

Self-testing and management of chronic conditions: A qualitative study of INR patients

Journal:	<i>Scandinavian Journal of Caring Sciences</i>
Manuscript ID	SCS-2015-0284
Manuscript Type:	Original Article
Keyword-Area of Expertise:	Care Giving, Chronic Illness, Community Care, Decision-making, Patient Participation, Recipients of Care
Keyword-Research Expertise:	Qualitative Approaches, Research in Practice, Textual Analysis, Case Study Research

SCHOLARONE™
Manuscripts

Copy

Self-testing and management of chronic conditions: A qualitative study of INR patients

Abstract

Background: Technology assisted self-testing and management is seen as one of the key areas in which quality of care can be improved whilst reducing costs. Nevertheless, levels of patient engagement in self-testing and management remain low. To date, little research emphasis has been placed on understanding the patients' perspectives for low engagement. The typical approach adopted by healthcare providers is to provide patient education programmes, with the expectation that individual patients will change their behaviour and adopt new self-care strategies. However, healthcare providers must also develop a better understanding of how their clinical service provision is perceived by patients and make adaptations, if levels of patient engagement are to be increased.

Objective: Explore patient views, needs and expectations of an anticoagulation service and the self-testing and management services provided to them.

Methods: Interviews were carried out with 17 patients who currently engage in INR self-testing and management. Thematic coding and analysis was carried on the interview transcripts.

Results: Four high-level themes emerged from interviews: (1) Role of clinic (2) Motivations for self-testing (3) Managing INR (4) Trust in the clinic. The clinic was seen as adding value in terms of specifying testing frequency, dosage profiles, and calibrating equipment. Prompt communication from clinic to patient was also valued, although more personalised/real-time communication would help avoid feelings of isolation. Patients felt more in control as self-tester/managers and often took decisions about adjustments in treatment themselves. However, some also felt it necessary to adapt test results so as to avoid 'unnecessary' interventions as their expert patient knowledge/expertise was not being sufficiently recognised, valued or utilised.

Conclusions and recommendations: More personalised/real-time communication, pragmatic and collaborative patient-clinician partnerships, and recognition of expert patient knowledge and expertise are needed if increased levels of engagement with self-testing and management service provision is to be realised.

Key words: Self-care, self-testing, self-management, chronic conditions, patient perceptions, service quality, technology assisted healthcare, oral anticoagulation therapy

Introduction

The world population is ageing, trend that is much more pronounced in developed countries. For example, one-in-six of the UK's population is currently aged 65 and over, by 2050 this figure will have risen to one-in-four [1]. The increased burden that an ageing population puts on health care services is driving a search for new models of care that will be capable of meeting patient needs whilst also adhering to anticipated budgetary constraints. There is already an evident shift away from dominantly paternalistic models of healthcare, where the patient is a passive recipient, to more patient-centred models where the patient is often responsible for carrying out their own point of care self-testing and management (STM) of their condition [2]. For chronic and long-term health conditions, delivery is becoming less about the patient as a passive recipient and more about supporting patients to play a more central role in the delivery of their own care [3-5]. Part of this shift is related to the emergence of the notion of the 'expert patient', who is expected to be able to access relevant information and make independent decisions about their own care [6].

The motivation for STM, however, is not simply about potential cost-savings, although clearly cost and resources are motivators, these trends are also being driven by the availability of portable technology, a political drive to provide patient choice, and a desire to achieve better and quantifiable health outcomes. Technological advances and the development of portable medical devices, designed to be used within the home, has played a key role in STM becoming an increasingly common form of healthcare delivery [7, 8]. There is now available a range of affordable portable self-testing/monitoring devices aimed at patients affected by chronic conditions, such as diabetes (testing blood glucose and blood ketone levels), and hypertension (measuring blood pressure and pulse). In terms of the effectiveness, there is evidence that STM can often be more effective than more traditional clinic-based service delivery [9]. Some of the key benefits of STM include the convenience to patients of not having to make the journey frequently into clinic, carrying out tests at more appropriate times, improved levels of patient knowledge relating to the condition, self-efficacy and health status, but also importantly, it is believed that STM empowers individual patients to have and make important choices about their care and hence become more equal partners in their own health care provision [6, 10]. The extent to which patients feel that they have a choice in the care that they receive is now recognised as a key mechanism for the improvement of healthcare [11]. Indeed, there appears to be consensus across the political spectrum that the value of allowing patients to have more say in the decisions made relating to their healthcare is self-evident [12]. Therefore, shifting some of the responsibility for testing and management of chronic conditions from the traditional healthcare providers to patients themselves may have a number of tangible and intangible benefits, both for patients and service providers.

In light of the potential benefits to patients and to service providers and the potential cost savings that could be made, it is perhaps not surprising that for the last ten years, best practice guidelines have suggested that a more patient-centred approach to care should be adopted [2, 13-15]. Increased engagement in STM offers a promising way to enact these guidelines; however, thus far patients have not always embraced this possibility [16, 17]. A survey [18] of 383 participants found that 77% of patients were either not willing or did not feel able to adopt new behaviours associated with STM; the remaining 23% that had engaged in STM believed they could maintain these changes when in crisis. While this is a relatively small proportion, when seen over the health service as a whole, allowing this 23% to perform STM could have a dramatic impact on service provision and in freeing up financial resources. Until now, little research emphasis has been placed

1
2
3 on understanding patient perspectives and the reasons for limited patient engagement with this
4 new care paradigm, but rather, there has been a focus on demonstrating the efficacy of this
5 approach via numerous randomised control trials with patients who already engage in STM [19].
6

7
8 There is an urgent need to identify the needs of patients who engage in STM, and cater for these
9 more effectively, particularly if increased levels of patient engagement with STM care delivery
10 models are to be realised in practice. This paper explores the perceptions of individuals who are
11 currently enrolled as patient self-testers at an oral anticoagulation clinic. In particular, the perceived
12 benefits, drawbacks and expectations of STM, from a patient perspective, are considered in detail.
13 Based on the results of this study, the extent to which STM is a viable and valuable mode of care
14 delivery is then considered, again from a patient perspective.
15
16

17 **Background: oral anticoagulation self-testing and management**

18
19 People identified as being at high risk of developing blood clots need to be treated using oral
20 anticoagulation therapy (OAT). OAT allows the clottability of the blood to be managed and is used in
21 the treatment of several medical conditions including deep vein thrombosis, pulmonary embolism,
22 and those at risk of having a stroke [20]. Blood clots can also form in patients who have to stay in
23 bed for long periods of time after hip replacement or abdominal surgery, or who have a genetic
24 clotting disorder. Oral anticoagulants, such as warfarin, are prescription drugs that reduce the body's
25 ability to form clots in the blood; in effect they increase the amount of time it takes to form a clot. In
26 2005, it was estimated that more than 1.25 million people in the UK (2% of the total general practice
27 population) were taking oral anticoagulants [21]. This figure has been increasing steadily since then
28 [9].
29

30
31 The goal of warfarin therapy is to decrease the clotting tendency of blood but not to prevent
32 clotting completely [22]. A blood test called INR (International Normalised Ratio) is a standardised
33 way of expressing the time it takes blood to clot (called the prothrombin, or PT, test time). If the INR
34 is too low, blood clots are a major risk, but if the INR is too high, there is an increased risk of
35 bleeding [22]. In practice a target INR value of around 2.5 is often set, but the ideal value for a
36 patient may vary with physiological and pharmacological factors such as interacting drugs or
37 illnesses that affect how warfarin behaves, dietary or gastrointestinal factors associated with the
38 vitamin K1, and the consumption of alcohol [23]. Even though taking an incorrect dose of warfarin
39 would usually not cause any immediate severe effects, the long-term mismanagement of the
40 condition can have a serious impact on a patient's health. Therefore, regular monitoring and, if
41 necessary, warfarin dose adjustment is crucial.
42
43
44

45 **Technology and service provision**

46
47 Coagulometers are devices that test the PT and the INR of patients who take oral anticoagulants to
48 reduce the clottability of the blood [24]. The aim is to keep the INR within the prescribed range.
49 There are several types of coagulometers ranging in price, portability and size, from large monitors
50 to small hand-held self-testing devices. The most widely used in the UK is probably the CoaguChek
51 (Roche Diagnostics, Basel, Switzerland). In the UK there are typically two categories of patients that
52 utilise anticoagulation services:
53
54

- 55 • Clinic-based testers (CBTs): Patients visit the anticoagulation clinic regularly for INR testing,
56 treatment and advice.
57
58
59
60

- Patient self-tester-managers (PSTMs): Patients use a portable coagulometer to regularly test their own INR levels at home. They stay in contact with the anticoagulation clinic via the telephone and visit the clinic every 6-12 months for treatment, advice and support.

Uptake of oral anticoagulation therapy self-testing and management (OAT STM) in the UK has remained low; of the 1.2 million people on warfarin less than two percent opted are PSTMs [25]. As a consequence of the low levels of uptake, in October 2012, the AntiCoagulation Self-Monitoring Alliance (ACSMA) was launched to campaign for greater choice for patients on warfarin in terms of how their condition may be managed [25].

Benefits of OAT STM

In terms of clinical benefits, several studies considered the effects of OAT STM compared to standard clinic-based approaches. A comprehensive review [26] found a decrease in the number of thromboembolic events and mortality in patients undertaking OAT STM. A review of OAT STM studies [27] found a 26% lower risk of death and a 42% lower rate of major blood clotting events. A recent meta-analysis study that used individual patient data for assessment of OAT STM [9] found a significant reduction in thromboembolic events in the OAT STM group and a striking reduction in thrombotic events for participants younger than 55 years and participants with mechanical heart valves but did not find any significant effects for major haemorrhage or mortality. That study also showed that OAT STM is a safe option for suitable patients of all ages and advocated that patients should be offered this option to self-manage their disease with suitable health-care support as back-up. The results of all studies indicate no adverse effects of OAT STM compared to standard monitoring. The results do not support the superiority of OAT STM over traditional clinic-based approaches in reducing the risk of stroke, major bleeding episode, and mortality [8]. Other benefits include a potentially better utilisation of healthcare resource by releasing the physicians' and laboratory personnel's time that would otherwise be used for scheduling and carrying out the INR testing [20]. OAT STM patients have been found to test more frequently, hence reducing the chances of complications directly associated with being outside the therapeutic range [20, 21]. OAT STM is also seen to enable patients to be more actively involved in their own healthcare, hence improving their feeling of having a choice in their treatment plan leading to a higher satisfaction with their healthcare overall [17, 28] and in some cases, improved quality of life [27].

A number of PT/INR studies have shown mixed results when comparing the effectiveness of OAT STM compared with clinic-based OAT [29]. For example, Lafata et al. [30] have reported that OAT STM is less cost effective than the clinic-based equivalent, while others report that OAT STM is more cost effective than clinic-based OAT [31-33]. However, the cost effectiveness of OAT STM has been challenged based on the cost of both selecting and training patients and maintaining devices [34]. The OAT STM model is also criticised for only being suitable for a minority of patients and it has been suggested that there is a need for further research into both health economic and clinical outcomes in the UK [21]. Reasons noted for low uptake include a reported lack of patient motivation and unwillingness of the physician to fully support OAT STM [9].

Motivation for this research

Given the low levels of STM and OAT STM uptake to date, there is an urgent need to better understand how clinical service provision can be adapted to better accommodate the needs of STM

1
2
3 patients. Whilst a range of research has been carried out to assess the clinical benefits of OAT STM,
4 to the best of our knowledge, no research specifically explores existing PSTMs views about OAT STM
5 in order to better understand the needs of these patients and how these can be met. In order for the
6 engagement with STM to become more widespread, it is crucial that patient experiences, views,
7 needs and expectations of such service delivery models are well understood and catered for
8 effectively. Specifically, little is known about what motivates a patient to become a PSTM; what
9 types of support and practice PSTMs value most from clinical services; what PSTMs feel they require
10 most from healthcare professionals when self-testing and managing their condition; how PSTMs
11 perceive engaging in STM affects their quality of life.
12

13
14 Based on a series of patient focused interviews with PSTMs who currently engage in STM, this
15 study provides valuable patient insights into their experiences of engaging with STM in practice, and
16 considers implications for clinical service provision based on these insights. The remainder of this
17 paper is structured as follows. The next section provides some contextual information regarding the
18 typical procedures followed by OAT STM patients in the UK. The interview study carried out with
19 PSTMs from the Queens Medical Centre Anticoagulation Clinic is then presented, followed by the
20 interview findings and discussion of these results respectively. Conclusions are drawn in the final
21 section of this study.
22
23

24 25 **Procedures and processes followed by self-testing patients on OAT**

26
27 To provide a better understanding of the context in which OAT STM is carried out in the UK, the
28 existing contract of care between self-testing patients and the anticoagulation clinic is outlined
29 through a set of procedures and processes, presented Figure 1.
30

31 [Insert Figure 1 about here]
32

33 Figure 1a outlines the procedure in which all prerequisites required prior to patients embarking on
34 self-testing need to be fulfilled. Once the procedure is completed, a patient can start performing
35 self-testing. The actual self-testing procedure that patients need to follow in order to obtain their
36 INR reading is outlined in Figure 1(b). Routine interactions which PSTMs have with the
37 anticoagulation clinic are presented in Figure 1(c). Periodically, patients also need to replenish the
38 supply of lancets, test strips and obtain a new warfarin prescription. Calibrating the coagulometer is
39 usually done once a year at the anticoagulation clinic. Each time the test is carried out, the PSTM
40 must have the test equipment ready for use. 2(a) shows the typical equipment required to carry out
41 a test, Figure 2(b) shows a test strip inserted into the coagulometer, and Figure 2(c) shows the
42 device displaying the test result.
43
44
45

46 [Insert Figure 2 about here]
47

48 The testing procedure outlined in Figure 1(b) is relatively simple and straightforward if everything is
49 going according to plan. However, there are several possible things that can go wrong as transpired
50 in the interviews. These together with the other findings from the study are reported in next section.
51
52

53 **Methods**

54
55 In response to the need to better understand how STM service delivery can be adapted to increase
56 and sustain better levels of patient uptake and engagement in STM service delivery, we conducted a
57 study that explores the views, needs and expectations of patients who currently engage in STM in
58
59
60

1
2
3 practice. Our study explores the extent to which existing support provided by an anti-coagulation
4 clinic fulfils the needs of these patients and also identifies issues that are encountered in the self-
5 testing and management process. Semi-structured interviews were conducted with patients who
6 were all enrolled as PSTMs at the Queens Medical Centre Anticoagulation Clinic (QMCACC), which is
7 part of Nottingham University Hospitals NHS Trust.
8
9

10 **Participants**

11
12 Approximately 180 PSTMs were registered at QMCACC at the time of study. A convenience sampling
13 method was used to recruit participants for this study. A two-fold recruitment strategy was used. All
14 participants were recruited through the QMCACC. In the first instance an invitation letter was sent
15 out to a total of 53 PSTMs, who had expressed an interest in taking part in further research, having
16 taken part in an earlier quantitative study exploring patient perceptions and expectations of an
17 anticoagulation service [4]. Participants that responded to invitation letter were then incrementally
18 invited to take part in the interview sessions. Recruitment of participants for interviews ceased with
19 data saturation, that is, when the researcher leading the analysis observed a clear pattern emerging
20 in participant responses and subsequent responses appeared to become repetitious with no new
21 themes being identified from the data. Consequently, interview data from a total of 17 PSTMs is
22 considered in this study. Fourteen Interviews were carried out on an individual basis, and two
23 interview sessions were carried out with two patients present in each (four participants in total).
24 One pair of participants (husband and wife), both participated in the interview however there was
25 not sufficient input from the husband; therefore, only the interview data from the wife was
26 considered in this study. The remaining pair of participants (father and son who were both OAT
27 PSTMs) provided individual inputs to the majority of questions and therefore, both participants'
28 interview data was included. Table 1 provides details about the participants who were included in
29 this study.
30
31
32
33
34

35 **[Insert Table 1 about here]**

36
37 In terms of demographics, there were 12 male and five female participants. Nine participants were
38 in the 56-70 age group, three in 71-80, three in 26-40, and two in 41-55 age group. In terms of
39 educational background (i.e. highest education completed): eight participants had secondary
40 education, four postgraduate degrees, three University degrees and three had other qualifications.
41 Participant experience as PSTMs ranged from one year to 10 years.
42
43
44

45 **Ethics Approval**

46
47 This study was reviewed and approved by Brunel University Research Ethics Committee prior to
48 review and approval by the NHS London City and East REC and Nottingham University Hospitals
49 Research and Innovation, Nottingham Integrated Clinical Research Centre. All participants taking
50 part in this research were guaranteed confidentiality and anonymity. Participants were informed of
51 their right to withdraw from the study at any time.
52
53
54

55 **Procedure**

56
57 All participants volunteered to take part in the study and received an introductory letter containing
58 relevant details of the study and completed informed consent forms prior to interview. Interviews
59
60

1
2
3 took place in participants' homes or at the QMCACC, depending on the participant's preference and
4 were no longer than 60 minutes in duration. All the interviews were conducted by the second author
5 and were also audio recorded. An interview schedule, in the form of a set of pre-prepared high-level
6 question prompts were followed in the same order during each interview. The main focus of the
7 interview schedule was to explore participants' experience as self-testing and management patients
8 and their views about the support they receive from the clinic. The initial set of questions focused on
9 the experience, the process, associated problems, day-to-day management, and the role of the
10 clinic. The questions were expanded upon, based on participant responses during each respective
11 interview. The participants were also asked if they wished to demonstrate how they carry out self-
12 testing. Without exception, all participants were more than happy to perform the test during the
13 interview. All participants were using the CoaguChek® INR self-testing device [35] by Roche, identical
14 to the device presented in Figure 2(a). Interviews lasted
15
16
17
18

19 **Data Analysis**

20
21 A process of thematic coding was used for analysing the data and categorising it into themes [36]. All
22 audio recordings of interviews were transcribed verbatim. Thematic analysis was then carried out to
23 analyse the transcripts and categorise their content into themes and sub-themes. Initially, the
24 transcripts were read in full to obtain an overarching view of the main and pertinent themes that
25 were present within the dataset. The approach taken to this analysis was both inductive, as some
26 themes were closely linked to the data, and other themes were driven by the researchers' analytical
27 interests [36]. Analysis often begins with some a priori themes/codes that are of interest to the
28 researcher. The approach taken in the analysis of this data is in line with what Madhill et al. [37]
29 refer to as the 'contextual constructivist' position. In this case, it is accepted that there are many
30 interpretations that may be made of a given phenomenon, which depends upon the focus of the
31 researcher, and the context in which the research is carried out. Hence, the themes and sub-themes
32 that emerge as a result of the analysis are partly a product of these factors. Within themes and
33 subthemes the focus was on identifying areas of consensus and of diversity. An iterative process
34 moving between the developing thematic structure and the data was used to move to the final
35 analysis reported below. The initial coding was done by the first author (JK) and the resulting themes
36 were discussed with all other authors (TY, AM, MP and JB) and refined accordingly. Coding was done
37 using the Nvivo qualitative analysis software package produced by QSR International [38]. Nvivo
38 allows users organise and analyse non-numerical or unstructured data. It facilitates classifying,
39 sorting and arranging data and examining relationships in the data.
40
41
42
43
44
45

46 **Results**

47 Four dominant themes arose from the data analysis of interview transcripts: Role of clinic;
48 Motivations for self-testing; Managing INR; Trust in the clinic. An overview of the themes and
49 corresponding sub-themes is presented in Figure 3.
50

51
52 **[Insert Figure 3 about here]**
53

54 The findings by the dominant themes are summarised in the four subsequent sections. Relevant
55 direct quotes from participants are included throughout these sections. Each quote is attributed to a
56 participant where the participant is identified by their ID followed by the number of years they have
57 been PSTMs (see Table 1); this information is enclosed within round parentheses (e.g., PSTM01 (2))
58
59
60

and appears after the quote. Text enclosed in square brackets that appears within quotes provide information that is required for clarification purposes.

Role of clinic

Core clinic functions

For effective STM, patients need to have some sustained support and OAT advice from their GP or anticoagulation nurse. The main communication with the clinic was seen as occurring over the telephone, when patients give their regular INR reading.

“I do the test the date that they recommend it, and then I phone it through, and then when it’s phoned through, they then send me a card back again telling me when the next test is.” PSTM04 (2)

The INR outpatient clinic thus plays an important role in the life of PSTMs, as dosages of anticoagulation drugs are reviewed and, depending on the results of their INR readings, are adjusted when deemed necessary. In line with this, most participants saw the main roles of the anticoagulation clinic as providing guidance on the frequency of testing, the warfarin dosage, and to calibrate the coagulometer annually.

Communication

Participants reported that they experienced and valued prompt communication and intervention from the clinic to the patient, but only in the event of their INR reading being outside the recommended range. When an intervention was required, advice on what action was required was also appreciated. Generally, participants valued the belief that the clinic is reliable and would make every effort to make immediate contact with the patient when and if an intervention is required. The perception that this communication would be made promptly and without fail when needed, contributed towards participants feeling confident and at ease about performing self-testing. This also implicitly supported their belief that no contact from the clinic implied no cause for concern:

“I know that when I phone my INR in, if it’s not within the band, I know that I’ll either get a phone call on my mobile, even if I’m abroad, or a phone call at home or whatever, to tell me what my dose is for that day, because I won’t get the re-dose sheet until the following day in the post, but that’s what you need. You need a fast response to tell you...” PSTM16 (5)

“... if I was to ring in and give them an abnormal result, then someone will ring me back the same day, and then they’ll say up it or down it accordingly.” PSTM05 (6-7)

In terms of potential lines of communication from the patient to clinic, in addition to the answer phone service for leaving test results, patients are also provided with a separate phone number which they can call if they feel the need to speak to someone in person:

“I’ve got an open appointment, and that’s, in theory, what we’ve got with these guys, you know – we know they’re there or that there is a service available, people that know what they’re talking about, should something go drastically wrong.” PSTM17 (1)

1
2
3 *"I've got the option to ring if I need to speak to somebody. If you were to remove that option, then I*
4 *think...although I don't think about it on a day-to-day basis, I think ... a piece of me would be quite*
5 *worried."* PSTM07 (>1)
6

7
8 This telephone facility was highly valued and helped to contribute further to participants'
9 confidence in carrying out self-testing and management activities in the belief that, if ever necessary,
10 prompt and personalised advice and support would be available on request.
11

12 **Suggested improvements**

13 Although participants reported that they were very satisfied with the service the clinic provided
14 overall, when asked about possible improvements to the current service, some expressed that they
15 sometimes wondered how much the anticoagulation service actually knows about them personally,
16 or the particularities of their cases. Several participant stated that at times they felt a little isolated
17 and that more of the face-to-face contact may enable them to become more knowledgeable about
18 managing their condition, such as, how dosage decisions are formulated and how their lifestyle
19 choices affect the effectiveness of the treatment. Two relatively experienced self-testers (PSTM08
20 and PSTM12), who have been PSTMs for several years respectively, raised questions about how
21 much the anticoagulation clinic knew about them personally:
22

23
24
25 *"I just feel like there's an awful lot that they don't know about me ... I feel like they don't have*
26 *enough contact with me to know, to really know anything about me."* PSTM08 (8-9)
27

28
29 *"I don't know why I want to see somebody, but I do feel a little bit left on my own ... nobody actually*
30 *sees me to actually talk to me about me. And I'm one of the lucky ones because I know what I'm*
31 *doing..."* PSTM12 (6-7)
32

33
34 Some patients commented that it would be useful to better understand the basis on which the
35 clinic decides which dosage to recommend:
36

37 *"I'd like to understand a bit more what they...like how...what they base my dose on. I think I would*
38 *benefit from just understanding what factors they take into account, and I think it would...I think it*
39 *would be better if I saw someone, like every now and then."* PSTM17 (1)
40

41 These patients felt that such knowledge would empower them to become more effective PSTMs.
42 The comment above exemplifies this and also supports the notion that some degree of personalised
43 contact with clinicians, albeit perhaps infrequent, could also contribute to improving the experience
44 as a PSTM.
45

46 **Motivations for self-testing**

47 **Choice and control**

48
49 When considering what motivated patients to opt into becoming a PSTM, several factors seemed to
50 be important. Certainly, having a sense of being involved and managing one's own health is an
51 important motivation. Day-to-day management was considered as the means to larger more long
52 term and worthwhile ends:
53
54
55
56
57
58
59
60

1
2
3 *“To be in a bit of control of your own destiny, so to speak – it’s not really of destiny, because I don’t*
4 *have any control, but it, you know, it gives me a feeling of being involved, and that’s important to*
5 *me.” PSTM01 (2)*
6

7
8 *“Yeah, well, for me, it was my choice. I actually approached the clinic and said, ‘I’ve read about this*
9 *– if there’s the opportunity, I’d like to do it,’ because, you know, I want an element of control in*
10 *terms of my own health.” PSTM15 (2-3)*
11

12 Maintaining independence was another key motivation: the means to the end of leading a life
13 that was not constrained by the routines that would be involved under a clinic testing regimen. This
14 was not simply a question of saving time – it was also about valuing independence and the freedom
15 that this afforded. The ability to work full time without the hindrance involved in regular hospital
16 visits to do the tests resulting in lot of time wasting was also considered as an important factor:
17
18

19 *“Because it gives you the independence. You know, I travel a lot with work, so I can fly off to*
20 *Germany and not worry if I’ve got to get a test in while I’m in Germany. I can just do it ... so it’s*
21 *definitely an independence thing.” PSTM03 (>2)*
22
23

24 *“The reason I wanted to self-test, and the only reason I wanted to self-test, was because I am self-*
25 *employed and I cannot abide sitting about in waiting rooms.” PSTM05 (6-7)*
26

27 Other considerations were more pragmatic - relating to convenience. Self-testing conferred the
28 ability to travel without needing to arrange clinic visits for blood testing in unfamiliar places where
29 these visits may also need to be paid for.
30
31

32 *“We live in France for 6 months of the year, and when he has to have tests frequently, you have to*
33 *go to a laboratory there for the test, and then you get the results later on, and that all costs money,*
34 *so it’s [being a PSTM] ideal for that as well.” PSTM10 (> 2)*
35
36

37 **Cost**

38 Continuing the focus on pragmatic issues, it was clear that the cost involved in self-testing was
39 mentioned as a reason why some PSTMs might choose not to do it. This was not always simply a
40 question of not being able to afford it, but certainly it was recognised that cost may be a justification
41 for not self-testing.
42
43

44 *“I’ve got a lot of friends who are also on Warfarin. We play golf, you know, and we’re all the same*
45 *age, and loads of them [have their INR levels tested], and I’m the only one that’s got a machine. ...*
46 *because golfers are notably tight, you know, especially retired people. They like to spend their*
47 *money on...holidays and things.” PSTM01 (2)*
48
49

50 Participants were well aware of the financial costs of buying the device although they generally
51 considered that this was worthwhile. There were issues for some regarding the purchase of testing
52 strips. Typically participants obtained test strips on prescription through the NHS, but several noted
53 that they had to negotiate with their GPs in order for them to agree to this. More broadly it is
54 noteworthy that participants were aware of the savings that might accrue to the NHS through self-
55 testing and greater costs of testing through the clinics.
56
57
58
59
60

1
2
3 *"...how much money do I save the National Health Service? I mean, I'd have to go into the clinic, get*
4 *a blood-test, a phlebotomist there to take my blood test, and that has to be sent off into*
5 *Nottingham, tested in the thing in the hospital, and then they have to send it back, and then they*
6 *have to..." PSTM01 (2)*
7

8
9 *"Even though the strips are supposedly quite expensive, overall it's got to be cost-saving for the NHS*
10 *somewhere because you're not couriering samples around, you're not taking up a nurse's time."*
11 *PSTM03 (>2)*
12

13 **Managing INR**

14 ***Independence and self-management***

15
16 It was clear that in addition to carrying out self-testing, participants were exercising choices about
17 their self-management practices. In some cases, participants described a process akin to an
18 apprenticeship, which involved contacting the clinic in the early stages of self-testing and then
19 replicating that advice themselves at a later date. The ability to self-test also allowed patients to
20 determine the effectiveness of this self-medication themselves afterwards to assess and refine their
21 dosages:
22
23

24
25 *"But I, you know, I just thought, well, you know, I've done this once after advice from a hospital*
26 *[anticoagulation clinic], I'm in a very, very similar circumstance now, instead of bothering the*
27 *hospital, I'll do what I did last time and then test again in 2 days, and it's worked so ..."* PSTM15 (2-
28 3)
29
30

31 Many participants spoke about their day-to-day self-management and the choices they make
32 independently of the anticoagulation clinic. Some had clearly moved on in terms of consciously
33 replicating advice given previously by the clinic to the point that, in cases of small variations above
34 or below the recommended range, they were making independent decisions about their own dosage
35 and treatment. One clear example of this was how participants adjusted their prescribed intake of
36 warfarin.
37
38

39 *"... the recommended level is that you are between 2 to 3 and that they would like it to be around*
40 *about 2.5. So if I go to 3.2, then I know that's a bit too high, so I would take a little bit less*
41 *medication to bring it back to the 2.5."* PSTM04 (2)
42
43

44 For some, such adjustments to warfarin dosage were managed in conjunction with selective
45 communication to the clinic sometimes which involved withholding some information at times, so as
46 to maintain their autonomy and utilise their expert self-knowledge in order manage their INR levels
47 in a way that was perceived to be more efficient and effective.
48

49 *"Because, if I'm phoning up, I make sure it's a normal one, because I know then that they're going to*
50 *say 'Let us know again in a week's time then' so I've got to phone up again, when [actually] I can*
51 *deal with it myself."* PSTM02 (6)
52
53

54 *"I test regularly, so if...and my range is, say, 2.5 to 3.5 – if I'm 3.6, I'm not going to tell them that I'm*
55 *3.6 because I've actually got a really nice dosage now that keeps me very constant, and that would*
56 *trigger the computer to change the dosage. So if I can just drop half a tab for one day, which will*
57 *bring me back in range."* PSTM03 (>3)
58
59
60

1
2
3 *"if I...for instance, had a reading that was 3.8 or something, I mean, I wouldn't bother telling*
4 *anybody. I'd just cut down half a tablet that day, or vice versa ... I'm not stupid enough to abuse the*
5 *system and suddenly take loads or stop taking them altogether."* PSTM05 (6-7)
6
7

8 **Expert patients**

9 PSTMs presented themselves as being experts in their condition and its treatment and, in the light of
10 this, were confident to take decisions about small adjustment in treatment without having to refer
11 to the clinic. They justified their actions by outlining a variety of reasons that could be responsible
12 for small variations in readings and that therefore necessitated temporary adjustment of their
13 medication dosage. For others, the experience of self-monitoring and the associated responsibility
14 for doing so acts as an incentive to observe patterns of cause and effect, to find out more about
15 their condition and how best to manage it. Many participants were knowledgeable about what and
16 how certain types of food and alcohol affect INR readings:
17
18

19
20 *"We've got an app on our phone and it's got everything that you're likely to eat. I mean, the highest*
21 *Vitamin K, which really thickens the blood, is curly kale. And spinach and asparagus and broccoli,*
22 *more or less in that order, all things I like, but I have to eat them in moderation."* PSTM10 (>2)
23

24 *"When you have change of medication, it can, depending on the meds, affect your INR. So if you*
25 *have, say, you take antibiotics for a week or 10 days or whatever, that can have an effect of altering*
26 *your INR."* PSTM16 (5)
27

28
29 *"I know generally if I'm high because my gums might start bleeding a bit, so I'll probably have a test*
30 *then. All the little tell-tale ..."* PSTM03 (>3)
31

32 One participant demonstrated their expertise by outlining their role in setting the prescribed
33 dosage levels themselves.
34

35
36 *"When I used to go to the [phlebotomist] ... she would send it off, and I would get my report back ...*
37 *but it was always wrong and so I didn't take any notice. So, I wrote to them and said this isn't*
38 *correct – this is what actually take, and this is what keeps me stable, and they then adjusted it, and*
39 *then, from then on, they send back that...that pattern".* PSTM14 (10)
40
41

42 **Collaborative management**

43 For some participants, the tensions of adjusting dosage and managing INR levels in a way that was
44 above and beyond official directives were clear. This is very evident in the following quote where
45 this participant wanted an endorsement from the clinic to perform day-to-day management of their
46 INR within certain limits.
47

48
49 *"It would be nice if they could say, look, if you're within that, and you are happy dosing, even if it's*
50 *'Sign this waiver', we're happy for you to dose yourself within that range, I think to have that official*
51 *support, rather than sort of thinking, oh God, I can't do this, now I've got to sort it out, because I*
52 *can't tell them I've done that otherwise they'll go barmy at me. So, I know my range is 2.5 to 3.5, so*
53 *anything up to 4, I should be expected that I can manage that down if I need to."* PSTM03 (>3)
54
55
56
57
58
59
60

Trust in the clinic

Specialist knowledge and expertise

Although there was evidence that many of the participants were involved in active self-management of their conditions, they also were keen to acknowledge the expertise and experience of clinical staff and the value which this brings to their STM activity. In particular, the notion that the clinic is a specialist service focusing solely on anticoagulation, as opposed to providing support for a range of therapies, appeared to be valued by participants and enhanced trust in the advice and support they received from the clinic.

"I just think that the clinic's got so much experience, haven't they, because, you know, that's what they specialise in. They've got so much experience and so much...it's like a stock of scenarios, isn't it, and cases that they've had in the past." PSTM15 (2-3)

This specialist knowledge and experience was valued so much so by some participants, that they expressed the belief that anticoagulation nurse specialists provided much more well founded and reliable advice than other health experts such as general practitioners.

"Well, [named anticoagulation clinic nurse specialist] ... I would class as what people would call an expert. The doctor [general practitioner] is not an expert ... unless it's a particular, you know, unless he's been involved in that sort of thing ... I mean, they've got that many letters after their name in our surgery ...and they teach at the hospital, but I don't know what they teach." PSTM10 (>2)

Trust beyond understanding

In some cases, participants trusted the advice given by the clinic and acknowledged the clinical expertise, so much so, that they did not necessarily feel the need to know how the clinic came to their decisions and recommendations. Rather, they believed that the advice would be valuable simply as a function of being formulated by the clinic.

"It's probably linked to some extent to the sense of ... trust that you have in the service ... in that ... you know, you believe that whatever information you give them, they give you back valuable information in return..." PSTM05 (6-7)

What transpired was the implicit trust that participants have in the expertise and reliability of the clinic. It seemed that a key mechanism which facilitated and sustained this model of STM was this high level of trust from patients in the support and advice received from the clinic. Furthermore, this was also seen as a two way process, which was perceived as requiring the clinic to place some trust in the patient to responsibly undertake their OAT. Their assumption was that the clinic exercised an implicit trust in patients by agreeing with their choice to undertake OAT STM activities:

"It's a team, isn't it, really? You know, you feel part of something, and I think, just as...just as I trust them, they've got to be able to trust you" PSTM15 (2-3)

Discussion

In light of the existing low levels of patient uptake of STM service delivery in practice, there is an urgent need to better understand patient perceptions of STM service delivery, and to identify how this mode of service delivery can be adapted to increase and sustain better levels of patient

1
2
3 engagement. In this section, the results of this study are discussed and a series of service provision
4 recommendations are proposed based on the findings of this study. Table 2 presents the service
5 provision recommendations in the context of the high-level themes that emerged from interviews
6 with anticoagulation PSTMs.
7

8 **[Insert Table 2 about here]**
9

10 In terms of the *role of the clinic*, participants recognised that the core functions of the clinic are
11 threefold: providing advice on testing frequency; advising on appropriate dosage; and ensuring that
12 the self-testing devices are calibrated accurately on an annual basis. The overwhelming message
13 from the participants was that they were satisfied with the service they receive, and hence, this
14 provides some support to the notion that the core functions currently offered should be maintained.
15 The various forms of communication that patients and clinicians engage in as part this service
16 delivery model featured strongly in the views of participants. The prompt and proactive
17 communication that is currently provided when INR readings are out of range is very much valued by
18 participants, which, to a large extent, instils patient confidence in the service. This communication
19 mechanism is reported to be so robust and reliable, that participants feel able to go about their daily
20 management activity with confidence and peace of mind, and with the belief that the clinic will,
21 without fail, make contact with them if they believe it to be necessary. The ability to be able to make
22 synchronous/real-time contact with an INR specialist is also a highly valued aspect of the service, and
23 hence a function which would seem sensible to preserve.
24
25
26
27

28 With regards to how the role of clinic might change in light of the suggested improvements, it
29 was suggested that patients may benefit from more synchronous/real-time and personalised
30 communication with the clinic, primarily to help overcome feelings of isolation. This finding is
31 perhaps not surprising when considering that existing research has found that personalised
32 communication between the patient and practitioner delivers a powerful means of supporting
33 patients and facilitating sustained engagement in positive health behaviours [39]. Related health
34 communication research suggests that the direct and personalised interactions that occur within the
35 privacy and trust of the patient-provider relationship has an important influence on the perceived
36 quality of care for both the patient and the practitioner, adherence, and patient motivation [40-43].
37 There is also some evidence, specifically relating to chronic disease patients, which suggests that
38 delivery of care purely via asynchronous and less personalised communication mechanisms may lead
39 to higher levels of patient disengagement [44]. However, increasing the frequency of face-to-face
40 contact with PSTMs may be counterproductive to the convenience and the service efficiencies
41 afforded by OAT STM. Nevertheless, additional effort in developing communication modes that are
42 considered as a more personalised and effective proxy for face-to-face communication may enhance
43 PSTMs satisfaction with the services provided by the clinic. Indeed, patient satisfaction may be
44 higher if patients are provided with a variety of modes of interaction with clinical services [45].
45 Advances in internet-based communication technologies, such as real-time messaging applications
46 and video call applications, may provide some potential proxies that afford personalised
47 communications with service users, whilst maintaining the convenience and service efficiencies
48 afforded by OAT STM [46]. Enabling additional channels of personalised communication, albeit
49 remotely, may also provide an opportunity to fulfil the recommendation of offering the OAT PSMTs
50 the necessary information and knowledge in order to better understand the rationale behind dosage
51
52
53
54
55
56
57
58
59
60

1
2
3 recommendations. This in turn would foster a more collaborative working relationship between
4 patient and practitioner.
5

6 Views relating to *motivations for self-testing* revealed that PSTMs value the sense of
7 independence and sense of control that the OAT STM affords. Indeed, this is seen as a key
8 motivating factor in making the decision to become a PSTM in the first place. Therefore, any changes
9 made to existing service delivery should ensure maintaining the sense of independence and control
10 if the current PSTMs were to continue to engage in OAT STM. It was suggested that the cost
11 overhead of the equipment required to become a PSTM is likely to be a factor which deters larger
12 numbers of individuals opting to engage in self-testing. Therefore, exploring the strategies for
13 alleviating the cost overhead may result in the desired increased level of uptake by patients. This
14 outcome is in line with existing research on the uptake of OAT STM which found cost of equipment
15 to be a factor hindering the uptake of INR self-testing in the United States [47]. Continuing to
16 support the consumables required to carry out self-tests, i.e. providing prescriptions for test strips, is
17 a crucial factor in maintaining engagement in INR STM. Given that some PSTMs reported
18 experiencing some resistance in reaching an agreement with GPs to issue prescriptions for test
19 strips, suggests that if patient engagement is to be maintained and increased, there is still work to be
20 done in standardising the policy with regards to this.
21
22
23
24
25

26 Views relating to *Managing INR* revealed that in the early stages of becoming a PSTM, a natural
27 product of this process is that patients begin to accumulate knowledge about the dosage and testing
28 frequency recommendations that are made by experts. It seems that PSTMs naturally begin to
29 recognise patterns the clinic's dosage response to a given test result, and begin to make dosage
30 decisions (i.e. engage in self-management practice) of their own. However, part of this self-
31 management practice included withholding information from the clinical service provider so as to
32 maintain necessary levels of control over their own care. Participants reported that they sometimes
33 chose not to report out of range INR readings to the clinic. The motivation for which was not to
34 inconvenience the clinic with out of range readings that were perceived as being easily retrievable
35 by making small adaptations to their dosage themselves. Others believed that reporting an INR
36 reading that was only just out of range would result in an overly complex and drawn out response (in
37 terms of dosage adjustments) from the clinic which they would rather avoid. Nevertheless, in either
38 scenario, the outcome was that the relationship between the clinic and the patient had been
39 compromised and was no longer one of collaboration, transparency and openness. In the case of
40 current OAT STM practice, clinic policy dictates that dosage decisions will be made by the
41 practitioner and not by the patient. However, this study has revealed that this does not happen in
42 practice. Clinical services must recognise that there is often a natural progression in terms of
43 patients' knowledge about their condition and its treatment, and that service providers will need to
44 embrace and support the process of patient empowerment by working alongside patients to make
45 choices about their own care accordingly. This would help to ensure that decisions about treatment
46 are made in an informed and collaborative way, and that clinicians do not make dosage decisions
47 based on incomplete information. For this to work, the clinic would need to provide necessary
48 education to PSTMs as well as offer a more personalised service when required. Existing research
49 supports this recommendation and suggests that enabling and empowering patients to make
50 choices about their own care is a central component in improving health and deploying STM services
51 effectively [13]. Choice is also seen as a key component in the shift towards technology assisted STM
52 service provision, patient empowerment, patient-centeredness, and patient-practitioner shared
53
54
55
56
57
58
59
60

1
2
3 decision making [11, 48, 49]. Existing studies have also found that knowledge acquisition empowers
4 patients [50, 51] and heightens patient readiness to participate in their own care [52].
5

6 *Trust in the clinic* and the advice given were considered to be closely linked to the level of
7 expertise and specialist knowledge that clinicians have about OAT. Despite several PSTMs reporting
8 withholding information from the clinic when slightly out of INR range, PSTMs also reported that in
9 scenarios where the INR was significantly out of range, their first point of contact would be the INR
10 clinic and the advice provided by the clinic would be adhered to. The fact that the clinic specialises
11 solely in INR and associated OAT was highly valued by PSTMs, so much so that advice given by
12 specialist anticoagulation nurses was considered to be much more reliable and trustworthy
13 information than advice given by general practitioners and physicians. In some cases, the trust
14 PSTMs placed in the clinic was so robust that they did not even consider necessary to know how
15 dosage decisions were arrived at in the belief that if the advice originated from the clinic then it
16 would be sound and well founded. However, when exploring the trust relationship further, it
17 transpired that in order to have a robust and sustainable trusting relationship, some PSTMs
18 suggested that trust must be reciprocated, i.e. from the clinic to the PSTM as well as from the PSTM
19 to the clinic. Existing research which considers the impact of communication and trust on health
20 outcomes suggests that if trust is to be sustained in patient-practitioner relationships, practitioners
21 must provide clear explanations of proposed treatment decisions to patients, be skilled in
22 understanding others' points of view and frames of reference, and proactively seek these out and
23 incorporate these into the delivery of care [53, 54]. Whilst the specialist element of current OAT STM
24 service delivery is very much valued by PSTMs and appears to contribute to patients placing trust in
25 the clinic, clinical STM services would benefit from ensuring that a personalised and collaborative
26 approach to communication with patients is delivered in order to sustain long-term reciprocal
27 patient-practitioner trust relationships.
28
29
30
31
32
33

34 **Conclusions**

35
36 This study investigated experiences and views of 17 PSTMs who engage in OAT STM delivered by an
37 anticoagulation clinic in the United Kingdom. A thematic analysis was carried out on the transcribed
38 semi-structured interviews which revealed a range of novel insights into PSTMs views and
39 experiences of engaging in OAT STM. Based on the results we made several recommendations
40 regarding the improvements to the current model of care for OAT STM. These recommendations
41 provide valuable insights into how clinical services can be delivered to engage and sustain
42 engagement of patients in OAT STM. In particular, this study identified the anticoagulation clinic as a
43 highly specialist service which is highly valued by PSTMs and offering the following valued services:
44 dosage advice; calibration of coagulometers; access to the clinicians; prompt and reliable
45 interventions, when necessary. Recommendations likely to improve service delivery relate
46 specifically to patient-practitioner communication and the extent to which PSTMs are able to
47 participate as equals in decisions made about their care. In particular, clinics should maintain a
48 degree of personalised contact with PSTMs; proactively share the reasoning guiding dosage
49 decisions; recognise expert knowledge that PSTMs develop about their condition over time and
50 should therefore involve them when making decisions about their care; develop reciprocal/bi-
51 directional trust relationships so as to sustain patient engagement with the clinic and to ensure that
52 transparent, open and collaborative patient-practitioner relationships are not compromised. Future
53 work is required to explore clinicians' views and experiences of providing OAT STM services to
54
55
56
57
58
59
60

PSTMs, and to develop service provision recommendations that will further improve levels of patient engagement with STM service delivery models.

References

1. UK Parliament. *The ageing population*. 2010 [cited 2014 18 March]; Available from: <http://www.parliament.uk/business/publications/research/key-issues-for-the-new-parliament/value-for-money-in-public-services/the-ageing-population/>.
2. Department of Health, *Liberating the NHS: No decision about me without me*. Vol. 16942. 2012, London, UK: The Stationery Office. 1-41.
3. Atwal, A., A.G. Money, and M. Harvey, *Occupational Therapists' Views on Using a Virtual Reality Interior Design Application Within the Pre-Discharge Home Visit Process*. Journal of Medical Internet Research, 2014. **16**(12): p. e283.
4. Money, A.G., J. Barnett, and J. Kuljis, *Patient perceptions and expectations of an anticoagulation service: a quantitative comparison study of clinic-based testers and patient self-testers*. Scandinavian Journal of Caring sciences, 2015. **29**(4): p. 662-678.
5. Money, A.G., et al., *Patient perceptions of epinephrine auto-injectors: exploring barriers to use*. Scandinavian Journal of Caring sciences, 2013. **27**(2): p. 335-344.
6. Barlow, J., et al., *Self-management approaches for people with chronic conditions: a review*. Patient Education and Counseling, 2002. **48**(2): p. 177-187.
7. Swan, M., *Emerging Patient-Driven Health Care Models: An Examination of Health Social Networks, Consumer Personalized Medicine and Quantified Self-Tracking*. International Journal of Environmental Research and Public Health, 2009. **6**(2): p. 492-525.
8. Matchar, D.B., et al., *Effect of Home Testing of International Normalized Ratio on Clinical Events*. New England Journal of Medicine, 2010. **363**(1608-1620).
9. Heneghan, C., et al., *Self-monitoring of oral anticoagulation: systematic review and meta-analysis of individual patient data*. The Lancet, 2012. **379**(9813): p. 322-334.
10. Robinson, J., et al., *Patient-centred care and adherence: definitions and applications to improve outcomes*. Journal of the American Academy of Nursing Practitioners, 2008. **20**: p. 600-607.
11. Barnett, J., J. Ogden, and E. Daniels, *The value of choice: a qualitative study*. British Journal of General Practice, 2008. **58**(554): p. 609-613.
12. Appleby, J., A. Harrison, and N. Devlin, *What is the real cost of more patient choice?* 2003, London, UK: The Kings' Fund.
13. Department of Health, *Equity and Excellence: Liberating the NHS (White Paper)* 2010, London, UK: The Stationery Office. 61.
14. Goudswaard, A.N., et al., *Long-term effects of self management education for patients with type 2 diabetes taking maximal oral hypoglycaemic therapy: a randomized trial in primary care*. Diabetic Medicine, 2004. **21**(5): p. 491-496.
15. Lip, G.Y., M. Rudolf, and P. Kakar, *Management of atrial fibrillation: the NICE guidelines*. International Journal of Clinical Practice, 2007. **61**: p. 9-11.
16. Kitchener, T., *Anticoagulation Therapy*. Nursing Standard, 2011. **25**(21): p. 59.
17. Shah, S.G.S. and I. Robinson, *Patients' perspectives on self-testing of oral anticoagulation therapy: Content analysis of patients' internet blogs*. BMC Health Services Research, 2011. **11**(25).
18. Hibbard, J., et al., *Do increases in patient activation result in improved self-management behaviours?* Health Services Research, 2007. **42**: p. 1443-1463.
19. Greenhalgh, T., et al., *New models of self-management education for minority ethnic groups: pilot randomized trial of a story-sharing intervention*. Journal of Health Services Research Policy, 2011. **16**(1): p. 28-36.

20. Yang, D.T., R.S. Robetorye, and G.M. Rodgers, *Home prothrombin time monitoring: A literature analysis*. American Journal of Haematology, 2004. **77**(2): p. 177-186.
21. Fitzmaurice, D.A., et al., *An evidence-based review and guidelines for patient self-testing and management of oral anticoagulation*. British Journal of Haematology, 2005. **131**(2): p. 156-165.
22. Fiumara, K. and S. Goldhaber. *A patient's guide to taking Coumadin/warfarin*. Circulation 119:e220-e222 2009 [cited 2013 12 December]; Available from: <http://ahajournals.org/content/119/8/e220.full>.
23. Ansell, J., et al., *Managing Oral Anticoagulant Therapy*. Chest, 2001. **119**(1_suppl): p. 22S-38S.
24. Quin, J., et al., *Home Anticoagulation Testing: Accuracy of patient reported values*. Journal of Surgical Research, 2007. **140**(2): p. 189-193.
25. AntiCoagulation Self-Monitoring Alliance. *About ACSMA*. 2013 [cited 2014 18 March]; Available from: <http://www.acsma.org.uk>.
26. Garcia-Alamino, J., et al., *Self-monitoring and self-management of oral anticoagulation*. Sao Paulo Medical Journal, 2010. **128**(4).
27. Bloomfield, H., et al., *Meta-analysis: Effect of patient self-testing and self-management of long-term anticoagulation on major clinical outcomes*. Annals of Internal Medicine, 2011. **154**(7): p. 472-482.
28. Hush, J.M., K. Cameron, and M. Mackey, *Patient Satisfaction With Musculoskeletal Physical Therapy Care: A Systematic Review*. Journal of the American Physical Therapy Association, 2011. **91**(1): p. 25-36.
29. Maddox, J.M., et al., *Quality assurance for point-of-care testing of oral anticoagulation: a large-scale evaluation of the Hemochron Junior Signature Microcoagulation System*. International Journal of Laboratory Hematology, 2009. **31**(2): p. 142-150.
30. Lafata, J.E., et al., *The Cost-Effectiveness of Different Management Strategies for Patients on Chronic Warfarin Therapy*. Journal of General Internal Medicine, 2000. **15**(1): p. 31-37.
31. Taborski, U., F.J. Wittstamm, and A. Bernardo, *Cost-effectiveness of self-managed anticoagulant therapy in Germany*. Seminars in Thrombosis and Hemostasis, 1999. **25**(1): p. 103-107.
32. Cheung, D.S., et al., *Cost-Savings Analysis of Using a Portable Coagulometer for Monitoring Homebound Elderly Patients Taking Warfarin*. American Journal of Geriatric Cardiology, 2003. **12**(5): p. 283-287.
33. Regier, D.A., et al., *Cost-effectiveness of self-managed versus physician-managed oral anticoagulation therapy*. CMAJ, 2006. **174**(13): p. 1847-1852.
34. Marasinghe, J.P. and A.A.W. Amarasinghe, *Self-managed oral anticoagulation therapy*. CMAJ, 2007. **176**(6): p. 813.
35. Roche Diagnostics Ltd. *The CoaguChek INR tester*. 2014 [cited 2014 31 March]; Available from: <https://shop.coaguheck.com>.
36. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. Qualitative Research in Psychology, 2006. **3**(2): p. 77-101.
37. Madill, A., A. Jordan, and C. Shirley, *Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies*. British Journal of Psychology, 2000. **91**: p. 1-20.
38. QSR International. *NVivo 10 for Windows*. 2014 [cited 2014 1 April]; Available from: http://www.qsrinternational.com/products_nvivo.aspx.
39. Wanyonyi, K.L., et al., *A systematic review and meta-analysis of face-to-face communication of tailored health messages: Implications for practice*. Patient Education and Counseling, 2011. **85**: p. 348-355.
40. Heritage, J. and D.W. Maynard, *Communication in medical care: interaction between primary care physicians and patients*. 2006, Cambridge: Cambridge University Press.
41. Francis, L.P., *The Physician-Patient Relationship and a National Health Information Network*. The Journal of Law, Medicine & Ethics, 2010. **38**(1): p. 36-49.

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
42. Adler, R., A. Vasiliadis, and N. Bickell, *The relationship between continuity and patient satisfaction: a systematic review*. Family Practice, 2010. **27**(2): p. 171-178.
43. Mohr, D.C., P. Cuijpers, and K. Lehman, *Supportive accountability: A model for providing human support to enhance adherence to eHealth interventions*. Journal of Medical Internet Research. Journal of Medical Internet Research, 2011. **13**(1): p. e30.
44. Rosser, B.A., et al., *Technologically assisted behaviour change: a systematic review of studies of novel technologies for the management of chronic illness*. Journal of Telemedicine and Telecare, 2009. **15**: p. 327-338.
45. McGeady, D., J. Kujala, and K. Ilvonen, *The impact of patient–physician web messaging on healthcare service provision*. International Journal of Medical Informatics, 2008. **77**(1): p. 17-23.
46. Money, A.G., J. Barnett, and J. Kuljis, *Patient perceptions and expectations of an anticoagulation service: a quantitative comparison study of clinic-based testers and patient self-testers*. Scandinavian Journal of Caring sciences, 2015: p. In Press.
47. Wittkowsky, A.K., et al., *Barriers to Patient Self-Testing of Prothrombin Time: National Survey of Anticoagulation Practitioners*. Pharmacotherapy, 2005. **25**(2): p. 265-269.
48. Ogden, J., E. Daniells, and J. Barnett, *The value of choice: the development of a new measurement tool*. British Journal of General Practice, 2008. **58**(554): p. 614-618.
49. Barry, M.J. and S. Edgman-Levitan, *Shared Decision Making: The Pinnacle of Patient-Centered Care*. The New England Journal of Medicine, 2012. **366**: p. 780-781.
50. Fiveash, B. and R. Nay, *Being active supports client control over health care*. Contemporary Nursing, 2004. **17**: p. 192-204.
51. Schoot, T., et al., *Recognition of client values as a basis for tailored care: the view of Dutch expert patients and family care givers*. Scandinavian Journal of Caring sciences, 2005. **19**: p. 169-176.
52. Eldh, A., M. Ehnfors, and I. Ekman, *The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure*. European Journal of Cardiovascular Nursing, 2006. **5**(1): p. 45-53.
53. Street, R.L., et al., *How does communication heal? Pathways linking clinician–patient communication to health outcomes*. Patient Education and Counseling, 2009. **74**(3): p. 295-301.
54. Gordon, H.S., et al., *Racial differences in trust and lung cancer patients' perceptions of physician communication*. Journal of clinical oncology, 2006. **24**: p. 904-909.

List of abbreviations

ACSMA	AntiCoagulation Self-Monitoring
CBT	Clinic-Based Tester
INR	International Normalised Ratio
OAT	Oral Anticoagulation Therapy
PSTM	Patient Self-Tester-Manager
PT	Prothrombin
QMCACC	Queens Medical Centre Anticoagulation Clinic
STM	Self-Testing and Management

Legends for Figures and Tables

Figure 1: Current OAT STM procedures and processes

Figure 2: (a) CoaguChek testing kit; (b) Test Strip inserted; (c) Test results on CoaguChek [35]

Figure 3: Thematic map of themes and sub-themes

Table 1. Participant details

Table 2. Service provision recommendations

Table 1. Participant details

Participant ID	Gender	Age Group	Education	Years on OAT	Years as PSTM
PSTM01	Male	71-80	University degree	1-2	2
PSTM 02	Female	56-70	Postgraduate degree	< 1	< 1
PSTM 03	Male	26-40	Secondary	3-5	> 2
PSTM 04	Male	56-70	Postgraduate degree	3-5	2
PSTM 05	Male	56-70	Secondary	6-10	6-7
PSTM 06	Male	41-55	Postgraduate degree	1-2	> 1
PSTM 07	Male	56-70	Secondary	> 10	> 1
PSTM 08	Female	26-40	Postgraduate degree	6-10	8-9
PSTM 09	Male	56-70	Secondary	< 1	> 1
PSTM 10	Male	56-70	Secondary	3-5	> 2
PSTM 11	Female	71-80	Secondary	6-10	4.5
PSTM 12	Female	56-70	Secondary	6-10	6-7
PSTM 13	Female	71-80	University degree	1-2	2
PSTM 14	Male	56-70	Higher education	> 10	10
PSTM 15	Male	41-55	Higher vocational	6-10	2-3
PSTM 16	Male	56-70	Secondary	6-10	5
PSTM 17	Male	26-40	Secondary	> 10	1

Table 2. Service provision recommendations

Theme	OAT STM service provision recommendations
Role of clinic	- Provide advice on testing frequency, dose and annual calibration
	- Prompt (same day) and reliable communication with patient when INR is out of range
	- Real-time access to clinician by telephone when required (reactive)
	- Initiate and maintain some degree of real-time and personalised contact with patients (proactive)
	- Share rationale behind dosage recommendations with patients
Motivations for self-testing	- Continued service provision which enables independence and a sense of control
	- Explore strategies to overcome the cost overhead of becoming a self-tester
	- Provision of prescriptions for INR testing consumables, e.g. test strips
Managing INR	- Recognise the process of apprenticeship and become partners with patients in their learning
	- More pragmatic/collaborative patient-clinician partnerships to overcome withholding information
	- Recognise the value and utilise expert knowledge of experienced/expert patients
Trust in the clinic	- Deliver specialist services specific to the condition as opposed to more general service provision
	- Reciprocal trust relationships i.e. patient to service and service to patient

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

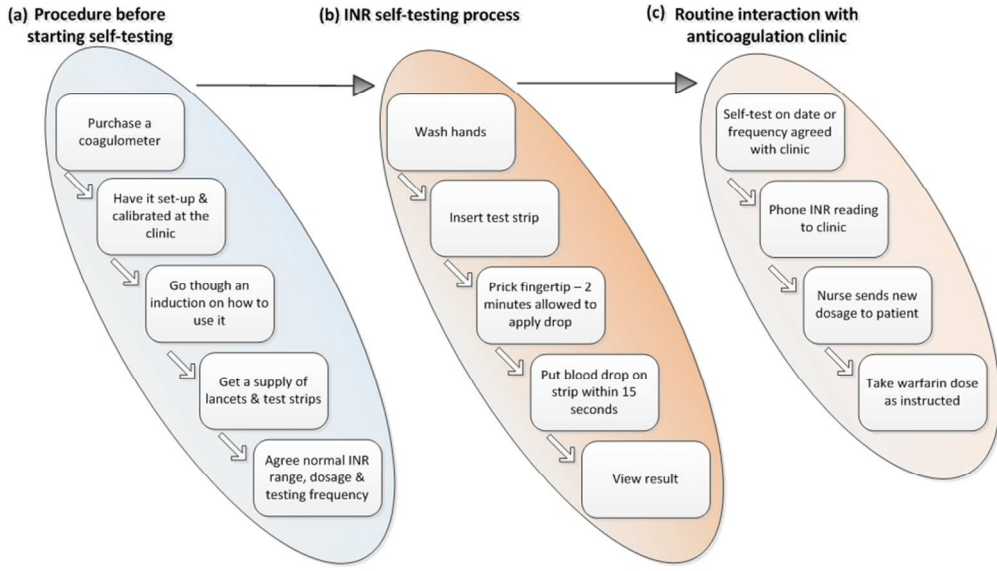


Figure 1: Current OAT STM procedures and processes
259x148mm (96 x 96 DPI)



Figure 2: (a) CoaguChek testing kit; (b) Test Strip inserted; (c) Test results on CoaguChek [35]
338x75mm (96 x 96 DPI)

Review Copy

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

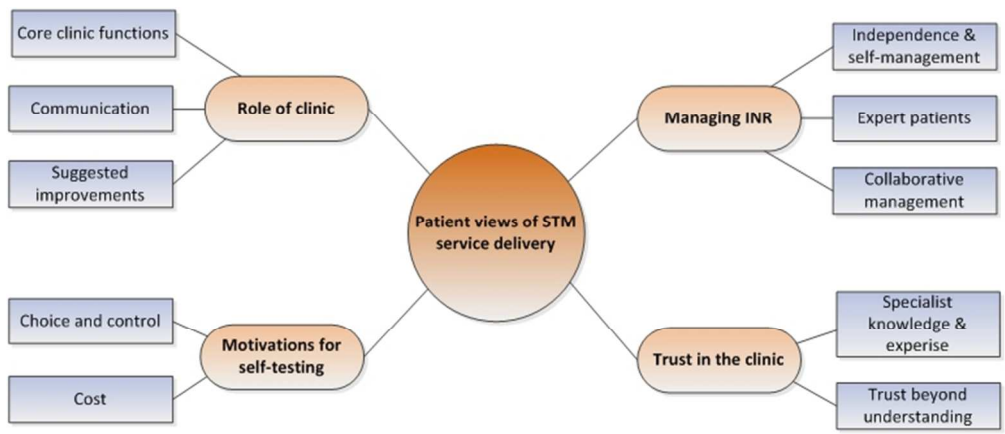


Figure 3: Thematic map of themes and sub-themes
203x87mm (96 x 96 DPI)

Review Copy