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Implementing shared-decision-making for diabetes care across country settings: What really matters to people?



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ABSTRACT

Context: Growing evidence of improved clinical outcomes and patient/professional satisfaction supports shared-decision-making (SDM) services as an effective primary care interventions for diabetes. However, only a few countries have actually adopted them (e.g. England). In other European countries (e.g. Cyprus) there is awareness that patients play a crucial role in decision-making, and SDM services could be considered as innovative strategies to promote the actual implementation of patient rights legislation and strengthen primary care.

Objective: to understand preferences of people with diabetes when choosing their care, and how they value alternative SDM services compared to their 'current' option. Preferences were collected from patients based in England, where SDM is already in place at national level, and Cyprus, where people are new to it, using a discrete-choice-experiment (DCE) survey.

Results: Cypriots valued choosing alternative SDM services compared to their 'current' option, whereas the English preferred their status quo to other services. Having the primary-care-physician as health-care provider, receiving compassionate care, receiving detailed and accurate information about their care, continuity of care, choosing their care management and treatment, and reduced waiting time were the SDM characteristics that Cypriots valued; the English preferred similar factors, apart from information/continuity of care.

Conclusion: People with diabetes do value SDM and different SDM models may fit different groups according to their personal experience and country specific settings.

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1. Background

Shared-decision-making (SDM) requires a partnership between patients and professionals, working together to select tests, treatments and support packages of care based on patient preferences and patients' needs, clinician experience and research evidence. It can improve people's engagement in healthcare and help the delivery of effective services [1]. although there is limited evidence from randomised controlled trials to show improved clinical outcomes for diabetes care with SDM use, there is research (mainly looking at

patient and professional satisfaction) supporting SDM as an effective intervention for long-term conditions, such as diabetes [1–3]. Its implementation is often discussed in health and social sciences and successful case studies are available from Northern Europe and the overseas contexts [2]. Research evidence suggests that the most effective strategies may include: decision aids of various types; action plans and goal setting; structured one-to-one or group support for patients; training to enhance the skills of professionals [2].

In England SDM is embedded in the National Health Service (NHS) Constitution and the NHS Mandate [4]. The NHS Constitution states that 'we have the right to full information about treatment options, and to participate in decisions'. The Mandate includes an objective 'to ensure the NHS becomes dramatically better at involving patients and their caregivers, and empowering them to manage

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and make decisions about their own care and treatment.' In order to support developments in this area, a Shared Decision Making Collaborative has been established in 2015. It comprises members from the statutory sector, patient and voluntary sector organisations and academia committed to thinking collectively about the role of SDM in UK health systems [4,5]. Their recommendations describe a multi-component approach based on seven factors: leadership and culture change; local leadership, education and training, shared decision making tools, guidance development and evidence reviews, measurements of successful shared decision making and research. Taken together, these factors would aim at encouraging a shift in England heath care delivery to SDM services.

In other European countries there is awareness that patients play a crucial role in decision-making, and SDM practices could be considered as innovative strategies to promote patient rights [6] and support the development of a framework for action towards people-centred health services delivery [7]. Although most research on SDM in Europe has occurred in Northern European countries, the SDM model fits also within the priorities of the Mediterranean region, to include: the improvement of health literacy, the improvement of patient provider communication, and the empowerment of individuals to be more involved in their healthcare [8]. To our knowledge, discussion about its development in the Mediterranean region and Cyprus is limited. The case study of diabetes care offers examples of good SDM practices at international level and can provide common ground for developing a SDM framework to fit the needs of a series of European settings and the management of alternative chronic conditions [2,3]. More specifically this project will cover two countries, England and Cyprus. These two countries at the edges of Europe, have been both hit by the economic crisis in different ways and to different extents, and their health care systems are now facing severe consequences with direct impact on the delivery of diabetes care [9]. It is important to underline that in Cyprus the Public Health Care system was implemented when the country was part of the British Empire, and as such, its philosophy resembles NHS. Nevertheless, due to lack of a universal coverage Health System, only marginal reforms occurred. This is imputed to an extended anticipation of the National Health System which is perceived to be a deus ex machina for the efficiency enhancement of Health Care Sector. As a result, all major health reforms, are scheduled to occur once the NHS is implemented [10]. Interestingly, introduction of NHS has been postponed for late 2018, thus prolonging uncertainty and perpetuating inertias of the system. The situation is further aggravated in Cyprus; after being pushed to the verge of bankruptcy, this country is now facing radical healthcare reforms toward the implementation of a new scheme of Health Insurance [11,12]. The British and Cypriot case studies report also on different experience of diabetes care. In the former SDM is already in place at a national level, and we can draw from people direct experience [2]; in the latter people are new to it, although there could be room for future implementation. There is already evidence that Cypriot patients, their carers and health care professionals are prepared to welcome new diabetes management models able to promote patient autonomy and selfmanagement, and closer relationship between patient and health care professional [13,14].

This study aimed at understanding patients' preferences when choosing health care services for their diabetes care, and how they value SDM, as a process in which healthcare professionals and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and patients' informed preferences. Results allowed to estimate the components of SDM that people value, their relative importance; but also the potential participation rates to SDM programmes.

2. Methods

2.1. Participants, recruitment and data collection

We involved a convenient sample of primary care sites in each country to act as participant recruitment sites, from which a purposive sample of people with diabetes was drawn.

The research team approached about 150 participants from each country; assuming a 70% recruitment rate, and 30% attrition rate (i.e. incomplete questionnaire or inconsistent responses in questionnaire), the final sample size included 51 respondents in England and 90 respondents in Cyprus with completed questionnaires suitable for analysis. This followed current guideline for discrete choice experiment questionnaire [15].

Participants were eligible for the study if they were: seeking care for their diabetes; aged 18 years or more; and able to read and understand English and Greek (in Cyprus). In order to facilitate data collection form the Cypriot sites, Greek copy of the questionnaires were made available as necessary. Participants were excluded if they: did not agree to complete the questionnaire; appeared to be too physically or mentally unwell to approach based on the practice staff's judgment; or were in clinic to assist another patient who is seeking care.

Potential participants were approached by clinic staff when attending the clinic for their visits. Completed questionnaires were collected by a member of the practice staff, and sent to the research team. If patients felt that the time at the clinic was not sufficient for them to read the information sheet and complete the questionnaire, they were given the opportunity to complete the questionnaire at home and return it to the research team via post using a reply-paid envelope. To better enable participants to complete the questionnaire alone, an example question was presented in the material (Supplementary Material Fig. S1). Ethical approval was granted by the London School of Economics Research Ethics Committee, the Health Research Authority in England (13/NW/0893), the Ministry of Health in Cyprus, the Cyprus Bioethics Committee and the Cyprus Office of Commission for the Protection of Personal Data. Data collection took place between May and September 2014.

2.2. Discrete choice experiment

A Discrete Choice Experiment (DCE) questionnaire was distributed to diabetes patients to value patient preferences for SDM compared with current care. DCE is a quantitative technique for eliciting individual preferences. It is becoming a frequently used tool in international clinical practice research to estimate the average participation rates of healthcare interventions and to provide knowledge about the components of the interventions that determine the participation rates. Their application to develop and value healthcare interventions has been reported across healthcare settings and conditions [16–18], including diabetes care [19]. There is no publication of their use to inform health service development comparing patient experiences from Northern to Southern Europe nations.

2.2.1. Attributes and levels

The attributes and levels included in the current study were determined in a stepwise manner, which subsequently covered a literature review, clinician interviews and field testing with patients and their representatives. First, a list of characteristics for describing SDM practices in diabetes patients was compiled based on previously published literature [20]. Second, the list of SDM characteristics was discussed during expert interviews with physicians (GPs) and nurses (diabetes-specialist-nurses, DSNs) and clinicians with a specific interest in diabetes care based both in England and Cyprus (7 overall). These expert interviews were con-

 Table 1

 Expected participation rates (choice probabilities) for different SDM services based on the attribute estimates of the DCE results.

Alternative model	CyprusParticipation rate%	EnglandParticipation rate%	P value	Explanation
Alternative SDM service 1	47.42	43,43	0.45	The alternative SDM service 1 presents: 'always' detailed and accurate information about their care; 'always' care and compassion for their personal situation; 'choosing their treatment options, and manage their care'; 50% decrease in their 'waiting time'; 'receiving care from the same provider(s)'; receiving care from GP, hospital specialist and nurse (Primary care physician, hospital physician/specialist, and nurse, in Cyprus) (alternative scenario with the most preferred attribute levels apart from who is providing care).
Alternative SDM service 2	90.08	52.39	0.01	The alternative SDM service 2 presents: 'always' detailed and accurate information about their care'; 'always' care and compassion for their personal situation'; 'choosing their treatment options, and manage their care'; 50% decrease in their 'waiting time'; 'receiving care from the GP/physician only' (best scenario with the most preferred attribute levels).

Note: Expected participation rates were calculated by using the following formula: Pc (alternative diabetic service 1) = $\exp(V1n)/\Sigma j$ exp Vjn, where individual n will choose alternative diabetic service 1 within a choice set C of J (j=1,...,J) options.

ducted in order to shorten the list of potential attributes and to ensure that the attributes and levels were consistent with current practice in both countries. A third step, testing with patients was conducted in order to ensure that the most important attributes for the decision-making process of people with diabetes were included in the DCE and proper levels were used to each of the attributes as well as its length, its ability to be completed, and need for additional questions or possible rewording. No changes in the attributes and/or levels were deemed necessary based on the feedback received from discussion with 8 patients from both countries.

The DCE questionnaire collected information on: patient preferences for alternative SDM services (defined by the set of attributes and levels emerging from the stepwise approach described above) vs. usual care (using a DCE set of choices); their experience in seeking care; and their socio-demographic characteristics.

2.2.2. DCE choice design

Based on the selected attributes and levels, NGene (ChoiceMetrics, 2011) software was used to develop a D-efficient design with 12 unique choice tasks. To limit the burden of respondents, we divided these 12 choice tasks over three sets of four choice tasks, each set of DCE tasks was disseminated among a third of the study population. Besides choosing between two different combinations of healthcare services, participants could also choose to opt-out and prefer their current care. This opt-out option was included because, in real life, people can also choose not to receive an alternative diabetes care to the one they are currently receiving. A summary of DCE attributes, levels and regression coding. The attributes and levels that were included in this DCE are reported in Supplementary Material Table 1.

2.2.3. Statistical analyses

NLogit 4.0 (Econometric Software, 2007) was used to construct the econometric models that were estimated within this study. When analysing responses to multiple-choice DCE survey, typically the multinomial logit (MNL) model is used, although there is growing application of alternative models when relaxing its assumptions. MNL was compared with alternative mixed logit models to allow for unobserved heterogeneity across individuals [15]. Based on measure of the relative quality of statistical models for a given set of data (Akaike information criterion (AIC) and log-likelihood ratio index (LLRI)) The preferred conditional logit model is presented here:

$$Uji = Vji + eji \tag{1}$$

Where

$$\label{eq:Vji} Vji = \text{constant}_{\text{alternative service}} + \beta_1 \text{INFO1} + \beta_2 \text{INFO2} + \beta_3 \\ \text{INFO3} + \beta_4 \text{COMPASSION1} + \beta_5 \text{COMPASSION2} + \beta_6 \\ \text{COMPASSION3} + \beta_7 \text{MANAGMENT1} + \beta_8 \text{MANAGMENT2} + \beta_9 \\ \text{MANAGMENT3} + \beta_{10} \text{TIME1} + \beta_{11} \text{CONTINUITY1} + \beta_{12} \\ \text{PROVIDER1} + \beta_{13} \text{PROVIDER2} + \beta_{14} \\ \text{PROVIDER3} + \beta_{15} \text{PROVIDER4} \end{aligned} \tag{2}$$

Uij = the utility of the jth choice to the ith individual, Vij is the systematic part of the utility function observable by the researcher and eji is the error term.

Vij describes the measurable utility of (preference for) an alternative SDM practice j for individual i based on the attributes that were included in the DCE. For analysis, the reference alternative was the 'current' option. The constant alternative_service estimated the utility of (preference for) moving, to an alternative healthcare service rather than staying with the 'current' option.

 β_1 – β_{15} are the attribute estimates that indicate the relative importance of each attribute.

The DCE results allowed to identify what characteristics of the service respondents value (for example they could value 'choosing treatment options, and managing care', reducing their 'waiting time' rather than other aspects) and the relative values that they attach to these (for example they could value 'being involved in decision about the management of their care and treatment' more than other aspects). In order to calculate patients' marginal willingness to wait, the negative of the time attribute was used as a

Table 2Responses, patient characteristics.

		Cyprus		England		P value*
		no.	%	no.	%	
Sites	GP (primary care physician) sites	46	51	51	100	
	Hospital diabetic clinic	44	49	n/a		
	Total	90		51		
Blocks	1	28	31.1	17	33.3	0.84
	2	28	31.1	12	23.5	
	3	34	37.8	22	43.1	
What age are you on your next birthday?	Mean (sd)	59.32	16.3	69.16	11.6	< 0.01
Gender	Male	37	48.1	26	54.2	0.50
	Female	40	51.9	22	45.8	
How would you	Very poor	0	0	0	0	< 0.01
describe your overall	Poor	1	1.2	5	10.4	
health on a 0-5 scale	Average	17	19.8	18	37.5	
ranging from very poor	Good	55	64.0	17	35.4	
to excellent	Very good	13	15.1	8	16.7	
No. of years with diabetes		12.84	9.7	10.85	3.25	0.16
Have you been	Cancer	4	4.4	9	16.7	< 0.01
diagnosed with any of	Heart disease	14	15.4	7	13.0	
these other illnesses?	Asthma	3	3.3	3	5.6	
	Other	5	5.5	11	20.4	
	No co-morbidities/ missing data	65	71.4	24	44.4	
What best describes	In paid work	24	27.3	9	20	0.63
your current situation	Unemployed	4	4.5	0	0	
	Retired from paid work	45	51.1	32	71.1	
	Unable to work because of disability	1	1.1	3	6.7	
	Looking after family, home, or dependents	8	9.1	1	2.2	
	In full-time education	4	4.5	0	0	
	Others	2	2.3	0	0	

^{*} Anova test for independent groups.

measure of the marginal utility of time. The ratio of either attribute estimate to this negative of the time attribute provides an estimation of patients' willingness to wait in the community care site for a unit change in that specific attribute (e.g. willingness to wait to 'receive continuity of care'). In addition, expected participation rates (choice probabilities) to alternative SDM services were calculated compared with 'current' option. Explanation of the alternative SDM services 1–2 is presented in Table 1.

3. Results

3.1. Responses

Data came from community sites in England (51 respondents from two primary care physician sites) and Cyprus (90 respondents, from three primary care physician sites (46) and one diabetes specialist clinic in hospital providing community services to diabetes patients, 44). Both country-specific samples presented comparable socio-demographic characteristics, apart from age (p < 0.01), overall health state (p < 0.01) and comorbidities (p < 0.01) (see Table 2).

3.2. Current experience of care

In both countries the majority of patients received information about their care (most of the times/always; 93% Cyprus, 86% England); compassionate care (93.3% Cyprus; 86.3% England); continuity of care (93.3% Cyprus; 58.8% England; see Fig. 1). In Cyprus the majority of patients were involved in decision about the management of their care only (75.6%), whilst in England they were involved in decision about both the management of their care and treatment options (58.8%). In Cyprus patients had to wait one hour or more for their visit (82.2%), whilst in England they experienced shorter waiting time (less than 1 h 68.6%). In Cyprus the majority of patients received care from primary care physician and hospital diabetes clinic (54.4%) or primary care physician and nurse (40.0%), whilst in England the respondents had experience of receiving

care from primary care team/GP only (71%). For all attributes the difference between Cyprus and England groups was statistically significant at 1%.

3.3. Preferences about their care

The results from the DCE model are presented in Supplementary Material Table 2. A few of the attribute estimates were significant, indicating that they are important for people with diabetes when choosing about their healthcare. Scaling factor issues did not allow a direct comparison of parameter estimates across groups [15]. Willingness to wait estimates (see Fig. 2) were employed for such comparisons. They were calculated for the significant attributes only

Cypriot respondents valued the opportunity to choose alternative healthcare services compared to their 'current' option (they were willing to wait extra 2 more hours to be able to receive alternative service to their 'current' option with everything else constant). When choosing their care they prefer (in order of importance):

- Care provider they were willing to wait 8 more hours to 'receive care from GP only' rather than from staff at the diabetes centre in the hospital;
- Compassion they were willing to wait 8 more hours to 'receive always care and compassion for their personal situation';
- Information they were willing to wait 6–7 more hours to 'receive most of the times/always detailed and accurate information about their care';
- Continuity of care they were willing to wait 5 more hours to receive care from the same healthcare provider(s);
- *Care management and treatment* they were willing to wait almost 4 more hours to 'choose treatment options and manage their care';

They least valued attribute was 'waiting time'.

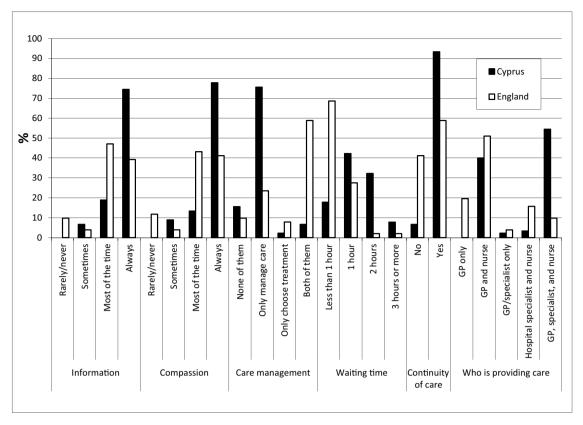


Fig. 1. Current care.

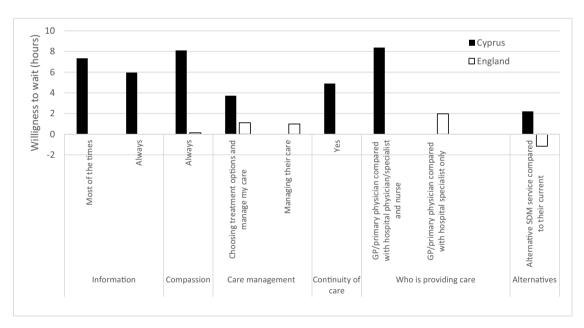


Fig. 2. Willingness to wait results.

English respondents preferred their 'current' option compared with alternative community care services. When choosing their care they valued fewer characteristic compared with Cypriot respondents and they were (in order of importance):

- *Care provider* they were willing to wait 2 more hours to 'receive care from their GP compared with hospital specialist only':
- *Compassion* they were willing to wait almost 2 more hours to 'receive sometimes compassionate care';

 Care management and treatment – they were willing to wait about one more hour to manage their care (either in association with choosing their treatment or alone).

They also valued reducing their *waiting time*, whereas other aspects of care important to Cypriot respondents, such as receiving *detailed and accurate information about their care*, or receiving *continuity of care*, were not important to them.

When comparing willingness to wait estimates across groups (see Fig. 2) it appeared that Cypriot respondents valued more SDM care compared English respondents, characterized by: 'receiving always detailed and accurate information about your care' or 'continuity of care' (valued by Cypriots 7.34 and 4.90 h respectively, whereas the English reported them as not important); 'compassionate care' (8.10 vs. 0.13 h, Cypriot and English respondents respectively); or 'being involved in care management and choice of treatment option' (3.72 vs. 1.10 h). Everything else constant, Cypriot patients valued more an alternative SDM compared with their current, whereas English patients preferred their current experience to other services. Differences between groups were statistically significant at 1%.

3.4. Expected participation rates and policy analysis

Two different scenarios were considered and they are fully explained in Table 1.

The most preferred SDM service (best scenario, alternative SDM service 2), which includes 'always' detailed and accurate information about their care', 'always' care and compassion for their personal situation', 'choosing their treatment options, and manage their care', 50% decrease in their 'waiting time' and 'receiving care from the GP/physician only', resulted in an estimated potential participation rate of 90.08% in Cyprus and 52.39% in England (compared with 'current' option; p < 0.01).

4. Discussion

4.1. Main findings

This study demonstrates the complexity of patient decision making processes regarding their care for diabetes in community setting. Our findings suggested that people with diabetes value SDM services although the importance of the service features may change across healthcare systems. Cypriot patents valued choosing alternative SDM services compared to their 'current' option, whereas English respondents preferred their status quo (where they had already experience of SDM and shorter waiting times). Receiving support from the 'primary physician', 'compassionate care', 'detailed and accurate information about their care', 'continuity of care', 'choosing their care management and treatment', and reduced 'waiting time' were the service characteristics that Cypriots valued mostly; the English preferred similar factors, apart from 'detailed and accurate information about their care' or 'continuity of care' that were not valued. Participation rates to alternative SDM services to their 'current' option ranged between 47 and 90% in Cyprus and 43-52% in England.

4.2. Comparison with other studies

Results from a recent DCE experiment looking at estimating the relative importance of organisational, procedural, and interpersonal characteristics of healthcare delivery systems from the patient perspective showed that elements such as SDM were considered as the most important across country settings [21]. Receiving support from their GP was one of the most important variables to explain satisfaction among primary care patients across groups and this is confirmed by recent data in Europe [22].

Compassionate care [23,24] was also reported an important factor in helping patient managing their chronic condition in England, as well as self-management, decreased waiting time and receiving care from primary care provider [25]. Access to information and continuity of care did not appear to be important factors associated to patient satisfaction; although there is evidence in England that patients do value them [26,27], there are also papers arguing

that for example continuity of care is not valued by all patients or across all settings (for example see [28]). Findings from the Cypriot case study also substantiate previous studies in the country [29,30] which concluded that patients are satisfied with outpatient services provided by both private and public sectors. They also reported that for patients SDM is a necessity and not an option and should be embedded within the Cyprus health care framework.

4.3. Strengths, limitations and future work

The added value of this study is that this is the first application of a DCE survey to value patient care in Cyprus and compare information on what aspects of care are important to patients. But also it allows to calculate trade-off between them, and value the benefit for policy changes vs other healthcare system in England. Cyprus health care system, largely a legacy from the English colonial era, has exceeded its functional capacity and the need to move forward is imperative. This study offers a new and largely unexplored insight on what people actually value; importantly this enriches the policy framework in Cyprus, since is the first study to address patient preferences. These findings could serve as a benchmark in the design phase of the NHS and by capitalising on these performance indicators it is feasible that a patient-centred and more efficient system can be developed. Moreover, by using patient preferences to inform policy change, a mutual consensus by stakeholders is more likely to occur. This would allow to relieve tensions that have accumulated due to delays in the introduction of NHS and consequent protracted inconvenience of patients [31]. The current fragmentation of health sector in Cyprus between public (virtually the only sector where people with diabetes can receive care from a limited number of multidisciplinary teams) and private (where care is delivered by physicians only) can explain the significance difference regarding the participation rates (47% for multidisciplinary care, 90% for care delivered by physician only). Capitalising on these findings, Cyprus health authorities-even prior to the introduction of NHS- can gradually shift into a patient-centred health care, which does not assume significant financial burden. Parameters such as providing compassionate care' or detailed and accurate information stem out of health care professionals' role. Indeed, health care professionals can be trained to address such aspects in the consultation with their patients; this could be easily carried out through awareness and targeted education initiatives (see examples in England) [32–34]. To this direction, a pivotal work – embedded within the EU funded EUBIROD project (European best information through regional outcomes in diabetes; http://www. eubirod.eu/) – was introduced in Cyprus diabetes hospital clinic aiming to incorporate SDM into clinical practice. Early unpublished data indicate positive impact on patient's compliance, satisfaction and engagement while an improved glycaemic control was also observed. On the contrary, the English NHS due to its constant and relentless reforms offers value to patients and constitute a key example of SDM as good clinical practice that can improve value and cost-effectiveness [35] and can be used to inform a policy shift to SDM in Cyprus within the forthcoming new NHS. Specific lessons for Cypriot policy makers and the new NHS that is under development may include: Fostering SDM in chronic disease management could have a positive impact on patients satisfaction and probably also in disease outcomes; training of the healthcare professionals and the patients on SDM, its benefit and its practical implementation would be needed to support the implementation of SDM in the country; developing a country specific guideline for SDM could be beneficial to institutionalise the SDM model in the NHS; the SDM evaluation tool proposed in this paper could be further developed and applied as useful approach in evaluating the quality of healthcare service and SDM provision under the reformed system.

This paper presents the comparison between public providers in England (based in GP practices) and Cypriot public sites including both primary care practices (primary care physicians and practice nurses) and hospital settings (staff from a hospital-based diabetes clinic and practice). Due to time and budget constraints data from hospital-based diabetes clinics in England are missing from the comparison. More work would be needed to investigate patient and clinician experiences across healthcare settings in the different countries. Crucially the DCE-based model presented here does appear to be a successful framework to capture patient preferences for diabetes care and it could also be used as springboard for a much needed larger scale evaluation of stakeholder preferences in the Mediterranean area when applying SDM processes to the management of diabetes and other chronic diseases.

5. Conclusion

Policy decision making requires consideration of patient preferences and, moreover, the information on preferences can be used to develop effective delivery of diabetes care. People with diabetes do value SDM and different SDM models may fit different groups according to their personal experience and country specific health care systems.

Declaration of interest

there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.healthpol.2017. 05.001.

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