



## Implementing, embedding and integrating self-management support tools for people with long-term conditions in primary care nursing: A qualitative study<sup>☆</sup>



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### ABSTRACT

**Background:** An implementation gap exists between policy aspirations for provision and the delivery of self-management support in primary care. An evidence based training and support package using a whole systems approach implemented as part of a randomised controlled trial was delivered to general practice staff. The trial found no effect of the intervention on patient outcomes. This paper explores why self-management support failed to become part of normal practice. We focussed on implementation of tools which capture two key aspects of self-management support – education (guidebooks for patients) and forming collaborative partnerships (a shared decision-making tool).

**Objectives:** To evaluate the implementation and embedding of self-management support in a United Kingdom primary care setting.

**Design:** Qualitative semi-structured interviews with primary care professionals.

**Settings:** 12 General Practices in the Northwest of England located within a deprived inner city area.

**Participants:** Practices were approached 3–6 months after undergoing training in a self-management support approach. A pragmatic sample of 37 members of staff – General Practitioners, nurses, and practice support staff from 12 practices agreed to take part. The analysis is based on interviews with 11 practice nurses and one assistant practitioner; all were female with between 2 and 21 years' experience of working in general practice.

**Methods:** A qualitative design involving face-to-face, semi-structured interviews audio-recorded and transcribed. Normalisation Process Theory framework allowed a systematic evaluation of the factors influencing the work required to implement the tools.

**Findings:** The guidebooks were embedded in daily practice but the shared decision-making tools were not. Guidebooks were considered to enhance patient-centredness and were minimally disruptive. Practice nurses were reluctant to engage with behaviour change discussions. Self-management support was not formulated as a practice priority and there was minimal support for this activity within the practice: it was not auditable;

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was insufficiently differentiated from existing content and processes of work to value in its own right, and considered too disruptive and time-consuming.

*Conclusion:* Supporting self-management through the encouragement of lifestyle change was problematic to realise with limited evidence of the development of the needed collaborative partnerships between patients and practitioners required by the ethos of self-management support.

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### What is already known about this topic?

- Practice nurses are increasingly responsible for most long-term condition management in primary care.
- The development of more collaborative patient–practitioner relationships is key to the ethos of supporting patient self-management of long-term conditions.
- Whilst ostensibly widely and rhetorically valued, the necessary increased patient involvement in self-management support via the consultation process is challenging for practitioners to implement in practice.

### What this paper adds

- The current organisational priorities of General Practice means that the work needed to implement self-management support remains under-initiated and valued by the current system so is not given the priority required for it to be embedded in the day-to-day work of primary care.
- Displacing existing practices in order to incorporate new ones is discouraged by the task-driven nature of nurses' routines that hinder incorporating alternative ways of working.
- Underlying scepticism of the will of many patients to take adequate responsibility for their health undermines the motivation of some nurses to engage with self-management support activities.

## 1. Introduction

A randomised controlled trial of an approach to improve the health outcomes of patients with long-term conditions through improving the self-management support they received from primary care showed no effect (Kennedy et al., 2013). The trial was one of the largest ever to be conducted of self-management support, recruiting 5599 patients. This paper uses qualitative methods to explore the work of self-management support and explain why the implementation of a systemised evidence-based approach failed to engage the nurses tasked with supporting patients to self-manage.

The organisation of care for people with long-term conditions is in transition and self-management support policies have been designed to enhance peoples' self-management capabilities aiming to improve health outcomes and reduce the fiscal burden on health care systems (Department of Health, 2005). Self-management has been defined as: 'the care taken by individuals towards their own health and well-being; it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents'

(Department of Health, 2005). In relation to long-term condition management and based on a systematic review, the interventions most likely to be effective in the context of primary care were engagement for self-management support through education and training for general practitioners and practice nurses (Dennis et al., 2008). Primary care potentially provides ready access and continuity of care for patients and therefore an appropriate location for guideline-based *disease management* programmes for patients, and more recently as a key provider of self-management support (Truglio et al., 2012). In United Kingdom primary care, long-term condition management operates through an increasingly biomedical, specialised and reductionist framework, partly as a result of the Quality and Outcomes Framework (DoH, 2004), a system of payment to practices for activities done and outcomes achieved. To gain through the pay for performance system, practices have to demonstrate through clinical information systems using computer templates, the undertaking of specific processes and tasks (such as setting up a register of patients with hypertension and regular recording of blood pressure with an aim of ensuring blood pressure is controlled according to a target). These financially incentivised tasks have been shown to have both intended and unintended consequences and are, in the case of long-term condition management, usually delegated to practice nurses (McDonald and Roland, 2009).

Self-management support holds out the offer of a more patient-centred, social and psychological approach. There have been numerous studies of the effectiveness of self-skills training delivered to patients and the factors relating to acceptability and uptake by patients of one-off training courses. We know much less about the implementation of a whole systems approach to self-management support and an implementation gap has been identified between the national aspirations for self-management policy and local means of delivery (Lee et al., 2006; Rogers, 2009). Thus, there is a need to understand how a systemic approach to self-management support reconfigures existing relationships, communication and practices and how the principles of a whole systems patient-centred approach to self-management can translate and become embedded and integrated into routine practice (Gray et al., 2011; Macdonald et al., 2008). The latter is particularly salient in a context where the labour of primary care professionals has ostensibly become biomedical and bureaucratic due to the pressures and demands of governance arrangements linked to pay-for-performance (Doran et al., 2011) and in the diverse and widely spread context of primary care (Greenhalgh et al., 2004).

We have based our theoretical understanding of the implementation of self-management support in primary

care on Normalisation Process Theory which is concerned with the extent to which complex interventions (in particular new technologies) are implemented and embedded in health care and provides an orientating conceptual framework to identify the social processes influencing the embedding of self-management support within existing practice (Bamford et al., 2012; May and Finch, 2009). Normalisation Process Theory focuses on the work that participants engage in and how this contributes to processes becoming normalised in everyday practice and is useful in conceptualising barriers to implementation (Bamford et al., 2012). Normalisation Process Theory sensitises analytical thinking to four implementation processes. 'Coherence' refers to the extent to which technology or health care practice makes sense to stakeholders for successful adoption. 'Cognitive participation' concerns the commitment and collective engagement of stakeholders. 'Collective action' refers to the relationships and the work required for a new intervention to be taken up in practice and to identify the factors that serve as barriers to implementation and embedding. 'Reflexive monitoring' holds that successful embedding of resources and technologies in everyday practice relies upon a continuous process of evaluation that can feed back into refining the object of implementation to ensure it is fit for purpose. The four constructs are outlined in Table 1. Normalisation Process Theory has been the guiding theory throughout the process of implementing the WISE approach (Whole System Informing Self-management Engagement); in developing the intervention

(Kennedy et al., 2010) and setting up the randomised controlled trial (Murray et al., 2010) and as such, it is appropriate that it forms the framework for the process evaluation of the trial (Grant et al., 2013).

### 1.1. The implementation of a programme of self-management support

The WISE approach (Kennedy et al., 2007) is predicated on a Whole Systems perspective that engages patients, practitioners and the service organisation and is informed by an understanding of the ways in which healthcare professionals and patients respond to long-term conditions. One aspect of promoting partnership working was the inclusion and foregrounding of the patient's perspective and ways of self-managing during self-management support consultations. A large-scale randomised controlled trial was designed to test its effectiveness and cost-effectiveness (Bower et al., 2012; Kennedy et al., 2010). The exemplar conditions were: diabetes, chronic obstructive pulmonary disease and irritable bowel syndrome. Fig. 1 outlines the two training sessions delivered to the practices in the trial. The training was well attended. 90% of eligible staff attended session 1 ( $n = 179$ ) and 82% ( $n = 85$ ) attended session 2. Training was rated positively (mean score over 2.5 on a 5 point scale) by 76% of session 1 participants and by 89% of session 2 participants.

Within the trial, all primary care health professionals were considered relevant to implementing self-management support, however, practice nurses were a focus

**Table 1**  
Key findings and their relation to Normalisation Process Theory constructs.

Construct definitions	Findings from nurses	Propositions supported
<i>Coherence and cognitive participation:</i> Understanding and buy-in	WISE principles not seen as different to those underpinning their practice, perceptions that this is what they do already	4
<i>Collective action – contextual integration:</i> How well self-management support supported by infrastructure and culture in primary care	Self-management support is not remunerated by Quality and Outcomes Framework thus it has little value or priority for the practice Seen as generically a 'good thing' but not discussed within practice teams	1, 2
<i>Collective action – skills set workability:</i> Allocation of the work and fit with routines	Nurses do the work of self-management support – but it is hidden and seen as additional to the more valued work related to Quality and Outcomes Framework Guidebook fits education role and patient-centred approach but PRISMS disrupts routines and not easily 'to hand'	1, 2, 3, 7
<i>Collective action – relational integration:</i> Confidence in worth and safety of providing self-management support	Guidebook handy, trusted, easy to distribute but in competition with existing long-established sources PRISMS seen as impeding tasks and priorities, generates new needs to respond to	7
<i>Collective action – interactional workability:</i> Ways in which self-management support helps or hinders care for patients with long-term conditions	Potential to spoil established relationships with patients Difficult to engage most patients with behaviour change and self-management support approach seen as time-consuming	4, 5, 6
<i>Reflexive monitoring:</i> Appraising and sustaining	Of minimum value – not measured or audited, not worth the effort. A few who tried PRISMS noted a positive impact on patient engagement	1, 3

1: The delegation, prioritisation and auditability of work associated with self-management support is not a priority for practices.

2: The responsibility for self-management is passed 'down' from General Practitioner to nurse to patient.

3: Autonomous working practices provide space for optimal self-management support discussions between nurses and patients.

4: Self-management support is not perceived as different enough to warrant the further investment of time and effort.

5: The lack of feasibility and success of changing behaviour is a demotivator of praxis.

6: It's easy to dismiss or under-acknowledge the needs of patients.

7: Self-management support resources need to be readily accessible and trustworthy.

## Session 1: 3 hours WHOLE PRACTICE – General Practitioners, nurses and administrative staff

- Brief introduction to WISE
- Care pathways exercise - Mapping the Process of Care From Reception to Self-management
- Interactive session - making the WISE tools work in your practice: PRISMS form, guidebooks and options for support:
  - Information sources
    - Web based information
    - Guidebooks
  - Group training and support
    - Expert Patients Programme courses
    - Group education
    - Exercise classes
  - Voluntary sector and local support
    - Patient support groups
    - Health trainers

## Session 2: 3 hours CLINICIANS – General Practitioners and nurses

- Refresh on WISE approach
- Show DVD giving examples of WISE approach consultations plus discussion
- Skills training – role play to practice three core skills:
  - **How to assess what each patient can do and needs to do**
  - **How to share decisions with patients**
  - **How to make sure patients get the right support**
- Discussion on how to ensure sustainability of WISE

Fig. 1. The WISE training.

because of their increased role in long-term condition management within the practice. Generally, incentivised payment for long-term condition management has resulted in General Practitioners delegating work to practice nurses (Charles-Jones et al., 2003; McDonald and Roland, 2009; Department of Health, 2004). For nurses, two aspects of self-management support implementation have been identified: using education, techniques and tools to help patients improve their self-management abilities and a more demanding requirement to transform the patient–caregiver relationship into a collaborative partnership (Bodenheimer et al., 2005).

### 1.2. The tools

A number of tools were developed as part of the WISE intervention and practice staff were trained in their use (Kennedy et al., 2010). Tools included an online directory of local self-management support resources, a patient report tool, written information (guidebooks) for patients and explanatory models to explain the need for behavioural change. For this paper, we focus on the implementation of two of these tools which exemplify the two aspects of self-management support – forming collaborative partnerships and education – because implementation processes are illuminated most clearly when technologies are involved (Elwyn et al., 2008; May et al., 2011).

- The PRISMS (Patient Report Informing Self-Management Support) tool (Protheroe et al., 2010) aims to promote patient engagement in the consultation by asking

patients to identify what was important to them and using this as the basis for an open discussion about self-management support. The self-report form encouraged patients to reflect on their support needs through considering how they were managing and which symptoms and illness-related matters required attention in their everyday lives. This was designed to highlight the patients' priorities as a basis for negotiated decision-making and access to appropriate information or resources.

- The guidebooks were developed with patients and provided information based on the experience of patients and medical evidence about treatment options (Kennedy et al., 2003; Kennedy and Rogers, 2002). The guidebooks were intended to encourage patients to consider changes they could make to manage their condition.

### 1.3. Aims

The WISE randomised controlled trial found no effect of the intervention. This paper aims to explain this by evaluation of the extent to which WISE was implemented and embedded in primary care through an examination of the attempts to normalise the WISE tools and services within everyday practice.

## 2. Design

The study adopted a qualitative design involving face-to-face, semi-structured interviews. Framework analysis

informed by Normalisation Process Theory constructs was used to systematically identify the work of self-management support and how the WISE tools were embedded in existing routines.

### 2.1. Participants

Practices located within a deprived inner city area in a Northwest English Primary Care Trust were approached 3–6 months after undergoing training in the WISE approach. A pragmatic sample of 37 members of staff – General Practitioners, nurses, and practice support staff from 12 practices agreed to take part in qualitative interviews. A decision was made to base the analysis on interviews with 11 practice nurses and one assistant practitioner because all interviewees were in agreement that the work of self-management support was done by nurses. All nurses were female with between 2 and 21 years' experience of working in general practice. Interviews with other staff provided context concerning the way the practices were organised.

### 2.2. Data collection

The interviews were conducted by VL and RB in 2011/2012. An interview schedule was developed with reference to pilot interviews carried out by AR with two practices prior to main trial commencing (Kennedy et al., 2010). The schedule was used to ask nurses about their involvement in supporting patients' self-management of diabetes, chronic obstructive pulmonary disease and irritable bowel syndrome, their impressions of PRISMS and the guidebooks, and attempts to integrate the tools within their daily routines. Interviews lasted up to 1 h. The interviews were recorded using digital audio equipment. Field-notes summarising the interviews and highlighting key issues were written up soon after each interview.

### 2.3. Ethical considerations

The study was approved by the Salford & Trafford Local Research Ethics Committee. REC reference number was 09/H1004/6.

To ensure the anonymity of the participants and the practices where they work, all identifiers have been removed.

### 2.4. Data analysis

Verbatim transcriptions of the audio-recorded interviews were discussed over the course of data collection during meetings attended by all authors enabling an iterative approach to data collection, coding, discussion of emerging themes and further exploration needed. Questions relating to each component within the four core Normalisation Process Theory constructs were generated (Murray et al., 2010) (see Table 1) and a coding framework was drawn up based on these questions which allowed a systematic evaluation of the factors influencing the work required to implement and embed the tools (Ritchie and Spencer, 1994). The content of the interviews was

considered on a case-by-case basis and comparisons drawn across cases to identify similarities and differences in the understanding and values attached to the tools and individuals' attempts to integrate them in everyday practice. The analysis focussed on the ways nurses spoke about the work of managing patients with long-term conditions and how using WISE tools impacted on or changed their everyday and self-management support practices. All authors contributed to the coding of individual transcripts, RB read and coded all the transcripts providing inter-rater reliability. The main analysis was done by AK, RB and AR.

## 3. Results

Some elements of WISE were reported to work well, such as distribution of the guidebooks and their acceptance by patients, but other elements, such as using the PRISMS tool to help address patient's needs and priorities, were rarely engaged with, acknowledged or taken up.

As advocated by other researchers, Normalisation Process Theory has been used as a method to sensitise the analysis to concepts and processes of implementation (MacFarlane and O'Reilly-de Brun, 2012). A number of themes emerged as a result of coding and thinking about the data using a Normalisation Process Theory framework which we have posed as a set of theoretical propositions (Bradley et al., 2007). Table 1 provides a summary of how the systematic identification of work undertaken by nurses mapped onto the Normalisation Process Theory framework. Illustrative data is presented and labelled with respondent identifier.

### 3.1. Who pays the piper calls the tune

**Proposition 1.** *The delegation, prioritisation and auditability of work associated with self-management support is not a priority for practices.*

Although all the practices involved had signed up to the trial and participated in the training, the WISE self-management support approach did not emerge as a priority and failed to disrupt the status quo of the existing orientation and work of the nurses.

Practice nurses generally work to a set of tasks in a way which is dictated by practice priorities. One priority is to ensure Quality and Outcomes Framework financially incentivised targets are reached – this involves setting up and carrying out review appointments with patients on the practice disease register. In these appointments, nurses monitor and record vital signs such as blood pressure, blood sugars and lung capacity as required by Quality and Outcomes Framework. Such prioritisation marginalises other non-incentivised work such as self-management support with more complex and challenging work of providing self-management support remaining hidden. Within practices, nurses were viewed as having the specific skills, time and opportunity to do lifestyle change work with patients and delegated this without interest from other practice staff in how this was actually achieved.



This meant that for nurses, the work of providing self-management support had to be fitted between other tasks which were generally formulaic and box-ticking on computer templates. This led to cognitive and practical tensions for nurses who were at pains to convey their ability to provide holistic care for their patients, yet servicing the Quality and Outcomes Framework agenda for which they had been tasked took precedence.

'Well now. The thing is I've always been taught to focus on the patient and you've got to tick ... you know you've got to fulfil your Quality and Outcomes Framework criteria and stuff so ... It's chronic obstructive pulmonary disease, looking if there are any changes in their condition over a period of 12 months. If there is anything they can't do, if it's impacting on their lifestyle, are they more breathless, are they getting more exacerbations. You are looking at depression and how it's impacting on that kind of thing generally.' (Nurse E, P12)

Nurses identify patient education as key to self-management support, but the need to fulfil Quality and Outcomes Framework criteria wins out, producing a didactic approach to dealing with patients in consultations. Handing out written information whilst telling patients what to do is the easiest and quickest way to undertake the task.

'I have loads of literature, yeah. That's it. We have a raft of information for diabetes. So I do give out information. And I think chronic obstructive pulmonary disease ... diabetes, I'm the same. With the diabetic ones we manage them and we sort of tell them. It sounds awful tell them. We don't tell anybody but we do sort of tell them, "You need to do this. You need to do that. You need to do the other."' (Nurse N P28)

Handing out the WISE guidebooks fitted readily into this way of working and the guidebooks were seen as filling in the missing patient-centredness of their practice. In this respect guidebooks were minimally disruptive so were easily normalised (May et al., 2009).

'We give them the WISE book. And we just ask them to read that and if they have any concerns, that there's a little problem thing at the back they can always talk to us about it when they next come ... I think it's made people more aware of how to manage their own condition. The information is in the book. They know they can look at that any time. If there is something there they don't understand or whatever, I think the information is all in there, you know, and we go through it with them when they come, and we tell them, 'If you're ever stuck or worried, please look at the book. Please read and see where you can make these changes if you need it.' (Nurse F P3)

**Proposition 2.** *The responsibility for self-management is passed 'down' from General Practitioner to nurse to patient.*

The demarcation of roles within the practice impacted on how nurses viewed and dealt with self-management

support. General Practitioners delegated self-management support to nurses and in their turn, nurses delegate responsibility to patients. In both cases, this was not necessarily an empowering process based in a partnership and shared decision-making approach – little was shared with patients and work outside the testing of biomedical markers of disease was not considered a central element of consultations. Nurses viewed General Practitioners as ignorant of the work they did.

'They tend to leave us to our own devices, I know it sounds awful, but, to our own devices, because, they don't really know what we do, in the clinics.' (Nurse M P19)

The general lack of interest in nurses' work within the practice was given as justification for why the WISE approach was not taken up or engaged with by nurses.

'It's alright being a pilot and stuff, but you've got to want to do it and if they're not ... Why should one person do it on their own.' (Nurse E P12)

The few nurses who did make use of the tools to change their practice found WISE provided a structured approach to self-help and brought a more patient-centred focus to consultations previously 'driven by targets and guidelines'. Patients were felt to need time to understand what they had to do and the work of self-management support could be done in a gradual and shared way.

'It sort of has changed my practice quite a lot, but what I mean, I think, is I didn't necessarily say to the patient, what do you want to talk about today? Whereas maybe I do now, because they've gone away with the booklet and they've come back with ... they've highlighted what it is that's really worth talking about.' (Nurse B P22)

**Proposition 3.** *Autonomous working practices provide space for optimal self-management support discussions between nurses and patients.*

Some nurses recognised that although they had certain core tasks to perform, they did have autonomy in planning their work. A few nurses built in elements of the WISE approach and were enabled to do this by being seen to be efficient managers of Quality and Outcomes Framework-related work. The recognition and respect they garnered as a result meant they were left with autonomy to create space for working in other spheres:

'I've done this job for 21 years now, I've been here a long time, so we do have a very good understanding of each other's roles and I certainly know where my limits are and I don't overstep that. But within my sphere of expertise I do all the respiratory care, I do all the diabetes care, the chronic health disease stuff, ... I'm really left to it because my, it's obvious what I'm doing, it's in there, it's all auditable, it's easy to see. So you know and the Quality and Outcomes Framework has been good for that' (Nurse B P22)

This nurse went on to talk about how she had been able to use the PRISMS tool in her consultations and how it had

helped to open up the conversation and focus on the priorities of patients rather than the priorities of the practice.

'Basically what it does, it enables me to talk about the things that are worrying them, and things like, for example, sexual health. Unless you ask the question they are never, ever, ever going to bring it up in a consultation in a million years. So having something like that does help focus on the whole shebang, really. But I think it just enables the patient to feel that they're bringing something, it's not just about me yappy, yacky, yapping on at them, it's about them sharing more and having, [whispering] (because I do talk a lot at times) ... you know it's allowing them to have a little bit of time to ... for me to shut up.' (Nurse B P22)

For others, having autonomy allowed nurses to identify with acting in a patient-centred manner through establishing relationships with patients. Relationality, ideologically, is seen as a central part of their work (Blakeman et al., 2006; Macdonald et al., 2008). However, in practice most nurses were not able to use their existing style of relating to engage patients in in-depth conversations and agendas about support or lifestyle behaviour change. This was because they gave more superficial and brief relationality work priority over the more negative and hard work of challenging 'problem' behaviours.

'Yeah. It just depends, because, a lot of the time, you can get them chatting when you're doing other things, as well.' (Nurse M P19)

### 3.2. Old habits die hard

**Proposition 4.** *Self-management support is not perceived as different enough to warrant the further investment of time and effort.*

In terms of making sense of the new innovation there appeared to be little differentiation made between self-management support and the WISE approach from normal practice. Self-management support work was viewed in terms of being patient-centred; addressing lifestyle and behaviours and effecting change; and having time to listen – all of which were considered to be 'normal practice'. This sense of there being nothing new translated into the view that there was no need for change. Indeed to the following respondent, the time constraints of practice meant that thought of adopting new ways of managing was ridiculous:

'I know it sounds awful, it was, like, it was teaching us to suck eggs! ... Because, we've all been clinicians for a long time, I know it gives you another way of looking at things, but, it's, like, we already know what the patients are going through, we've all been experienced clinicians, it's not, like, we're new to the post and the fact that, it's, like, we have a limited amount of time, in a consultation, we've not got an hour, per patient, I wish we did, ... we have ten minutes and you try and get everything done in them ten minutes and, then, somebody is coming along and telling you, oh, this is

what you should be doing and this is this and this and this and it's, like, and where are we supposed to fit everything in, in ten minutes.' (Nurse M P19)

**Proposition 5.** *The lack of feasibility and success of changing behaviour is a demotivator of praxis.*

Changing people's behaviour is seen as difficult or impossible. In this respect this viewpoint is supported by the literature on behavioural change. There was little or no talk about how health professionals could change people's behaviour in everyday practice. Giving patients information and instructions was seen as easy and routine, but examples of how to motivate and engage people with new practices and behaviours were missing from the narratives of respondents. PRISMS was supposed to assist this process, but the few nurses who reported using PRISMS did not get much further than using it to open the consultation to patient needs and had well-formulated views born out of previous experience of working with patients shown in the metaphors used to describe non behaviour change:

'We can point ... take a horse to water but I can't make him drink. I can give them all these things, but I can't make them access them. But I can do my best and ... that's all.' (Nurse E P12)

Nurses suggested that their patients were not suitable candidates for a self-management approach, their lives were too chaotic or they had too many other problems. They found it hard to engage patients with lifestyle change and a patient-centred approach was thought to be at odds with providing self-management support where the shifting of responsibility is a longer-term aim. This has the effect that self-management support work is put on hold for another time or indefinitely.

'I think chronic obstructive pulmonary disease, I mean, the main lifestyle is you have to address there is obviously smoking and I will go straight in and say do you smoke, have you thought about stopping. ... If they don't want to address it, if they're not interested then I just leave it because it's pointless trying to force somebody to do something that they're not prepared to do. And I'll just leave it open.' (Nurse D P12)

### 3.3. The trouble with paper

**Proposition 6.** *It's easy to dismiss or under-acknowledge the needs of patients.*

The PRISMS tool was easy to dismiss for several reasons: lack of time; it could open up too many complexities in structured time-limited consultations; practice systems were not geared up to support it; and cost to the practice:

'The happy, smiley face-y thing. We didn't use it. We primarily, I'll be honest and say I didn't use it because I didn't have the time because there's only me and I only work part-time. And I think it was another tool, you know what I mean? And I'd love to be able to sit here and have half an hour consultation about patient's

priorities and I'm going to say that I do but in a more roundabout way, and you know. But I didn't have the time really to be fair.' (Nurse N P28)

'I am doing it, but not quite in the same form as they thought. I'm not doing the PRISMS because nobody has given the forms out. You see we don't send letters out for appointments because it's too expensive. If we could send letters we could send the PRISM forms and they could bring it in when they come for an appointment.' (Nurse E P12)

Some nurses were more reflexive and the following quote illustrates how PRISMS could be dismissed as something that was not possible to fit into the constraints of daily practice and how she went on to rationalise its use.

'They're thinking, they're weighing everything in, I've got Quality and Outcomes Framework, I've got this coming out, I've got a meeting here, I've got da-da-da, I've got all... And you can do this, it's human nature, it's natural, you think, 'oh no, not another thing coming at us!'... Yeah, it's a reactional thing. But if you... really, you know it is beneficial, it's a couple of minutes difference. So it's how you see it...' (Nurse S P5)

**Proposition 7.** *Self-management support resources need to be readily accessible and trustworthy.*

Nurses work within a structured primary care team, however, their day-to-day work can be distant from other practice staff. Thus in terms of tools and technologies, they will use what is readily to hand, and draw on resources that they use trust.

The guidebooks were seen as a positive benefit to patients, a nice 'gift' for nurses to hand out and superior to computer print outs. So long as the supplies were on the office shelf, they were easy to work with.

'Say I have a new diabetic that's the... usually the time that I would introduce the booklet because I find the information is very easy to understand. So and they can take away that is a form it's not just an A4 piece of paper because we tend to use an awful lot of the patient.co.uk stuff which is excellent, but it's only a scrap of paper, isn't it. Whereas the booklet I think [whispering] you know, and they go away with a nice little booklet and it's nice, but it's also very pertinent information, it's easy to read, it has pictures that are coloured in, and I think that helps the eye, and all of that.' (Nurse B P22)

For some, their use of resources was determined by the trust they had in the organisation which produced the information, rather than any engagement with the content.

'I mean the British Lung Foundation is a well-recognised organisation, so they're the ones that I tend to use. There are also some other booklets which, to be honest with you, I don't remember where they're from but they're... they will be from a recognised organisation.' (Nurse D P12)

Forms such as PRISMS were more troublesome to deal with because more thought was needed into how and when they are utilised in the consultations and integrated

into practice systems. The logistics of distributing forms to patients was viewed as problematic. A number of options were considered including sending them out with patient reminders to attend review appointments, however, practices either lacked the impetus to consider change, or immediately dismissed the possibility of engaging in the work necessary to coordinate the adjustments to staff routines.

'I've got to be 100 percent and tell you the truth, I don't know out there because I'm in here [in the consulting room] from eight o'clock in the morning 'til half four. I don't really go out to be honest. So I've got me hand on heart and say I don't really know.' (Nurse G P2)

One practice did embrace WISE and were able to integrate the forms into their systems; however, most practices did not attempt to find ways to make PRISMS easily accessible for staff.

'Yes, we have them out in Reception for them to complete. Well the Reception staff know who's diabetic or who's chronic obstructive pulmonary disease or whatever, the long-standing condition, and they will give them the form at Reception when they come in, if they can please fill this form in before you see the nurse.' (Nurse F P3)

#### 4. Discussion

The aim of this study was to evaluate the implementation and embedding of a self-management support approach in primary care. The WISE approach failed to be normalised in routine care, apart from handing out the guidebooks. WISE was intended to encourage reassessment of work practices whilst introducing new elements that fitted with existing work and improved patient care. The long-term condition management work delegated to nurses was the routinised biomedical processes of monitoring and recording necessary for Quality and Outcomes Framework. Practice nurses viewed themselves as being patient-centred and holistic, yet respondents reported use of didactic and non-tailored information-giving and generally, they did not incorporate psychosocial and behaviour change support; all indicators that patient-centred practice was not happening. Nurses had concerns about the burden of providing enhanced self-management support both in terms of their own workloads, and in what they felt their patients could accommodate; provision of the guidebooks was the one element that could be considered minimally disruptive work, fulfilling their need to provide good information whilst enhancing their ability to be patient-centred (May et al., 2009).

The challenges of changing professional behaviour and attitudes in order to implement self-management support are widely reported (Blakeman et al., 2006; Harris et al., 2008; Hibbard et al., 2010; Macdonald et al., 2008; Walters et al., 2012). The WISE approach aimed to pragmatically address existing evidence and recommendations and provided tools and training in skills to assist self-management support in the context of an organisation geared up



to provide appropriate resources (Kennedy et al., 2007). Using Normalisation Process Theory was of value as it made us focus on the everyday work of nurses to find an explanation as to why WISE did not embed: self-management support was not a practice priority as it was not part of Quality and Outcomes Framework; it was not seen as different enough to existing work to value yet considered too disruptive and time-consuming; and there was lack of communication or support within the practice.

The *collective action* Normalisation Process Theory construct helped provide most insight into the work of nurses and how it fitted within practice procedures and priorities for patient care. The three themes which emerged (“Who pays the piper calls the tune”, “Old habits die hard” and “The trouble with paper”) and the seven resulting propositions reflect the nature of this work. Nurses’ work is constrained by the financial requirements of the practice; money gained from reaching Quality and Outcomes Framework pay-for-performance targets dictates how nurses are required to work and it is only when nurses feel they have gained enough trust and experience to have autonomy in their practice that they are able to build in self-management support. On top of this, past experience and the belief (*cognitive participation*) that it is futile and time-consuming to take on the work of self-management support with patients, meant the PRISMS tool in particular was not used. PRISMS was a paper based tool and the *collective action* required of staff to get it to patients was not worthwhile, especially as any data from the form was not being collected or appraised in any formal way (*reflexive monitoring*); the sustainability of handing out forms is feasible only if there is continual reflection and reappraisal of the benefit of PRISMS at all levels of the practice. The guidebook, however, did fit with how nurses considered self-management support should be delivered (*coherence and cognitive participation*).

Other researchers have used Normalisation Process Theory as a framework to study the embedding of new innovations. Elwyn et al. (2008) conducted a ‘thought experiment’ using Normalisation Process Theory to identify factors promoting and inhibiting implementation of shared decision-making support technologies in health-care, the insights they gained were that negotiations surrounding the introduction of new technologies were influenced and characterised by asymmetries of power and knowledge. Our findings add empirically to this with the added insight that the partnership working aspect of self-management support is far removed and too disruptive to nurse/patient relationships to initiate. Ehrlich et al. (2013) used Normalisation Process Theory to assist understanding of the implementation of nurse-provided chronic care co-ordination in primary care in Australia. They found the major challenge was the organisational context and shared understandings and claimed that nurses needed to be autonomous practitioners as well as team players to allow the new role to become embedded. Autonomous practice was the one enabler of self-management support we found but is difficult to maintain given the competing priorities within primary care; it is easier to accede to the task-related Quality and Outcomes Framework activities – to go with the status quo and not to challenge pre-existing

notions of what patients are capable of when it comes to engagement with self-management support. As with the findings of Murray et al. (2011) Normalisation Process Theory is useful in explaining observed variations in implementation processes rather than simply focusing on notions of barriers and facilitators.

In showing reluctance to engage in behavioural change discussions with patients, nurses demonstrated an awareness that for patients, self-care involves a complex, embodied, practical knowledge that clashes with the abstract, rationalised models assumed both in biomedical approaches to long-term condition management and in programmes like the Expert Patients Programme (Department of Health, 2001). We know that patients demonstrate the enacting of self-care as not something acquired externally but something you use existing resources to do, and in a biographical domestic as well as clinical context. Whilst nurses did not articulate an understanding of the practice of embodied self-care (Pickard and Rogers, 2012), we suggest grounding self-management into everyday life may have been key to providing effective professional support and discussions which would have challenged the pre-existing focus on Quality and Outcomes Framework work and the more biomedical regimes of the practices to which the tools of self-management support were being added. Dressing up more complex processes as tools in the hope that they will be adopted and normalised in everyday practice proved erroneous. The claim by nurses to integrate patients’ lived experience and priorities into clinical encounters is not new, but for the most part this is treated as an addition or as something to fit into the tasks of monitoring and testing in a way which represents only marginal movement towards patient needs and knowledge concerning self-management support. In this respect nurses were not able to deploy the bases of WISE which included recognition of knowledge as practical activity and interventions that fitted with patients’ agendas, needs or experience of managing a condition in their daily lives. Rather, they could not adopt and embed a new system at odds with their protocol-based system which is biomedical and reductionist, but which ensures the financial income of the practices which employ them.

Limitations of the study included our inability to observe nurse patient consultations post-training because practices refused access (though we were able to gain some validation of the nature of routine work and fit with accounts of practice from audiotapes of consultations with patients undertaken as part of the pilot work prior to the trial). The reluctance to allow access in itself may indicate the lack of engagement with provision of self-management support in practices. Observations might have clarified where and how opportunities to provide support were taken up or missed. Normalisation Process Theory highlighted the near universal lack of interest in thinking about and building self-management support into practice, but consideration of the patient perspective on implementation is missing – as in most other implementation theories.

The rare occasions where aspects of self-management support were reported to be incorporated were by nurses experienced and confident enough to disrupt the prevailing system, and prepared to overcome the unaudited and

therefore hidden nature of self-management support, and the lack of recognition of the work entailed in providing it. In other words those individuals were willing to try different approaches, were professionally confident enough for independence/autonomy and thus able to reflect on the benefits they saw for their patients. Even so, they were not able to report moving beyond opening up the consultation to address patient priorities – lifestyle change is not readily doable in primary care and falls more within the day-to-day world of the patient (Rogers et al., 2011). In terms of policy, a culture of collaborative partnerships between patients and practitioners is still a long way away.

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