 8%, and mean diabetes duration was approximately 17 years.

Mean PAM score (0-100) was 58.5 (± 10.1). In terms of activation stage, 11.5% and 28% were in stages 1 and 2, respectively (low activation); 39.4% were in stage 3; and 20.7% were in the highest stage of activation (stage 4).

Amongst the 201 respondents, 42.7% had a computer at home, and 47% had Internet available at home. Additionally, 63.5% (n=127) reported that they used the Internet (at any location) less than once monthly; 36.5% (n=73) used it one or more times per month.

Internet use

There were no statistically significant differences in gender between the two groups of Internet use. Of those who used the Internet at least once monthly, the great majority did not have computer (97.3%) or Internet (94.5%) at home. In contrast, amongst patients who used the Internet less than once monthly, 65.9% had a computer at home, and 70.9% had Internet at home.

Respondents who used the Internet more than once monthly were younger (p=0.001), had slightly lower A1c values (7.7 versus 8.1; p=0.141), and higher PAM scores (58.7 versus 58.3; p=0.826). Furthermore, a higher proportion (21.9%) of these respondents was employed (compared to 10.2% in the group using the Internet less often), and a lower proportion was retired (64.4% versus 81.9%; p=0.001).

The number of years of schooling tended to be lower in respondents who used the internet less than once monthly: 59.8% had 4 or less years of education (compared to 15.1% in the group of higher Internet use), and 3.9% (versus 34.2%) had more than 12 years of schooling (p<0.001).

Table 1: Characteristics of the 201 respondents, by frequency of Internet use

	Internet use (times per month)		
Characteristic	**< 1**	**≥1**	Total

		(n= 127)		(n= 73)				
		Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)	n	(%)
Gender	Female		60 (47.2)		25 (34.2)		85	(42.5)
	Male		67 (52.8)		48 (65.8)		115	(57.5)
Age	(years)	68.7 (±8.7)	127*	63.9 (±11.3)	73*	67.0 (±10.0)	200*	
Years of schooling	≤ 4		76 (59.8)		11 (15.1)		87	(43.5)
	]4; 9]		33 (26.0)		19 (26.0)		52	(26.0)
	]9; 12]		13 (10.2)		18 (24.7)		31	(15.5)
	>12		5 (3.9)		25 (34.2)		30	(15.0)
Occupation	Retired		104 (81.9)		47 (64.4)		151	(75.5)
	Employed		13 (10.2)		16 (21.9)		29	(14.5)
	Unemployed		10 (7.9)		10 (13.7)		20	(10.0)
A1c	(%)	8.1 (±0.2)	107*	7.7 (±0.19)	65*	8.0 (±1.6)	172*	
Diabetes duration	(years)	18.9 (±1.0)	127*	16.2 (±1.3)	73*	17.3 (±10.1)	200*	
Oral diabetes medication	Yes		100 (78.7)		56 (76.7)		156	(78.0)
	No		27 (21.3)		17 (23.3)		44	(22.0)
Insuline use	Yes		78 (61.4)		40 (54.8)		118	(59.0)
	No		49 (38.6)		33 (45.2)		82	(41.0)
Mean PAM score	(0-100)	58.3 (±9.7)	124*	58.7 (±10.9)	69*	58.5 (±10.1)	193*	
Computer at home	Yes		83 (65.9)		2 (2.7)		85	(42.7)
	No		43 (34.1)		71 (97.3)		114	(52.3)
Internet at home	Yes		90 (70.9)		4 (5.5)		94	(47.0)
	No		37 (29.1)		69 (94.5)		106	(53.0)

Abbreviations: SD, standard deviation

* Represents the total number of individuals for which there were valid data concerning each continuous variable

Discussion

To the best of our knowledge, this is the first study analyzing access and use of IT by Portuguese patients with type 2 diabetes. Our sample had a mean age of 67.0 (±10.0) years, and 42.5% were female. Approximately half of the respondents reported having access to computer and Internet at their home, but close to two thirds reported using the internet less than once monthly. Less frequent users of the Internet were older and had a lower level of education.

Our results are in line with published research showing an inverse association of IT use with age, as well as a direct association with educational level, in patients with diabetes[9,30,31].

Barriers to computer use in patients with type 2 diabetes may include lack of access to a computer, lack of digital literacy, and absence of interest in IT[30]. In our study, the majority of patients who used the Internet at least monthly reported not having a

computer or Internet at home. Since a considerable proportion of these patients was employed, it is possible that the working place is one of the points of access these patients are using to go online. Other possible locations are public spaces (e.g. libraries, community centers), which have been reported to be frequently used by patients to search health-related information[9,30].

Another interesting aspect in our study was that around 70% of patients who rarely used the Internet had in fact a computer and Internet at home, possibly used by others in the household. This suggests that lack of digital literacy may be a more important contributor for less frequent use of the Internet in this population, than lack of access. Nevertheless, having others in the household who are digitally literate and able to access the internet may mean these patients could potentially benefit from the help of caretakers in using health information technology (HIT) to manage their illness.

Studies have shown that among patients not knowing how to use a computer, a great proportion of them would be willing to learn[30], and would consider using IT to manage their diabetes[31]. Promising research has also shown that older age and lack of IT familiarity were not barriers to access and use of diabetes-related health information systems[31–33], and there is evidence that these systems are able to improve diabetes control in such patients[19,34]. Indeed, there is a growing body of literature regarding the use of IT for chronic disease self-management in older adults, with encouraging results[35,36].

Finally, although we found no association between activation and internet use, previous studies have shown that patients with higher activation levels used the internet more often as a source of health information[37,38]. Future research should continue to explore the potential relationship between patient activation and IT use, especially regarding health-related purposes.

Strengths and limitations

Strengths of this study include a good response rate, and the absence of age and gender differences between respondents and non-respondents, which minimizes selection bias.

One important limitation of this study is the lack of socioeconomic status data, which is known to be associated with internet access and use[9]. Furthermore, ethnicity data is not usually allowed to be collected in Portugal, hampering a comprehensive analysis of health care disparities in ethnic minority groups.

Lastly, it is important to bear in mind that access and use of IT by patients with type 2 diabetes is likely overestimated in our study, since we only surveyed patients who were able to read and write Portuguese.

Implications of this study

The results of this study have important implications for clinicians, policy-makers, and researchers.

From a clinical practice perspective it is important to have an understanding of patients' potential difficulties in accessing and navigating a more digitized health care system. Despite increasing availability and use of IT, a considerable proportion of patients with diabetes is still unable to access the internet. Clinicians should be attentive to this aspect so that care can be tailored to patients' needs, and help may be provided to overcome existing barriers.

From a health policy perspective, these results should draw attention to the potential increase in health care disparities resulting from the digital divide. Unless there is concerted effort to improve public availability of IT, and to minimize barriers to internet use by people with lower digital literacy, HIT may exacerbate current health disparities[39]. Furthermore, design of HIT interventions should be considerate of all populations, ensuring good usability and easy understanding by people with different levels of education[40].

Future research should further characterize the digital divide in Portuguese patients with type 2 diabetes. Additionally, given the wide availability of mobile phones in the country, their use should be further explored in HIT interventions for this population.

Conclusion

There appears to exist a digital divide in patients with type 2 diabetes, especially amongst elderly and less educated individuals. As health care progresses into a digital era, further attention should be drawn to this issue, in order to prevent the widening of health disparities in this population.

References

1. Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes - estimates for the year 2000 and projections for 2030. Diabetes Care. 2004;27(5):1047–53.
2. Observatório Nacional da Diabetes. Diabetes: Factos e Números 2013 - Relatório Anual do Observatório Nacional da Diabetes. Sociedade Portuguesa de Diabetologia; 2014.
3. UK Prospective Diabetes Study Group. Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. BMJ. 1998;317(7160):703–13.
4. Tricco A, Ivers N, Grimshaw J, Moher D, Turner L, Galipeau J. Effectiveness of quality improvement strategies on the management of diabetes: a systematic review and meta-analysis. Lancet. 2012;379(9833):2252–62.
5. Samoocha D, Bruinvels DJ, Elbers N a., Anema JR, van der Beek AJ. Effectiveness of web-based interventions on patient empowerment: a systematic review and meta-analysis. J Med Internet Res. 2010;12(2):1–21.
6. Murray E, Burns J, See T, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. Cochrane Database Syst Rev. 2009;(1):e40.
7. Mazzi CP, Kidd M. A framework for the evaluation of Internet-based diabetes management. J Med Internet Res. 2002;4(1):5–16.
8. Bull SS, Gaglio B, McKay HG, Glasgow RE. Harnessing the potential of the internet to promote chronic illness self-management: diabetes as an example of how well we are doing. Chronic Illn. 2005;1:143–55.
9. Cho AH, Edelman DE, Hartwell PH, Oddone EZ, Yancy WS, Carolina N. Do Diabetic Veterans Use the Internet ? Telemed J E Health. 2010;16(5):595–602.
10. Nagykaldi Z, Aspy CB, Chou a., Mold JW. Impact of a Wellness Portal on the Delivery of Patient-Centered Preventive Care. J Am Board Fam Med. 2012;25(2):158–67.
11. Solomon M, Wagner SL, Goes J. Effects of a Web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial. J Med Internet Res. 2012 Jan;14(1):e32.
12. Jackson CL, Bolen S, Brancati FL, Batts-Turner ML, Gary TL. A systematic review of interactive computer-assisted technology in diabetes care: Interactive information technology in diabetes care. J Gen Intern Med. 2006;21:105–10.
13. Costa BM, Fitzgerald KJ, Jones KM, Dunning Am T. Effectiveness of IT-based diabetes management interventions: a review of the literature. BMC Fam Pract. 2009;10:72.
14. Balas E a, Boren S a, Griffing G. Computerized management of diabetes: a synthesis of controlled trials. Proc AMIA Symp. 1998;295–9.
15. Cho JH, Chang SA, Kwon HS, Choi YH, Ko SH, Moon SD, et al. Long-term effect of the internet-based glucose monitoring system on HbA1c reduction and glucose stability: A 30-month

follow-up study for diabetes management with a ubiquitous medical care system. Diabetes Care. 2006;29(12):2625–31.

16. Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VBB, et al. Online Diabetes Self-Management Program. Diabetes Care. 2010;33(6):1275–81.

17. Cotter AP, Durant N, Agne A a, Cherrington AL. Internet interventions to support lifestyle modification for diabetes management: A systematic review of the evidence. J Diabetes Complications. 2014;28:243–51.

18. Osborn CY, Mayberry LS, Mulvaney SA, Hess R. Patient web portals to improve diabetes outcomes: A systematic review. Curr Diab Rep. 2010;10(6):422–35.

19. McMahon GT, Gomes HE, Hohne SH, Hu TMJ, Levine BA, Conlin PR. Web-based care management in patients with poorly controlled diabetes. Diabetes Care. 2005;28:1624–9.

20. Noh J-H, Cho Y-J, Nam H-W, Kim J-H, Kim D-J, Yoo H-S, et al. Web-based comprehensive information system for self-management of diabetes mellitus. Diabetes Technol Ther. 2010;12(5):333–7.

21. Hsu J, Huang J, Kinsman J, Fireman B, Miller R, Selby J, et al. Use of e-Health services between 1999 and 2002: A growing digital divide. J Am Med Informatics Assoc. 2005;12:164–71.

22. Brodie M, Flournoy RE, Altman DE, Blendon RJ, Benson JM, Rosenbaum MD. Health information, the Internet, and the digital divide. Health Aff. 2000;19:255–65.

23. Mandl KD, Feit S, Peña BM, Kohane IS. Growth and determinants of access in patient e-mail and Internet use. Arch Pediatr Adolesc Med. 2000;154(May 2000):508–11.

24. Green BB, Cook AJ, Ralston JD, Fishman PA, Catz SL, Carlson J, et al. Effectiveness of home blood pressure monitoring, Web communication, and pharmacist care on hypertension control: a randomized controlled trial. JAMA. 2008;299(24):2857–67.

25. Instituto Nacional de Estatistica - Statistics Portugal. Inquérito à Utilização de Tecnologias da Informação e da Comunicação pelas Famílias. 2012.

26. Santana S. Trends of internet use for health matters in Portugal: 2005-2007. Acta Med Port. 2009;22:5–14.

27. Santana S, Sousa Pereira A. On the use of the Internet for health and illness issues in Portugal: repercussions in the physician-patient relationship. Acta Med Port. 2007;20:47–57.

28. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res. 2005 Dec;40(6 Pt 1):1918–30.

29. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004 Aug;39(4 Pt 1):1005–26.

30. Jackson CL, Batts-Turner ML, Falb MD, Yeh H-C, Brancati FL, Gary TL. Computer and internet use among urban African Americans with type 2 diabetes. J Urban Health. 2005;82(4):575–83.

31. Watson AJ, Bell AG, Kvedar JC, Grant RW. Reevaluating the digital divide: Current lack of internet use is not a barrier to adoption of novel health information technology. Diabetes Care. 2008;31(3):433–5.

32. Feil EG, Glasgow RE, Boles S, McKay HG. Who participates in Internet-based self-management programs? A study among novice computer users in a primary care setting. Diabetes Educ. 2000;26:806–11.

33. Adaji A, Schattner P, Jones K. The use of information technology to enhance diabetes management in primary care: A literature review. Inform Prim Care. 2008;16:229–37.

34. Bond GE, Burr R, Wolf FM, Price M, McCurry SM, Teri L. The effects of a web-based intervention on the physical outcomes associated with diabetes among adults age 60 and older: a randomized trial. Diabetes Technol Ther. 2007;9(1):52–9.

35. Irvine AB, Gelatt VA, Seeley JR, Macfarlane P, Gau JM. Web-based intervention to promote physical activity by sedentary older adults: Randomized controlled trial. J Med Internet Res. 2013;15(2).

36. Stellefson M, Chaney B, Barry AE, Chavarria E, Tennant B, Walsh-Childers K, et al. Web 2.0 chronic disease self-management for older adults: A systematic review. Journal of Medical Internet Research. 2013.

37. Nijman J, Hendriks M, Brabers A, de Jong J, Rademakers J. Patient Activation and Health Literacy as Predictors of Health Information Use in a General Sample of Dutch Health Care Consumers. J Health Commun. 2014;(March 2014):37–41.

38. Smith SG, Pandit A, Rush SR, Wolf MS, Simon C. The association between patient activation and accessing online health information: results from a national survey of US adults. Heal Expect. 2014;n/a – n/a.

39. Viswanath K, Kreuter MW. Health Disparities, Communication Inequalities, and eHealth. Am J Prev Med. 2007;32:1–4.

40. Gammon D, Berntsen GKR, Koricho AT, Sygna K, Ruland C. The Chronic Care Model and Technological Research and Innovation: A Scoping Review at the Crossroads. J Med Internet Res. 2015;17(2):e25.

Paper V

Adoption of a national integrated Personal Health Record in Portugal - Who are the early adopters?

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All the authors contributed substantially to the design of the study and the acquisition, analysis and/or interpretation of data. The paper was drafted by the first author and critically reviewed by all the remaining authors.

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Adoption of a national integrated Personal Health Record in Portugal –

Who are the early adopters?

Abstract

Background and aim

Personal Health Records (PHRs) are increasingly being deployed worldwide, but their rates of adoption by patients vary widely across countries and health systems. In 2012, an integrated web-based PHR was implemented in Portugal, named 'Portal do Utente'. We aimed to evaluate the adoption of this PHR, namely by analysing registered patients and their use of the system to input and manage health information.

Methods

Cross-sectional study of patients who were registered in the PHR by June 2013. Users of the PHR were compared with non-users with regard to demographic and clinical variables, and were further categorized and analysed according to their intensity of PHR use, measured by the quantity of health information they contributed to the system.

Results

A total of 110,529 people were registered in the PHR at the time of study (mean age: 44.7 ± 18.1 years; 60.5% women). Approximately 17% of registered people were considered users of the system. There were a total of 45,039 data entries for height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol, triglycerides, allergies and emergency contacts. People engaging in comprehensive use of the PHR totalled 12,549. People with two or more health problems and those taking one or more medications had higher odds of engaging in comprehensive use of the system.

Conclusions

This study adds insight to the growing body of evidence on the adoption and use of PHRs, suggesting some of the early adopters of this particular PHR may include chronic patients in greatest need of health care.

Background

Patient-centered care and health information technology are increasingly being recognized as crucial components of quality improvement efforts[1], particularly in chronic care[2].

One of the aspects of patient-centered care that is gaining increasing attention is the access of patients to their medical records. Indeed, putting patients in control of their health information has been advocated as one of the solutions for the fragmentation of health care[1]. Increasing patient participation in care is especially important given the growing burden of chronic illness[3].

In this context, Personal Health Records (PHRs) are gaining momentum, as electronic applications that enable individuals to access, manage and share their health information in a private, secure and confidential environment[4]. There are three main types of PHRs[4–10]: 1) stand-alone, in which content is solely uploaded by the user; 2) tethered, which are 'patient portals' based on the health care provider's Electronic Health Record (EHR); and 3) integrated, patient-controlled electronic health records where content may be uploaded from multiple caregivers and different sources.

Evidence regarding the effectiveness of PHRs for improving the quality of health care is increasing[11–14]. Published literature suggests PHRs may lead to improvements in communication with health care providers[15–17], medication safety[17–19], medication adherence[20–22], satisfaction with care[6,15], and also in several processes of care[23–27], among other benefits. Furthermore, PHRs are increasingly being used in chronic disease management, showing promising results[6,28], namely in diabetes[29].

Nevertheless, despite the increasing deployment of PHRs by health care institutions and governments worldwide, their adoption by patients has remained slower than expected[30–37]. Therefore, understanding the individual factors that impact PHR adoption is a crucial step in the PHR research agenda[36].

Five main categories of adopters are usually considered when evaluating the diffusion of innovations: innovators, early adopters, early majority, late majority, and

laggards[38]. Characterizing the early adopters of PHRs is one of the primordial steps in delineating an informed strategy for the promotion of PHR use.

In July 2012, a web-based PHR ('Portal do Utente') was launched in Portugal, provided freely by the Ministry of Health. During the first year of deployment, 'Portal do Utente', evolved from a stand-alone platform to an integrated PHR, with increased functionalities.

The present study aimed at assessing the current adoption of the Portuguese PHR 'Portal do Utente', namely by analysing the frequency and geographic distribution of registrations as of July 2013. A further aim was to assess the key characteristics of the early adopters of the PHR, namely in terms of their demographic characteristics, number of health problems, number of medications taken, and frequency of PHR use.

Methods

The Personal Health Record

The PHR 'Portal do Utente' is a web-based platform provided freely by the Ministry of Health. It was created as part of a national strategy to promote the development and implementation of an interoperable health IT infrastructure, based on a national data-sharing platform.

The architecture adopted for the PHR 'Portal do Utente' and for the national data-sharing platform draws on the one implemented in England for the PHR 'HealthSpace' and for the data-sharing platform 'Summary Care Record' (SCR, a platform of 'shared electronic patient records', created by uploading data from clinicians' EHRs)[39]. In both countries, the PHRs were implemented in an opt-in model, meaning that people had to actively sign up if they wanted to have an account, and the data-sharing platforms were created in an opt-out model, meaning that there was implied consent for the creation of a record for each person[40].

One important factor that facilitates health data aggregation in Portugal is that patients registered with the National Health Service (NHS) have a unique patient identifier (NHS

number), which enables the correct integration of individual health data originating from different health care institutions.

In July 2013, when this study was conducted, the PHR allowed patients to input their health information (e.g. health problems, chronic medication, biometric measurements) and book primary care consultations (through an ebooking system). At that time, data integration between the PHR and the data-sharing platform was residual and very few patients had access to a summary of their medical record (summary records were still being developed and were not available for the majority of patients; furthermore, access was only possible via an e-card reader, a device not commonly used and rarely owned by the general public in Portugal).

Study design

This was a cross-sectional study analysing individual-level data from a PHR. Data collection was performed in July 2013 by the information technology services of the Ministry of Health (Serviços Partilhados do Ministério da Saúde). The dataset provided to the research team was de-identified (a pseudonymised identifier was used for each individual patient).

Individual-level data from patients registered in the PHR were collected regarding the following variables: age, gender, region and district of residence, chronic conditions, chronic medication, and number of times information had been entered in specific PHR fields (emergency contacts, allergies, height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol, triglycerides). Data on age, gender, and residence are automatically populated in the PHR for each patient upon registration (these administrative data are associated with each NHS number). Remaining variables were collected from information entered by patients in the PHR.

Since patients may access 'Portal do Utente' for the single purpose of booking primary care consultations, not making use of more PHR-specific features (e.g. recording and managing personal health information), we decided not to use logins as a proxy for PHR adoption, and focused instead on the actual input of information by patients to the platform.

For the purpose of this study, registered individuals were defined as having an account created in the PHR, independently of their actual use of the platform to input information. On the contrary, registered 'users' were defined as patients that had entered information in at least one of the following fields: allergies, emergency contacts, height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol or triglycerides levels. Registered 'non-users' were defined as the individuals who had signed up for an account in 'Portal do Utente', but who had not entered any information in the PHR at the time of the study.

Among registered users, we defined 'limited use' as the input of only one piece of information regarding any of the fields mentioned above (allergies, emergency contacts, height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol, or triglycerides). If more than one piece of information had been entered on different occasions, this was considered 'comprehensive use', for the purposes of this study (e.g. more than one entry of blood pressure, on different logins). We reasoned that allergies and emergency contacts were likely to be updated less often than other fields in the PHR, and they were therefore given a weight three times lower, when combining the individual variables.

In summary, we analysed data from all individuals registered in the PHR: firstly, we compared users (those who had some information added to the PHR, regarding specific variables) with non-users (those who had never entered information in those fields of the PHR); secondly, we focused on users, and classified their usage pattern into 'limited use' or 'comprehensive use', for further analysis. We hypothesized that multimorbidity and polymedication would be associated with 'comprehensive use' of the PHR.

The study had approval by the Ethics Committee of Lisbon's Medical School.

Statistical analysis

SAS statistical software (version 9.2; SAS Institute, Inc, Cary, North Carolina) was used for all analyses. The distribution of continuous variables was checked for normality, and means and standard deviations were calculated; proportions and counts were calculated for categorical variables. Chi-square tests were used to compare the characteristics of non-users and users. Univariate logistic regression models of the odds

of being a frequent user as a function of each individual predictor were used to calculate crude odds ratios. Multivariate logistic regression was used to model the probability of being a frequent user as a function of age category, gender, region of residence, number of health problems (categorical variable) and number of medications (categorical variable). The ArcMap functionality of ArcGis (version 10; ESRI) was used to create maps of the proportion of PHR registrations by region and district.

Results

Use of the PHR

We identified 109,619 individuals registered in 'Portal do Utente' (60.5% women; mean age: 44.7 ± 18.1 years) (Table 1). The highest proportion of registrations was observed in the age category from 30 to 39 years of age (23.5%). The districts with the highest number of registered individuals were Lisbon and Oporto (Figure 1).

Amongst the 109,619 registered individuals, 91,115 had not yet entered any information in the PHR regarding emergency contacts, allergies, height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol, or triglycerides.

On the contrary, the remaining 18,504 individuals were classified as PHR 'users' (see methods), corresponding to 16.9% of registered individuals. Users provided a total of 45,039 data entries in the specified fields, of which the most common were height, weight, allergies, and emergency contacts (data not shown). Users tended to be male, younger, and Lisbon residents, when compared to non-users (Table 1).

Data regarding health problems and chronic medication were provided by users and non-users, although the latter did in a smaller proportion (Table 1). The most commonly reported health problems were high blood pressure, diabetes, and asthma (Table 2).

PHR users were further characterized as engaging in 'limited use' (n=5,955) or 'comprehensive use' (n=12,549) (see methods). The differences between them are

illustrated in Table 3, as well as the unadjusted odds ratios. Younger patients had higher odds of engaging in 'comprehensive use', as well as male patients. The differences between regions of the country were not statistically significant. Patients with two or more health problems had more than twice the odds of engaging in 'comprehensive use' [two reported health problems: odds ratio (OR) 2.36; 95% confidence interval (CI) 1.98-2.83; more than two health problems: OR 2.23, CI 1.89-2.63] and patients with no reported health problems had slightly higher odds of engaging in 'comprehensive use', compared with patients with one health problem. Regarding medication, only patients reporting taking two or more medications had statistically significant higher odds of engaging in 'comprehensive use', compared with patients that reported not taking any medication. In adjusted analysis, similar odds ratios were found for age, gender and number of health problems. In terms of medication, the multivariate logistic regression model showed that patients doing two or more different medications, as well as the ones doing just one, had higher odds of engaging in 'comprehensive use', when compared with individuals that reported not doing any medication (one medication: OR 1.19, CI 1.04 - 1.37; two or more medications: OR 1.99, CI 1.68 - 2.35).

Table 1: Characteristics of individuals registered in the Personal Health Record 'Portal do Utente', according to their classification as 'non-users' or 'users' [a] [b]

Characteristic	Non-users		Users		Total	
	n	(%)	n	(%)	n	(%)
Age category (years)						
< 30	18,130	(19.9)	4,189	(22.6)	22,319	(20.4)
[30 ; 40[	20,157	(22.1)	5,653	(30.6)	25,810	(23.6)
[40 ; 50[	17,111	(18.8)	3,601	(19.5)	20,712	(18.9)
[50 ; 65[	20,603	(22.6)	3,198	(17.3)	23,801	(21.7)
≥ 65	15,114	(16.6)	1,863	(10.1)	16,977	(15.5)
Total	*91,115*	*(83.1)*	*18,504*	*(16.9)*	*109,619*	*(100)*
Gender						
Female	56,585	(62.1)	9,823	(53.1)	66,408	(60.6)
Male	34,530	(37.9)	8,681	(46.9)	43,211	(39.4)
Region						
Lisbon and Tagus Valley	39,925	(43.8)	8,414	(45.5)	48,339	(44.1)
North	34,486	(37.9)	6,698	(36.2)	41,184	(37.6)
Other	16,704	(18.3)	3,392	(18.3)	20,096	(18.3)
Total	*91,115*	*(83.1)*	*18,504*	*(16.9)*	*109,619*	*(100)*
Health problems						
None	230	(21.2)	1,238	(14.6)	1,468	(15.4)
1	589	(54.2)	5,058	(59.8)	5,647	(59.2)
2	149	(13.7)	1,017	(12.0)	1,166	(12.2)
≥ 3	118	(10.9)	1,144	(13.5)	1,262	(13.2)
Total	*1,086*	*(11.4)*	*8,457*	*(88.6)*	*9,543*	*(100)*
Medication						
0	255	(15.7)	1,679	(18.1)	1,934	(17.7)
1	658	(40.6)	3,793	(40.8)	4,451	(40.8)
≥ 2	707	(43.6)	3,821	(41.1)	4,528	(41.5)
Total	*1,620*	*(14.8)*	*9,293*	*(85.2)*	*10,913*	*(100)*

Abbreviations: PHR, Personal Health Record

[a] 'Users' were defined as individuals who were registered in 'Portal do Utente' and had entered information in at least one of the following fields: allergies, emergency contacts, height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol or triglycerides levels. 'Non-users' were defined as individuals who had signed up for an account in 'Portal do Utente', but who had not entered any information in the PHR at the time of the study.

[b] Age, gender and region of residence correspond to information from each patient's unique identifier number for the National Health Service. Other variables were collected from patient-entered information in the PHR.

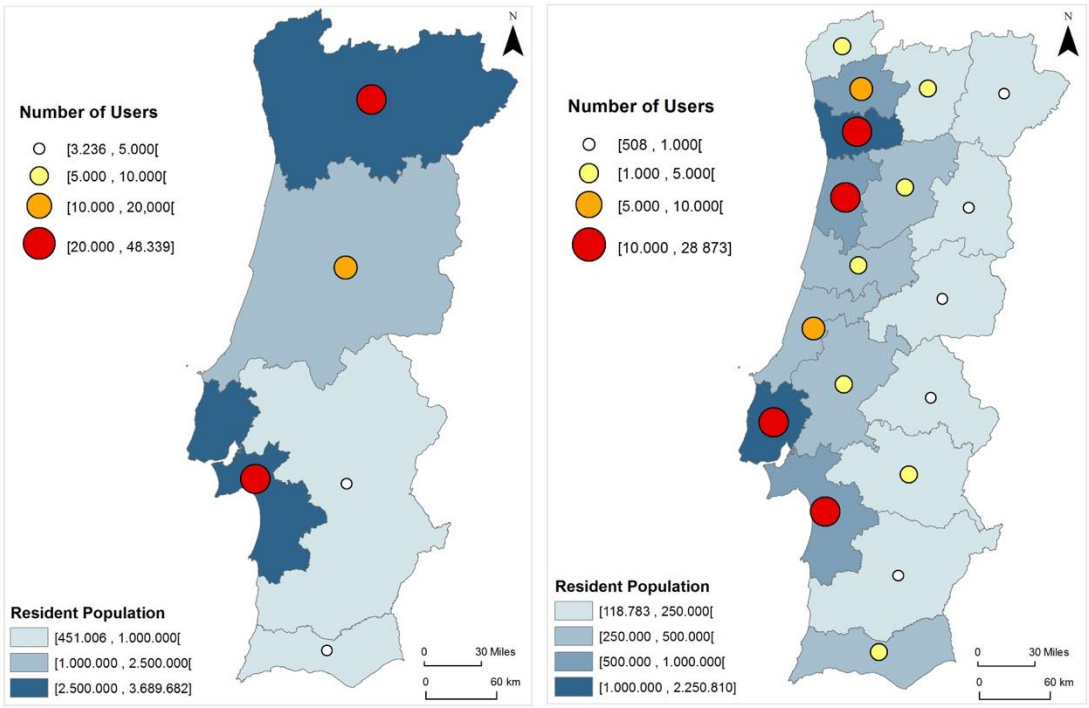

Figure 1: Number of patients registered in the Portuguese Personal Health Record 'Portal do Utente', by region (left image) and district (right image).

Table 2: Frequency of health problems reported by patients in the Personal Health Record 'Portal do Utente'

Health problem	N	%
High blood pressure	764	8.0
Diabetes	723	7.6
Asthma	588	6.2
Cardiovascular disease - unspecified	374	3.9
High cholesterol	305	3.2
Rhinitis	128	1.3
Other	6661	69.8
Total	9543	≈100

Table 3: Characteristics of users, according to their engagement in 'limited use' or 'comprehensive use' of the PHR, with crude and adjusted odds ratios [a,b,c,d]

Characteristic	Limited use		Comprehensive use		Crude Odds Ratio [e] (95% CI)	Adjusted Odds Ratio [f] (95% CI)
	n	(%)	n	(%)		
Age category (years)						
< 30	1,106	(18.6)	3,083	(24.6)	1.46 (1.32 - 1.60)	1.52 (1.29 - 1.80)
[30 ; 40[	1,694	(28.5)	3,959	(31.5)	1.22 (1.12 - 1.33)	1.46 (1.25 - 1.7)
[40 ; 50[	1,235	(20.7)	2,366	(18.9)	[Reference]	[Reference]
[50 ; 65[	1,126	(18.9)	2,072	(16.5)	0.96 (0.87 - 1.06)	0.84 (0.71 - 1.0)
≥ 65	794	(13.3)	1,069	(8.5)	0.7 (0.63 - 0.79)	0.60 (0.49 - 0.73)
Total	*5,955*	*(32.2)*	*12,549*	*(67.8)*	-	-
Gender						
Female	3,342	(56.1)	6,481	(51.7)	[Reference]	[Reference]
Male	2,613	(43.9)	6,068	(48.4)	1.20 (1.13 - 1.27)	1.32 (1.19 - 1.48)
Region						
Lisbon and Tagus Valley	2,706	(45.4)	5,708	(45.5)	[Reference]	[Reference]
North	2,189	(36.8)	4,509	(35.9)	0.98 (0.91 - 1.05)	0.95 (0.84 - 1.06)
Other	1,060	(17.8)	2,332	(18.6)	1.04 (0.96 - 1.14)	1.12 (0.96 - 1.30)
Total	*5,955*	*(32.2)*	*12,549*	*(67.8)*	-	-
Health problems						
None	295	(13.6)	943	(15.0)	1.39 (1.2 - 1.61)	1.51 (1.29 - 1.77)
1	1,533	(79.6)	3,525	(56.1)	[Reference]	[Reference]
2	158	(7.3)	859	(13.7)	2.36 (1.98 - 2.83)	2.01 (1.68 - 2.53)
≥ 3	187	(8.6)	957	(15.2)	2.23 (1.89 - 2.63)	2.22 (1.81 - 2.72)
Total	*2,173*	*(25.7)*	*6,284*	*(74.3)*	-	-
Medication						
0	509	(21.3)	1,170	(17.0)	[Reference]	[Reference]
1	1,104	(46.2)	2,689	(39.0)	1.06 (0.94 - 1.2)	1.19 (1.04 - 1.37)
≥ 2	776	(32.5)	3,045	(44.1)	1.71 (1.50 - 1.95)	1.99 (1.68 - 2.35)
Total	*2,389*	*(25.7)*	*6,904*	*(74.3)*	-	-

Abbreviations: Confidence interval, CI; PHR, Personal Health Record.

[a] 'Users' were defined as individuals who were registered in 'Portal do Utente'and had entered information in at least one of the following fields: allergies, emergency contacts, height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol or triglycerides levels. 'Non-users' were defined as individuals who had signed up for an account in 'Portal do Utente', but who had not entered any information in the PHR at the time of the study.

[b] 'Limited use' was defined as the input of only one piece of information regarding any of the following fields: allergies, emergency contacts, height, weight, systolic blood pressure, diastolic blood pressure, glycemia, cholesterol, or triglycerides). If more than one piece of information had been entered on different occasions, this was considered 'comprehensive use'.

[c] Age, gender and region of residence correspond to information from each patient's unique identifier number for the National Health Service. Other variables were collected from patient-entered information in the PHR.

[d] Some percentages do not total 100% due to rounding.

[e] Crude odds ratios calculated from univariate logistic regression where the probability of comprehensive use was modeled (more than one record of height, weight, systolic and diastolic blood pressure measurements, glycemia, cholesterol, triglycerides, allergies or emergency contacts).

[f] Logistic regression model with predictors: age category, gender, region of residence, number of health problems, number of chronic medications.

Discussion

This is the first study analysing the adoption of a Personal Health Record in Portugal. The number of registered individuals in 'Portal do Utente' at the time of the study was 109,619, from which 18,504 were considered 'users' and 91,115 were 'non-users'. PHR users were also characterized as engaging in 'limited use' (n=5,955) or 'comprehensive use' (n=12,549). Adjusted analysis showed that patients with more than one health condition had higher odds of engaging in 'comprehensive use' of the PHR, when compared to individuals with only one reported health problem. Similarly, people doing one or more chronic medications had higher odds of engaging in 'comprehensive use' of the PHR.

Comparison with published literature

As hypothesized, multimorbidity and polymedication seemed to be positively associated with PHR use in our study population, which is consistent with previous studies[41–47].

Chronic diseases appeared to be the most recorded health problems in the PHR, namely hypertension and diabetes. This is in line with a study from Kaiser Permanente showing that early adopters of their portal were more likely to have diabetes than non-adopters[48].

On the other hand, in our study, people with no registered health problems also had higher odds of engaging in comprehensive PHR use. This apparent discrepancy may be explained by the 'worried well' phenomenon (i.e. health-minded people with an inclination to engage in health monitoring activities)[49], and should be further investigated.

Previous studies have shown higher adoption and use of PHRs in women[42,43,48,50]. In our study, PHR registration and use was more frequent in females, but males showed higher odds of engaging in comprehensive use. A possible explanation might be that women make less use of information-entering features, possibly preferring other capabilities of the system (e.g. appointment booking). Further research should be conducted to investigate this finding.

Barriers and facilitators of PHR adoption

Several aspects influencing PHR adoption have been described in the literature, including individual-level, technology-related, and environmental factors[4,51–55]. Their contribution to PHR adoption is not likely isolated, but rather resulting from a combination of interacting factors.

Individual-level barriers

We found lower registration rates and lower use of the PHR by people above 65 years, which is in line with published research [49,43,50,56,57], and is likely associated with the low levels of computer/digital literacy in this population[32]. However, studies have shown that, once enrolled, older patients were more likely to use the portal than their younger counterparts[50]. As future generations become more computer literate, the importance of the age divide in adoption of PHRs is likely to decrease.

Geographic analysis revealed a gap in PHR adoption between urbanized centers and the more rural regions of the country, namely the south of Portugal. This raises concerns regarding the possible widening of disparities due to the digital divide – the gap that exists between individuals, groups, or communities in availability and use of information technology[32,58,59]. Disparities in PHR adoption have also been previously shown to be associated with race/ethnicity[49,43,45,46,48,50,58], as well as to socio-economic status, education level[49,41,43,48,60] and health literacy[58], raising concerns that access to this type of technology may be limited to a more socially advantaged population. Unfortunately, we did not have access to these types of data in our study, limiting further analysis of the digital divide in this population.

Technology-related barriers

One of the models that tries to explain users' acceptance of information technology is the Technology Acceptance Model (TAM), where two important aspects are considered: perceived usefulness (the degree to which a person believes that using the technology will be useful for task completion) and perceived ease of use (the degree to which a person believes that using the technology will be effortless)[61,62]. Interestingly, one study of PHR adoption has found that perceived usefulness, but not perceived ease of use, was associated with actual PHR use[63]. According to these findings, more attention should be focused on designing useful systems with features

which have been shown to be valued by patients, such as communication with providers, access to medical records, and administrative functionalities such as prescription refills or appointment booking[13,63–68]. These functionalities are becoming increasingly common in integrated PHRs, and are core features of two of the most successfully adopted PHRs described in the literature – the ones from Kaiser Permanente and the Veterans Administration[51,63,64,69].

Currently, the Portuguese PHR allows patient access to a summary of their medical record, but this is only available after authentication with the Portuguese citizen card, requiring the use of a card reader to which the great majority of patients does not have easy access. This important limitation may negatively influence future adoption of the PHR, as well as it may increase disparities and widen the digital divide, and should be further analysed.

Finally, technical problems and low usability may also limit PHR adoption[74], and are particularly important when thinking about disadvantaged groups[41]. Involving patients in the design and evaluation of PHRs, and improving their usability by using adaptive interfaces, audio, video, and graphical information, are important aspects to the success of a PHR[58]. The usability of the PHR 'Portal do Utente' was the focus of another paper, in which a design strategy was proposed to improve its structure[75].

Environmental barriers

Other important factors for PHR adoption by patients are providers' endorsement and engagement with the platform[60,68,76]. Several physician-related barriers to adoption have been described, such as lack of knowledge, lack of perceived relevance, time constraints, and lack of alignment with workflow[30].

Finally, awareness promotion plays an important role in implementation[57], and several marketing strategies have been described in the literature[33,59]. However, it seems that awareness campaigns may be a necessary but not a sufficient factor for PHR adoption. One example is the UK's national integrated PHR 'HealthSpace', which had very low uptake despite large public information programmes[35,77], and ended up being abandoned in 2012[34,40]. Additional issues in implementation and dissemination of PHRs may hinder their adoption, and should be further studied[68].

Strengths and limitations

This study has several strengths. It was the first to analyse the adoption of a PHR in Portugal, doing so at an early stage of its deployment. We studied adoption both in terms of number of registrations, and actual use of the PHR to input health information, providing a comprehensive perspective on the uptake of the PHR by citizens. We were able to collect and analyse individual-level data regarding region and district of residence, which allowed for the use of geographic information systems to study the geographic distribution of PHR adoption in the country. Also, the large sample size of our study ensures some robustness to the results.

The results of our study need to be interpreted in the context of its cross-sectional design. Selection bias cannot be excluded, and unmeasured confounding is a possibility. Potentially important variables could not be evaluated, namely socio-economic status and educational level, as they were not available in the PHR at the moment of the study. Furthermore, ethnicity data is not usually allowed to be collected in Portugal, hampering a comprehensive analysis of disparities in the adoption and use of PHRs by ethnic minority groups. Our definition of 'users', 'comprehensive use' and 'limited use' of the PHR was conditioned by the particularities of this specific PHR, namely the types of data that were able to be collected at the time. We included both dynamic and more static types of data to define PHR use, and to characterize frequency of use. The impact of the different types of data on the characterization of adopters should be further studied. Finally, this study was limited to a specific country, so caution should be taken when trying to generalize the results to other populations and health care systems.

Implications for clinical practice, health policy and research

Dissemination of PHRs will imply a significant culture change for medicine, into a more patient-centered model of care. This will require some adaptation by clinicians in Portugal, where patients' access to medical records is still highly uncommon[78].

Implementation and dissemination of PHRs may also have some unanticipated consequences, such as the widening of disparities. Therefore, ensuring universal internet and computer access seems paramount as we move into a world where health care is increasingly relying on information technology[58]. At the same time, it is crucial to accommodate the needs of those with less access to IT, and make sure they are provided the same quality of care.

Conclusion

Adoption of PHRs is highly dependent on individual-level characteristics of the target audience, as well as on the characteristics of the technology itself, and on environmental aspects. This study characterized the early adopters of the Portuguese PHR 'Portal do Utente', adding further insight to the growing body of evidence concerning the adoption and use of PHRs.

References

1. Institute of Medicine. Crossing the Quality Chasm: a new health system for the 21st century. Building a Better Delivery System. 2001.
2. Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. Milbank Q. 1996;74:511–44.
3. Bodenheimer T, Wagner EH, Grumbach K. Improving Primary Care for Patients With Chronic Illness. JAMA. 2002 Oct 9;288(14):1775–9.
4. Tang P, Ash J, Bates D, Overhage J, Sands D. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. J Am Med Informatics Assoc. 2006;13(2):121–6.
5. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. BMC Med Inform Decis Mak. 2008 Jan;8:45.
6. Otte-Trojel T, de Bont A, Rundall TG, van de Klundert J. How outcomes are achieved through patient portals: a realist review. J Am Med Inform Assoc. 2014 Jul;21(4):751–7.
7. Steinbrook R. Personally controlled online health data--the next big thing in medical care? N Engl J Med. 2008;358:1653–6.
8. Mandl KD, Simons WW, Crawford WCR, Abbett JM. Indivo: a personally controlled health record for health information exchange and communication. BMC Med Inform Decis Mak. 2007;7:25.
9. Simons WW, Mandl KD, Kohane IS. The PING personally controlled electronic medical record system: Technical architecture. J Am Med Informatics Assoc. 2005;12(1):47–54.
10. Weitzman ER, Kaci L, Mandl KD. Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. J Med Internet Res. 2009;11(2).

11. Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: A systematic review of controlled trials. Journal of Medical Internet Research. 2012.

12. Heyworth L, Paquin A. Engaging patients in medication reconciliation via a patient portal following hospital discharge. J Am Med Informatics Assoc. 2014;24036155.

13. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved Quality At Kaiser Permanente Through E-Mail Between Physicians And Patients. Health Aff. 2010 Jul;29(7):1370–5.

14. Gustafson DH, Hawkins R, Boberg E, Pingree S, Serlin RE, Graziano F, et al. Impact of a patient-centered, computer-based health information/support system. Am J Prev Med. 1999;16(1):1–9.

15. Lin CT, Wittevrongel L, Moore L, Beaty BL, Ross SE. An internet-based patient-provider communication system: Randomized controlled trial. J Med Internet Res. 2005;7.

16. Weingart SN, Carbo A, Tess A, Chiappetta L, Tutkus S, Morway L, et al. Using a patient internet portal to prevent adverse drug events: a randomized, controlled trial. J Patient Saf. 2013;9:169–75.

17. Weingart SN, Hamrick HE, Tutkus S, Carbo A, Sands DZ, Tess A, et al. Medication safety messages for patients via the web portal: The MedCheck intervention. Int J Med Inform. 2008;77:161–8.

18. Schnipper JL, Gandhi TK, Wald JS, Grant RW, Poon EG, Volk L a., et al. Effects of an online personal health record on medication accuracy and safety: a cluster-randomized trial. J Am Med Informatics Assoc. 2012;19:728–34.

19. Chrischilles E a, Hourcade JP, Doucette W, Eichmann D, Gryzlak B, Lorentzen R, et al. Personal health records: a randomized trial of effects on elder medication safety. J Am Med Inform Assoc. 2014;21:679–86.

20. Sarkar U, Lyles CR, Parker MM, Allen J, Nguyen R, Moffet HH, et al. Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. Med Care. 2014;52:194–201.

21. Ross SE, Moore L a., Earnest M a., Wittevrongel L, Lin CT. Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: Randomized trial. J Med Internet Res. 2004;6(2):1–15.

22. Keith McInnes D, Shimada SL, Rao SR, Quill A, Duggal M, Gifford AL, et al. Personal health record use and its association with antiretroviral adherence: Survey and medical record data from 1871 US veterans infected with HIV. AIDS Behav. 2013;17:3091–100.

23. Tom JO, Chen C, Zhou YY. Personal health record use and association with immunizations and well-child care visits recommendations. J Pediatr. Elsevier Ltd; 2014;164:112–7.

24. Druss BG, Ji X, Glick G, von Esenwein S a. Randomized trial of an electronic personal health record for patients with serious mental illnesses. Am J Psychiatry. 2014;171:360–8.

25. Lau A, Sintchenko V, Crimmins J, Magrabi F, Gallego B, Coiera E. Impact of a web-based personally controlled health management system on influenza vaccination and health services utilization rates: a randomized controlled trial. J Am Med Informatics Assoc. 2012;19:719–27.

26. Horvath M, Levy J, Engle P, Carlson B, Ahmad A, Ferranti J. Impact of health portal enrollment with Email reminders on adherence to clinic appointments: A pilot study. J Med Internet Res. 2011;13(2).

27. Palen TE, Ross C, Powers JD, Xu S. Association of online patient access to clinicians and medical records with use of clinical services. JAMA. 2012;308:2012–9.

28. Jones DW, Peterson ED, Bonow RO, Gibbons RJ, Franklin B a., Sacco RL, et al. Partnering to reduce risks and improve cardiovascular outcomes: American Heart Association initiatives in action for consumers and patients. Circulation. 2009;119:340–50.

29. Grant RW, Wald JS, Schnipper JL, Gandhi TK, Poon EG, Orav EJ, et al. Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. Arch Intern Med. 2008;168(16):1776–82.

30. Nazi KM. The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings. J Med Internet Res. 2013 Jan;15(4):e70.

31. Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. J Am Med Inform Assoc. 2011 Dec;18 Suppl 1:i8–12.

32. Kim E-H, Stolyar A, Lober WB, Herbaugh AL, Shinstrom SE, Zierler BK, et al. Challenges to using an electronic personal health record by a low-income elderly population. J Med Internet Res. 2009 Jan;11(4):e44.

33. North F, Hanna BK, Crane SJ, Smith S a, Tulledge-Scheitel SM, Stroebel RJ. Patient portal doldrums: does an exam room promotional video during an office visit increase patient portal registrations and portal use? J Am Med Inform Assoc. 2011 Dec;18 Suppl 1(April 2010):i24–7.

34. Greenhalgh T, Morris L, Wyatt J, Thomas G, Gunning K. Introducing a nationally shared electronic patient record: Case study comparison of Scotland, England, Wales and Northern Ireland. Int J Med Inform. 2013;82(e):125–38.

35. Greenhalgh T, Hinder S, Stramer K, Bratan T, Russell J. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. BMJ. 2010 Nov 16;341(nov16 1):c5814–c5814.

36. Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A Research Agenda for Personal Health Records (PHRs). J Am Med Inform Assoc. 2008;15(6):729–36.

37. Archer N, Fevrier-Thomas U, Lokker C, McKibbon K a, Straus SE. Personal health records: a scoping review. J Am Med Inform Assoc. 18(4):515–22.

38. Rogers E. Diffusion of innovations. 5th ed. New York: Free Press; 2003.

39. Bratan T, Stramer K, Greenhalgh T. "Never heard of it"- Understanding the public's lack of awareness of a new electronic patient record. Heal Expect. 2010;13:379–91.

40. Greenhalgh T, Wood GW, Bratan T, Stramer K, Hinder S. Patients' attitudes to the summary care record and HealthSpace: qualitative study. BMJ. 2008 Jun 7;336(7656):1290–5.

41. Ancker JS, Silver M, Kaushal R. Rapid growth in use of personal health records in New York, 2012-2013. J Gen Intern Med. 2014 Feb 12;29(6):850–4.

42. Ralston JD, Rutter CM, Carrell D, Hecht J, Rubanowice D, Simon GE. Patient use of secure electronic messaging within a shared medical record: a cross-sectional study. J Gen Intern Med. 2009 Mar;24(3):349–55.

43. Ancker JS, Barrón Y, Rockoff ML, Hauser D. Use of an Electronic Patient Portal Among Disadvantaged Populations. J Gen Intern Med. 2011;26(10):1117–23.

44. Jung C, Padman R, Shevchick G, Paone S. Who are Portal Users vs. Early E-Visit Adopters? A Preliminary Analysis. AMIA Annu Symp Proc. 2011;1070–9.

45. Nielsen a S, Halamka JD, Kinkel RP. Internet portal use in an academic multiple sclerosis center. J Am Med Informatics Assoc. 2012;19(1):128–33.

46. Miller H, Vandenbosch B, Ivanov D, Black P. Determinants of personal health record use: a large population study at Cleveland Clinic. J Healthc Inf Manag. 2007;21(3):44–8.

47. Krist AH, Woolf SH, Rothemich SF, Johnson RE, Eric Peele J, Cunningham TD, et al. Interactive preventive health record to enhance delivery of recommended care: A randomized trial. Ann Fam Med. 2012;10:312–9.

48. Roblin D, Houston T, Allison J, Joski P, Becker E. Disparities in Use of a Personal Health Record in a Managed Care Organization. J Am Med Informatics Assoc. 2009;16(5):683–9.

49. Weingart S, Rind D, Tofias Z, Sands D. Who Uses the Patient Internet Portal? The PatientSite Experience. J Am Med Informatics Assoc. 2006;13(1):91–5.

50. Goel MS, Brown TL, Williams A, Hasnain-Wynia R, Thompson J a, Baker DW. Disparities in enrollment and use of an electronic patient portal. J Gen Intern Med. 2011 Oct;26(10):1112–6.

51. Logue MD, Effken J a. Validating the personal health records adoption model using a modified e-Delphi. J Adv Nurs. 2013 Mar;69(3):685–96.

52. Lober W, Zierler B. Barriers to the use of a personal health record by an elderly population. AMIA Annu Symp Proc. 2006;(3 Suppl 1):514–8.

53. Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc. 2008;15(1):1–7.

54. Xu J, Gao X, Sorwar G, Croll P. Implementation of E-health Record Systems in Australia. Int Technol Manag Rev. 2013;3(2):92–104.

55. Reeve J, Hosking R, Allinson Y. Personal electronic health records: the start of a journey. Aust Prescr. 2013;36(7656):70–3.

56. Tang PC, Black W, Buchanan J, Young CY, Hooper D, Lane SR, et al. PAMFOnline: integrating EHealth with an electronic medical record system. AMIA Annu Symp Proc. 2003 Jan;644–8.

57. Wagner PJ, Dias J, Howard S, Kintziger KW, Hudson MF, Seol Y-H, et al. Personal health records and hypertension control: A randomized trial. J Am Med Inform Assoc. 2012 Jul 1;19(4):626–34.

58. Sarkar U, Karter A, Liu J, Adler NE, Nguyen R, López A, et al. The Literacy Divide: Health Literacy and the Use of an Internet-Based Patient Portal in an Integrated Health System—Results from the Diabetes Study of Northern California (DISTANCE). J Health Commun. 2010;15(Suppl 2):183–96.

59. Yamin CK, Emani S, Williams DH, Lipsitz SR, Karson AS, Wald JS, et al. The digital divide in adoption and use of a personal health record. Arch Intern Med. 2011 Mar 28;171(6):568–74.

60. California HealthCare Foundation. Consumers and Health Information Technology: A National Survey. 2010.

61. Davis F, Bagozzi R, Warshaw P. User acceptance of computer technology: a comparison of two theoretical models. Manage Sci. 1989;35(7):982–1003.

62. Davis F. Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. MIS Q. 1989;(September):982–1003.

63. Silvestre A-L, Sue VM, Allen JY. If you build it, will they come? The Kaiser Permanente model of online health care. Health Aff. 2009;28(2):334–44.

64. Nazi KM, Hogan TP, McInnes DK, Woods SS, Graham G. Evaluating patient access to Electronic Health Records: results from a survey of veterans. Med Care. 2013 Mar;51(3 Suppl 1):S52–6.

65. Gu Y, Day K. Propensity of people with long-term conditions to use personal health records. Stud Heal Technol Inf. 2013;188:46–51.

66. Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. Health Aff (Millwood). 2009;28(2):323–33.

67. Zhou YY, Garrido T, Chin HL, Wiesenthal AM, Liang LL. Patient access to an electronic health record with secure messaging: Impact on primary care utilization. Am J Manag Care. 2007 Jul;13(7):418–24.

68. Wald JS. Variations in patient portal adoption in four primary care practices. AMIA Annu Symp Proc. 2010 Jan;837–41.

69. Tsai J, Rosenheck R a. Use of the internet and an online personal health record system by US veterans: comparison of Veterans Affairs mental health service users and other veterans nationally. J Am Med Inform Assoc. 2010;19(6):1089–94.

70. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res. 2008 Jan;10(3):e22.

71. Paton C, Hansen M, Fernandez-Luque L, Lau a YS. Self-Tracking, Social Media and Personal Health Records for Patient Empowered Self-Care. Contribution of the IMIA Social Media Working Group. Yearb Med Inform. 2012 Jan;7(1):16–24.

72. Lau AY, Dunn AG, Mortimer N, Gallagher A, Proudfoot J, Andrews A, et al. Social and self-reflective use of a Web-based personally controlled health management system. J Med Internet Res. 2013 Jan;15(9):e211.

73. Laranjo L, Arguel A, Neves AL, Gallagher AM, Kaplan R, Mortimer N, et al. The influence of social networking sites on health behavior change: a systematic review and meta-analysis. J Am Med Inform Assoc. 2014;1–10.

74. Kim MI, Johnson KB. Personal health records: Evaluation of functionality and utility. J Am Med Informatics Assoc. 2002;9(2):171–80.

75. Rodolfo I, Laranjo L, Correia N, Duarte C. Design strategy for a national integrated personal health record. Proceedings of the 8th Nordic Conference on Human-Computer Interaction Fun, Fast, Foundational - NordiCHI '14. New York, New York, USA: ACM Press; 2014. p. 411–20.

76. Lyles CR, Sarkar U, Ralston JD, Adler N, Schillinger D, Moffet HH, et al. Patient-provider communication and trust in relation to use of an online patient portal among diabetes patients: The Diabetes and Aging Study. J Am Med Inform Assoc. 2013;20:1128–31.

77. Greenhalgh T, Stramer K, Bratan T, Byrne E, Russell J, Potts HWW. Adoption and non-adoption of a shared electronic summary record in England: a mixed-method case study. BMJ. 2010;340(May):c3111.

78. Laranjo L, Neves A, Villanueva T, Cruz J, Brito de Sá A, Sakellarides C. Patients' access to their medical records. Acta Med Port. 2013;26(3):265–70.

79. Bennett GG, Glasgow RE. The delivery of public health interventions via the Internet: actualizing their potential. Annu Rev Public Health. 2009 Jan;30:273–92.

80. Agarwal R, Anderson C, Zarate J, Ward C. If we offer it, will they accept? Factors affecting patient use intentions of personal health records and secure messaging. J Med Internet Res. 2013 Jan;15(2):e43.

Paper VI

The influence of social networking sites on health behavior change – a systematic review and meta-analysis

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Cited in:

1. Kim S. An exploratory study of inactive health information seekers. Int J Med Inform. 2015.
2. Sillence E, *et al*. Assessing Patient Experience and Patient Preference when Designing Web Support for Smoking Cessation. Proceedings of the 5th International Conference on Digital Health 2015 - DH '15. ACM Press; 2015.
3. Mooney SJ, *et al*. Epidemiology in the Era of Big Data. Epidemiology. 2015.
4. Iyngkaran P, *et al*. Technology-Assisted Congestive Heart Failure Care. Curr Heart Fail Rep. 2015.
5. Bissonnette-Maheux V, *et al*. Exploring Women's Beliefs and Perceptions About Healthy Eating Blogs: A Qualitative Study. J Med Internet Res. 2015.
6. Sampasa-Kanyinga H, *et al*. Frequent Use of Social Networking Sites Is Associated with Poor Psychological Functioning Among Children and Adolescents. Cyberpsychology, Behav Soc Netw. 2015.
7. Robillard JM, *et al*. Fueling Hope: Stem Cells in Social Media. Stem Cell Rev Reports. 2015.
8. Scott K, *et al*. Opportunities for Exploring and Reducing Prescription Drug Abuse through Social Media. J Addict Dis. 2015.
9. Joseph RP, *et al*. Print versus a culturally-relevant Facebook and text message delivered intervention to promote physical activity in African American women: a randomized pilot trial. BMC Womens Health. 2015.
10. Balatsoukas P, *et al*. The Role of Social Network Technologies in Online Health Promotion: A Narrative Review of Theoretical and Empirical Factors Influencing Intervention Effectiveness. J Med Internet Res. 2015.
11. Tague, R, et al. Assessing user engagement in a health promotion website using social networking. Global Telehealth 2014, IOS Press. 2015.

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The influence of social networking sites on health behavior change: a systematic review and meta-analysis

Abstract

Background and aim

Social Networking Sites (SNSs) are growing in popularity, showing great potential in the health domain. Our aim was to evaluate the use and effectiveness of interventions using SNSs to change health behaviors.

Materials and methods

Five databases were scanned using a predefined search strategy. Studies were included if they focused on patients/consumers, involved a SNS intervention, had an outcome related to health behavior change, and were prospective. Studies were screened by independent investigators, and assessed using Cochrane's 'risk of bias' tool. Randomized controlled trials were pooled in a meta-analysis.

Results

The database search retrieved 4656 citations; twelve studies (7411 participants) met the inclusion criteria. Facebook was the most utilized SNS, followed by health-specific SNSs, and Twitter. Eight randomized controlled trials were combined in a meta-analysis. A positive effect of SNS interventions on health behavior outcomes was found [Hedges' g 0.24; 95% confidence interval (CI) 0.04 - 0.43]. There was considerable heterogeneity (I^2=84.0%; T^2=0.058) and no evidence of publication bias.

Discussion

To the best of our knowledge, this is the first meta-analysis evaluating the effectiveness of SNS interventions in changing health-related behaviors. Most studies evaluated multi-component interventions, posing problems in isolating the specific effect of the SNS aspect. Health behavior change theories were seldom mentioned in the included articles, but two particularly innovative studies used 'network alteration', showing a positive effect. Overall, SNS interventions appeared to be effective in promoting changes in health-related behaviors, and further research regarding the application of

these promising tools is warranted.

Conclusion

Our study showed a positive effect of SNS interventions on health behavior-related outcomes, but there was considerable heterogeneity.

Protocol registration: The protocol for this systematic review is registered at www.crd.york.ac.uk/PROSPERO with the number CRD42013004140

Background and significance

Social Networking Sites (SNSs) have become a global phenomenon. They are generally defined as web-based platforms that allow individuals to create their personal profile and build a network of connections with other users[1]. As of September 2013, 73% of online adults were using a SNS of some kind and 42% were using more than one[2,3]. Facebook is the most popular platform (with more than 1.19 billion monthly active users[4]), followed by Twitter (500 million users worldwide[5]).

In parallel to general purpose SNSs like Facebook and Twitter, health-specific SNSs are also emerging[6]. Some are oriented towards patients with a specific chronic condition (e.g. TuDiabetes), others are more general and open to patients with any chronic condition (e.g. PatientsLikeMe), and a few others target people wanting to change a particular health-risk behavior (e.g. smoking cessation[7]), or other health-related lifestyle factors.

The application of SNSs in the health domain shows tremendous potential[8]. At the population level, they are currently being used for public health surveillance[9], both for communicable[9,10] and non-communicable diseases[11,12]. At the individual level, they are able to facilitate the access to health-related information[13–16] and social support[7,17], promoting better-informed treatment decisions[18,19]. Given that lifestyle behaviors are nowadays responsible for the global burden of noncommunicable diseases[20], attention has been growing on how to use SNSs to

fight this trend[21,22]. Interestingly, studies of offline social networks have demonstrated the actual role of social influence in spreading certain risk behaviors, such as in the case of alcohol consumption[23], smoking[24], and obesity[25]. Researchers are now focusing on how to leverage social influence to promote healthy behaviors. The fact that SNSs are widely accessible across geographical barriers, and that they are increasingly being used by people on a daily basis (namely through mobile phones), turn them into especially interesting loci for public health interventions in the behavioral domain.

The aim of this study was to systematically review the literature regarding the use and effectiveness of SNSs in health behavior change.

Materials and methods

Search strategy

A systematic search of the literature from the last ten years was performed in March 2013, on PubMed, Embase, CINAHL, ACM Digital and PsycINFO, using several search terms regarding social media, social networking sites and health behavior change (complete search strategy available in Supplement 1). The reference lists of relevant articles were also screened. To capture grey literature we reviewed the proceedings (last five years) of several related conferences (AMIA, MedInfo, MIE, Medicine 2.0, Medicine X) and tweets from key opinion leaders regarding possible additional studies that met the inclusion criteria.

Study selection criteria and risk of bias assessment

Studies were included in this review if they[26]: focused on patients/consumers; involved a SNS(3), either isolated or as part of a multi-component intervention; included any type of comparison (e.g. with a control group, with another intervention, pre-post); had an outcome related to health behavior change or presumed to be a consequence of it (e.g. weight loss in a fitness or dieting intervention); had a prospective study design.

Studies were excluded if they: had an intervention based on non-SNS types of social media (e.g. online forum, message board, chat group, mailing list); described the use of SNSs for other purposes (e.g., recruitment, data collection); focused on health care providers instead of patients; focused on behaviors unrelated to health; were centered on psychology aspects or on the e-Sociology phenomenon (e.g. cyber-bullying); were duplicate or were not in English.

The screening form was piloted before the beginning of the screening process. The initial screening of the studies was based on the information contained in their titles and abstracts and conducted by four teams, each consisting of two independent investigators. When a decision on inclusion or exclusion could not be reached by reading the title and abstract, the full text was retrieved. If doubts subsisted, a third person was called to make a decision.

The initial screening was purposely broad in order to retrieve articles that could inform the background and discussion, and to avoid missing any important studies. In the full-paper screening, completed by two independent investigators, the inclusion and exclusion criteria described above were applied more strictly, and any disagreements were resolved by a third person. Kappa statistic was used to measure inter-coder agreement in the screening phase as a whole (including the initial screening and the full-paper screening).

The complete eligible studies were reviewed by two researchers in order to appraise their risk of bias, according to the Cochrane Collaboration's 'risk of bias' tool[26]. Disagreements were resolved by a third person.

Data extraction strategy and synthesis procedures

One reviewer abstracted information from the included studies into a standardized computer-based form. Another investigator reviewed the completed abstraction form for consistency. Disagreements were referred to a third person.

The following information was collected: first author, year, health domain, type of SNS used in the intervention, study type, number of participants, population characteristics, study duration, intervention characteristics, health behavior theories or models underlying the intervention, and retention rates. Data from one outcome measure in

each study were extracted. When more than one measure was present, a decision was made based on the following: 1) primary outcomes were used whenever possible; 2) if several health behavior-related outcomes were available (none of which being the primary outcome), decision was based on clinical importance. Additional criteria for data extraction included: 1) use of intention-to-treat analysis whenever possible; 2) in repeated-measures studies, selection of the baseline and longest follow-up; 3) where more than one intervention was present, selection of the one for which the primary outcome was determined. In the event data were missing we planned to contact the study authors.

Data synthesis and meta-analysis

The main characteristics of each study were synthesized.

As suggested in the literature, we did not use the argument of heterogeneity to avoid conducting a meta-analysis[27–29]. The studies included in our review were deemed comparable in relevant ways, as well as measuring the same outcome, and were therefore pooled together for a summary effect.

Due to a high risk of bias, quasi-experimental studies were not included in the meta-analysis. Furthermore, to avoid unit of analysis issues, a cluster-randomized trial was also excluded from the meta-analysis. For these studies, a narrative synthesis was elaborated.

In the meta-analysis, continuous and dichotomous outcomes were pooled together[28]. We transformed all effect sizes to a common metric comparable across studies – the bias-corrected standardized difference in means (Hedges' g) - and classified it as positive when in favor of the intervention and negative when in favor of the control.

We used the random effects model to combine the results in a more conservative way, and used the method of moments to estimate the between-studies variance (T^2). I^2 was used to assess the presence of heterogeneity[28,29]. A subgroup analysis was performed to assess the effect of two particularly different studies[30,31] on heterogeneity. The presence of publication bias was evaluated by use of a funnel plot and the Duval and Tweedie's trim and fill method. Comprehensive Meta-analysis

version 2.2 was used for all computations.

The study protocol was registered with PROSPERO (International prospective register of systematic reviews)[32] and the PRISMA statement was followed in writing this report[33].

Results

The database search retrieved 4656 citations (Figure 1). Their titles and abstracts were screened and 778 duplicates were excluded, as well as 3836 articles that did not meet the inclusion criteria. After reviewing the full-text of the remaining articles, an additional 33 were excluded (exclusion details available in Supplement 2). The screening of the reference lists of the remaining eleven papers revealed an extra study that met our pre-defined criteria. The kappa statistic measuring inter-coder agreement was 0.41 (fair agreement)[26].

Description of included studies

The twelve included studies involved a total of 7411 participants (Table 1). One study was conducted in Australia[34] and another in the United Kingdom[35]; the remaining were from the United States of America. The health domains covered were: fitness[31,34–39]; sexual health[40,41]; food safety[42]; smoking[43]; and health promotion[30]. All the studies were experimental in nature – three were quasi-experimental and the remaining were randomized controlled trials (RCTs). Publication year ranged from 2010 to 2013; study duration varied from 21 days to 18 months. Participants were diverse in age; three studies recruited students[37,38,42], and two studies involved young adults. Unfortunately, not all studies reported age data, and socioeconomic and ethnicity data were seldom mentioned, so a complete characterization of the population in this meta-analysis was not possible.

Recruitment strategies were diverse and often included offline and online approaches; SNSs were used in four studies[37,39–41]. Two studies used respondent-driven

sampling to identify further contacts from participants' networks[40,41].

In two studies it was not possible to assess whether there was enough power to detect a statistically significant difference in the primary outcome[34,43].

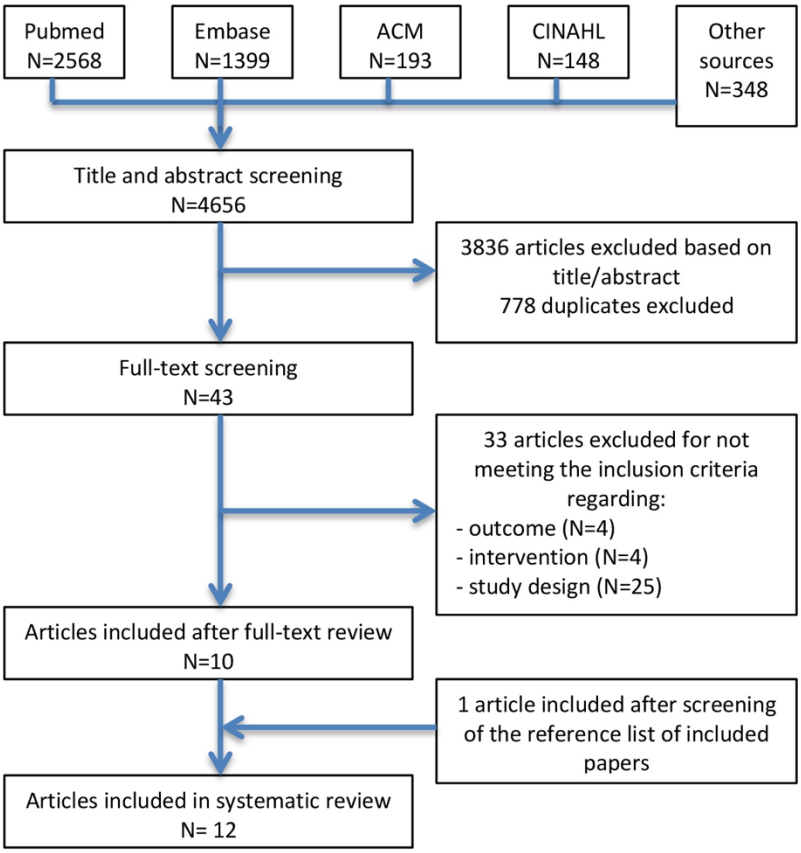


Figure 1: Flow diagram of included studies

Table 1: Characteristics of included studies

Study identifiers Author, year *(Publication)*	Health domain	SNS	Study type	N Total[a] (I;C)	Participants	Study duration	Intervention	Outcomes[d]
Brindal, 2012 *(J Med Internet Res)*[34]	Fitness (weight loss)	Health specific SNS	RCT	435 (213; 16)	Overweight and obese adults	12 weeks	Participants were randomized to one of *three arms*[f]: I) Access to website (Total Wellbeing Diet portal) with diet and exercise information + interactive meal planner + compliance feedback + diet and weight self-monitoring + SNS; or C) Access to information-only website.	Weight loss (%)[e]
Bull, 2012 *(Am J Prev Med)*[40]	Sexual health	Facebook	Cluster RCT	1578 (942; 636)	Young adults	6 months	Participants were randomized to either: I) Exposure to Just/Us Facebook page regarding 8 sexual health topics; or C) Exposure to content on 18–24 News Facebook page with news and events.	Condom use at last sex and proportion of sex acts protected by condom[e]
Cavallo, 2012 *(Am J Prev Med)*[38]	Fitness (physical activity)	Facebook	RCT	134 (67; 67)	Female undergraduate students	12 weeks	Participants were randomized to: I) Facebook group + SHAPE website for education, goal setting and self-monitoring; or C) SHAPE website providing education only.	Physical activity (Kcal; measured by a questionnaire)[g]
Centola, 2010 *(Science)*[30]	Health promotion	Health specific SNS	RCT (6 trials)	1528 (764; 764)	Visitors of health-specific internet sites	3 weeks (each trial)	Participants were randomized into two different situations in an online social network: I) Clustered network (with more redundant ties between individuals); or C) Random network.	Registration in an internet-based health forum[e]
Centola, 2011 *(Science)*[31]	Fitness (diet diary)	Health specific SNS	RCT (5 trials)	710 (355; 355)	Participants in an online fitness program	7 weeks (each trial)	Participants were randomized into two different situations in an online social network: I) Homophilous network, where individual traits (gender, age, and body mass index) were aggregated; or C) Unstructured population, where participants were mixed at random regardless of their individual characteristics.	Adoption of an internet-based diet diary[e]
Foster, 2010 *(ACM)*[35]	Fitness (physical activity)	Facebook	Quasi-experimental	10 (5; 5)	Nurses	21 days	Participants were assigned to: I) Exposure to Step Matron + Facebook application to view and comment each other's step data; or C) Access to their own personal step data only.	Number of steps[d]
Mayer, 2012 *(J Food Protect)*[42]	Food safety	Facebook	Quasi-experimental	710 (101; 83)	College students	4 weeks	Participants were divided into *eight groups*[f]: I) Exposure to a food safety lecture and access to the "Safe Eats" Facebook page for 15 min or more each week; C) No exposure to food safety education.	Food safety practice score (scale of 1 to 5)[e]
Graham, 2011 *(Arch Intern Med)*[43]	Smoking cessation	Health specific SNS	RCT	2005 (675; 679)	Smokers	18 months	Participants were randomized to one of *three arms*[f]: I) Access to the QuitNet website (includes SNS feature) + telephone and email counselling; C) Access to a static, information-only website composed of the content on QuitNet.com.	Smoking abstinence at 18 months[d]
Napolitano, 2012 *(Obesity)*[37]	Fitness (weight loss)	Facebook	RCT	52 (18; 17)	College students	8 weeks	Participants were randomized to one of *three arms*[f]: I) Facebook Plus + Facebook group + text messaging for personalized feedback + self-monitoring + education + health buddy; or C) Waiting List.	Weight loss (Kg)[e]
Turner-McGrievy, 2011 *(J Med Internet Res)*[36]	Fitness (weight loss)	Twitter	RCT	96 (47; 49)	Overweight adults	6 months	Participants were randomized to: I) Podcast+Mobile + access to podcasts + mobile app for diet and physical activity monitoring + interaction with study counselors and other participants on Twitter; or C) Podcast only	Weight loss (%)[e]
Valle, 2012 *(J Cancer Surv)*[39]	Fitness (physical activity)	Facebook	RCT	86 (45; 41)	Young adult cancer survivors	12 weeks	Participants were randomized to either: I) Facebook FITNET intervention (Pedometer + Website + enhanced Facebook group); or C) Facebook self-help comparison (Pedometer + Facebook group without moderator, reminders, or behavioral lessons and strategies)	Moderate-to-vigorous physical activity (min)[e]
Young, 2013 *(Sex Transm Dis)*[41]	Sexual health	Facebook	Quasi-experimental	57[h] (57; 36)	Men who have sex with men	12 weeks	Participants were exposed to a 'secret' group on Facebook where trained peer leaders posted HIV-related content.	Request of an HIV test[e]

App: application; C: Control group; I: Intervention group; Kcal: Kilocalories; RCT: Randomized Controlled Trial; SNS: Social networking site; Studies included in the meta-analysis are in shaded rows. [a] 'N total' indicates the total number of participants per study, followed by the numbers in the I and C groups (the sum of the participants in the I and C groups might not correspond to the total N in studies with more than two groups); [b] The comparison group was not included by the authors in the analysis - only results for the intervention group were presented; [c] In studies with more than two arms, only the most complex intervention and the control were considered; [d] Only health behavior-related outcomes were considered; [e] Study's main/primary outcome; [f] Four behavioral outcomes were measured - heavy, moderate, light and total physical activity - the latter was chosen; [g] The outcomes measured were attitudes, knowledge and practices regarding food safety - the latter was the only behavior outcome and was therefore chosen.

Interventions and adherence

Facebook was the most utilized SNS (seven studies) - either isolated[40], or as part of a more complex intervention with other components[35,37–39,41,42]. Twitter was used in one study[36] and health-specific SNSs in four[30,31,34,43]. Table 2 presents a detailed characterization of the various interventions, as well as their respective retention rates.

The SNS component of each intervention was primarily used as a means of providing education and social support. Only one study used the SNS in the intervention for data sharing, with the goal of promoting accountability and social competition[35]. Intervention components other than the SNS were primarily used for educational and self-monitoring purposes and were most often web-based.

Only five studies mentioned a health behavior theory or model underlying the intervention[30,31,36,39,42]. Retention rates were above 80% in four studies[35–38], and between 65% and 75% in two others[39,43]. Four studies did not report retention rates[30,31,41,42].

Usage data were seldom and inconsistently reported. Data concerning Facebook use were provided in three studies[37,39,40]. Two studies reported usage data regarding website access[34,38]. Finally, one study reported podcast downloads, mean days per week of self-monitoring activity, and number of tweets[36]. Four studies reported having conducted dose-response analysis[34,36,38,39]. The four studies that evaluated engagement variation throughout the study duration reported its decline, both in the intervention and control groups[34,36,38,39].

Table 2: Characteristics of the interventions and retention rates

Study identifiers Author, year *(Publication)*	SNS type	SNS component of the intervention		Other components of the intervention (non-SNS)		Health behavior theories or models underlying the intervention	Retention rates Intervention (control) n/%
		Characteristics	Functions	Components	Functions		
Bull, 2012 *(Am J Prev Med)*[40]	Facebook page	Discussions, Q&A with youth facilitators, videos, quizzes, games	Education Social support	N/A		None mentioned	45 (59)
Mayer, 2012 *(J Food Protect)*[42]		Discussions, Q&A, images, videos, games, polls	Education Social support	Lectures	Education	Social cognitive and Social constructivism	N/R
Cavallo, 2012 *(Am J Prev Med)*[38]	Facebook group	Discussions, Q&A with a moderator	Education Social support	Website	Education Physical activity self-monitoring Goal setting	None mentioned	84 (96)
Napolitano, 2012 *(Obesity)*[37]		Leaflets, podcasts, polls, invitations to fitness events, links to weekly report of tracked data	Education Social support Physical activity promotion Self-monitoring	Book + text messaging + digital scale + pedometer + food measuring utensils	Education Diet and physical activity self-monitoring Personalized goal setting and feedback Social support with a buddy	None mentioned	89 (100)
Valle, 2012 *(J Cancer Surv)*[39]		Discussions, Q&A with moderator, videos, news, links, information and tips regarding physical activity, reminders, behavioral lessons and strategies	Education Social support Physical activity promotion Self-efficacy promotion	Pedometer + Website	Physical activity self-monitoring Goal setting and feedback Reminders	Social cognitive	71 (83)
Young, 2013 *(Sex Transm Dis)*[41]		Discussions, Q&A with trained peer leaders	Education Social support	N/A	None mentioned	None mentioned	N/R
Foster, 2010 *(ACM)*[35]	Facebook app	Data sharing (number of steps)	Social support Social influence	Pedometer	Physical activity self-monitoring	None mentioned	100 (100)
Turner-McGrievy, 2011 *(J Med Internet Res)*[36]	Twitter	Health and fitness messages, Q&A	Education Social support	Podcasts + smartphone app	Education Diet and physical activity self-monitoring	Social cognitive	89 (90)
Brindal, 2012 *(J Med Internet Res)*[34]	Health specific SNS	(SNS is part of a website) Discussions, Q&A	Education Social support	Website	Education Diet and weight self-monitoring Interactive meal planner + compliance feedback	None mentioned	5.2 (8.7)
Centola, 2010 *(Science)*[30]		Clustered network; Notification when a health buddy adopts a health behavior (registration in an internet-based health forum)	Social influence	N/A		Social network	N/R
Centola, 2011 *(Science)*[31]		Homophilous network; Notification when a health buddy adopts a health behavior (registration in an internet-based diet diary)	Social influence	N/A		Social network	N/R
Graham, 2011 *(Arch Intern Med)*[43]		(SNS is part of a website) Discussions	Social support	Website + telephone + email	Education Assistance in setting a quit date + tailored help and guidance	None mentioned*	67 (69)

App: application; N/A: not applicable; N/R: not reported; Q&A: questions and answers; SNS: social networking site
*Authors mention 'theory-driven hypothesis' and 'evidence-based cessation treatment', but specific theories or models are not reported.

Comparisons and outcomes

The comparisons in seven studies were active controls: access to a Facebook page/group with a different content than in the intervention[39,40]; access to an information or education-only website[34,38,43]; access to personal step information[35]; and podcasts-only[36]. In two studies the comparisons were 'life-as-usual', involving no action from the investigators[37,42]. One study did not consider the comparison group in its analysis and only presented results for the intervention group[41]. Finally, two studies[30,31] were particularly different in their design - the network structure in each group was purposely manipulated so that random and unstructured networks (controls) were compared with clustered and homophilous ones.

The outcomes were self-reported in seven studies[34–40,42,43] and directly measured by the outcome assessor in three studies: registration in a health forum[30]; adoption of a diet diary[31]; and request of an HIV test[41]. For all the outcomes the intervention group was compared with the control group, except for Young 2013[41].

Risk of bias assessment

Authors of the included studies seldom detailed two aspects of the experiments: random sequence allocation and allocation concealment (Table 3). Additionally, trial protocol registration was only mentioned in four studies[38–40,43], which made the 'selective reporting' domain difficult to assess. The quasi-experimental studies[35,41,42] had, in general, a high risk of bias. Most RCTs lacked sufficient information for risk assessment in several domains. However, two RCTs[30,31] stood out as having the lowest risk of bias, according to the Cochrane Collaboration's 'risk of bias' tool.

Table 3: Assessment of the risk of bias for the included studies

Study identifier (author, year)	Random sequence allocation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting
Brindal, 2012[34]	+	?	-	-	-	?
Bull, 2012[40]	?	?	-	-	+	+
Cavallo, 2012[38]	?	?	-	-	+	+
Centola, 2010[30]	?	?	+	+	+	?
Centola, 2011[31]	?	?	+	+	+	?
Foster, 2010[35]	-	-	-	-	+	?
Graham, 2011[43]	+	?	-	-	+	+
Mayer, 2012[42]	-	-	-	-	+	?
Napolitano, 2012[37]	?	?	-	?	+	?
Turner-McGrievy, 2011[36]	+	+	-	?	+	?
Valle, 2012[39]	+	-	-	-	+	+
Young, 2013[41]	-	-	-	+	-	- *

+: Low risk of bias; -:High risk of bias; ?: Unclear risk of bias

Outcome-related domains were assessed considering the outcomes mentioned in Table 1.

Outcome of interest reported for only 20 participants (the ones who posted about HIV prevention/testing). No information on the outcome for 37 participants.

Studies not included in the meta-analysis – narrative synthesis

The three quasi-experimental studies excluded from the meta-analysis due to a high risk of bias showed statistically significant results[35,41,42]. The remaining cluster randomized trial did not find a statistically significant difference between intervention and control groups[40].

Meta-analysis

Eight studies (3943 participants) were included in the meta-analysis: four with a continuous outcome[36–39] and three with a dichotomous outcome[30,31,43].

We found a slight positive effect of SNSs on health behavior-related outcomes [Hedges' g 0.24; 95% confidence interval (CI) 0.04 - 0.43] (Figure 2). Heterogeneity was high (I^2=84.0%; T^2=0.058). A subgroup analysis showed a decrease of I^2 to 9.5% when the two studies by Centola[30,31] were removed from the analysis, with the summary effect dropping to 0.05 (not statistically significant).

The funnel plot of standard error by Hedges' g appears symmetric, indicating a similar proportion of studies in each direction of the effect size (Supplement 3). Based on Duval and Tweedie's trim and fill method, no studies needed to be imputed for symmetry to be increased, suggesting that papers with negative results were published in approximately the same proportion as the ones with positive results, both being adequately represented in our review. Therefore, no evidence of publication bias was detected.

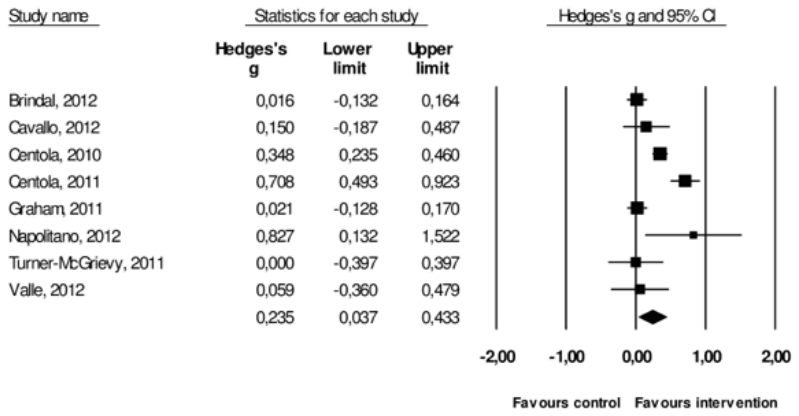


Figure 2: Forest plot of effect sizes and 95% confidence intervals representing the effect of interventions with social networking sites on health behavior-related outcomes (random effects model)

Discussion

To the best of our knowledge, this is the first meta-analysis evaluating the effectiveness of SNS interventions in changing health-related behaviors. Our study identified a slight positive effect of SNS interventions on health behavior change.

Similar literature

A recently published study concluded that interventions incorporating SNSs showed modest evidence of effectiveness in health behavior change[44]. Despite appearing to address the same research question, this systematic review differed from ours in several important ways. Firstly, the authors considered not only health behaviors as outcomes, but also associated cognitions (e.g. dietary awareness), whereas in our study the focus was primarily on health behaviors and their consequences, in order to enable the computation of a summary effect. Secondly, we reasoned that only prospective studies would be adequate to answer our research question, while *Maher et al.*, also included cross-sectional and retrospective studies. Thirdly, we specifically searched for grey literature, and did not limit our interest to particular health domains. Fourthly, we used the Cochrane risk of bias tool[26] to identify the studies with a higher risk, not pooling them together with the others, and cautioning readers in the interpretation of their results. Finally, we found a greater number of studies meeting inclusion criteria, and we were able to combine the effect sizes of eight RCTs in a meta-analysis[27–29].

Our results are in line with what has been shown for Interactive Health Communication Applications (IHCAs), where a positive effect on behavioral outcomes was found in a Cochrane meta-analysis[45]. IHCAs are computer-based (usually web-based) systems that combine health information with one of the following: social support, decision support, or behavior change support. In contrast, SNSs can be defined as web-based services that allow individuals to create a personal profile and build a list of connections to other users, originating innumerous interconnected and dynamic personal networks[1]. Although the two concepts are indeed different, many of the SNS interventions included in our review were in fact comparable to IHCAs, in that they generally provided education, social support, self-management, and tailoring. The combination of these functions has also been previously described as being commonly used in other social media interventions[46].

Finally, a modest number of systematic reviews have been published evaluating the effect of social media in health behavior change[46], health promotion[47], and health communication[48], showing feasibility but no definitive conclusion regarding effectiveness. Nevertheless, one must bear in mind that social media is much broader than the concept of SNSs, also including blogs, discussion boards, and wikis, among others.

Health domains and participants

The predominant health domain among the included studies was fitness-related (e.g. weight loss and physical activity), which reflects the growing interest of the medical informatics field on wellness and obesity[49,50]. In the future, as more patients with chronic illnesses become social media users[14,51], it is expected that SNS research will increasingly focus on chronic disease self-management.

Finally, amongst the participants of the twelve included studies, there appeared to be a preponderance of young adults, which is in line with previous characterizations of SNSs' common users[3].

Intervention components and underlying theories

The majority of interventions in our review consisted of other components in addition

to the SNS, most often in the form of a website. The scarcity of single-component interventions has been previously reported regarding social media and other web-based interventions[49–52], posing problems in determining the effectiveness of a particular component. It is unclear whether the observed effects in studies with multi-component interventions are attributable to either the SNS or the non-SNS component, or to a synergistic effect of both. Furthermore, the majority of studies did not address the effects of individual features of an intervention (e.g. education, feedback, tailoring, goal setting, self-monitoring) on effectiveness, engagement, or user satisfaction.

Only five studies mentioned a specific health behavior theory or model underlying the intervention[30,31,36,39,42], and the most frequently used theories were ones regarding interpersonal health behavior, such as 'social network' and 'social cognitive' theories. The two studies that were based on 'social network' theory[30,31] were amongst the three that showed a statistically significant positive effect on the behavioral outcome. There is now sufficient evidence showing that interventions grounded in theory lead to more powerful effects[53,54], and several models have already been proposed to explain behavior change in internet interventions[55–57]. However, few authors seem to take these theories and models into consideration when designing interventions, as was observed in our review. A possible consequence is that studies may be technology-driven instead of user-centered, and resources may be wasted in non-optimized and 'non-evidence-based' interventions that are likely to be ineffective.

Social networking sites

The type of SNS used was health-specific in four studies: two provided the SNS as part of a comprehensive website[34,43] and the other two studies used a purposely designed SNS [30,31]. The remaining eight studies used a general SNS: Facebook[35,37–42] and Twitter[36].

General SNSs present several advantages for the implementation of health interventions, compared to health-specific SNSs[58,59]. They have enormous reach - millions of regular users worldwide[2,4] - potentially minimizing problems of retention and lack of adherence to interventions. Also, they can be efficient ways of

disseminating interventions and recruiting participants[37,39–41], and they can take advantage of participants' existing social networks[60,61], instead of asking them to form new connections (which has been termed 'the stranger phenomenon'[49]). Finally, as general SNSs are nowadays a part of people's daily lives, and not focused only on health, they have a huge potential to improve engagement. This way, interventions can be incorporated in people's routines and habits, instead of being an extra burden on their already busy lives[62]. Indeed, retention rates of general SNS studies included in this review are very promising – around 80% - and they shed new light on the 'law of attrition' of online interventions[46,63].

Network interventions

Two of the studies showing a positive effect size were particularly different in their design[30,31], involving 'network alteration'[64]. In those studies, the interventions were based on two aspects of offline social networks: the tendency of people to associate with ones who resemble them – homophily[65]; and the tendency for people's friends to be connected between them, through redundant ties – clustering[65,66]. The author hypothesized that people were more likely to adopt a behavior if they knew someone similar to them, or some of their friends' friends, had done it before[67]. By modifying participants' networks in a SNS it was indeed demonstrated that homophily and clustering contribute to the social diffusion of 'easy' behaviors (e.g. adoption of a diet diary). Nonetheless, it remains to be demonstrated that the same mechanism applies to more complicated health behaviors (e.g. dieting, exercising, smoking cessation)[68]. Indeed, it is known that the need for social reinforcement increases when the adoption of a given behavior is difficult, costly or unfamiliar[67].

Strengths and limitations

This study has several strengths. First, we followed a rigorous and pre-defined protocol, openly available[32]. Second, we did an extensive search of the literature with the help of an academic librarian, to ensure sensitivity and specificity. Third, study selection was based on strict criteria, in order to avoid selection bias. Fourth, we used a pre-tested and piloted screening form, as well as four teams of two independent investigators, so

that an acceptable level of reliability could be reached. Fifth, we followed the Cochrane Collaboration's 'risk of bias' tool to appraise the included studies, so that results could be interpreted in the context of their quality. Sixth, we took a conservative approach and conducted a meta-analysis of the studies with the least risk of bias (the three non-included quasi-experimental studies were indeed statistically significant).

The results of this study need to be interpreted in the context of some limitations. There was fair agreement resulting from the screening phase, which can be attributed to a strategy that was intentionally used to increase sensitivity: screeners were instructed to classify papers in three different ways ('include', 'exclude', or 'uncertain'), and some researchers were more 'risk averse' than others, leading to discrepancies in classification.

Additionally, there was a moderate risk of bias in included studies. It is important to remember, though, that aspects like random sequence allocation and allocation concealment are frequently under-reported, not necessarily meaning that the adequate procedures were not followed[69,70]. Additionally, blinding is seldom possible in web-based interventions.

The small number of included studies reflects the current scarcity of experiments in this emerging and rapidly evolving field, and made it impossible to conduct analyzes according to type of intervention/outcome/health domain. Instead, all RCTs were grouped together, and their diverse nature contributed to the high heterogeneity observed.

Implications for research

Interventions for health-behavior change involving general and health-specific SNSs are feasible and show promise. However, more experimental studies are needed in order to increase meta-analytical power and determine their effectiveness more precisely. Future research should focus on identifying the features that increase engagement and retention of the target audience, as well as the specific characteristics that promote long-term behavior change and improve cost-effectiveness.

Intervention design

In designing interventions, theoretical models for behavior change should always be considered. Researchers are urged to evaluate existing literature on diffusion of innovations, social networks and health behavior change theories, so that they can leverage their interventions with the most up-to-date evidence. Future studies should also try to use the RE-AIM framework (Reach, Effectiveness, Adoption, Implementation, Maintenance)[59] to better plan and evaluate their interventions, aiming at the future translation of research to practice.

Study design

Single-component interventions, factorial design methods and adaptive designs should be considered more often, so that the effectiveness of SNS components can be clearly evaluated[71]. Additionally, the type of comparison group should be considered carefully: on one hand, standard of care, waiting list, or 'true' controls (i.e. no-intervention comparators) may exacerbate the Hawthorne effect in non-blinded studies; on the other hand, active controls may inappropriately give non-significant results. Study duration should also be thoughtfully planned, so that engagement and retention are optimized and enough time is allowed for the specific type of behavior change to occur. Finally, the accuracy of outcome measures should be optimized and, when possible, self-reporting bias should be avoided (e.g. data upload from digital sources).

Reporting recommendations

When reporting interventions, two aspects are particularly important: consistent engagement metrics should be used, so that future reviewers are able to provide recommendations for optimal intervention 'doses'; and effect sizes should be interpreted in terms of their potential clinical relevance, whenever possible.

Finally, authors are urged to follow the CONSORT and TREND[72] statements when reporting RCTs and non-randomized trials, so that a correct evaluation of the studies' risk of bias can be performed.

Public health impact

Social networking sites are becoming ubiquitous in people's everyday life, making them

especially appealing in the public health domain. On one hand, they present a low-cost opportunity to virally spread health information, possibly improving the cost-effectiveness of health interventions. On the other hand, they can promote social support and social influence, facilitating health behavior change. In particular, network interventions that increase clustering and homophily appear promising, warranting further investigation regarding their effectiveness in influencing long-term health behavior change.

An interesting hypothesis - that remains untested - is that SNSs may be used in a synergistic way with Personal Health Records and mobile devices[73,74], allowing consumers to continuously benefit from the daily knowledge, accountability, support, and influence that their social connections can provide.

Conclusion

The use of SNSs in health-related research has been rising, as they become more popular and ubiquitous. Our study is the first meta-analysis evaluating the effectiveness of SNSs in changing health behavior-related outcomes. We found a statistically significant positive effect of SNS interventions on behavior change, boosting encouragement for future research in this area.

References

1. Boyd DM, Ellison NB. Social Network Sites: Definition, History, and Scholarship. J Comput Commun. 2007 Oct 17;13(1):210–30.
2. Pew Research Center. Social Media Update [Internet]. 2013. Available from: http://www.pewinternet.org/2013/12/30/social-media-update-2013/
3. Pew Research Center. Social Networking Fact Sheet [Internet]. 2013. Available from: http://www.pewinternet.org/fact-sheets/social-networking-fact-sheet/
4. Facebook Newsroom [Internet]. 2014. Available from: http://newsroom.fb.com/content/default.aspx?newsareaid=22
5. Twitter, by the numbers [Internet]. 2013. Available from: http://news.yahoo.com/twitter-statistics-by-the-numbers-153151584.html
6. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. Health Promot Pract. 2013 Jan;14(1):15–23.
7. Cobb NK, Graham AL, Abrams DB. Social network structure of a large online community for smoking cessation. Am J Public Health. 2010 Jul;100(7):1282–9.
8. Coiera E. Social networks, social media, and social diseases. BMJ. 2013;3007(May):1282–9.

9. Eysenbach G. Infodemiology and Infoveillance: Framework for an Emerging Set of Public Health Informatics Methods to Analyze Search, Communication and Publication Behavior on the Internet. J Med Internet Res. 2009 Jan;11(1):e11.
10. Salathé M, Freifeld C, Mekaru S, Tomasulo A, Brownstein J. Influenza A (H7N9) and the importance of digital epidemiology. N Engl J Med. 2013;369:401–4.
11. Mandl KD, McNabb M, Marks N, Weitzman ER, Kelemen S, Eggleston EM, et al. Participatory surveillance of diabetes device safety: a social media-based complement to traditional FDA reporting. J Am Med Inform Assoc. 2014;21:687–91.
12. Weitzman ER, Kelemen S, Quinn M, Eggleston EM, Mandl KD. Participatory surveillance of hypoglycemia and harms in an online social network. JAMA Intern Med. 2013 Mar 11;173(5):345–51.
13. Hawn C. Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. Health Aff (Millwood). 2009;28(2):361–8.
14. Greene J a, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J Gen Intern Med. 2011 Mar;26(3):287–92.
15. Greaves F, Ramirez-Cano D, Millett C, Darzi A, Donaldson L. Harnessing the cloud of patient experience: using social media to detect poor quality healthcare. BMJ Qual Saf. 2013 Mar;22(3):251–5.
16. Rozenblum R, Bates DW. Patient-centred healthcare, social media and the internet: the perfect storm? BMJ Qual Saf. 2013 Mar;22(3):183–6.
17. Valente T. Social Networks and Health. Oxford University Press; 2010.
18. Wicks P, Vaughan TE, Massagli MP, Heywood J. Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. Nat Biotechnol. Nature Publishing Group; 2011 May;29(5):411–4.
19. Wicks P, Massagli M, Frost J, Brownstein C, Okun S, Vaughan T, et al. Sharing health data for better outcomes on PatientsLikeMe. J Med Internet Res. 2010 Jan;12(2):e19.
20. Narayan KMV, Ali MK, Koplan JP. Global noncommunicable diseases-where worlds meet. N Engl J Med. 2010 Sep 23;363(13):1196–11988.
21. Smith KP, Christakis N a. Social Networks and Health. Annu Rev Sociol. 2008 Aug;34(1):405–29.
22. Fowler J, Christakis N. Dynamic spread of happiness in a large social network: longitudinal analysis over 20 years in the Framingham Heart Study. Br Med J. 2008;(337):a2338–8.
23. Rosenquist J, Murabito J, Fowler J, Christakis N. The Spread of Alcohol Consumption Behavior in a Large Social Network. Ann Intern Med. 2010;152:426–33.
24. Christakis N a, Fowler JH. The collective dynamics of smoking in a large social network. N Engl J Med. 2008 May 22;358(21):2249–58.
25. Christakis N a, Fowler JH. The spread of obesity in a large social network over 32 years. N Engl J Med. 2007 Jul 26;357(4):370–9.
26. Higgins J, Green S. Cochrane Handbook for Systematic Reviews of Interventions. Chichester, UK: John Wiley & Sons, Ltd; 2008.
27. Ioannidis J, Patsopoulos N, Rothstein H. Reasons or excuses for avoiding meta-analysis in forest plots. BMJ. 2008 Jun 21;336(7658):1413–5.
28. Borenstein M, Hedges L, Higgins J. Introduction to Meta-Analysis. Chichester, UK: John Wiley & Sons, Ltd; 2009.
29. Higgins JPT, Thompson SG, Deeks JJ, Altman DG. Measuring inconsistency in meta-analyses. BMJ. 2003 Sep 6;327(7414):557–60.
30. Centola D. The spread of behavior in an online social network experiment. Science. 2010 Sep 3;329(5996):1194–7.
31. Centola D. An experimental study of homophily in the adoption of health behavior. Science. 2011 Dec 2;334(6060):1269–72.
32. PROSPERO - International prospective register of systematic reviews [Internet]. Available from: http://www.crd.york.ac.uk/PROSPERO/
33. PRISMA [Internet]. Available from: http://www.prisma-statement.org/
34. Brindal E, Freyne J, Saunders I, Berkovsky S, Smith G, Noakes M. Features predicting weight loss in overweight or obese participants in a web-based intervention: randomized trial. J Med Internet Res. 2012 Jan;14(6):e173.

35. Foster D, Linehan C, Kirman B, Lawson S, Gary J. Motivating physical activity at work: Using persuasive social media for competitive step counting. ACM. 2010;(6):111–6.
36. Turner-McGrievy G, Tate D. Tweets, Apps, and Pods: Results of the 6-month Mobile Pounds Off Digitally (Mobile POD) randomized weight-loss intervention among adults. J Med Internet Res. 2011 Jan;13(4):e120.
37. Napolitano M a., Hayes S, Bennett GG, Ives AK, Foster GD. Using Facebook and Text Messaging to Deliver a Weight Loss Program to College Students. Obesity. 2012 Apr 24;21(1):25–31.
38. Cavallo DN, Tate DF, Ries A V, Brown JD, Devellis RF, Ammerman AS. A Social Media–Based Physical Activity Intervention. Am J Prev Med. 2012;43(5):527–32.
39. Valle CG, Tate DF, Mayer DK, Allicock M, Cai J. A randomized trial of a Facebook-based physical activity intervention for young adult cancer survivors. J Cancer Surviv. 2013 Sep;7(3):355–68.
40. Bull S, Levine D, Black S, Schmiege S, Santelli J. Social Media–Delivered Sexual Health Intervention - A cluster randomized trial. Am J Prev Med. 2012;43(5):467–74.
41. Young SD, Jaganath D. Online social networking for HIV education and prevention: a mixed-methods analysis. Sex Transm Dis. 2013 Feb;40(2):162–7.
42. Mayer A, Harrison J. Safe Eats: an evaluation of the use of social media for food safety education. J Food Prot. 2012 Aug;75(8):1453–63.
43. Graham A, Cobb N, Papandonatos G, Moreno J, Kang H, Tinkelman D. A Randomized Trial of Internet and Telephone Treatment for Smoking Cessation. Arch Intern Med. 2011;171(8):46–53.
44. Maher C a, Lewis LK, Ferrar K, Marshall S, De Bourdeaudhuij I, Vandelanotte C. Are health behavior change interventions that use online social networks effective? A systematic review. J Med Internet Res. 2014 Jan;16(2):e40.
45. Murray E, Burns J, See T, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. Cochrane Database Syst Rev. 2009;(1):e40.
46. Williams G, Hamm MP, Shulhan J, Vandermeer B, Hartling L. Social media interventions for diet and exercise behaviours: a systematic review and meta-analysis of randomised controlled trials. BMJ Open. 2014 Jan;4(2):e003926.
47. Chou WS, Prestin A, Lyons C, Wen K. Web 2.0 for health promotion: reviewing the current evidence. Am J Public Health. 2013 Jan;103(1):e9–18.
48. Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. J Med Internet Res. 2013 Jan;15(4):e85.
49. Chang T, Chopra V, Zhang C, Woolford SJ. The role of social media in online weight management: systematic review. J Med Internet Res. 2013 Jan;15(11):e262.
50. Neve M, Morgan PJ, Jones PR, Collins CE. Effectiveness of web-based interventions in achieving weight loss and weight loss maintenance in overweight and obese adults: a systematic review with meta-analysis. Obes Rev. 2010 Apr;11(4):306–21.
51. Hamm MP, Chisholm A, Shulhan J, Milne A, Scott SD, Given LM, et al. Social media use among patients and caregivers: a scoping review. BMJ Open. 2013 Jan;3(5):1–10.
52. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. 2004;328(4):1166–0.
53. Webb TL, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res. 2010 Jan;12(1):e4.
54. Glanz K, Rimer B, Viswanath K. Health Behavior and Health Education. 4th ed. San Francisco: John Wiley & Sons; 2008.
55. Ritterband L, Thorndike F, Cox D, Kovatchev B. A Behavior Change Model for Internet Interventions. Ann Behav Med. 2009;38(1):18–27.
56. Skinner H a, Maley O, Norman CD. Developing Internet-Based eHealth Promotion Programs. Health Promot Pract. 2006 Oct;7(4):406–17.
57. Evers KE, Prochaska JM, Prochaska JO, Driskell M-M, Cummins CO, Velicer WF. Strengths and weaknesses of health behavior change programs on the internet. Journal of health psychology. 2003. p. 63–70.

58. Cobb NK, Graham AL. Health behavior interventions in the age of facebook. Am J Prev Med. 2012 Nov;43(5):571–2.
59. Bennett GG, Glasgow RE. The delivery of public health interventions via the Internet: actualizing their potential. Annu Rev Public Health. 2009 Jan;30:273–92.
60. Poirier J, Cobb NK. Social influence as a driver of engagement in a web-based health intervention. J Med Internet Res. 2012 Jan;14(1):e36.
61. Rice E. The positive role of social networks and social networking technology in the condom-using behaviors of homeless young people. Public Health Rep. 2010;125(4):588–95.
62. Jimison H, Gorman P, Woods S, Nygren P, Walker M, Norris S, et al. Barriers and drivers of health information technology use for the elderly, chronically ill, and underserved. Evid Rep Technol Assess (Full Rep). 2008 Nov;(175):1–1422.
63. Eysenbach G. The law of attrition. J Med Internet Res. 2005 Jan;7(1):e11.
64. Valente TW. Network interventions. Science. 2012 Jul 6;337(6090):49–53.
65. McPherson M, Smith-Lovin L, Cook J. Birds of a Feather: Homophily in Social Networks. Annu Rev Sociol. 2001;27:415–44.
66. Centola D, Macy M. Complex Contagions and the Weakness of long ties. Am J Sociol. 2007;113(3):702–34.
67. Centola D. Social media and the science of health behavior. Circulation. 2013 May 28;127(21):2135–44.
68. Van der Leij MJ. Sociology. Experimenting with buddies. Science. 2011 Dec 2;334(6060):1220–1.
69. Hill CL, LaValley MP, Felson DT. Discrepancy between published report and actual conduct of randomized clinical trials. J Clin Epidemiol. 2002 Aug;55(8):783–6.
70. Devereaux PJ, Choi PT-L, El-Dika S, Bhandari M, Montori VM, Schünemann HJ, et al. An observational study found that authors of randomized controlled trials frequently use concealment of randomization and blinding, despite the failure to report these methods. J Clin Epidemiol. 2004 Dec;57(12):1232–6.
71. Baker TB, Gustafson DH, Shah D. How can research keep up with eHealth? Ten strategies for increasing the timeliness and usefulness of eHealth research. J Med Internet Res. 2014 Jan;16(2):e36.
72. Des Jarlais DC, Lyles C, Crepaz N. Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: the TREND statement. Am J Public Health. 2004 Mar;94(3):361–6.
73. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res. 2008 Jan;10(3):e22.
74. Paton C, Hansen M, Fernandez-Luque L, Lau a YS. Self-Tracking, Social Media and Personal Health Records for Patient Empowered Self-Care. Contribution of the IMIA Social Media Working Group. Yearb Med Inform. 2012 Jan;7(1):16–24.

Supplement 1

Complete search strategy:

"Social Media"[Mesh] OR "social media*" OR "social web" OR facebook OR twitter OR youtube OR "social network site*" OR "online social network*" OR (("Social Environment"[Mesh] OR "social process*" OR "social competition*" OR "social norm*" OR "social feedback" OR "social influence*" OR "social comparison*" OR "social network*" OR "discussion group*" OR "support group*" OR "Social Support"[Majr]) AND (ehealth OR e-health OR "information technology" OR "communication technology" OR "web*" OR "website*" OR online OR "mobile*" OR electronic OR Personal Health Record* OR "Internet"[Majr] OR "Online Systems"[Majr]))

Filter: last 10 years

Supplement 2

List of papers excluded after full-text revision, for not meeting inclusion criteria regarding the outcome, intervention or study design:

A. Outcome

1. Litt DM, Stock ML. Adolescent alcohol-related risk cognitions: The roles of social norms and social networking sites. Psychology of Addictive Behaviors. 2011;25(4):708–13.
2. Kuwata S, Taniguchi S, Kato A, Inoue K, Yamamoto N, Ohkura T, et al. Metaboli-Net: online groupware system providing counseling guidance for patients with metabolic syndrome. Stud Health Technol Inform 2010;156:65-70.
3. Moreno MA, Brockman LN, Wasserheit JN, Christakis DA. A Pilot Evaluation of Older Adolescents' Sexual Reference Displays on Facebook. Journal of Sex Research. 2012 Jul;49(4):390–9.
4. Freyne J, Berkovsky S, Kimani S, Baghaei N, Brindal E. Improving health information access through social networking. 2010 Presented at: 23rd IEEE International Symposium on Computer-Based Medical Systems, CBMS; Oct 12-15, 2010; Perth p. 334-339.

B. Intervention

5. Richardson CR, Buis LR, Janney AW, Goodrich DE, Sen A, Hess ML, et al. An Online Community Improves Adherence in an Internet-Mediated Walking Program. Part 1: Results of a Randomized Controlled Trial. J Med Internet Res. 2010;12(4):e71.
6. Lau AY, Coiera EW. Impact of Web Searching and Social Feedback on Consumer Decision Making: A Prospective Online Experiment. J Med Internet Res. 2008;10(1):e2.
7. Justice-Gardiner H, Nutt S, Rechis R, McMillan B, Warf R. Using New Media to Reach Hispanic/Latino Cancer Survivors. J Canc Educ. 2011 Aug 30;27(1):100–4.
8. McKay HG, King D, Eakin EG, Seeley JR, Glasgow RE. The diabetes network internet-based physical activity intervention: a randomized pilot study. Diabetes Care. 2001 Aug;24(8):1328–34.

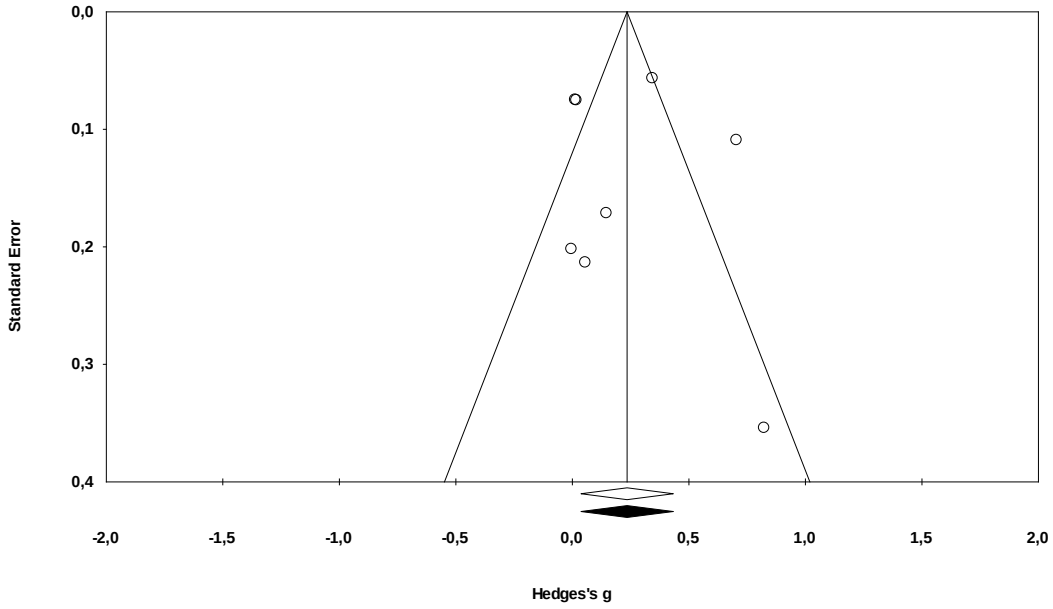
A. Study design

9. Jelenchick LA, Eickhoff JC, Moreno MA. “Facebook Depression?” Social Networking Site Use and Depression

in Older Adolescents. JAH. Elsevier Inc; 2013 Jan 1;52(1):128–30.
10. Ma X, Chen G, Xiao J. Analysis of an online health social network. 2010 Presented at: 1st ACM International Health Informatics Symposium, IHI'10; Nov 11-12, 2010; Arlington p. 297-306.
11. Pantic I, Damjanovic A, Todorovic J, Topalovic D, Bojovic-Jovic D, Ristic S, et al. Association between online social networking and depression in high school students: behavioral physiology viewpoint. Psychiatr Danub. 2012 Mar;24(1):90–3.
12. Moreno MA, Jelenchick LA, Egan KG, Cox E, Young H, Gannon KE, et al. Feeling bad on Facebook: depression disclosures by college students on a social networking site. Depress. Anxiety. 2011 Mar 11;28(6):447–55.
13. Wright KB, Rosenberg J, Egbert N, Ploeger NA, Bernard DR, King S. Communication Competence, Social Support, and Depression Among College Students: A Model of Facebook and Face-to-Face Support Network Influence. Journal of Health Communication. 2013 Jan;18(1):41–57.
14. Frost JH, Massagli MP, Wicks P, Heywood J. How the Social Web Supports patient experimentation with a new therapy: The demand for patient-controlled and patient-centered informatics. AMIA Annu Symp Proc. 2008;:217–21.
15. Lowe JB, Barnes M, Teo C, Sutherns S. Investigating the use of social media to help women from going back to smoking post-partum. Australian and New Zealand Journal of Public Health. 2012 Feb 7;36(1):30–2.
16. Martín G, Marinescu M-C, Singh DE, Carretero J. Leveraging social networks for understanding the evolution of epidemics. BMC Syst Biol. 2011 Dec 23;5 Suppl 3:S14.
17. RIDOUT B, CAMPBELL A, ELLIS L. "Off your Face(book)": Alcohol in online social identity construction and its relation to problem drinking in university students. Drug and Alcohol Review. 2011 Jan 5;31(1):20–6.
18. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook. J GEN INTERN MED. 2010 Oct 13;26(3):287–92.
19. Frost J, Okun S, Vaughan T, Heywood J, Wicks P. Patient-reported Outcomes as a Source of Evidence in Off-Label Prescribing: Analysis of Data From PatientsLikeMe. J Med Internet Res. 2011;13(1):e6.
20. Frost J, Massagli M. PatientsLikeMe the case for a data-centered patient community and how ALS patients use the community to inform treatment decisions and manage pulmonary health. Chron Respir Dis. 2009;6(4):225–9.
21. Bender JL, Jimenez-Marroquin M-C, Jadad AR. Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups. J Med Internet Res. 2011;13(1):e16.
22. Weitzman ER, Adida B, Kelemen S, Mandl KD. Sharing Data for Public Health Research by Members of an International Online Diabetes Social Network. Shea BJ, editor. PLoS ONE. 2011 Apr 27;6(4):e19256.
23. Wicks P, Massagli M, Frost J, Brownstein C, Okun S, Vaughan T, et al. Sharing Health Data for Better Outcomes on PatientsLikeMe. J Med Internet Res. 2010;12(2):e19.
24. Weitzman ER, Cole E, Kaci L, Mandl KD. Social but safe? Quality and safety of diabetes-related online social networks. Journal of the American Medical Informatics Association. 2011 Apr 12;18(3):292–7.
25. Frost JH, Massagli MP. Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. J Med Internet Res. 2008;10(3):e15.
26. van Mierlo T, Voci S, Lee S, Fournier R, Selby P. Superusers in Social Networks for Smoking Cessation: Analysis of Demographic Characteristics and Posting Behavior From the Canadian Cancer Society"s Smokers" Helpline Online and StopSmokingCenter.net. J Med Internet Res. 2012;14(3):e66.
27. Jones K, Baldwin KA, Lewis PR. The Potential Influence of a Social Media Intervention on Risky Sexual Behavior and Chlamydia Incidence. Journal of Community Health Nursing. 2012 Apr;29(2):106–20.
28. Orizio G, Schulz P, Gasparotti C, Caimi L, Gelatti U. The World of e-Patients: A Content Analysis of Online Social Networks Focusing on Diseases. Telemedicine and e-Health. 2010 Dec;16(10):1060–6.
29. Killackey E, Anda AL, Gibbs M, Alvarez-Jimenez M, Thompson A, Sun P, et al. Using internet enabled mobile devices and social networking technologies to promote exercise as an intervention for young first episode psychosis patients. BMC Psychiatry. 2011;11:80.
30. Ayubi S, Parmanto B. PersonA: Persuasive Social Network for Physical Activity. 2012 Jun 8;:1–5.
31. Takahashi Y, Uchida C, Miyaki K, Sakai M, Shimbo T, Nakayama T. Potential Benefits and Harms of a Peer Support Social Network Service on the Internet for People With Depressive Tendencies: Qualitative Content Analysis and Social Network Analysis. J Med Internet Res. 2009;11(3):e29.
32. Lau AYS, Kwok TMY, Coiera E. The influence of crowds on consumer health decisions: an online prospective study. Stud Health Technol Inform. 2010;160(Pt 1):33–7.
33. Prochaska JJ, Pechmann C, Kim R, Leonhardt JM. Twitter=quitter? An analysis of Twitter quit smoking social

networks. Tobacco Control. 2012 Jun 22;21(4):447–9.

Supplement 3



Funnel plot of standard error by Hedges' g showing no need to impute studies to increase symmetry
(based on the trim and fill analysis)

Paper VII

Use of electronic health records and geographic information systems in public health surveillance of type 2 diabetes

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All the authors contributed substantially to the design of the study and the acquisition, analysis and/or interpretation of data. The paper was drafted by the first author and critically reviewed by all the remaining authors.

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Use of electronic health records and geographic information systems in public health surveillance of type 2 diabetes

Abstract

Background

Data routinely collected in Electronic Health Records (EHRs) offer a unique opportunity to monitor chronic health conditions in real-time. Geographic information systems (GIS) may be an important complement in the analysis of those data.

Objective

The aim of this study was to explore the feasibility of using primary care EHRs, and GIS, for population care management and public health surveillance of chronic conditions, in Portugal. Specifically, type 2 diabetes was chosen as a case study, and we aimed to map its prevalence and the presence of comorbidities, as well as identify possible populations at risk for cardiovascular complications.

Methods

Cross-sectional study using individual-level data from 514 primary care centers, collected from three different types of EHR. Data were obtained on adult patients with type 2 diabetes (identified by the ICPC-2 code - T90 - in the problems list). Geographic information systems were used for mapping the prevalence of diabetes and comorbidities (hypertension, dyslipidemia, and obesity) by parish, in the region of Lisbon and Tagus Valley. Descriptive statistics and multivariate logistic regression were used for data analysis.

Results

We identified 205,068 individuals with the diagnosis of type 2 diabetes, corresponding to a prevalence of 5.6% in the study population. The mean age of these patients was 67.5 years, and hypertension was present in 71% of all individuals. There was considerable variation in diagnosed comorbidities across parishes.

Diabetes patients with concomitant hypertension or dyslipidemia showed higher odds of having been diagnosed with cardiovascular complications, when adjusting for age and gender [(hypertension odds ratio (OR) 2.16, confidence interval (CI) 2.10-2.22; dyslipidemia OR 1.57, CI 1.54-1.60)].

Conclusions

Individual-level data from EHRs may play an important role in chronic disease surveillance, namely through the use of GIS. Promoting the quality and comprehensiveness of data, namely through patient involvement in their medical records, is crucial to enhance the feasibility and usefulness of this approach.

Background

The burden of chronic conditions has now reached unprecedented levels[1]. One of the means to address this challenge seems to be through the meaningful use of health information technology[2,3]. Electronic tools have the potential to improve the quality of care for non-communicable diseases, namely by facilitating the collection, management, and analysis of vast amounts of health data.

Although Public Health surveillance has traditionally relied on population surveys, and sentinel and cohort studies, electronic registries are increasingly seen as paramount tools in planning population-level care[4]. Some registries are disease-focused (including only patients with a particular disease, e.g. diabetes)[3,5–7], while others are comprehensive population-wide databases, serving as a source of epidemiological data for public health, policy, and research.

Nowadays, data collected by health care providers in EHRs offer a unique opportunity to monitor acute and chronic health conditions in real-time[4,8,9]. Moreover, EHRs have the potential to become a cost-efficient, feasible and sustainable source of data for continuous population health management[8,10–12].

One interesting way to analyze EHR-collected data is with the use of geographic information systems (GIS). GIS can track regional changes in disease incidence and prevalence, analyze the environmental and social determinants of health, identify health trends in local communities, and help plan interventions for populations in greatest need of services[13,14]. Indeed, GIS is gathering increasing attention in the

identification and analysis of high-risk areas for non-communicable diseases, as is the case with “obesogenic environments”[15,16] and diabetes[13,17–20].

Although geovisualization does not substitute traditional epidemiological and statistical approaches to data analysis, it seems to be a valuable tool in analyzing health data from a biosocial perspective, suggesting trends and generating hypothesis for further testing. A recent OECD report highlighted the existence of huge geographic variations in healthcare, and reinforces the importance of their careful analysis, so that discrepancies may be understood and addressed through patient-centered approaches[21].

The main purpose of this study was to evaluate the feasibility of using primary care individual-level EHR data, and GIS, for population care management and public health surveillance of chronic conditions, in Portugal. We decided to use type 2 diabetes as a case study due to its high burden, rapidly increasing prevalence, and opportunities for primary and secondary prevention, as well as due to the potential EHRs seem to have to further improve diabetes care, at the population level[22,23].

Our objectives were to: 1) Map and analyze the distribution of diabetes and related comorbidities in the region of Lisbon, as well as at the parish level; 2) Analyze the ability to identify populations at risk for cardiovascular complications, based on the presence of known comorbidities (obesity, hypertension and dyslipidemia); 3) Externally validate our results by comparing them with published data; 4) Evaluate the feasibility of using this approach for population care management, in Portugal and globally.

Materials and methods

Setting

This study was based in Lisbon and in the neighboring region of Tagus Valley, involving a total of 514 primary care centers. All centers were computerized and had an EHR in use (out of three different types of EHR software available in primary care, in Portugal).

Patient-level data from primary care centers in the country is gathered in regional health information infrastructures. All Portuguese residents have a unique national

patient identifier, which allows data integration between different information systems. Data from the centers involved in this study (from approximately 4 million patients) were stored in the Regional Health Administration's data warehouse of Lisbon and Tagus Valley.

In Portugal, it is common practice for primary care physicians to enter data in a structured format regarding diagnoses and health problems, using the International Classification of Primary Care (ICPC-2). Indeed, current quality improvement indicators defined by the Ministry of Health are mostly dependent on the use of this classification.

Data collection

Data collection was performed in September 2013 by the Information Technology (IT) department of the Regional Health Administration in Lisbon, which had no further involvement in the study. The dataset provided was de-identified (a pseudonymised identifier was used for each individual patient).

Individual-level data were collected on adult patients (20 years of age or above) with the diagnosis of type 2 diabetes (identified by having the ICPC-2 code for type 2 diabetes - T90 - in the EHR field 'problems list'). We chose to use a cut-off for age to help avoid including misdiagnosed/misclassified people. Duplicates were removed from the dataset, as well as patients living outside of the study area of Lisbon and Tagus Valley.

Variables collected were: age, gender, parish of residence, comorbidities (obesity, hypertension and dyslipidemia), and cardiovascular complications (ischemic heart disease, myocardial infarction, transient cerebral ischemia, stroke, cerebrovascular disease, and peripheral vascular disease). Information on comorbidities and complications was collected from the 'problems list', by the presence or absence of the corresponding ICPC-2 codes (obesity- T82; hypertension- K86 or K87; dyslipidemia- T93; ischemic heart disease- K74 or K76; myocardial infarction- K75; transient cerebral ischemia- K89; stroke- K90; cerebrovascular disease- K91, and peripheral vascular disease- K92).

The study had approval by the National Data Protection Committee and by the Ethics Committee of the Regional Health Administration in Lisbon.

Data analysis

R Studio software (version 3.0.2) was used for the statistical analyses. The distribution of continuous variables was checked for normality, and means and standard deviations were calculated; proportions and counts were determined for categorical variables. Univariate logistic regression was used to calculate the odds of having at least one cardiovascular complication in the problems list, as a function of each individual predictor (crude odds ratios). Multivariate logistic regression was used to model the probability of having at least one cardiovascular complication in the problems list, as a function of comorbidities (i.e. obesity, hypertension, dyslipidemia), controlling for age and gender.

The ArcMap functionality of ArcGis (version 10; ESRI) was used to create cloropleth maps. The prevalence of diabetes by parish was mapped using a grey scale where the darkest tone represented the highest prevalence. The same method was applied to generate the comorbidities' maps.

Results

From a total of 3,659,868 individual records of people registered in the primary care centers studied, 205,921 had the diagnosis of type 2 diabetes. We identified and removed 559 duplicate records, as well as 72 individuals that were currently living outside Lisbon and Tagus Valley region. Therefore, the final number of patients with type 2 diabetes was 205,068, corresponding to a prevalence of 5.6% (Table 1). The mean age of these patients was 67.5 years (standard deviation 11.7) and 49.8% were female.

Hypertension was present in 71% of the patients with type 2 diabetes, obesity in 20%, and dyslipidemia in 45%; 19% of the patients had none of these comorbidities.

No cardiovascular complications were registered for 85% of the patients. Ischemic heart disease was the most prevalent complication, being present in 7% of the patients.

The unadjusted (crude) odds ratios (OR) for the probability of having at least one cardiovascular complication coded in the primary care electronic information system are represented in Table 1, as well as the adjusted OR. In terms of comorbidities,

people with hypertension or dyslipidemia showed higher odds of having cardiovascular complications in the problems list, when adjusting for age and gender [(hypertension OR 2.16, Confidence interval (CI) 2.10-2.22; dyslipidemia OR 1.57, CI 1.54-1.60)]. The same was not observed for obesity (OR 1.01, CI 0.99-1.04).

The maps of prevalence for diabetes, dyslipidemia, hypertension and obesity showed considerable variation across the region of Lisbon and Tagus Valley, with some parishes showing higher proportions than others (Figure 1).

Table 1: Characteristics of patients diagnosed with type 2 diabetes in the primary care electronic health records of Lisbon and Tagus Valley[a]

	Total 205 068 n (%)	**Crude Odds Ratio** (95% CI) [b]	**Adjusted Odds Ratio** (95% CI) [c]
Gender			
Male	102 913 (50.2)	[Reference]	[Reference]
Female	102 155 (49.8)	0.68 (0.66 – 0.69)	0.59 (0.57 – 0.60)
Age category			
<50	14 156 (6.9)	[Reference]	[Reference]
[50; 70[	96 862 (47.2)	3.50 (3.26 – 3.77)	2.82 (2.62 – 3.04)
≥70	94 050 (45.9)	6.52 (6.07 – 7.03)	5.40 (5.02 – 5.82)
Comorbidities			
None	37 949 (19)		
Hypertension	144 938 (71)	2.65 (2.58 – 2.72)	2.16 (2.10 – 2.22)
Obesity	41 473 (20)	1.06 (1.03 – 1.08)	1.01 (0.99 – 1.04)
Dyslipidemia	92 000 (45)	1.70 (1.67 – 1.74)	1.57 (1.54 – 1.60)
Diabetes complications		N/A	N/A
None	173 227 (85)		
Ischemic heart disease	14 981 (7)		
Myocardial infarction	5 012 (2)		
Transient cerebral ischemia	1 355 (1)		
Stroke	9 152 (5)		
Cerebrovascular disease	2 448 (1)		
Peripheral vascular disease	7 683 (4)		

Abbreviations: CI, Confidence Interval; N/A, Not applicable

[a] Based on information collected from the primary care electronic information system of Lisbon's Regional Health Administration in September 2013.

[b] Crude odds ratios calculated from univariate logistic regression, modeling the probability of having at least one diabetes complication.

[c] Logistic regression model for the probability of having at least one diabetes cardiovascular complication, controlling for age, gender, and comorbidities (hypertension, obesity, and dyslipidemia).

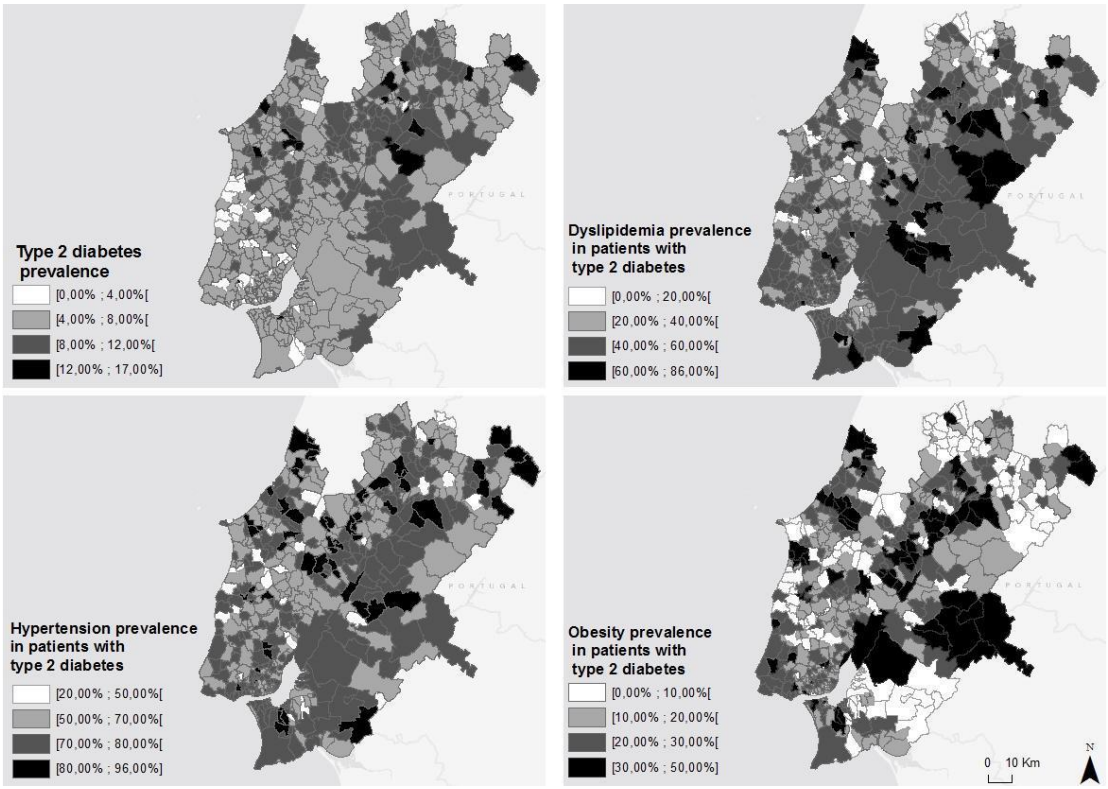

Figure 1: Mapping of diabetes prevalence and comorbidities' distribution, by parish, in Lisbon and Tagus Valley (based on data collected from the Regional Health Administration's data warehouse of Lisbon and Tagus Valley, in September 2013)

Discussion

This is the first study analyzing patient-level data from primary care EHRs, using GIS, in Portugal. Geographic analysis showed several parishes of high-prevalence for diabetes as well as for hypertension, dyslipidemia, and obesity. Diabetes patients with concomitant hypertension had more than twice the odds of having at least one cardiovascular complication registered in the problems list, when compared with patients without hypertension.

Principal results and comparison with other studies

Our study showed a prevalence of diagnosed diabetes similar to previously reported estimates[24,25], as well as a high proportion of diagnosed hypertension, consistent with the literature[26–28]. Additionally, although previous studies have identified high proportions of obesity and dyslipidemia in type 2 diabetes patients [usually above 50 and 70%, respectively[26,29], in our study the prevalence of these two risk factors was smaller (20 and 45%, respectively), as was the proportion of cardiovascular complications (85% of the patients had none coded). Another finding was that people with diabetes and concomitant hypertension or dyslipidemia had higher odds of having been diagnosed with at least one cardiovascular complication, which is in line with published literature[30], and may be helpful information when trying to identify high-risk areas for public health intervention. One way to apply this information would be to focus initial public health efforts in areas where the prevalence of diabetes and comorbidities (namely hypertension) seemed to be higher, analyzing and addressing possible reasons for that discrepancy, at the community-level.

Future studies should explore the effects of small-area characteristics (e.g. socioeconomic and environmental factors; health care services availability) on individual health, namely in regions where the burden of diabetes is higher. By identifying high-risk localities, public health efforts may be able to delineate and prioritize community-based strategies, an important element of the Chronic Care model[3].

Strengths and limitations

This study has several strengths. It was the first in Portugal to analyze data routinely collected from EHRs, producing small-area maps of the distribution of diabetes and comorbidities, in an entire region. The large sample size and considerable amount of structured data ensure some robustness to the results.

The results of our study need to be interpreted in the context of its cross-sectional design. Selection bias cannot be excluded, and two specific groups of individuals might be missing from our sample: people with health care accessibility issues, and people covered by private insurance, who do not normally use the public primary care services (estimated to be around 10% of the population)[31]. Additionally, this study

was limited to one geographic region in a specific country, so caution should be taken when trying to generalize the results to other populations and health care systems.

Misclassification and surveillance bias must be considered. The level of training in ICPC-2 coding varies between physicians, and adherence to quality improvement interventions is not uniform across primary care centers. Nonetheless, the fact that current EHRs offer some level of decision support in using ICPC-2, and the existence of national guidelines for the diagnosis of these health problems, are likely to ensure some level of diagnostic accuracy and consistency. Previous studies using primary care databases have shown an acceptable quality of diagnostic coding, with variations depending on physician expertise in using the coding system[32], and the type of morbidity being coded[33,34]. In Portugal, the coding of some health problems (e.g. diabetes, hypertension) is currently being more incentivized than others (e.g. stroke, myocardial infarction), possibly leading to discrepancies in their relative proportions. Indeed, the proportion of cardiovascular complications coded in our sample was lower than expected, and should be further validated using other sources of data.

Individual-level data regarding schooling, socio-economic level, diabetes medication, as well as last recorded values for body mass index, hemoglobin A1c, blood pressure, and LDL-cholesterol, were not able to be collected, contrary to our initial expectations. Therefore, we did not have access to biometric or lab data to cross-verify the validity of using coding diagnoses as surrogates for disease presence. This also hampered a comprehensive analysis of missing data.

Two other pieces of information were not possible to be collected: zip code of residence, which would have allowed for a more accurate GIS analysis; and ethnicity data, which is not usually allowed to be collected in Portugal, hampering a comprehensive analysis of health care disparities in ethnic minority groups.

Feasibility evaluation

We were able to obtain and analyze patient-level data from 514 primary care centers, specifically from three different types of EHR software, in the region of Lisbon. Given that all primary care centers in Portugal use one of these EHRs, this approach could potentially be extended to the 10 million individuals that live in the country.

It is important to keep in mind that the interpretation of EHR data is subject to several bias (e.g. selection, misclassification, surveillance), and must be done skeptically, to distinguish real signals from random noise[9,19]. Furthermore, aspects regarding data quality and comprehensiveness deserve special consideration.

Data quality

One way to assess data quality, and to validate EHR databases for use in public health and research, is by linking and cross-verifying different types of data and sources[35]. Two types of data are present in EHRs: free-text data and structured data. Free-text data constitutes a great part of most EHRs, but analyzing that information is currently very complicated. Further developments in Natural Language Processing[14] will be necessary, before those data may be meaningfully used[36].

On the contrary, structured data (e.g. ICPC-2 codes) are more easily extracted and commonly used in research, quality improvement, and public health[19,37]. However, entering structured data is more time-consuming than writing free-text, and is highly influenced by EHR characteristics. In Portugal, time spent with tasks other than direct patient contact accounts for a third of the family doctor's workload, and time spent on computer failures is significant[38], which may negatively impact data entry. EHR characteristics may also be an important barrier, and some aspects seem to particularly frustrating: time-consuming data-entry, interfaces that do not match clinical workflow, interference with face-to-face patient care, insufficient health information exchange, and information overload[39–43]. Therefore, a necessary condition to improve data quality is facilitating and streamlining its collection, with clinician-friendly EHRs.

Another advantage of collecting structured data is for physicians to be able to track their own performance and assess health indicators in their population of patients[36]. However, the majority of EHRs nowadays still lack built-in registry functionalities, have very limited data analysis capabilities, and rarely offer the possibility of extracting patient data for statistical analysis[5,44]. This is also the case in Portugal, where only a few pre-set queries and filtering tools are available in primary care EHRs, mostly limited to the evaluation of quality indicators defined by the Ministry of Health.

Data comprehensiveness

In Portugal, as confirmed by our study, individual-level data that is extractable from the primary care information system is still limited. For comprehensive outcomes monitoring to occur it should be possible to link data from primary care and hospital EHRs, as well as other health institutions (e.g. pharmacies, labs)[7,14,36,45,46]. The integration of these sources of data, in combination with information on the social and environmental determinants of health (e.g. area-based socioeconomic status indicators, walkability, green spaces, distance from grocery stores, fast food chains), would have the potential to render a more complete picture of the health state of communities[13,19,47,48]. A great amount of data remains siloed in institutions, fragmented, and generally inaccessible to the ones who could bring meaning to it: clinicians, public health workers, researchers and, most importantly, patients[36,45,49].

Nowadays, patient involvement in data gathering and integration is still far from ideal, despite growing availability of Personal Health Records (PHRs)[50,51]. Patient access and contribution to their medical records has the potential to help clinicians maintain accurate and up-to-date records, contributing to the quality and safety of health care[36,45,52–55]. Additionally, it may allow for more comprehensive population-level research, by enabling the combination of biomedical and clinical data routinely present in EHRs, with patient-reported measures from PHRs (e.g. demographic, psychosocial, behavioral), and data from other sources (e.g. wearable devices, social media), into one patient-controlled location[19,37,45,46,56–60].

In Portugal, patient access to their medical records is still uncommon[61], and currently only one PHR is (marginally) integrated with institutional EHRs, offering very limited access to clinical information, for now.

Implications for clinical practice, research and health policy

Our study demonstrated the feasibility of collecting, analyzing, and geographically displaying EHR data. Given the potential of this approach to improve chronic disease surveillance, awareness on the importance of data quality and comprehensiveness

should be promoted amongst policy makers, so that the necessary efforts are made in that direction. Furthermore, buy-in from clinicians should be promoted, and every effort should be made for data entry not to be an extra burden in daily practice. More importantly, patient involvement in their medical records is of paramount importance to enhance the feasibility and usefulness of this approach.

The opportunity for big data analytics in healthcare is enormous. From tracking diseases and evaluating their burden, to clinical prediction, clinical effectiveness research, monitoring of treatment side effects, and quality of care efforts. As we move forward, it is important to carefully balance the meaningful use of EHR data against the necessary high standards for privacy and security[9,53]. Appropriate storage and handling of data is not incompatible with easy access and control by patients, nor should it hamper integration between different sources. Clinical data should increasingly be treated as a public good, and as an essential element of a learning healthcare system[37,62].

Conclusions

Primary care EHR data shows potential to be used in public health surveillance of chronic diseases, in particular with the help of GIS. However, special attention must be given to data quality and comprehensiveness. Unless patients are actively involved, the full potential of big data in this area is not likely to be achieved.

References

1. Narayan KMV, Ali MK, Koplan JP. Global noncommunicable diseases--where worlds meet. N Engl J Med 2010 Sep 23;363(13):1196–8. PMID: 20860499
2. Institute of Medicine. Crossing the Quality Chasm: a new health system for the 21st century. Build a Better Deliv Syst. 2001.
3. Bodenheimer T, Wagner EH, Grumbach K. Improving Primary Care for Patients With Chronic Illness. JAMA 2002 Oct 9;288(14):1775–1779. PMID: 12365965
4. Chiolero A, Santschi V, Paccaud F. Public health surveillance with electronic medical records: at risk of surveillance bias and overdiagnosis. Eur J Public Health 2013 Jun;23(3):350–1. PMID: 23599219

5. Wright A, McGlinchey E a, Poon EG, Jenter C a, Bates DW, Simon SR. Ability to generate patient registries among practices with and without electronic health records. J Med Internet Res 2009 Jan;11(3):e31. PMID: 19674961

6. Bates DW, Bitton A. The future of health information technology in the patient-centered medical home. Health Aff (Millwood) 2010;29(4):614–621. PMID: 20368590

7. Chan WC, Jackson G, Wright CS, Orr-Walker B, Drury PL, Boswell DR, et al. The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement. BMJ Open 2014 Jan;4(4):e003975. PMID: 24776708

8. Klompas M, McVetta J, Lazarus R, Eggleston E, Haney G, Kruskal B a., et al. Integrating clinical practice and public health surveillance using electronic medical record systems. Am J Prev Med Elsevier Inc.; 2012;42(6):S154–S162. PMID: 22704432

9. Fihn SD, Francis J, Clancy C, Nielson C, Nelson K, Rumsfeld J, et al. Insights from advanced analytics at the veterans health administration. Health Aff 2014;33:1203–1211. PMID: 25006147

10. Chaudhry B, Wang J, Wu S, Maglione M, Mojica W, Roth E, et al. Systematic review: Impact of health information technology on quality, efficiency, and costs of medical care. Ann Intern Med. 2006. p. 742–752. PMID: 16702590

11. Institute of Medicine. Key Capabilities of an Electronic Health Record System: Letter Report. Washington, DC; 2003.

12. Curtis LH, Brown J, Platt R. Four health data networks illustrate the potential for a shared national multipurpose big-data network. Health Aff 2014;33:1178–1186. PMID: 25006144

13. Noble D, Smith D, Mathur R, Robson J, Greenhalgh T. Feasibility study of geospatial mapping of chronic disease risk to inform public health commissioning. BMJ Open 2012 Jan;2(1):e000711. PMID: 22337817

14. Bates DW, Saria S, Ohno-Machado L, Shah A, Escobar G. Big Data In Health Care: Using Analytics To Identify And Manage High-Risk And High-Cost Patients. Health Aff 2014 Jul 8;33(7):1123–1131. PMID: 25006137

15. Swinburn B, Egger G, Raza F. Dissecting obesogenic environments: the development and application of a framework for identifying and prioritizing environmental interventions for obesity. Prev Med (Baltim) 1999;29:563–570. PMID: 10600438

16. Curtis AJ, Lee W-AA. Spatial patterns of diabetes related health problems for vulnerable populations in Los Angeles. Int J Health Geogr 2010 Jan;9:43. PMID: 20796322

17. Mathur R, Noble D, Smith D, Greenhalgh T, Robson J. Quantifying the risk of type 2 diabetes in East London using the QDScore: a cross-sectional analysis. Br J Gen Pract 2012 Oct;62(603):e663–70. PMID: 23265225

18. Barker LE, Kirtland K a, Gregg EW, Geiss LS, Thompson TJ. Geographic distribution of diagnosed diabetes in the U.S.: a diabetes belt. Am J Prev Med Elsevier Inc.; 2011 Apr;40(4):434–9. PMID: 21406277

19. Eggleston EM, Weitzman ER. Innovative uses of electronic health records and social media for public health surveillance. Curr Diab Rep 2014;14. PMID: 24488369

20. Zhou M, T AB, Bi Y, Feng X, Jiang Y, Li Y, et al. Geographical variation in diabetes prevalence and detection in china: multilevel spatial analysis of 98058 adults. Diabetes Care 2015;2–3. PMID: 25352654

21. OECD. Geographic Variations in Health Care. 2014 p. 1–8.

22. Cebul RD, Love TE, Jain AK, Hebert CJ. Electronic health records and quality of diabetes care. N Engl J Med 2011 Sep 1;365(9):825–33. PMID: 21879900

23. Kupersmith J, Francis J, Kerr E, Krein S, Pogach L, Kolodner RM, et al. Advancing evidence-based care for diabetes: lessons from the Veterans Health Administration. Health Aff (Millwood) 26(2):w156–68. PMID: 17259199

24. Observatório Nacional da Diabetes. Diabetes: Factos e Números 2013 - Relatório Anual do Observatório Nacional da Diabetes. Sociedade Portuguesa de Diabetologia; 2014.

25. Gardete-Correia L, Boavida JM, Raposo JF, Mesquita a C, Fona C, Carvalho R, et al. First diabetes prevalence study in Portugal: PREVADIAB study. Diabet Med 2010 Aug;27(8):879–81. PMID: 20653744

26. Rato Q. Diabetes mellitus: a global health problem. Rev Port Cardiol 2010;29(4):539–543. PMID: 20734574

27. Ferrannini E, Cushman WC. Diabetes and hypertension: the bad companions. Lancet Elsevier Ltd; 2012 Aug 11;380(9841):601–10. PMID: 22883509

28. Soriguer F, Goday A, Bordiú E. Prevalence of diabetes mellitus and impaired glucose regulation in Spain : the Di@bet.es Study. 2012;88–93. PMID: 21987347

29. Colosia AD, Palencia R, Khan S. Prevalence of hypertension and obesity in patients with type 2 diabetes mellitus in observational studies: a systematic literature review. Diabetes Metab Syndr Obes 2013 Jan;6:327–338. PMID: 24082791

30. UK Prospective Diabetes Study Group. Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. BMJ 1998;703–713. PMID: 9732337

31. Barros P, Simões J, Machado S. Portugal Health System Review. Eur Obs Heal Syst Policies. 2011.

32. King MS, Sharp L, Lipsky MS. Accuracy of CPT Evaluation and Management Coding by Family Physicians. 2001;14(3). PMID: 11355050

33. Jordan K, Porcheret M, Croft P. Quality of morbidity coding in general practice computerized medical records: a systematic review. Fam Pract 2004 Aug;21(4):396–412. PMID: 15249528

34. Khan NF, Harrison SE, Rose PW. Validity of diagnostic coding within the General Practice Research Database: a systematic review. Br J Gen Pract 2010 Mar;60(572):e128–36. PMID: 20202356

35. Hassey A, Gerrett D, Wilson A. A survey of validity and utility of electronic patient records in a general practice. BMJ 2001;322:1401–1405. PMID: 11397747

36. Kukafka R, Ancker JS, Chan C, Chelico J, Khan S, Mortoti S, et al. Redesigning electronic health record systems to support public health. J Biomed Inform 2007 Aug;40(4):398–409. PMID: 17632039

37. Institute of Medicine. Clinical data as the basic staple of health learning: creating and Protecting a Public Good: Workshop Summary. Washington, DC; 2010.

38. Granja M, Ponte C, Cavadas LF. What keeps family physicians busy in Portugal? A multicentre observational study of work other than direct patient contacts. BMJ Open 2014 Jan;4(6):e005026. PMID: 24934208

39. Friedberg M, Chen P, Van Busum K, Aunom F, Pham C, Caloyeras J, et al. Factors Affecting Physician Professional Satisfaction and Their Implications for Patient Care, Health Systems, and Health Policy. 2013.

40. Christensen T, Grimsmo A. Instant availability of patient records, but diminished availability of patient information: a multi-method study of GP's use of electronic patient records. BMC Med Inform Decis Mak 2008 Jan;8:12. PMID: 18373858

41. Fernandopulle R, Patel N. How the EHR Did Not Measure Up To The Demands Of Our Medical home practice. Health Aff (Millwood) 2010 Apr;29(4):622–8. PMID: 20368591

42. Bates DW, Kuperman GJ, Wang S, Gandhi T, Kittler A, Volk L, et al. Ten Commandments for Effective Clinical Decision Support: Making the Practice of Evidence-based Medicine a Reality. J Am Med Informatics Assoc 2003;10(6):523–530. PMID: 12925543

43. Buntin MB, Burke MF, Hoaglin MC, Blumenthal D. The benefits of health information technology: a review of the recent literature shows predominantly positive results. Health Aff (Millwood) 2011 Mar;30(3):464–71. PMID: 21383365

44. Krist AH, Beasley JW, Crosson JC, Kibbe DC, Klinkman MS, Lehmann CU, et al. Electronic health record functionality needed to better support primary care. J Am Med Inform Assoc 2014;1–8. PMID: 24431335

45. Staroselsky M, Volk LA, Tsurikova R, Pizziferri L, Lippincott M, Wald J, et al. Improving electronic health record (EHR) accuracy and increasing compliance with health maintenance clinical guidelines through patient access and input. Int J Med Inform 2006;75(10-11):693–700. PMID: 16338169

46. Weber GM, Mandl KD, Kohane IS. Finding the missing link for big biomedical data. JAMA 2014;311:2479–80. PMID: 24854141

47. Berkowitz SA, Traore CY, Singer DE, Atlas SJ. Evaluating Area-Based Socioeconomic Status Indicators for Monitoring Disparities within Health Care Systems : Results from a Primary Care Network. 2011;1–20. PMID: 25219917

48. Voigtländer S, Vogt V, Mielck A, Razum O. Explanatory models concerning the effects of small-area characteristics on individual health. Int J Public Health 2014 Apr 26; PMID: 24770849

49. Luchenski SA, Reed JE, Marston C, Papoutsi C, Majeed A, Bell D. Patient and public views on electronic health records and their uses in the United Kingdom: Cross-sectional survey. J Med Internet Res. 2013. PMID: 23975239

50. Blumenthal D, Tavenner M. The “meaningful use” regulation for electronic health records. N Engl J Med 2010;363:501–504. PMID: 20647183

51. Steinbrook R. Personally controlled online health data--the next big thing in medical care? N Engl J Med 2008;358:1653–1656. PMID: 18420496

52. Otte-Trojel T, de Bont A, Rundall TG, van de Klundert J. How outcomes are achieved through patient portals: a realist review. J Am Med Inform Assoc 2014 Jul;21(4):751–757. PMID: 24503882

53. Wiljer D, Urowitz S, Apatu E, DeLenardo C, Eysenbach G, Harth T, et al. Patient accessible electronic health records: Exploring recommendations for successful implementation strategies. J Med Internet Res 2008;10(4).

54. Woods SS, Schwartz E, Tuepker A, Press NA, Nazi KM, Turvey CL, et al. Patient experiences with full electronic access to health records and clinical notes through the my healthevet personal health record pilot: Qualitative study. J Med Internet Res 2013;15(3). PMID: 23535584

55. Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: A systematic review of controlled trials. J Med Internet Res. 2012. PMID: 23183044

56. Mandl KD, McNabb M, Marks N, Weitzman ER, Kelemen S, Eggleston EM, et al. Participatory surveillance of diabetes device safety: a social media-based complement to traditional FDA reporting. J Am Med Inform Assoc 2014;21:687–91. PMID: 24355131

57. Estabrooks PA, Boyle M, Emmons KM, Glasgow RE, Hesse BW, Kaplan RM, et al. Harmonized patient-reported data elements in the electronic health record: supporting meaningful use by primary care action on health behaviors and key psychosocial factors. J Am Med Informatics Assoc. 2012. PMID: 22511015

58. Fleurence RL, Beal AC, Sheridan SE, Johnson LB, Selby J V. Patient-powered research networks aim to improve patient care and health research. Health Aff 2014;33:1212–1219.

59. Mega JL, Sabatine MS, Antman EM. Population and personalized medicine in the modern era. JAMA 2014;02115. PMID: 25399267

60. Otte-trojel T, Bont A De, Klundert J Van De, Rundall TG, Otte-trojel T. Characteristics of Patient Portals Developed in the Context of Health Information Exchanges: Early Policy Effects of Incentives in the Meaningful Use Program in the United States. J Med Internet Res 2014;16(11):e258. PMID: 25447837

61. Laranjo L, Neves A, Villanueva T, Cruz J, Brito de Sá A, Sakellarides C. Patients' access to their medical records. Acta Med Port 2013;26(3):265–270. PMID: 16460758

62. Krumholz HM. Big data and new knowledge in medicine: The thinking , training , and tools needed for a learning health system. Health Aff 2014;33:1163–1170. PMID: 25006142

Discussion

There is overwhelming evidence of the importance of person-centered care in achieving desirable health outcomes. Putting patients in control of their health, and facilitating easy access to health information, are increasingly recognized as essential aspects of good health care. In fact, quality of care may be defined as providing the right care, in the right way, at the right time, according to the patient's needs, wishes, and values[32].

Health care has been traditionally divided into three categories – primary, secondary, tertiary – and neither self-care nor lay medicine were included in this model[363]. However, six tiers of 'Information Age Medicine' have been proposed[363]: 1) Individual self-care; 2) Friends and family; 3) Self-help networks outside the immediate circle of family and friends; 4) Health professionals as facilitators, advisers, and supporters of self-care, outside clinical visits (e.g. phone, email); 5) Health professionals as partners; and 6) Health professionals as authorities (mostly in emergency situations where clinicians may be required to make quick decisions without involving the patient)[15].
In this model, citizens should be provided with the tools, skills, information, and support they need to play the role of primary caretakers. For that to happen, clinical skills should be taught in school, and the role of clinicians in supporting self-care should be strengthened, since it has known benefits in promoting patient activation[122,364–367]. Moreover, doctors should become increasingly able to help their patients assess the quality of medical websites (namely using the 'Health On the Net' - HON code certification), as well as teach patients where to find quality health information online[7,22,256,262].

Patient-centered care does not imply that clinicians have to provide unnecessary care to respond to patients' requests or choices[1,15,17,95]. Unnecessary care has the potential to cause harm, and clinicians should refuse to provide it when a conflict cannot be resolved through counseling and negotiation[1,368].

Going forward, evidence-based medicine should be taught to patients as well, so that the limits of medical care may be acknowledged jointly, and conflicts may be avoided[15,369]. One of the starting points could be the public dissemination of the 'Choosing Wisely' recommendations regarding unnecessary tests and procedures[370]. Fostering shared decision-making based on the discussion of evidence-based treatment options has great potential to improve the quality of health care[371].

Sharing decisions with patients is also important in coping with uncertainty in medicine[26]. Physicians should be willing to openly acknowledge uncertainty and invite patients to participate in uncertain decisions[26]. Indeed, the practice of medicine is moving from 'informed consent' to 'informed choice'[7,46]. Patients and families should not be labeled as 'difficult' when they request more involvement in care, as this promotes a culture of passivity, acquiescence, and paternalism[372]. Paternalism undermines people's ability to cope, encourages passivity, and reinforces dependence on health professionals[15].

Patient access to their medical records

One way to improve the quality and patient-centeredness of care is by facilitating patient access to medical records[1,263,264]. A growing body of evidence shows advantages in promoting patient access to medical records, namely in improving patient empowerment, patient–provider communication, medication adherence, and decreasing the fragmentation of health care[267–270]. Additionally, patient access to their medical records has the potential to help clinicians maintain accurate and up-to-date records, contributing to the quality and safety of health care[274,279,373–376].

The current fragmentation of clinical data is a threat to patient safety, as it tends to lead to information gaps and inefficient care[258]. Over the course of a lifetime, a patient may see dozens of doctors, in different institutions and health care systems, even in different countries. The only possible way to ensure that their health information will be available where and when it is needed, is if the patients themselves have easy access to their data and are able to collect it[10,14].

In the US, a government program to promote patient access to medical records, known as Blue Button initiative, enables patients to download their data from EHRs in several

institutions[14]. Since the data that is downloaded is not in a user-friendly format, third-party companies now exist that convert and display those data in a more usable manner[10]. In the future, it is expectable that each individual's health data will be portable and secured in a personal cloud or system, with the citizen having the ability to control and share that information in a granular manner[10].

Despite the favorable legal framework in many countries, such as Portugal, which gives patients the right to access their records, there is still some reluctance of healthcare institutions and clinicians in providing that access[1,258]. Furthermore, requesting access to medical records is often cumbersome and administratively complex, further discouraging patients from initiating that process[10,14].

There is growing consensus that medical records should be available to the person to whom they are most relevant – the patient[10,15,265]. Not only that, but patients should be encouraged to review their records, append their own comments, and to draw attention to any errors or omissions. There is intrinsic value in citizens having their health records, as part of the movement towards the democratization of medicine and against 'information asymmetry'[10]. Going forward, the guiding principle in health care should be "nothing about me without me"[7,43,377].

Patient Activation

The study "**Translation, cultural adaptation and validation of the Patient Activation Measure 13 in a population of Portuguese type 2 diabetes patients**" showed high reliability of the Portuguese PAM13, both at the item and person levels. The PAM13 is feasible to apply in the clinical setting, with minimal burden to patients and providers[92]. Studies have shown that tailoring care to activation levels is associated with improvements in intermediate outcomes and greater reductions in hospitalizations and in emergency department use[124]. Care may be tailored by encouraging small achievable steps for patients with low activation, and supporting the adoption and maintenance of more difficult behaviors for those at higher levels of activation[88,94,124,127,378]. A tailored approach starts with smaller goals that are appropriate for each patient's level

of competency, so that they experience small successes and enhance confidence in self-managing their disease, allowing them to increase activation step by step[132,143,150]. One other manner the PAM can be used in the clinical setting is the 'visual scan' approach, which involves analyzing a patient's responses to the questionnaire in order to identify where there is less agreement with the statements[92,100,125]. Then, the clinician may focus on skill development, problem-solving and/or peer support in the most problematic areas.

Tailoring and individualization of interventions is especially important to promote self-management in chronic patients, leading to improvements in several process and outcome measures[123,124,131,143,149,150,158,159,198,379,380]. Moreover, in patients with multimorbidity, increased patient activation seems to be associated with decreases in treatment burden[381], as well as with less care coordination problems[174].

Patients' perspectives and needs

In "**Facilitators, barriers and expectations in the self-management of type 2 diabetes – a qualitative study from Portugal**", lifestyle behavior change appeared to be the hardest part of self-management, for the majority of participants. Specifically, diet was the richest theme in our study, an aspect that has been previously documented in the literature[382–384]. Although it seemed that patients had general knowledge about the importance of diet and exercise in DM management, they appeared to be missing specific guidance to actually change habits and follow self-care recommendations.

In other studies, knowledge by itself has been inconsistently associated with behavior change, and information-only strategies have proven largely ineffective[143,385,386]. Therefore, there is now growing emphasis in the use of tailored advice, individual guidance, and goal-setting in self-management interventions[35,198,379]. Furthermore, innovative strategies involving nudging[7,387] and gamification[10,256] are also increasingly being investigated for their potential application in the health domain.

Previous research has also highlighted the importance of storytelling and 'illness narratives' to communicate medical knowledge to engage patients[22,38,388]. In fact, one qualitative study with type 2 diabetes patients made the distinction between 'know-that knowledge' (abstract, gained from health professionals) and 'know-how

knowledge' (practical understanding, gained from sharing stories with other patients), with the latter being more consistently recognized as important for self-management[22].

Finally, family and social ties were commonly mentioned across the three themes in our study, and were regarded as facilitators in some situations and as barriers in others. Previous studies have shown that good social support is associated with better self-management, health-promoting behaviors, and well-being in patients with type 2 diabetes[389,390]. Specifically, having a well-functioning social network and a sense of good social support have been associated with higher activation levels and less diabetes-related emotional distress in DM patients[389].

Digital divide

The study "**Internet use by Portuguese patients with type 2 diabetes mellitus – association with demographic and clinical characteristics**" showed an inverse association of information technology use with age, as well as a direct association with educational level, in patients with diabetes. These results are in line with published research[222,391–393].

Although reports indicate that access to information technology is steadily rising in Portugal, it is also known that adoption of these tools remains much lower among the elderly[394]. Furthermore, research shows that use of the internet for health purposes is much lower in the less educated, in Portugal[395,396].

Promising studies have shown that older age and lack of IT familiarity were not barriers to access and use of diabetes-related health information systems[391,392,397,398], and there is evidence that they are able to improve diabetes control in such patients[232,399–401]. Furthermore, even for patients not knowing how to use IT, having others in the household who are digital literate and able to access the internet, may mean they could potentially benefit from the help of caretakers in using health information technology (HIT) to manage their illness.

Nevertheless, growing use of IT in health brings the danger of widening disparities, due to the digital divide (the gap that exists between people who do and those who do not

have access to modern information technology)[402–404]. Concerted efforts are necessary to improve public availability of IT and to minimize barriers to internet use by people with lower digital literacy[405].

Interestingly, patient activation interventions seem to be particularly useful for less activated patients from lower SES populations[371] and may constitute a low-cost strategy to potentially reduce healthcare disparities[142,156]. In the future, culturally informed and personalized patient activation strategies could be explored as a means to reduce health disparities while improving the overall health of populations[64,406].

Personal Health records

The study "**Adoption of a national integrated Personal Health Record in Portugal - Who are the early adopters**?" found lower registration rates and lower use of the PHR by people above 65 years, which is in line with published research [314,322,407–409], and is likely associated with the low levels of IT literacy in this population[301].

Furthermore, a gap was found in PHR adoption between urbanized centers and the more rural regions of Portugal, which may be indicative of a digital divide[301,410,411]. Indeed, disparities in PHR adoption have been previously associated with socio-economic status, education level[314,408,412–414], health literacy[410], and race/ethnicity[314,407,408,410,414–416], raising concerns that access to this type of technology may be limited to a more socially advantaged population.

On the other hand, chronic diseases were the most recorded health problems in the Portuguese PHR, and multimorbidity and polymedication seemed to be positively associated with PHR use in our study population, which is consistent with previous published research[408,412,415–419].

Important aspects affecting the adoption of PHRs include technical issues and low usability[420], which are particularly relevant when thinking about disadvantaged groups[412]. Involving patients in the design and evaluation of PHRs, and improving usability by using adaptive interfaces, audio, video, and graphical information, are therefore essential to the success of a PHR[324,410].

Based on the available evidence regarding the most valued PHR features, a design proposal was elaborated for the PHR 'Portal do Utente', using human-centered design principles and a participatory development process (Appendices 8 e 9). One important aspect of this proposal concerned the need to enable patient access to their medical data, gathered at the national data-sharing platform. Furthermore, higher granularity in controlling health professionals' access to that platform was suggested, as the three consent options available at the moment were considered clearly insufficient to guarantee patient privacy. Until date, this design proposal for 'Portal do Utente' has not been implemented.

Social media and social networking sites

The results of the study "**The influence of social networking sites on health behavior change – a systematic review and meta-analysis**" show a positive effect of SNS interventions on health behavior-related outcomes. Most SNS interventions seem to provide education, social support, self-management support, and tailoring[421]. Therefore, the application of SNSs in the health domain is showing growing potential[337–340,344–348].

One aspect that is gaining increasing attention is the possibility of incorporating social features, particularly social networking, in PHRs[240,422], as these may boost adoption[423] and contribute to improvements in health behaviors[421,424]. The Australian PHR 'Healthy.me' already incorporates social features, which were found by users to be the most useful and engaging features in this PHR[425].

Moreover, the exponential uptake of SNSs offers a new approach to chronic care[14]. As an example, the site PatientsLikeMe helps patients with chronic conditions better understand their disease and therapeutic options, while offering connections to patient communities[185].

Finally, SNSs have the potential to lead to greater co-ownership and co-production of health and health care[89]. An interesting application of SNSs – and social media in general – is to gather patient experiences to prioritize areas where improvement is needed and to change health services to improve the quality of care[15,22]. SNSs may be an efficient way to listen to the voice of patients and include 'patient experience' as a

core component of healthcare quality[3,15,22]. Indeed, evidence shows that there is a good correlation between patients' perceptions and the actual quality of care[426].

Clinical data as a public good

The study "**Use of electronic health records and geographic information systems in public health surveillance of type 2 diabetes**" demonstrated the feasibility of collecting, analyzing, and geographically displaying EHR data.

Nevertheless, individual-level data that is extractable from the primary care information system in Portugal is still limited. For comprehensive outcomes monitoring to occur it should be possible to link data from primary care and hospital EHRs, as well as other health institutions (e.g. pharmacies, labs)[373,374,427–429]. The integration of these sources of data, in combination with information on the social and environmental determinants of health (e.g. area-based socioeconomic status indicators, walkability, green spaces, distance from grocery stores, fast food chains), would have the potential to render a more complete picture of the health state of communities[334,430–432].

Nowadays, patient involvement in data gathering and integration is still far from ideal. Higher patient involvement could allow for more comprehensive population-level research, by enabling the combination of biomedical and clinical data routinely present in EHRs, with patient-reported measures from PHRs (e.g. demographic, psychosocial, behavioral), and data from other sources (e.g. wearable devices, social media), into one patient-controlled location[89,258,334,335,374,428,433–437].

Unfortunately, a great amount of data remains siloed in institutions, fragmented, and generally inaccessible to the ones who could bring meaning to it: clinicians, public health workers, researchers and, most importantly, patients[373,374,437,438]. It is important that clinical data is increasingly treated as a public good and an essential element of a learning healthcare system[10,258,439].

Implications for clinical practice, research and health policy

Patient and public involvement in health care is essential. Citizens should be engaged in conversations about health needs, strategic planning, service design and decision-

making[16,440]. Furthermore, principles of user-centered design and design thinking should be used in order to better understand and improve person's experiences, involving both staff and patients in the redesign process[22,441]. Co-production, co-design, co-leadership and mutual learning are key for a more person-centered health care system[16,18,22,165].

Going forward, it seems important to strengthen primary health care models and increase their patient-centeredness, valuing interactions and communication between patients and providers[168,187,442–444]. Indeed, having a positive relationship with a primary care provider is associated with higher activation levels[364,444–446]. Furthermore, communication with patients outside of the consultation (e.g. telephone, email) are incredibly important means of improving accessibility, timeliness and overall quality of care, but are rarely considered in productivity and quality measurement[168,445]. This favors a climate of inertia[166,447,448], which hampers the necessary move towards patient-centered care. Health system changes are necessary, so that adequate compensation models and realistic consultation times are implemented, to improve communication and quality of care[15,63,75,449].

New technologies should help clinicians focus more on the patient[256], but evidence shows that physicians are spending more time entering data into the computer, than talking to their patients[10,450,451]. Indeed, given the complexity of eHealth implementation and its impact on the quality of care[18,452,453], HIT should become increasingly subjected to rigorous evaluation of effectiveness and safety[18,38], and its impact on clinical care should be assessed at different stages of the implementation process.

PHR use and participation in health-related SNSs seem promising in improving patient activation, being particularly helpful to individuals with lower levels of activation[190,454]. Nevertheless, the people who seem to have the most to gain from HIT (those with lower activation levels, poor health literacy, and difficult social circumstances) may be the least able to access it[88,166]. Therefore, ensuring universal internet and computer access seems paramount as we move into a world where health care is increasingly

relying on information technology[410]. Furthermore, the potential of mobile health (mHealth - the delivery of healthcare services via mobile communication devices) could be further explored in the future, given that there are currently 4 billion mobile phones in the world, and 1.08 billion are smartphones[262]. At the same time, it is crucial to accommodate the needs of those with lower IT access, and make sure they have access to the same quality of care.

In the future, integrated and synergistic use of EHRs, PHRs, SNSs, mobile phones, and personal devices[240,422,455,456] may bring further potential to HIT. However, robust information policy frameworks should be in place to clarify issues of control, ownership, storage, and access to clinical data[258,457], so that patients may be increasingly able to control their health information[1,258].

Health Information Technology can act as a lever for system change. However, technology is not the goal to be pursued. The goal is high quality patient-centered care – change and innovation should be focused on that.

Conclusion

Promoting person-centered care can be pursued at several levels, namely by facilitating patients' access to their medical records, increasing the use of patient-reported measures, and exploring patients' needs and perspectives regarding health care, as well as their limitations in an increasingly digital world. Furthermore, information technology has an important role to play in improving health care, through the meaningful use of Electronic Health Records, Personal Health Records and Social Networking Sites. Health Information Technology can act as a lever for system change. However, technology is not the goal to be pursued. The goal is high quality patient-centered care – change and innovation should be focused on that.

References

1. Institute of Medicine. Crossing the Quality Chasm: a new health system for the 21st century. Building a Better Delivery System. 2001.
2. The NHS Plan. London; 2000.
3. National Health Service Department of Health. High Quality Care For All - NHS Next Stage Review Final Report. London; 2008.
4. National Health and Hospitals Reform Commission. Principles for Australia's Health System [Internet]. 2008 [cited 2015 Apr 14]. Available from: http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/principles-lp
5. National Health Service Commissioning Board. Everyone counts - improving outcomes for patients. 2013.
6. Ashley E a. The precision medicine initiative: a new national effort. Jama. 2015;Published :E1–2.
7. DeBronkart D. Let Patients Help! CreateSpace Independent Publishing Platform; 2013.
8. James JT. A new, evidence-based estimate of patient harms associated with hospital care. J Patient Saf. 2013;9(3):122–8.
9. Starfield B. Is US health really the best in the world? JAMA. 2000;284(4):483–5.
10. Topol EJ. The patient will see you now: the future of Medicine is in your hands. Philadelphia: Basic Books; 2015. 384 p.
11. Leape LL, Shore MF, Dienstag JL, Mayer RJ, Edgman-Levitan S, Meyer GS, et al. Perspective: A Culture of Respect, Part 2: Creating a Culture of Respect. Acad Med. 2012 Jul;87(7):853–8.
12. Gawande A. The checklist manifesto: How to get things right. Profile books; 2009.
13. Makary M. Unaccountable: What Hospitals Won't Tell You and How Transparency Can Revolutionize Health Care. Bloomsbury Press; 2013. 256 p.
14. Topol E. The creative destruction of Medicine. New York: Basic Books; 2013. 336 p.
15. Coulter A. The autonomous patient: Ending Paternalism in Medical Care. London: Stationery Office (for the Nuffield Trust); 2002. 128 p.
16. Greenhalgh T, Humphrey C, Woodward F. User involvement in health care. Wiley-Blackwell; 2011.
17. Bleakley A. Patient-Centred Medicine in Transition. Springer; 2014.
18. Hill S. The knowledgeable patient. 240 p.
19. Neuberger J. Do we need a new word for patients? Lets do away with "patients". BMJ. 1999;318(7200):1756–7.
20. Herxheimer A, Goodare H. Who are you, and who are we? Looking through some key words. Heal Expect. 1999;2(1):3–6.
21. Balint E. The possibilities of patient-centered medicine. J R Coll Gen Pr. 1969;17(82):269–76.

22. Ziebland S, Coulter A, Calabrese JD, Locock L. Understanding and Using Health Experiences: Improving Patient Care. Oxford University Press; 2013. 169 p.
23. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977;196(4286):129–36.
24. Pauli HG, White KL, McWhinney IR. Medical education, research, and scientific thinking in the 21st century (part two of three). Educ Health (Abingdon). 2000;13(1):165–72.
25. Starfield B. Is patient-centered care the same as person-focused care? Perm J. 2011;15(2):63–9.
26. Laine C, Davidoff F. Patient-centered medicine. A professional evolution. JAMA. 1996;275(2):152–6.
27. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med. 2000;51(7):1087–110.
28. Holmström I, Röing M. The relation between patient-centeredness and patient empowerment: A discussion on concepts. Patient Educ Couns. 2010;79(2):167–72.
29. Health Foundation. Person-centred care made simple. London: Health Foundation; 2014.
30. Gerteis M, Edgman-Levitan S, Daley J, Delbanco T. Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care. Calif: Jossey-Bass; 1993.
31. Berry LL, Seiders K, Wilder SS. Innovations in Access to Care: A Patient-Centered Approach. Ann Intern Med. 2003;139(7):568–74.
32. Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. J Gen Intern Med. 2005;20(10):953–7.
33. Stewart M. Towards a global definition of patient centred care. BMJ. 2001;322(7284):444–5.
34. Entwistle V, Firnigl D, Ryan M, Francis J, Kinghorn P. Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map. J Health Serv Res Policy. 2012;17(2):70–8.
35. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient Self-management of Chronic Disease in Primary Care. JAMA. 2002 Nov 20;288(19):2469–75.
36. Siegler M. The progression of medicine. From physician paternalism to patient autonomy to bureaucratic parsimony. Arch Intern Med. 1985;145(4):713–5.
37. Mccullough LB. Was bioethics founded on historical and conceptual mistakes about medical paternalism? Bioethics. 2011;25(2):66–74.
38. Gigerenzer G, Gray JAM, editors. Better Doctors, Better Patients, Better Decisions: Envisioning Health Care 2020. The MIT Press; 2013. 416 p.
39. Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness. Annals of Internal Medicine. 1997. p. 1097–102.
40. Simmons L, Baker NJ, Schaefer J, Miller D, Anders S. Activation of patients for successful self-management. J Ambul Care Manage. 2009;32(1):16–23.

41. Institute of Medicine. Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement: Workshop Proceedings Roundtable on Value and Science-Driven Health Care. 2013.
42. Holman H, Lorig K. Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. BMJ. 2000;320(7234):526–7.
43. deBronkart D. From patient centred to people powered: autonomy on the rise. BMJ. 2015;350(feb10 14):h148–h148.
44. Moore JE, Titler MG, Low LK, Dalton VK, Sampselle CM. Transforming Patient-Centered Care: Development of the Evidence Informed Decision Making through Engagement Model. Women's Heal Issues. Jacobs Institute of Women's Health; 2015;1–7.
45. The expert patient: A new approach to chronic disease management for the 21st century. London; 2001.
46. Edwards A, Elwyn G. Shared decision-making in health care: achieving evidence-based patient choice. 2nd ed. Oxford: Oxford University Press; 2009. 432 p.
47. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (Or it takes, at least two to tango). Soc Sci Med. 1997;44(5):681–92.
48. Kaplan SH, Greenfield S, Ware JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Medical care. 1989. p. S110–27.
49. Stewart M a. Effective physician-patient communication and health outcomes: a review. CMAJ. 1995;152(9):1423–33.
50. Blasi Z Di, Harkness E, Ernst E, Georgiou A, Kleijnen J. Influence of context effects on health outcomes: a systematic review. Lancet. 2001;357(9258):757–62.
51. Mullen PD. Compliance becomes concordance. BMJ. 1997;314(7082):691–2.
52. Murray E, Burns J, See T, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. Cochrane Database Syst Rev. 2009;(1):e40.
53. O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews. 2009.
54. Vickery DM, Kalmer H, Lowry D, Constantine M, Wright E, Loren W. Effect of a self-care education program on medical visits. JAMA : the journal of the American Medical Association. 1983.
55. Kinnersley P, Edwards A, Hood K, Ryan R, Prout H, Cadbury N, et al. Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review. BMJ. 2008;337(3):a485.
56. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost in knowledge translation: time for a map? J Contin Educ Health Prof. 2006;26(1):13–24.

57. Wilson MG, Lavis JN, Travers R, Rourke SB. Community-based knowledge transfer and exchange: helping community-based organizations link research to action. Implement Sci. 2010;5:33.
58. Green LW, Ottoson JM, García C, Hiatt R a. Diffusion theory and knowledge dissemination, utilization, and integration in public health. Annu Rev Public Health. 2009;30:151–74.
59. Tugwell P. Systematic reviews and knowledge translation. Bull World Health Organ. 2006;84(8):643–51.
60. Davison CM, National Collaborating Centre for Determinants of Health. Critical examination of knowledge to action models and implications for promoting health equity. Int J Equity Health. International Journal for Equity in Health; 2013;32.
61. Légaré F, Ratté S, Stacey D, Kryworuchko J, Gravel K, Graham ID, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. Cochrane Database Syst Rev. 2010;(5):CD006732.
62. Pilling SA, Williams MB, Brackett RH, Gourley R, Weg MW Vander, Christensen AJ, et al. Part I, patient perspective: activating patients to engage their providers in the use of evidence-based medicine: a qualitative evaluation of the VA Project to Implement Diuretics (VAPID). Implement Sci. 2010;5:23.
63. Teh CF, Karp JF, Kleinman A, Reynolds CF, Weiner DK, Cleary PD. Older people's experiences of patient-centered treatment for chronic pain: A qualitative study. Pain Med. 2009;10(3):521–30.
64. Cunningham PJ, Hibbard J, Gibbons CB. Raising low "patient activation" rates among Hispanic immigrants may equal expanded coverage in reducing access disparities. Health Aff. 2011;30(10):1888–94.
65. Levinson W, Lesser CS, Epstein RM. Developing physician communication skills for patient-centered care. Health Aff. 2010;29(7):1310–8.
66. Mauksch LB, Dugdale DC, Dodson S, Epstein R. Relationship, communication, and efficiency in the medical encounter: creating a clinical model from a literature review. Arch Intern Med. 2008;168(13):1387–95.
67. Roter D, Hall J. Drs Talking With Patients - Patients Talking with Doctors. Improving Communication in Medical Visits. Auburn House; 2006. 238 p.
68. Hojat M, Louis DZ, Markham FW, Wender R, Rabinowitz C, Gonnella JS. Physicians' empathy and clinical outcomes for diabetic patients. Acad Med. 2011;86(3):359–64.
69. Naik AD, Kallen MA, Walder A, Street RL. Improving hypertension control in diabetes mellitus: The effects of collaborative and proactive health communication. Circulation. 2008;117(11):1361–8.
70. Street RL, Piziak VK, Carpentier WS, Herzog J, Hejl J, Skinner G, et al. Provider-patient communication and metabolic control. Diabetes Care. 1993;16(5):714–21.

71. Heisler M, Bouknight RR, Hayward R a., Smith DM, Kerr E a. The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. J Gen Intern Med. 2002;17:243–52.
72. Greenfield S, Kaplan SH, Ware JE, Yano EM, Frank HJ. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. J Gen Intern Med. 1988;3(5):448–57.
73. Heisler M, Vijan S, Anderson RM, Ubel PA, Bernstein SJ, Hofer TP. When Do Patients and Their Physicians Agree on Diabetes Treatment Goals and Strategies, and What Difference Does It Make? J Gen Intern Med. 2003;18(11):893–902.
74. Cooper L a., Roter DL, Carson K a., Bone LR, Larson SM, Miller ER, et al. A randomized trial to improve patient-centered care and hypertension control in underserved primary care patients. J Gen Intern Med. 2011;26(11):1297–304.
75. Parchman ML, Zeber JE, Palmer RF. Participatory decision making, patient activation, medication adherence, and intermediate clinical outcomes in type 2 diabetes: A starnet study. Ann Fam Med. 2010;8(5):410–7.
76. Lewin S a, Skea ZC, Entwistel V, Zwarentein M, Dick J. Intervention for providers to promote a patient-centered approach in clinical consultations (Cochrane Review). Cochrane Libr. 2001;(4).
77. Coulter A, Collins A. Making shared decision-making a reality - No decision about me, without me. The Kings Fund. 2011.
78. Isaac T, Zaslavsky AM, Cleary PD, Landon BE. The relationship between patients' perception of care and measures of hospital quality and safety. Health Serv Res. 2010;45(4):1024–40.
79. Street RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. Patient Educ Couns. 2009;74(3):295–301.
80. Lorig K, Sobel D, Stewart A. Evidence Suggesting That a Chronic disease self-management program Can Improve Health Status While Reducing Hospitalization. Med Care. 1999;37(1):5–14.
81. Keating NL, Green DC, Kao AC, Gazmararian J a., Wu VY, Cleary PD. How are patients' specific ambulatory care experiences related to trust, satisfaction, and considering changing physicians? J Gen Intern Med. 2002;17(1):29–39.
82. Haynes RB, Ackloo E, Sahota N, McDonald HP, Yao X. Interventions for enhancing medication adherence. Cochrane Database Syst Rev. 2008;(2).
83. Meterko M, Wright S, Lin H, Lowy E, Cleary PD. Mortality among patients with acute myocardial infarction: The influences of patient-centered care and evidence-based medicine. Health Serv Res. 2010;45(5 PART 1):1188–204.

84. Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. BMJ. 2002;325(7375):1263.
85. Menichetti J, Libreri C, Lozza E, Graffigna G. Giving patients a starring role in their own care: a bibliometric analysis of the on-going literature debate. Heal Expect. 2014;n/a – n/a.
86. Fumagalli LP, Radaelli G, Lettieri E, Bertele' P, Masella C. Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. Health Policy. Elsevier Ireland Ltd; 2014.
87. Aujoulat I, D'Hoore W, Deccache A. Patient empowerment in theory and practice: Polysemy or cacophony? Patient Educ Couns. 2007;66:13–20.
88. Hibbard JH, Greene J. What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. Health Aff. 2013;32(2):207–14.
89. Rigby M, Ronchi E, Graham S. Evidence for building a smarter health and wellness future-Key messages and collected visions from a Joint OECD and NSF workshop. International Journal of Medical Informatics. Elsevier Ireland Ltd; 2013;82(4):209–19.
90. Kish L. The Blockbuster Drug of the Century: An Engaged Patient [Internet]. HL7 standards. 2012. Available from: http://www.hl7standards.com/blog/2012/08/28/drug-of-the-century/
91. Institute of Medicine. The first annual Crossing the Quality Chasm Summit -A Focus on Communities. Washington, DC; 2004.
92. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res. 2005 Dec;40(6 Pt 1):1918–30.
93. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: A literature review. J Eval Clin Pract. 1999;5:401–16.
94. Hibbard JH. Moving toward a more patient-centered health care delivery system. Health Aff (Millwood). 2004 Jan;Suppl Vari:VAR133–5.
95. Parish E. BMJ roundtable debate: How can we get better at providing patient centred care? BMJ. 2015;350(February):h412–h412.
96. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004 Aug;39(4 Pt 1):1005–26.
97. Donabedian A. The effectiveness of quality assurance. Int J Qual Health Care. 1996;8(4):401–7.
98. Donabedian A. Evaluating the quality of medical care. 1966. Milbank Q. 2005;83(4):691–729.
99. Romano P, Hussey P, Ritley D. Selecting Quality and Resource Use Measures: A Decision Guide for Community Quality Collaboratives. 2010.

100. Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). Med Care. 2005;43(5):436–44.
101. Safran DG, Karp M, Coltin K, Chang H, Li A, Ogren J, et al. Measuring patients' experiences with individual primary care physicians. Results of a statewide demonstration project. J Gen Intern Med. 2006 Jan;21(1):13–21.
102. Goldstein E, Farquhar M, Crofton C, Darby C, Garfinkel S. Measuring hospital care from the patients' perspective: an overview of the CAHPS Hospital Survey development process. Health Serv Res. 2005 Dec;40(6 Pt 2):1977–95.
103. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Health technology assessment (Winchester, England). 1998. p. i – iv, 1–74.
104. Santana M-J, Feeny D. Framework to assess the effects of using patient-reported outcome measures in chronic care management. Qual Life Res. 2013;17:153–70.
105. Coulter A, Locock L, Ziebland S, Calabrese J. Collecting data on patient experience is not enough : they must be used to improve care. 2014;2225(March):1–4.
106. Fleurence R, Selby J V., Odom-Walker K, Hunt G, Meltzer D, Slutsky JR, et al. How The Patient-Centered Outcomes Research Institute Is Engaging Patients And Others In Shaping Its Research Agenda. Health Aff. 2013 Feb 1;32(2):393–400.
107. Collins FS, Hudson KL, Briggs JP, Lauer MS. PCORnet: turning a dream into reality. J Am Med Inform Assoc. 2014;21(4):576–7.
108. Beatrice DF, Thomas CP, Biles B. Grant Making with an Impact: The Picker/Commonwealth Patient-Centered Care Program. Health Aff. 1998;17(1):236–44.
109. Terwee CB, Mokkink LB, Knol DL, Ostelo RWJG, Bouter LM, De Vet HCW. Rating the methodological quality in systematic reviews of studies on measurement properties: A scoring system for the COSMIN checklist. Qual Life Res. 2012;21(4):651–7.
110. Valderas JM, Ferrer M, Mendívil J, Garin O, Rajmil L, Herdman M, et al. Development of EMPRO: A tool for the standardized assessment of patient-reported outcome measures. Value Heal. 2008;11(4):700–8.
111. Hung M, Carter M, Hayden C, Dzierzon R, Morales J, Snow L, et al. Psychometric assessment of the patient activation measure short form (PAM-13) in rural settings. Qual Life Res. 2013 Apr;22(3):521–9.
112. Maindal HT, Sokolowski I, Vedsted P. Translation, adaptation and validation of the American short form Patient Activation Measure (PAM13) in a Danish version. BMC Public Health. 2009 Jan;9:209.
113. Skolasky RL, Green AF, Scharfstein D, Boult C, Reider L, Wegener ST. Psychometric properties of the patient activation measure among multimorbid older adults. Health Serv Res. 2011 Apr;46(2):457–78.

114. Magnezi R, Glasser S. Psychometric Properties of the Hebrew Translation of the Patient Activation Measure (PAM-13). PLoS One. 2014;9(11):e113391.
115. Stepleman L, Rutter M-C, Hibbard J, Johns L, Wright D, Hughes M. Validation of the patient activation measure in a multiple sclerosis clinic sample and implications for care. Disabil Rehabil. 2010;32(19):1558–67.
116. Brenk-Franz K, Hibbard JH, Herrmann WJ, Freund T, Szecsenyi J, Djalali S, et al. Validation of the German version of the patient activation measure 13 (PAM13-D) in an international multicentre study of primary care patients. PLoS One. 2013 Jan;8(9):e74786.
117. Packer TL, Kephart G, Ghahari S, Audulv Å, Versnel J, Warner G. The Patient Activation Measure: a validation study in a neurological population. Qual Life Res. 2015;n/a(n/a):n/a.
118. Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). BMC Public Health. 2012 Jan;12(1):577.
119. Zill JM, Dwinger S, Kriston L, Rohenkohl A, Härter M, Dirmaier J. Psychometric evaluation of the German version of the patient activation measure (PAM13). BMC Public Health. 2013;13:1027.
120. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. Am J Heal Promot. 1997;12(1):38–48.
121. Prochaska JO. Decision making in the transtheoretical model of behavior change. Med Decis Making. 2008;28(November):845–9.
122. Hibbard JH, Greene J, Becker ER, Roblin D, Painter MW, Perez DJ, et al. Racial/ethnic disparities and consumer activation in health. Health Aff (Millwood). 2008;27(5):1442–53.
123. Hibbard JH, Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? Health Serv Res. 2007 Aug;42(4):1443–63.
124. Hibbard JH, Greene J, Tusler M. Improving the Outcomes of Disease Management by Tailoring Care to the Patient's Level of Activation. Am J Manag Care. 15(6):353–60.
125. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Med. 2012 May;27(5):520–6.
126. Frosch D, Rincon D, Ochoa S, Mangione C. Activating Seniors to Improve Chronic Disease Care: results from a pilot intervention study. J Am Geriatr Soc. 2010;58(8):1496–503.
127. Shively MJ, Gardetto NJ, Kodiath MF, Kelly A, Smith TL, Stepnowsky C, et al. Effect of patient activation on self-management in patients with heart failure. J Cardiovasc Nurs. 2013;28(1):20–34.
128. Marshall R, Beach MC, Saha S, Mori T, Loveless MO, Hibbard JH, et al. Patient activation and improved outcomes in HIV-infected patients. J Gen Intern Med. 2013 May;28(5):668–74.

129. Skolasky R, Mackenzie E, Riley L, Wegener S. Psychometric properties of the Patient Activation Measure among individuals presenting for elective lumbar spine surgery. Qual Life Res. 2009;18(10):1357–66.
130. Rask KJ, Ziemer DC, Kohler S a, Hawley JN, Arinde FJ, Barnes CS. Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population. Diabetes Educ. 2009;35(4):622–30.
131. Mosen DM, Schmittdiel J, Hibbard J, Sobel D, Remmers C, Bellows J. Is patient activation associated with outcomes of care for adults with chronic conditions? J Ambul Care Manage. 2007;30(1):21–9.
132. Hibbard JH, Tusler M. Assessing activation stage and employing a “next steps” approach to supporting patient self-management. J Ambul Care Manage. 2007;30(1):2–8.
133. Aung E, Donald M, Coll JR, Williams GM, Doi S a. R. Association between patient activation and patient-assessed quality of care in type 2 diabetes: results of a longitudinal study. Heal Expect. 2015;n/a – n/a.
134. Sacks RM, Greene J, Hibbard JH, Overton V. How well do patient activation scores predict depression outcomes one year later? J Affect Disord. Elsevier; 2014;169:1–6.
135. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When Patient Activation Levels Change, Health Outcomes And Costs Change, Too. Health Aff. 2015;34(3):431–7.
136. Katz ML, Fisher JL, Fleming K, Paskett ED. Patient activation increases colorectal cancer screening rates: A randomized trial among low-income minority patients. Cancer Epidemiol Biomarkers Prev. 2012;21(1):45–52.
137. Magnezi R, Glasser S, Shalev H, Sheiber A, Reuveni H. Patient activation, depression and quality of life. Patient Educ Couns. Elsevier Ireland Ltd; 2014;94(3):432–7.
138. Hibbard JH, Greene J, Shi Y, Mittler J, Scanlon D. Taking the Long View: How Well Do Patient Activation Scores Predict Outcomes Four Years Later? Med Care Res Rev. 2015;2015.
139. Smith SG, Pandit A, Rush SR, Wolf MS, Simon C. The association between patient activation and accessing online health information: results from a national survey of US adults. Heal Expect. 2014;n/a – n/a.
140. Donald M, Ware RS, Ozolins IZ, Begum N, Crowther R, Bain C. The role of patient activation in frequent attendance at primary care: a population-based study of people with chronic disease. Patient Educ Couns. Elsevier Ireland Ltd; 2011 May;83(2):217–21.
141. Salyers MP, Matthias MS, Spann CL, Lydick JM, Rollins AL, Frankel RM. The role of patient activation in psychiatric visits. Psychiatr Serv. 2009;60(11):1535–9.
142. Alegría M, Sribney W, Perez D, Laderman M, Keefe K. The role of patient activation on patient-provider communication and quality of care for US and foreign born Latino patients. J Gen Intern Med. 2009 Nov;24 Suppl 3:534–41.
143. Hibbard JH. Using systematic measurement to target consumer activation strategies. Med Care Res Rev. 2009;66(1 Suppl):9S – 27S.

144. Nijman J, Hendriks M, Brabers A, de Jong J, Rademakers J. Patient Activation and Health Literacy as Predictors of Health Information Use in a General Sample of Dutch Health Care Consumers. J Health Commun. 2014;(March 2014):37–41.
145. Remmers C, Hibbard J, Mosen D, Wagenfield M, Hoye R, Jones C. Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? J Ambul Care Manage. 2009;32(4):320–7.
146. Rost KM, Flavin KS, Cole K, McGill JB. Change in metabolic control and functional status after hospitalization. Impact of patient activation intervention in diabetic patients. Diabetes Care. 1991;
147. Rygg LØ, Rise MB, Grønning K, Steinsbekk A. Efficacy of ongoing group based diabetes self-management education for patients with type 2 diabetes mellitus. A randomised controlled trial. Patient Educ Couns. 2012 Jan;86(1):98–105.
148. Rogvi S, Tapager I, Almdal TP, Schiøtz ML, Willaing I. Patient factors and glycaemic control--associations and explanatory power. Diabet Med. 2012 Oct;29(10):e382–9.
149. Bolen SD, Chandar A, Falck-Ytter C, Tyler C, Perzynski AT, Gertz AM, et al. Effectiveness and safety of patient activation interventions for adults with type 2 diabetes: Systematic review, meta-analysis, and meta-regression. J Gen Intern Med. 2014;29(8):1166–76.
150. Wolever RQ, Dreusicke M, Fikkan J, Hawkins T V, Yeung S, Wakefield J, et al. Integrative health coaching for patients with type 2 diabetes: a randomized clinical trial. Diabetes Educ. 36(4):629–39.
151. Williams GC, McGregor H, Zeldman A, Freedman ZR, Deci EL, Elder D. Promoting glycemic control through diabetes self-management: Evaluating a patient activation intervention. Patient Educ Couns. 2005;56(1):28–34.
152. Willaing I, Rogvi S a., Bøgelund M, Almdal T, Schiøtz M. Recall of HbA1c and self-management behaviours, patient activation, perception of care and diabetes distress in Type 2 diabetes. Diabet Med. 2013;30(4):139–42.
153. Hendriks M, Rademakers J. Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. BMC Health Serv Res. 2014;14(1):393.
154. Begum N, Donald M, Ozolins IZ, Dower J. Hospital admissions, emergency department utilisation and patient activation for self-management among people with diabetes. Diabetes Res Clin Pract. Elsevier Ireland Ltd; 2011 Aug;93(2):260–7.
155. Kinney RL, Lemon SC, Person SD, Pagoto SL, Saczynski JS. The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: A systematic review. Patient Educ Couns. Elsevier Ireland Ltd; 2015;98(5):545–52.
156. Alegría M, Polo A, Gao S, Santana L. Evaluation of a patient activation and empowerment intervention in mental health care. Med Care. 2008;46(3):247–56.

157. Green C a, Perrin N a, Polen MR, Leo MC, Hibbard JH, Tusler M. Development of the Patient Activation Measure for mental health. Adm Policy Ment Health. 2010 Jul;37(4):327–33.
158. Deen D, Lu W-H, Rothstein D, Santana L, Gold MR. Asking questions: the effect of a brief intervention in community health centers on patient activation. Patient Educ Couns. 2011 Aug;84(2):257–60.
159. Druss BG, Zhao L, von Esenwein SA, Bona JR, Fricks L, Jenkins-Tucker S, et al. The Health and Recovery Peer (HARP) Program: A peer-led intervention to improve medical self-management for persons with serious mental illness. Schizophr Res. 2010;118(1-3):264–70.
160. Daar AS, Singer P a, Persad DL, Pramming SK, Matthews DR, Beaglehole R, et al. Grand challenges in chronic non-communicable diseases. Nature. 2007;450(November):494–6.
161. Narayan KMV, Ali MK, Koplan JP. Global noncommunicable diseases-where worlds meet. N Engl J Med. 2010 Sep 23;363(13):1196–11988.
162. WHO - Department of Noncommunicable Disease Surveillance. Global status report on noncommunicable diseases. 2014.
163. Institute of Medicine. Living Well with Chronic Illness: A Call for Public Health Action. Washington, DC: The National Academies Press; 2012.
164. Murray CJL, Lopez AD. Measuring the Global Burden of Disease. N Engl J Med. 2013;369(5):448–57.
165. Coulter A. Engaging patients in healthcare. Open University Press. 2011. 224 p.
166. Eaton S, Roberts S, Turner B. Delivering person centred care in long term conditions. BMJ. 2015;350(feb10 14):h181–h181.
167. Caring for people with chronic conditions. A health system perspective. European Observatory on Health Systems and Policies series. Open University Press; 2008. 1-256 p.
168. Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. Milbank Q. 1996;74:511–44.
169. The Kings Fund. From vision to action: Making patient-centred care a reality. 2012.
170. Bodenheimer T, Wagner EH, Grumbach K. Improving Primary Care for Patients With Chronic Illness. JAMA. 2002 Oct 9;288(14):1775–9.
171. Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the Chronic Care Model in the new millennium. Health Aff. 2009;28(1):75–85.
172. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition-multimorbidity. Jama 307. 2012;20(23):2493–4.
173. Valderas JM, Starfield B, Sibbald B, Salisbury C, Roland M. Defining Comorbidity: Implications for Understanding Health and Health Services. Ann Fam Med. 2009 Jul 1;7(4):357–63.
174. Maeng DD, Martsolf GR, Scanlon DP, Christianson JB. Care coordination for the chronically ill: Understanding the patient's perspective. Health Serv Res. 2012;47(2007):1960–79.
175. Boyd CM, Darer J, Boult C, Fried LP, Boult L, Wu AW. Clinical Practice Guidelines and Quality of Care for Older Patients. JAMA. 2005;294(6):716.

176. Bayliss E a., Edwards AE, Steiner JF, Main DS. Processes of care desired by elderly patients with multimorbidities. Fam Pract. 2008;25(4):287–93.
177. Hughes LD. Guidelines for people not for diseases : the challenges of applying UK clinical guidelines to people with multimorbidity. 2012;62–9.
178. Tinetti ME, Bogardus ST, Agostini J V. Potential pitfalls of disease-specific guidelines for patients with multiple conditions. N Engl J Med. 2004;351:2870–4.
179. Mangin D, Heath I, Jamoulle M. Beyond diagnosis: rising to the multimorbidity challenge. BMJ. 2012. p. e3526–e3526.
180. Røsstad T, Garåsen H, Steinsbekk A, Sletvold O, Grimsmo A. Development of a patient-centred care pathway across healthcare providers: a qualitative study. BMC Health Serv Res. 2013;13:121.
181. De Maeseneer J, Roberts RG, Demarzo M, Heath I, Sewankambo N, Kidd MR, et al. Tackling NCDs: A different approach is needed. Lancet. 2012;379(11):1860–1.
182. Snyder L, Neubauer RL. Pay-for-performance principles that promote patient-centered care: An ethics manifesto. Annals of Internal Medicine. 2007. p. 792–4.
183. May C, Montori VM, Mair FS. We need minimally disruptive medicine. BMJ. 2009 Aug 11;339(aug11 2):b2803–b2803.
184. Noel PH, Chris Frueh B, Larme a C, Pugh J a. Collaborative care needs and preferences of primary care patients with multimorbidity. Heal Expect. 2005;8(1):54–63.
185. Braunstein ML. Health Informatics in the Cloud. New York, NY: Springer New York; 2013.
186. Tsai AC, Morton SC, Mangione CM, Keeler EB. A meta-analysis of interventions to improve care for chronic illnesses. Am J Manag Care. 2005;11(8):478–88.
187. Renders C, Valk G, Griffin S, Wagner E, Eijk Van J, Assendelft W. Interventions to improve the management of diabetes in primary care, outpatient, and community settings: a systematic review. Diabetes Care. 2001;24(10):1821–33.
188. Parchman ML, Zeber JE, Romero RR, Pugh J a. Risk of coronary artery disease in type 2 diabetes and the delivery of care consistent with the chronic care model in primary care settings: a STARNet study. Med Care. 2007;45(12):1129–34.
189. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. JAMA. 2002;288(15):1909–14.
190. Solomon M, Wagner SL, Goes J. Effects of a Web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial. J Med Internet Res. 2012 Jan;14(1):e32.
191. Alegría M, Carson N, Flores M, Li X, Shi P, Lessios AS, et al. Activation, self-management, engagement, and retention in behavioral health care: a randomized clinical trial of the DECIDE intervention. JAMA psychiatry. 2014;71(5):557–65.

192. Turner A, Anderson JK, Wallace LM, Bourne C. An evaluation of a self-management program for patients with long-term conditions. Patient Educ Couns. Elsevier Ireland Ltd; 2015;98(2):213–9.
193. Lorig K, Ritter PL, Villa FJ, Armas J. Community-based peer-led diabetes self-management: a randomized trial. Diabetes Educ. 2015;35(4):641–51.
194. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Annals of behavioral medicine : a publication of the Society of Behavioral Medicine. 2003. p. 1–7.
195. Hill-Briggs F. Problem solving in diabetes self-management: A model of chronic illness self-management behavior. Ann Behav Med. 2003;25(3):182–93.
196. Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. Lancet. 2004;364(3):1523–37.
197. Coleman MT, Newton KS. Supporting self-management in patients with chronic illness. Am Fam Physician. 2005;72(8):1503–10.
198. Linden A, Butterworth SW, Prochaska JO. Motivational interviewing-based health coaching as a chronic care intervention. J Eval Clin Pract. 2010;16(1):166–74.
199. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns. 2002;48(2):177–87.
200. Chodosh J, Morton SC, Mojica W, Maglione M, Suttorp MJ, Hilton L, et al. Meta-analysis: Chronic disease self-management programs for older adults. Ann Intern Med. 2005;143:427–38.
201. Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes - estimates for the year 2000 and projections for 2030. Diabetes Care. 2004;27(5):1047–53.
202. Gregg EW, Zhuo X, Cheng YJ, Albright AL, Narayan KMV, Thompson TJ. Trends in lifetime risk and years of life lost due to diabetes in the USA, 1985-2011: a modelling study. lancet Diabetes Endocrinol. 2014 Aug 12;8587(14):1–2.
203. Guariguata L, Whiting DR, Hambleton I, Beagley J, Linnenkamp U, Shaw JE. Global estimates of diabetes prevalence for 2013 and projections for 2035. Diabetes Res Clin Pract. Elsevier Ireland Ltd; 2014;103(2):137–49.
204. Zimmet PZ, Magliano DJ, Herman WH, Shaw JE. Diabetes: A 21st century challenge. Lancet Diabetes Endocrinol. 2014;2:56–64.
205. Wild S, Roglic G, Green A, Sicree R, King H. Global Prevalence of Diabetes: Estimates for the year 2000 and projections for 2030. Diabetes Care. 2004;27(5):1047–53.
206. Observatório Nacional da Diabetes. Diabetes: Factos e Números 2013 - Relatório Anual do Observatório Nacional da Diabetes. Sociedade Portuguesa de Diabetologia; 2014.
207. Grundy SM, Benjamin IJ, Burke GL, Chait a., Eckel RH, Howard B V., et al. Diabetes and Cardiovascular Disease : A Statement for Healthcare Professionals From the American Heart Association. Circulation. 1999 Sep 7;100(10):1134–46.

208. American Diabetes Association. Standards of medical care in diabetes--2014. Diabetes Care. 2014 Jan;37 Suppl 1(October 2013):S14–80.
209. Teljeur C, Smith SM, Paul G, Kelly A, O'Dowd T. Multimorbidity in a cohort of patients with type 2 diabetes. Eur J Gen Pract. 2013;19(1):17–22.
210. Haffner SM, Lehto S, Ronnemaa T, Pyorala K, Laakso M. Mortality from Coronary Heart Disease in Subjects with Type 2 Diabetes and in Nondiabetic Subjects with and without Prior Myocardial Infarction. N Engl J Med. 1998;339:229–34.
211. Hex N, Bartlett C, Wright D, Taylor M, Varley D. Estimating the current and future costs of Type1 and Type2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. Diabet Med. 2012;29:855–62.
212. Yang W, Dall TM, Halder P, Gallo P, Kowal SL, Hogan PF, et al. Economic costs of diabetes in the U.S. in 2012. Diabetes Care. 2013;36:1033–46.
213. Norris S, Engelgau M, Narayan K. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. Diabetes Care. 2001;24(3):561–87.
214. Norris S, Lau J, Smith S, Schmid C, Engelgau M. Self-management education for adults with type 2 diabetes: a meta-analysis of the effect on glycemic control. Diabetes Care. 2002;25(7):1159–71.
215. UK Prospective Diabetes Study Group. Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. BMJ. 1998;317(7160):703–13.
216. Tricco A, Ivers N, Grimshaw J, Moher D, Turner L, Galipeau J. Effectiveness of quality improvement strategies on the management of diabetes: a systematic review and meta-analysis. Lancet. 2012;379(9833):2252–62.
217. Haas L, Maryniuk M, Beck J, Cox C, Duker P, Edwards L. National Standards for Diabetes Self-Management Education and Support. Diabetes Care. 2012;36(Supplement 1):S100–8.
218. Deakin T, McShane CE, Cade JE, Williams RDRR. Group based training for self-management strategies in people with type 2 diabetes mellitus. Cochrane Database Syst Rev. 2005;(2):CD003417.
219. Samoocha D, Bruinvels DJ, Elbers N a., Anema JR, van der Beek AJ. Effectiveness of web-based interventions on patient empowerment: a systematic review and meta-analysis. J Med Internet Res. 2010;12(2):1–21.
220. Mazzi CP, Kidd M. A framework for the evaluation of Internet-based diabetes management. J Med Internet Res. 2002;4(1):5–16.
221. Bull SS, Gaglio B, McKay HG, Glasgow RE. Harnessing the potential of the internet to promote chronic illness self-management: diabetes as an example of how well we are doing. Chronic Illn. 2005;1:143–55.
222. Cho AH, Edelman DE, Hartwell PH, Oddone EZ, Yancy WS, Carolina N. Do Diabetic Veterans Use the Internet ? Telemed J E Health. 2010;16(5):595–602.

223. Nagykaldi Z, Aspy CB, Chou a., Mold JW. Impact of a Wellness Portal on the Delivery of Patient-Centered Preventive Care. J Am Board Fam Med. 2012;25(2):158–67.
224. Gammon D, Berntsen GKR, Koricho AT, Sygna K, Ruland C. The Chronic Care Model and Technological Research and Innovation: A Scoping Review at the Crossroads. J Med Internet Res. 2015;17(2):e25.
225. Jackson CL, Bolen S, Brancati FL, Batts-Turner ML, Gary TL. A systematic review of interactive computer-assisted technology in diabetes care: Interactive information technology in diabetes care. J Gen Intern Med. 2006;21:105–10.
226. Costa BM, Fitzgerald KJ, Jones KM, Dunning Am T. Effectiveness of IT-based diabetes management interventions: a review of the literature. BMC Fam Pract. 2009;10:72.
227. Balas E a, Boren S a, Griffing G. Computerized management of diabetes: a synthesis of controlled trials. Proc AMIA Symp. 1998;295–9.
228. Cho JH, Chang SA, Kwon HS, Choi YH, Ko SH, Moon SD, et al. Long-term effect of the internet-based glucose monitoring system on HbA1c reduction and glucose stability: A 30-month follow-up study for diabetes management with a ubiquitous medical care system. Diabetes Care. 2006;29(12):2625–31.
229. Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VBB, et al. Online Diabetes Self-Management Program. Diabetes Care. 2010;33(6):1275–81.
230. Cotter AP, Durant N, Agne A a, Cherrington AL. Internet interventions to support lifestyle modification for diabetes management: A systematic review of the evidence. J Diabetes Complications. 2014;28:243–51.
231. Osborn CY, Mayberry LS, Mulvaney SA, Hess R. Patient web portals to improve diabetes outcomes: A systematic review. Curr Diab Rep. 2010;10(6):422–35.
232. McMahon GT, Gomes HE, Hohne SH, Hu TMJ, Levine BA, Conlin PR. Web-based care management in patients with poorly controlled diabetes. Diabetes Care. 2005;28:1624–9.
233. Noh J-H, Cho Y-J, Nam H-W, Kim J-H, Kim D-J, Yoo H-S, et al. Web-based comprehensive information system for self-management of diabetes mellitus. Diabetes Technol Ther. 2010;12(5):333–7.
234. Ralston JD, Revere D, Robins LS, Goldberg HI. Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study. BMJ. 2004;328(7449):1159.
235. Glasgow RE, Boles SM, McKay HG, Feil EG, Barrera M. The D-Net diabetes self-management program: Long-term implementation, outcomes, and generalization results. Prev Med (Baltim). 2003;36(4):410–9.
236. Hartzband P, Groopman J. Untangling the Web--patients, doctors, and the Internet. N Engl J Med. 2010;362(12):1063–6.
237. Oh H, Rizo C, Enkin M, Jadad A. What is eHealth (3): A systematic review of published definitions. J Med Internet Res. 2005;7(1):1–12.

238. Eysenbach G. What is e-health? J Med Internet Res. 2001;3(2):1–5.
239. Pagliari C, Sloan D, Gregor P, Sullivan F, Detmer D, Kahan JP, et al. What is eHealth (4): A scoping exercise to map the field. J Med Internet Res. 2005;7(1):1–20.
240. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res. 2008 Jan;10(3):e22.
241. Poon EG, Keohane C a, Yoon CS, Ditmore M, Bane A, Levtzion-Korach O, et al. Effect of bar-code technology on the safety of medication administration. N Engl J Med. 2010;362:1698–707.
242. Bates DW, Leape LL, Cullen DJ, Laird N, Petersen LA, Teich JM, et al. Effect of computerized physician order entry and a team intervention on prevention of serious medication errors. JAMA. 1998;280(15):1311–6.
243. Evans RS, Pestotnik SL, Classen DC, Clemmer TP, Weaver LK, Orme JF, et al. A computer-assisted management program for antibiotics and other antiinfective agents. N Engl J Med. 1998;338:232–8.
244. Hunt DL, Haynes RB, Hanna SE, Smith K. Effects of computer-based clinical decision support systems on physician performance and patient outcomes: a systematic review. JAMA. 1998;280:1339–46.
245. Kawamoto K, Houlihan C a, Balas EA, Lobach DF. Improving clinical practice using clinical decision support systems: a systematic review of trials to identify features critical to success. BMJ. 2005;330(March):765.
246. Mishuris RG, Linder JA, Bates DW, Bitton A. Using Electronic Health Record Clinical Decision Support Is Associated With Improved Quality of Care. 2014;20(10):445–52.
247. Amarasingham R, Plantinga L, Diener-West M, Gaskin DJ, Powe NR. Clinical information technologies and inpatient outcomes: a multiple hospital study. Arch Intern Med. 2009;169(2):108–14.
248. Garrido T, Jamieson L, Zhou Y, Wiesenthal A, Liang L. Effect of electronic health records in ambulatory care: retrospective, serial, cross sectional study. BMJ. 2005;330:581.
249. Zhou L, Soran CS, Jenter C a., Volk L a., Orav EJ, Bates DW, et al. The Relationship between Electronic Health Record Use and Quality of Care over Time. J Am Med Informatics Assoc. 2009;16(4):457–64.
250. Institute of Medicine. The Role of Telehealth in an Evolving Health Care Environment: Workshop Summary. 2012. 158 p.
251. Bates DW, Bitton A. The future of health information technology in the patient-centered medical home. Health Aff (Millwood). 2010;29(4):614–21.
252. WHO-Global Observatory for eHealth. Telemedicine: Opportunities and developments in Member States. Observatory. 2010;2:96.

253. Schickedanz A, Huang D, Lopez A, Cheung E, Lyles CR, Bodenheimer T, et al. Access, interest, and attitudes toward electronic communication for health care among patients in the medical safety net. J Gen Intern Med. 2013;28:914–20.
254. Dixon RF. Enhancing primary care through online communication. Health Aff. 2010;29(7):1364–9.
255. Liederman EM, Morefield CS. Web messaging: A new tool for patient-physician communication. J Am Med Informatics Assoc. 2003;10:260–70.
256. Meskó B. The Guide to the Future of Medicine: Technology AND The Human Touch. Dr. Bertalan Meskó; 2014. 274 p.
257. Blumenthal D, Tavenner M. The "meaningful use" regulation for electronic health records. N Engl J Med. 2010;363:501–4.
258. Institute of Medicine. Clinical data as the basic staple of health learning: creating and Protecting a Public Good: Workshop Summary. Washington, DC; 2010.
259. Webb TL, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res. 2010 Jan;12(1):e4.
260. Burrington-Brown J. Information therapy. J AHIMA. 2009;80:28–31.
261. Gustafson DH, Hawkins R, Boberg E, Pingree S, Serlin RE, Graziano F, et al. Impact of a patient-centered, computer-based health information/support system. Am J Prev Med. 1999;16(1):1–9.
262. Meskó B. Social Media in Clinical Practice. Springer London; 2013. 155 p.
263. Al-Ubaydli M. Patients must have control of their medical records. BMJ (Clinical research ed.). 2012. p. e5575.
264. Department of Health. The power of information: putting all of us in control of the health and care information we need. London; 2012.
265. Shenkin BN, Warner DC. Giving the patient his medical record: a proposal to improve the system. N Engl J Med. 1973;289:688–92.
266. Greenfield S, Kaplan S, Ware JE. Expanding patient involvement in care: Effects on patient outcomes. Ann Intern Med. 1985;102(4):520–8.
267. Ross SE, Lin CT. The effects of promoting patient access to medical records: A review. J Am Med Informatics Assoc. 2003;10(2):129–38.
268. Cimino JJ, Patel VL, Kushniruk a W. What do patients do with access to their medical records? Studies in health technology and informatics. 2001. p. 1440–4.
269. Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, et al. Inviting patients to read their doctors' notes: A quasi-experimental study and a look ahead. Ann Intern Med. 2012;157:461–70.
270. Royal College of General Practitioners. Enabling Patients to Access Electronic Health Records - guidance for health professionals. 2010.

271. Tang P, Ash J, Bates D, Overhage J, Sands D. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. J Am Med Informatics Assoc. 2006;13(2):121–6.
272. Sakellarides C. Novo contrato social da saúde - incluir as pessoas. Diário de Bordo, editor. Lisboa; 2010.
273. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. BMC Med Inform Decis Mak. 2008 Jan;8:45.
274. Otte-Trojel T, de Bont A, Rundall TG, van de Klundert J. How outcomes are achieved through patient portals: a realist review. J Am Med Inform Assoc. 2014 Jul;21(4):751–7.
275. Steinbrook R. Personally controlled online health data--the next big thing in medical care? N Engl J Med. 2008;358:1653–6.
276. Mandl KD, Simons WW, Crawford WCR, Abbett JM. Indivo: a personally controlled health record for health information exchange and communication. BMC Med Inform Decis Mak. 2007;7:25.
277. Simons WW, Mandl KD, Kohane IS. The PING personally controlled electronic medical record system: Technical architecture. J Am Med Informatics Assoc. 2005;12(1):47–54.
278. Weitzman ER, Kaci L, Mandl KD. Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. J Med Internet Res. 2009;11(2).
279. Ammenwerth E, Schnell-Inderst P, Hoerbst A. The impact of electronic patient portals on patient care: A systematic review of controlled trials. Journal of Medical Internet Research. 2012.
280. Heyworth L, Paquin A. Engaging patients in medication reconciliation via a patient portal following hospital discharge. J Am Med Informatics Assoc. 2014;24036155.
281. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved Quality At Kaiser Permanente Through E-Mail Between Physicians And Patients. Health Aff. 2010 Jul;29(7):1370–5.
282. Lin CT, Wittevrongel L, Moore L, Beaty BL, Ross SE. An internet-based patient-provider communication system: Randomized controlled trial. J Med Internet Res. 2005;7.
283. Weingart SN, Carbo A, Tess A, Chiappetta L, Tutkus S, Morway L, et al. Using a patient internet portal to prevent adverse drug events: a randomized, controlled trial. J Patient Saf. 2013;9:169–75.
284. Weingart SN, Hamrick HE, Tutkus S, Carbo A, Sands DZ, Tess A, et al. Medication safety messages for patients via the web portal: The MedCheck intervention. Int J Med Inform. 2008;77:161–8.
285. Schnipper JL, Gandhi TK, Wald JS, Grant RW, Poon EG, Volk L a., et al. Effects of an online personal health record on medication accuracy and safety: a cluster-randomized trial. J Am Med Informatics Assoc. 2012;19:728–34.

286. Chrischilles E a, Hourcade JP, Doucette W, Eichmann D, Gryzlak B, Lorentzen R, et al. Personal health records: a randomized trial of effects on elder medication safety. J Am Med Inform Assoc. 2014;21:679–86.
287. Sarkar U, Lyles CR, Parker MM, Allen J, Nguyen R, Moffet HH, et al. Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. Med Care. 2014;52:194–201.
288. Ross SE, Moore L a., Earnest M a., Wittevrongel L, Lin CT. Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: Randomized trial. J Med Internet Res. 2004;6(2):1–15.
289. Keith McInnes D, Shimada SL, Rao SR, Quill A, Duggal M, Gifford AL, et al. Personal health record use and its association with antiretroviral adherence: Survey and medical record data from 1871 US veterans infected with HIV. AIDS Behav. 2013;17:3091–100.
290. Tom JO, Chen C, Zhou YY. Personal health record use and association with immunizations and well-child care visits recommendations. J Pediatr. Elsevier Ltd; 2014;164:112–7.
291. Druss BG, Ji X, Glick G, von Esenwein S a. Randomized trial of an electronic personal health record for patients with serious mental illnesses. Am J Psychiatry. 2014;171:360–8.
292. Lau A, Sintchenko V, Crimmins J, Magrabi F, Gallego B, Coiera E. Impact of a web-based personally controlled health management system on influenza vaccination and health services utilization rates: a randomized controlled trial. J Am Med Informatics Assoc. 2012;19:719–27.
293. Horvath M, Levy J, Engle P, Carlson B, Ahmad A, Ferranti J. Impact of health portal enrollment with Email reminders on adherence to clinic appointments: A pilot study. J Med Internet Res. 2011;13(2).
294. Palen TE, Ross C, Powers JD, Xu S. Association of online patient access to clinicians and medical records with use of clinical services. JAMA. 2012;308:2012–9.
295. Jones DW, Peterson ED, Bonow RO, Gibbons RJ, Franklin B a., Sacco RL, et al. Partnering to reduce risks and improve cardiovascular outcomes: American Heart Association initiatives in action for consumers and patients. Circulation. 2009;119:340–50.
296. Grant RW, Wald JS, Schnipper JL, Gandhi TK, Poon EG, Orav EJ, et al. Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. Arch Intern Med. 2008;168(16):1776–82.
297. Krist AH, Woolf SH. A vision for patient-centered health information systems. JAMA. 2011;305(3):300–1.
298. Crouch P-CB, Rose CD, Johnson M, Janson SL. A pilot study to evaluate the magnitude of association of the use of electronic personal health records with patient activation and empowerment in HIV-infected veterans. PeerJ. 2015;3:e852.
299. Nazi KM. The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings. J Med Internet Res. 2013 Jan;15(4):e70.

300. Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. J Am Med Inform Assoc. 2011 Dec;18 Suppl 1:i8–12.
301. Kim E-H, Stolyar A, Lober WB, Herbaugh AL, Shinstrom SE, Zierler BK, et al. Challenges to using an electronic personal health record by a low-income elderly population. J Med Internet Res. 2009 Jan;11(4):e44.
302. North F, Hanna BK, Crane SJ, Smith S a, Tulledge-Scheitel SM, Stroebel RJ. Patient portal doldrums: does an exam room promotional video during an office visit increase patient portal registrations and portal use? J Am Med Inform Assoc. 2011 Dec;18 Suppl 1(April 2010):i24–7.
303. Greenhalgh T, Morris L, Wyatt J, Thomas G, Gunning K. Introducing a nationally shared electronic patient record: Case study comparison of Scotland, England, Wales and Northern Ireland. Int J Med Inform. 2013;82(e):125–38.
304. Greenhalgh T, Hinder S, Stramer K, Bratan T, Russell J. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. BMJ. 2010 Nov 16;341(nov16 1):c5814–c5814.
305. Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A Research Agenda for Personal Health Records (PHRs). J Am Med Inform Assoc. 2008;15(6):729–36.
306. Archer N, Fevrier-Thomas U, Lokker C, McKibbon K a, Straus SE. Personal health records: a scoping review. J Am Med Inform Assoc. 18(4):515–22.
307. Logue MD, Effken J a. Validating the personal health records adoption model using a modified e-Delphi. J Adv Nurs. 2013 Mar;69(3):685–96.
308. Lober W, Zierler B. Barriers to the use of a personal health record by an elderly population. AMIA Annu Symp Proc. 2006;(3 Suppl 1):514–8.
309. Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc. 2008;15(1):1–7.
310. Xu J, Gao X, Sorwar G, Croll P. Implementation of E-health Record Systems in Australia. Int Technol Manag Rev. 2013;3(2):92–104.
311. Reeve J, Hosking R, Allinson Y. Personal electronic health records: the start of a journey. Aust Prescr. 2013;36(7656):70–3.
312. Sprague L. Personal health records: the people's choice? NHPF Issue Brief. 2006;(820):1–13.
313. Making primary care people-centred: A 21st century blueprint. Lancet. Elsevier Ltd; 2014;384(9940):281.
314. Weingart S, Rind D, Tofias Z, Sands D. Who Uses the Patient Internet Portal? The PatientSite Experience. J Am Med Informatics Assoc. 2006;13(1):91–5.
315. Silvestre A-L, Sue VM, Allen JY. If you build it, will they come? The Kaiser Permanente model of online health care. Health Aff. 2009;28(2):334–44.
316. Nazi KM, Hogan TP, McInnes DK, Woods SS, Graham G. Evaluating patient access to Electronic Health Records: results from a survey of veterans. Med Care. 2013 Mar;51(3 Suppl 1):S52–6.

317. Gu Y, Day K. Propensity of people with long-term conditions to use personal health records. Stud Heal Technol Inf. 2013;188:46–51.
318. Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. Health Aff (Millwood). 2009;28(2):323–33.
319. Zhou YY, Garrido T, Chin HL, Wiesenthal AM, Liang LL. Patient access to an electronic health record with secure messaging: Impact on primary care utilization. Am J Manag Care. 2007 Jul;13(7):418–24.
320. Wald JS. Variations in patient portal adoption in four primary care practices. AMIA Annu Symp Proc. 2010 Jan;837–41.
321. Tsai J, Rosenheck R a. Use of the internet and an online personal health record system by US veterans: comparison of Veterans Affairs mental health service users and other veterans nationally. J Am Med Inform Assoc. 2010;19(6):1089–94.
322. Wagner PJ, Dias J, Howard S, Kintziger KW, Hudson MF, Seol Y-H, et al. Personal health records and hypertension control: A randomized trial. J Am Med Inform Assoc. 2012 Jul 1;19(4):626–34.
323. Eason K, Waterson P. Fitness for purpose when there are many different purposes: Who are electronic patient records for? Health Informatics J. 2013;1460458213501096 – .
324. Van Gemert-Pijnen JEWC, Nijland N, van Limburg M, Ossebaard HC, Kelders SM, Eysenbach G, et al. A holistic framework to improve the uptake and impact of eHealth technologies. J Med Internet Res. 2011;13(4).
325. Williams G, Hamm MP, Shulhan J, Vandermeer B, Hartling L. Social media interventions for diet and exercise behaviours: a systematic review and meta-analysis of randomised controlled trials. BMJ Open. 2014 Jan;4(2):e003926.
326. Chou WS, Prestin A, Lyons C, Wen K. Web 2.0 for health promotion: reviewing the current evidence. Am J Public Health. 2013 Jan;103(1):e9–18.
327. Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. J Med Internet Res. 2013 Jan;15(4):e85.
328. Boyd DM, Ellison NB. Social Network Sites: Definition, History, and Scholarship. J Comput Commun. 2007 Oct 17;13(1):210–30.
329. Pew Research Center. Social Media Update [Internet]. 2013. Available from: http://www.pewinternet.org/2013/12/30/social-media-update-2013/
330. Pew Research Center. Social Networking Fact Sheet [Internet]. 2013. Available from: http://www.pewinternet.org/fact-sheets/social-networking-fact-sheet/
331. Facebook Newsroom [Internet]. 2014. Available from: http://newsroom.fb.com/content/default.aspx?newsareaid=22

332. Twitter, by the numbers [Internet]. 2013. Available from: http://news.yahoo.com/twitter-statistics-by-the-numbers-153151584.html
333. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. Health Promot Pract. 2013 Jan;14(1):15–23.
334. Eggleston EM, Weitzman ER. Innovative uses of electronic health records and social media for public health surveillance. Curr Diab Rep. 2014;14.
335. Mandl KD, McNabb M, Marks N, Weitzman ER, Kelemen S, Eggleston EM, et al. Participatory surveillance of diabetes device safety: a social media-based complement to traditional FDA reporting. J Am Med Inform Assoc. 2014;21:687–91.
336. Weitzman ER, Kelemen S, Quinn M, Eggleston EM, Mandl KD. Participatory surveillance of hypoglycemia and harms in an online social network. JAMA Intern Med. 2013 Mar 11;173(5):345–51.
337. Wicks P, Massagli M, Frost J, Brownstein C, Okun S, Vaughan T, et al. Sharing health data for better outcomes on PatientsLikeMe. J Med Internet Res. 2010 Jan;12(2):e19.
338. Wicks P, Vaughan TE, Massagli MP, Heywood J. Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. Nat Biotechnol. Nature Publishing Group; 2011 May;29(5):411–4.
339. Cobb NK, Graham AL, Abrams DB. Social network structure of a large online community for smoking cessation. Am J Public Health. 2010 Jul;100(7):1282–9.
340. Coiera E. Social networks, social media, and social diseases. BMJ. 2013;3007(May):1282–9.
341. Eysenbach G. Infodemiology and Infoveillance: Framework for an Emerging Set of Public Health Informatics Methods to Analyze Search, Communication and Publication Behavior on the Internet. J Med Internet Res. 2009 Jan;11(1):e11.
342. Salathé M, Freifeld C, Mekaru S, Tomasulo A, Brownstein J. Influenza A (H7N9) and the importance of digital epidemiology. N Engl J Med. 2013;369:401–4.
343. Mandl KD, McNabb M, Marks N, Weitzman ER, Kelemen S, Eggleston EM, et al. Participatory surveillance of diabetes device safety: a social media-based complement to traditional FDA reporting. J Am Med Inform Assoc. 2014;21(4):687–91.
344. Hawn C. Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. Health Aff (Millwood). 2009;28(2):361–8.
345. Greene J a, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J Gen Intern Med. 2011 Mar;26(3):287–92.
346. Greaves F, Ramirez-Cano D, Millett C, Darzi A, Donaldson L. Harnessing the cloud of patient experience: using social media to detect poor quality healthcare. BMJ Qual Saf. 2013 Mar;22(3):251–5.
347. Rozenblum R, Bates DW. Patient-centred healthcare, social media and the internet: the perfect storm? BMJ Qual Saf. 2013 Mar;22(3):183–6.

348. Valente T. Social Networks and Health. Oxford University Press; 2010.
349. Fowler J, Christakis N. Dynamic spread of happiness in a large social network: longitudinal analysis over 20 years in the Framingham Heart Study. Br Med J. 2008;(337):a2338–8.
350. Smith KP, Christakis N a. Social Networks and Health. Annu Rev Sociol. 2008 Aug;34(1):405–29.
351. Chiolero A, Santschi V, Paccaud F. Public health surveillance with electronic medical records: at risk of surveillance bias and overdiagnosis. Eur J Public Health. 2013 Jun;23(3):350–1.
352. Klompas M, McVetta J, Lazarus R, Eggleston E, Haney G, Kruskal B a., et al. Integrating clinical practice and public health surveillance using electronic medical record systems. Am J Prev Med. Elsevier Inc.; 2012;42(6):S154–62.
353. Fihn SD, Francis J, Clancy C, Nielson C, Nelson K, Rumsfeld J, et al. Insights from advanced analytics at the veterans health administration. Health Aff. 2014;33:1203–11.
354. Chaudhry B, Wang J, Wu S, Maglione M, Mojica W, Roth E, et al. Systematic review: Impact of health information technology on quality, efficiency, and costs of medical care. Ann Intern Med. 2006;144(10):742–52.
355. Institute of Medicine. Key Capabilities of an Electronic Health Record System: Letter Report. Washington, DC; 2003.
356. Curtis LH, Brown J, Platt R. Four health data networks illustrate the potential for a shared national multipurpose big-data network. Health Aff. 2014;33:1178–86.
357. Lev-ram M. What's the next big thing in big data? Bigger data. Fortune. 2014;169(8):233–8.
358. Moody A. Perspective: The big picture. Nature. 2013;502(7473):S95.
359. Mooney SJ, Westreich DJ, El-Sayed AM. Epidemiology in the Era of Big Data. Epidemiology. 2015;XXX(Xx):1.
360. Schwartz A. Larry Page Wants To Open Up Anonymous Medical Records For All Researchers To Use [Internet]. Fast Company. 2014. Available from: http://www.fastcoexist.com/3027942/larry-page-wants-to-open-up-anonymous-medical-records-for-all-researchers-to-use
361. Ferenstein G. Larry Page's Wish To Make All Health Data Public Has Big Benefits — And Big Risks [Internet]. Tech Crunch. 2014. Available from: http://techcrunch.com/2014/03/19/larry-pages-wish-to-make-all-health-data-public-has-big-benefits-and-big-risks/
362. Kohane IS, Altman RB. Health-information altruists--a potentially critical resource. N Engl J Med. 2005;353:2074–7.
363. Ferguson T. Health online: How To Find Health Information, Support Groups, And Self Help Communities In Cyberspace. Da Capo Press; 1996. 336 p.
364. Becker ER, Roblin DW. Translating primary care practice climate into patient activation: the role of patient trust in physician. Med Care. 2008;46(8):795–805.

365. Hibbard JH, Collins PA, Mahoney E, Baker LH. The development and testing of a measure assessing clinician beliefs about patient self-management. Health Expect. 2010 Mar;13(1):65–72.

366. Vallis M. Are Behavioural Interventions Doomed to Fail? Challenges to Self-Management Support in Chronic Diseases. Can J Diabetes. Elsevier Inc; 2015;1–5.

367. Ampt AJ, Amoroso C, Harris MF, McKenzie SH, Rose VK, Taggart JR. Attitudes, norms and controls influencing lifestyle risk factor management in general practice. BMC Fam Pract. 2009;10:59.

368. Levenstein JH, McCracken EC, McWhinney IR, Stewart M a, Brown JB. The patient-centred clinical method. 1. A model for the doctor-patient interaction in family medicine. Fam Pract. 1986;3(1):24–30.

369. Barros P. Pela sua saúde. Fundação Francisco Manuel dos Santos; 2013. 96 p.

370. Cassel CK, Guest JA. Choosing wisely: helping physicians and patients make smart decisions about their care. JAMA. 2012 May 2;307(17):1801–2.

371. Deen D, Lu WH, Weintraub MR, Maranda MJ, Elshafey S, Gold MR. The impact of different modalities for activating patients in a community health center setting. Patient Educ Couns. Elsevier Ireland Ltd; 2012;89(1):178–83.

372. Aronson L. “Good” Patients and “Difficult” Patients — Rethinking Our Definitions. N Engl J Med. 2013;369(9):9–10.

373. Kukafka R, Ancker JS, Chan C, Chelico J, Khan S, Mortoti S, et al. Redesigning electronic health record systems to support public health. J Biomed Inform. 2007 Aug;40(4):398–409.

374. Staroselsky M, Volk LA, Tsurikova R, Pizziferri L, Lippincott M, Wald J, et al. Improving electronic health record (EHR) accuracy and increasing compliance with health maintenance clinical guidelines through patient access and input. Int J Med Inform. 2006;75(10-11):693–700.

375. Wiljer D, Urowitz S, Apatu E, DeLenardo C, Eysenbach G, Harth T, et al. Patient accessible electronic health records: Exploring recommendations for successful implementation strategies. J Med Internet Res. 2008;10(4).

376. Woods SS, Schwartz E, Tuepker A, Press NA, Nazi KM, Turvey CL, et al. Patient experiences with full electronic access to health records and clinical notes through the my healthevet personal health record pilot: Qualitative study. J Med Internet Res. 2013;15(3).

377. Delbanco T, Berwick DM, Boufford JI, Edgman-Levitan P a., Ollenschläger G, Plamping D, et al. Healthcare in a land called peoplepower: Nothing about me without me. Heal Expect. 2001;4:144–50.

378. Lubetkin EI, Lu W-H, Gold MR. Levels and correlates of patient activation in health center settings: building strategies for improving health outcomes. J Health Care Poor Underserved. 2010 Aug;21(3):796–808.

379. Glanz K, Rimer B, Viswanath K. Health Behavior and Health Education. 4th ed. San Francisco: John Wiley & Sons; 2008.
380. Gillani SM, Nevill A, Singh BM. Provision of structured diabetes information encourages activation amongst people with diabetes as measured by diabetes care process attainment: the WICKED Project. Diabet Med. 2015;n/a – n/a.
381. Boyd CM, Wolff JL, Giovannetti E, Reider L, Weiss C, Xue Q-L, et al. Healthcare task difficulty among older adults with multimorbidity. Med Care. 2014;52 Suppl 3(3):S118–25.
382. Hill-Briggs F, Cooper D, Loman K, Brancati F, Cooper L. Qualitative Study of Problem Solving and Diabetes Control in Type 2 Diabetes Self-Management. Diabetes Educ. 2003;29(6):1018–28.
383. Vijan S, Stuart N, Fitzgerald J, Ronis D, Hayward R, Slater S. Barriers to following dietary recommendations in Type 2 diabetes. Diabet Med. 2005;22(1):32–8.
384. Dixon A, Hibbard J, Tusler M. How do people with different levels of activation self-manage their chronic conditions? Patient. 2009;2(4):257–68.
385. Heisler M, Piette J, Spencer M, Kieffer E, Vijan S. The relationship between knowledge of recent HbA(1c) values and diabetes care understanding and self-management. Diabetes Care. 2005;28(4):816–22.
386. Persell S, Keating N, Landrum M, Landon B, Ayanian J, Borbas C. Relationship of diabetes-specific knowledge to self-management activities, ambulatory preventive care, and metabolic outcomes. Prev Med. 2004;39(4):746–52.
387. Thaler RH. Nudge: Improving Decisions About Health, Wealth, and Happiness. Penguin Books; 2009. 312 p.
388. Kleinman A. The Illness Narratives: Suffering, Healing, And The Human Condition. Basic Books; 1989. 304 p.
389. Schiøtz ML, Bøgelund M, Almdal T, Jensen BB, Willaing I. Social support and self-management behaviour among patients with Type 2 diabetes. Diabet Med. 2012;29(5):654–61.
390. Rosland AM, Kieffer E, Israel B, Cofield M, Palmisano G, Sinco B, et al. When is social support important? The association of family support and professional support with specific diabetes self-management behaviors. J Gen Intern Med. 2008;23(12):1992–9.
391. Jackson CL, Batts-Turner ML, Falb MD, Yeh H-C, Brancati FL, Gary TL. Computer and internet use among urban African Americans with type 2 diabetes. J Urban Health. 2005;82(4):575–83.
392. Watson AJ, Bell AG, Kvedar JC, Grant RW. Reevaluating the digital divide: Current lack of internet use is not a barrier to adoption of novel health information technology. Diabetes Care. 2008;31(3):433–5.
393. Green BB, Cook AJ, Ralston JD, Fishman PA, Catz SL, Carlson J, et al. Effectiveness of home blood pressure monitoring, Web communication, and pharmacist care on hypertension control: a randomized controlled trial. JAMA. 2008;299(24):2857–67.

394. Instituto Nacional de Estatistica - Statistics Portugal. Inquérito à Utilização de Tecnologias da Informação e da Comunicação pelas Famílias. 2012.
395. Santana S. Trends of internet use for health matters in Portugal: 2005-2007. Acta Med Port. 2009;22:5–14.
396. Santana S, Sousa Pereira A. On the use of the Internet for health and illness issues in Portugal: repercussions in the physician-patient relationship. Acta Med Port. 2007;20:47–57.
397. Feil EG, Glasgow RE, Boles S, McKay HG. Who participates in Internet-based self-management programs? A study among novice computer users in a primary care setting. Diabetes Educ. 2000;26:806–11.
398. Adaji A, Schattner P, Jones K. The use of information technology to enhance diabetes management in primary care: A literature review. Inform Prim Care. 2008;16:229–37.
399. Bond GE, Burr R, Wolf FM, Price M, McCurry SM, Teri L. The effects of a web-based intervention on the physical outcomes associated with diabetes among adults age 60 and older: a randomized trial. Diabetes Technol Ther. 2007;9(1):52–9.
400. Irvine AB, Gelatt VA, Seeley JR, Macfarlane P, Gau JM. Web-based intervention to promote physical activity by sedentary older adults: Randomized controlled trial. J Med Internet Res. 2013;15(2).
401. Stellefson M, Chaney B, Barry AE, Chavarria E, Tennant B, Walsh-Childers K, et al. Web 2.0 chronic disease self-management for older adults: A systematic review. Journal of Medical Internet Research. 2013.
402. Hsu J, Huang J, Kinsman J, Fireman B, Miller R, Selby J, et al. Use of e-Health services between 1999 and 2002: A growing digital divide. J Am Med Informatics Assoc. 2005;12:164–71.
403. Brodie M, Flournoy RE, Altman DE, Blendon RJ, Benson JM, Rosenbaum MD. Health information, the Internet, and the digital divide. Health Aff. 2000;19:255–65.
404. Mandl KD, Feit S, Peña BM, Kohane IS. Growth and determinants of access in patient e-mail and Internet use. Arch Pediatr Adolesc Med. 2000;154(May 2000):508–11.
405. Viswanath K, Kreuter MW. Health Disparities, Communication Inequalities, and eHealth. Am J Prev Med. 2007;32:1–4.
406. Chen J, Cd M, Novak P, Sb T. Personalized Strategies to Activate and Empower Patients in Health Care and Reduce Health Disparities. Heal Educ Behav. 2015;
407. Goel MS, Brown TL, Williams A, Hasnain-Wynia R, Thompson J a, Baker DW. Disparities in enrollment and use of an electronic patient portal. J Gen Intern Med. 2011 Oct;26(10):1112–6.
408. Ancker JS, Barrón Y, Rockoff ML, Hauser D. Use of an Electronic Patient Portal Among Disadvantaged Populations. J Gen Intern Med. 2011;26(10):1117–23.
409. Tang PC, Black W, Buchanan J, Young CY, Hooper D, Lane SR, et al. PAMFOnline: integrating EHealth with an electronic medical record system. AMIA Annu Symp Proc. 2003 Jan;644–8.

410. Sarkar U, Karter A, Liu J, Adler NE, Nguyen R, López A, et al. The Literacy Divide: Health Literacy and the Use of an Internet-Based Patient Portal in an Integrated Health System—Results from the Diabetes Study of Northern California (DISTANCE). J Health Commun. 2010;15(Suppl 2):183–96.
411. Yamin CK, Emani S, Williams DH, Lipsitz SR, Karson AS, Wald JS, et al. The digital divide in adoption and use of a personal health record. Arch Intern Med. 2011 Mar 28;171(6):568–74.
412. Ancker JS, Silver M, Kaushal R. Rapid growth in use of personal health records in New York, 2012-2013. J Gen Intern Med. 2014 Feb 12;29(6):850–4.
413. California HealthCare Foundation. Consumers and Health Information Technology: A National Survey. 2010.
414. Roblin D, Houston T, Allison J, Joski P, Becker E. Disparities in Use of a Personal Health Record in a Managed Care Organization. J Am Med Informatics Assoc. 2009;16(5):683–9.
415. Nielsen a S, Halamka JD, Kinkel RP. Internet portal use in an academic multiple sclerosis center. J Am Med Informatics Assoc. 2012;19(1):128–33.
416. Miller H, Vandenbosch B, Ivanov D, Black P. Determinants of personal health record use: a large population study at Cleveland Clinic. J Healthc Inf Manag. 2007;21(3):44–8.
417. Ralston JD, Rutter CM, Carrell D, Hecht J, Rubanowice D, Simon GE. Patient use of secure electronic messaging within a shared medical record: a cross-sectional study. J Gen Intern Med. 2009 Mar;24(3):349–55.
418. Jung C, Padman R, Shevchick G, Paone S. Who are Portal Users vs. Early E-Visit Adopters? A Preliminary Analysis. AMIA Annu Symp Proc. 2011;1070–9.
419. Krist AH, Woolf SH, Rothemich SF, Johnson RE, Eric Peele J, Cunningham TD, et al. Interactive preventive health record to enhance delivery of recommended care: A randomized trial. Ann Fam Med. 2012;10:312–9.
420. Kim MI, Johnson KB. Personal health records: Evaluation of functionality and utility. J Am Med Informatics Assoc. 2002;9(2):171–80.
421. Laranjo L, Arguel A, Neves AL, Gallagher AM, Kaplan R, Mortimer N, et al. The influence of social networking sites on health behavior change: a systematic review and meta-analysis. J Am Med Inform Assoc. 2014;1–10.
422. Paton C, Hansen M, Fernandez-Luque L, Lau a YS. Self-Tracking, Social Media and Personal Health Records for Patient Empowered Self-Care. Contribution of the IMIA Social Media Working Group. Yearb Med Inform. 2012 Jan;7(1):16–24.
423. Lau AY, Dunn AG, Mortimer N, Gallagher A, Proudfoot J, Andrews A, et al. Social and self-reflective use of a Web-based personally controlled health management system. J Med Internet Res. 2013 Jan;15(9):e211.
424. Maher C a, Lewis LK, Ferrar K, Marshall S, De Bourdeaudhuij I, Vandelanotte C. Are health behavior change interventions that use online social networks effective? A systematic review. J Med Internet Res. 2014 Jan;16(2):e40.

425. AY L, Dunn A, Mortimer N, Proudfoot J, Andrews A, ST L, et al. Consumers' online social network topologies and health behaviours. Stud Heal Technol Inf. 2013;192:77–81.
426. Greaves F, Pape UJ, King D, Darzi A, Majeed A, Wachter RM, et al. Associations Between Web-Based Patient Ratings and Objective Measures of Hospital Quality. Archives of Internal Medicine. 2012. p. 435–6.
427. Bates DW, Saria S, Ohno-Machado L, Shah A, Escobar G. Big Data In Health Care: Using Analytics To Identify And Manage High-Risk And High-Cost Patients. Health Aff. 2014 Jul 8;33(7):1123–31.
428. Weber GM, Mandl KD, Kohane IS. Finding the missing link for big biomedical data. JAMA. 2014;311:2479–80.
429. Chan WC, Jackson G, Wright CS, Orr-Walker B, Drury PL, Boswell DR, et al. The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement. BMJ Open. 2014 Jan;4(4):e003975.
430. Berkowitz SA, Traore CY, Singer DE, Atlas SJ. Evaluating Area-Based Socioeconomic Status Indicators for Monitoring Disparities within Health Care Systems: Results from a Primary Care Network. Health Serv Res. 2014;n/a – n/a.
431. Noble D, Smith D, Mathur R, Robson J, Greenhalgh T. Feasibility study of geospatial mapping of chronic disease risk to inform public health commissioning. BMJ Open. 2012 Jan;2(1):e000711.
432. Voigtländer S, Vogt V, Mielck A, Razum O. Explanatory models concerning the effects of small-area characteristics on individual health. Int J Public Health. 2014 Apr 26;59(3):427–38.
433. Estabrooks PA, Boyle M, Emmons KM, Glasgow RE, Hesse BW, Kaplan RM, et al. Harmonized patient-reported data elements in the electronic health record: supporting meaningful use by primary care action on health behaviors and key psychosocial factors. J Am Med Informatics Assoc. 2012;
434. Fleurence RL, Beal AC, Sheridan SE, Johnson LB, Selby J V. Patient-powered research networks aim to improve patient care and health research. Health Aff. 2014;33:1212–9.
435. Mega JL, Sabatine MS, Antman EM. Population and Personalized Medicine in the Modern Era. JAMA. 2014;312(19):1969.
436. Otte-trojel T, Bont A De, Klundert J Van De, Rundall TG, Otte-trojel T. Characteristics of Patient Portals Developed in the Context of Health Information Exchanges: Early Policy Effects of Incentives in the Meaningful Use Program in the United States. J Med Internet Res. 2014;16(11):e258.
437. Mandl KD, Kohane IS. Federalist principles for healthcare data networks. Nat Biotechnol. Nature Publishing Group; 2015;33(4):360–3.
438. Luchenski SA, Reed JE, Marston C, Papoutsi C, Majeed A, Bell D. Patient and public views on electronic health records and their uses in the United Kingdom: Cross-sectional survey. J Med Internet Res. 2013;15(8).

439. Krumholz HM. Big data and new knowledge in medicine: The thinking , training , and tools needed for a learning health system. Health Aff. 2014;33:1163–70.
440. Cartwright J, Crowe S. Patient and Public Involvement Toolkit. Heneghan C, Perera R, Badenoch D, editors. BMJ books. Blackwell Publishing Ltd.; 2011. 112 p.
441. Brown T. Change by Design: How Design Thinking Transforms Organizations and Inspires Innovation. HarperBusiness; 2009. 272 p.
442. Davies M, Heller S, Skinner T, Campbell M, Carey M, Cradock S. Effectiveness of the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed type 2 diabetes: cluster randomised controlled trial. BMJ. 2008;336(7642):491–5.
443. Whitlock E, Orleans C, Pender N, Allan J. Evaluating primary care behavioral counseling interventions: an evidence-based approach. Am J Prev Med. 2002;22(4):267–84.
444. Between AC, Individuals H. Patient Activation in Primary Healthcare and Those With a Chronic Illness. 2011;49(5):469–79.
445. Alexander J a., Hearld LR, Mittler JN, Harvey J. Patient-physician role relationships and patient activation among individuals with chronic illness. Health Serv Res. 2012;47(3 PART 1):1201–23.
446. Greene J, Hibbard JH, Sacks R, Overton V. When seeing the same physician, highly activated patients have better care experiences than less activated patients. Health Aff. 2013;32(7):1299–305.
447. Chew-Graham C a, Hunter C, Langer S, Stenhoff A, Drinkwater J, Guthrie E a, et al. How QOF is shaping primary care review consultations: a longitudinal qualitative study. BMC Fam Pract. BMC Family Practice; 2013;14(1):103.
448. Coiera E. Why system inertia makes health reform so difficult. BMJ. 2011;342:d3693.
449. Howie JG, Heaney DJ, Maxwell M, Walker JJ, Freeman GK, Rai H. Quality at general practice consultations: cross sectional survey. BMJ. 1999;319(7212):738–43.
450. Block L, Habicht R, Wu AW, Desai S V., Wang K, Silva KN, et al. In the wake of the 2003 and 2011 duty hours regulations, how do internal medicine interns spend their time? J Gen Intern Med. 2013;28(8):1042–7.
451. Montague E, Asan O. Dynamic modeling of patient and physician eye gaze to understand the effects of electronic health records on doctor-patient communication and attention. Int J Med Inform. Elsevier Ireland Ltd; 2014;83(3):225–34.
452. Ammenwerth E, Shaw NT. Bad health informatics can kill--is evaluation the answer? Methods of information in medicine. 2005. p. 1–3.
453. Han YY, Carcillo J a, Venkataraman ST, Clark RSB, Watson RS, Nguyen TC, et al. Unexpected increased mortality after implementation of a commercially sold computerized physician order entry system. Pediatrics. 2005;116(6):1506–12.

454. Magnezi R, Bergman YS, Grosberg D. Online activity and participation in treatment affects the perceived efficacy of social health networks among patients with chronic illness. J Med Internet Res. 2014 Jan;16(1):e12.

455. Dykes PC, Samal L, Donahue M, Greenberg JO, Hurley AC, Hasan O, et al. A patient-centered longitudinal care plan: vision versus reality. J Am Med Informatics Assoc. 2014;21(6):1082–90.

456. Phillips SM, Glasgow RE, Bello G, Ory MG, Glenn BA, Sheinfeld-Gorin SN, et al. Frequency and Prioritization of Patient Health Risks from a Structured Health Risk Assessment. Ann Fam Med. 2014;12(6):505–13.

457. Greenhalgh T, Wood GW, Bratan T, Stramer K, Hinder S. Patients' attitudes to the summary care record and HealthSpace: qualitative study. BMJ. 2008 Jun 7;336(7656):1290–5.