A QUALITATIVE STUDY TO INVESTIGATE THE OUTCOMES OF SELF-MANAGEMENT THAT MATTER TO STAKEHOLDERS



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Background

- More than 15 million people are living with a long term condition (LTC) in UK (Department of Health, 2012).
- LTCs accounts for 70% of the health and social care budget (Department of Health, 2013).
- Self-management (SM) has received growing attention as an effective approach for LTC management.
- Little is known about which outcomes of SM are valued by patients, their families, health care professionals and those who commission health care services.

Research aims

- 1) To identify the outcomes of selfmanagement support that each stakeholder group consider important.
- 2) To identify areas of generic thematic similarity and disparity in the self-management outcomes of importance across each stakeholder group.

Methods

The interview method was selected to provide individuals the opportunity to explore their opinions, values and beliefs regarding the outcomes of self-management they considered important (Silverman, 2005). Focus groups were used with patients and 'family and friend' stakeholder groups; semistructured interviews were used with health care professionals and commissioners. The interview schedule was based on a systematic literature review conducted for phase 1 of the SM:VOICED* study (Boger et al, in print).

Participants:

- lived or worked within 50 miles of London, Southampton, Leeds,
- were over the age of 18 years,
- had expertise in one of three exemplar conditions; diabetes (type 1 or 2), colorectal cancer and stroke.

Results

174 people were interviewed, 91% of whom reported white British ethnicity. 61% were female. Socio-demographic details for each stakeholder group are presented in tables 1-4.

Table 1: Patient Stakeholder Group												
Condition	Total	Diagnosis (years)			Diabetes		Age	Age			Gender	
		<2	2-10	<10	T1	T2	18-35	35-55	55+	Male	Female	White British
Diabetes	38	3*	16*	16*	14	24	3*	6*	28*	21	17	97
Colorectal Cancer	19	6	9	4	_	-	1	5	13	4	15	100
Stroke	40	6*	19*	8*	-	-	-	9	31	21	19	85
*Missing infor	mation											

Condition	Total	Carer fo	Age			Gender		% White			
		Spouse	Parent	Child	Friend	18-35	35-55	55+	Male	Female	British
Diabetes	14	10	3	-	1	4	4	6	3	11	64
Colorectal Cancer	10	7	2	1	1	1	2	7	2	8	100
Stroke	11	8	2	-	1	2	_	9	4	7	82

Table 3: Health Care Professional Stakeholder Group												
	Gender	Gender		Years Qualified			Condition					
	Male	Female	<5	5-15	15+	Diabetes	Colorectal Cancer	Stroke	Generic			
20	5	15	1	7	12	3	3	6	8	95		

Table 4: Commissioner Stakeholder Group												
Total	Gender		Structu	ıre		% White British						
	Male	Female	CCG	CSU	NHS England Regional	NHS England National						
22	8	14	17	1	1	3	100					

Findings

Data revealed differences in opinions between stakeholder groups regarding the desired outcomes of self-management.

Commissioners and HCPs talked of achieving more process related and biomedical outcomes from self-management. These are arguably easier outcomes to measure. They also recognised that quality of life was an important outcome for patients.

'Reduction of hospital admissions come high on your list of just the reality of what you're trying to grapple with. So I think things like that are naturally where commissioners are looking for evidence.' — Commissioner, NHS England

'At a rather narrow level, you can look at their biochemical parameters, so we've got the measures of blood glucose which – HBa1C,...you can tell whether they're taking their cholesterol medications, you can look at their blood pressure, you can look at their weight. And those are very important end points. They're not really – they're not the whole story at all.' — HCP, diabetes

Patients and family members talked of having appropriate information, particularly a central point of contact to contact in times of need was important. For patients 'feeling normal' and making the most of life were also desired outcomes of SM, and they would manage their condition in a way that would encourage this.

'It's not so much that you need any medical intervention but what you need is a point of contact every so often so that if it goes wrong, because it's all about prevention isn't it?'

— Family and Friend, Colorectal Cancer

'I've only ever gone get to see them (grandchildren) a little, I used to or bake (with them pre stroke)...but then I didn't want them to come as they didn't recognise me. They didn't recognise, I couldn't bake, or cuddle them, I didn't want them coming round when I couldn't do anything with them... when I'm normal they can come.' — Female, stroke

Conclusion

This research is one of the first to identify what commissioners, health professionals, people with LTCs and their family want from self-management. It is clear that each stakeholder group views the outcomes of SM differently. What remains unknown is how far each of these stakeholder groups values and prioritises these outcomes. The following phase of SMVOICED seeks to fill this void. A national Delphi survey will be conducted (June 2015-Sept 2015) to investigate the value placed on these outcomes by each stakeholder group.



* Self-Management VOICED is a 3 phase study exploring which outcomes of self-management are important to different stakeholders:

Phase 1: reviewing the literature; Phase 2: talking to stakeholders;

Phase 3: national consensus survey.

Further information

If you would like to know more or take part in the Delphi survey, please visit our website: www.southampton.ac.uk/smvoiced