## Title

Explaining engagement in self-monitoring among participants of the DESMOND Self-Monitoring Trial: a qualitative interview study

## Running head

DESMOND self-monitoring qualitative study

### Article category

Qualitative Research

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## Abstract

## Background

The DESMOND Self-Monitoring Trial reported that people with newly diagnosed type 2 diabetes attending community based structured education and randomised to self-monitoring blood glucose (SMBG) or urine-monitoring had comparable improvements in biomedical outcomes, but differences in satisfaction with, and continued use of monitoring method, well-being and perceived threat from diabetes.

#### **Objectives**

To explore experiences of SMBG and urine-monitoring following structured education. We specifically addressed the perceived usefulness of each monitoring method and the associated well-being.

#### Methods

Qualitative semi-structured interviews with eighteen adults with newly diagnosed type 2 diabetes participating in the DESMOND Self-Monitoring Trial (SMBG, N=10; urine-monitoring, N=8) approximately 12 months into the trial. Analysis was informed by the constant comparative approach.

#### Results

Interviewees reported SMBG as accurate, convenient and useful. Declining use was explained by having established a pattern of managing blood glucose with less frequent monitoring or lack of feedback or encouragement from healthcare professionals. Many initially positive views of urinemonitoring progressively changed due to perceived inaccuracy, leading some to switch to SMBG. Perceiving diabetes as less serious was attributable to lack of symptoms, treatment with diet alone, and - in the urine-monitoring group - consistently negative readings. Urine-monitoring also provided less visible evidence of diabetes and of the effect of behaviour on glucose.

## Conclusions

The findings highlight the importance for professionals of considering patients' preferences when using self-monitoring technologies, including how these change over time, when supporting the self-care behaviours of people with type 2 diabetes.

# MeSH compliant keywords:

Diabetes Mellitus, Type 2; Blood Glucose Self-Monitoring; Urinalysis; Self Care; Education; Primary Health Care.

## **Background**

While self-monitoring of blood glucose (SMBG) is recommended as a core aspect of management for people with type 1 diabetes and those with type 2 diabetes using insulin, its use by people with non-insulin treated type 2 diabetes remains contentious and continues to provoke ongoing debate. While systematic reviews and meta-analyses have challenged the overall clinical benefit of SMBG in this population, there is considerable heterogeneity among published trials. These differ in how they have operationalised and implemented SMBG as well as in design, study population and approaches to recruitment.

Those who oppose SMBG in individuals with non-insulin treated type 2 diabetes argue that that there is little they or their GPs can do with the results, rendering the technology a waste of time and resources. Others argue that, like any tool, SMBG is used most appropriately by those trained to use it and motivated and able to act upon the results. Thus, based on the argument that such training would lead to better self-management of the condition and a reduced rate of complications, SMBG may save money in the long term. Self-monitoring of *urine* glucose is just as contentious. While urine monitoring is considerably less expensive than SMBG and easier to perform, it is also regarded as less hygienic and less informative. Urine monitoring cannot identify hypoglycaemia, (a significant risk in those taking sulphonylureas) since urine strips only indicate when glucose rises above the renal threshold of around 11mmol/l. Urine monitoring is also unreliable in those taking SGLT2 inhibitors since they promote increased urinary loss of glucose by lowering the renal threshold. Given the prominence of the debate about the role of SMBG and urine monitoring in adults with non-insulintreated T2DM (for example 8,9), primary care staff may have strong opinions about one or both technologies and/or may be wary about what to recommend regarding self-monitoring.

The DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) Self-Monitoring Trial - a multi-site cluster randomised controlled trial - has contributed to this debate by assessing the equivalence of SMBG and urine glucose monitoring in adults with newly diagnosed type 2 diabetes, while controlling for provision of self-management education. The trial reported a significant reduction of the primary outcome (glycated haemoglobin; HbA1c), in both groups over 18 months of follow-up, but no significant between-group difference. Other biomedical and psychosocial outcomes also improved over 18 months with no differences between the groups. Of

note, participants in the blood monitoring group were more likely to report continued use of their allocated method at 18 months than those randomised to urine monitoring, with 18% of the urine monitoring group switching to blood monitoring after 18 months. In contrast, very few participants swapped from blood to urine monitoring. While there was a decline over time in the number of participants continuing to use blood monitoring (86% at 6 months, 85% at 12 months and 79% at 18 months), there was a steeper decline in the urine monitoring group (74%, 69% and 59% respectively).

Sensitivity analysis revealed greater satisfaction with treatment and a more threatening view of diabetes in the blood monitoring group (although the latter was only present at six months).

Previous qualitative research exploring the experiences of people with type 2 diabetes provides insight into the acceptability of the two monitoring methods. Negative views about the usability of urine monitoring have been reported due to confusion about the readings and a perception that it is unhygienic. <sup>10</sup> SMBG has been reported as more useful – providing individuals with direct evidence of the effects of their behaviour on glucose levels (through understanding of the relationship between blood glucose and symptoms), and providing positive reassurance when achieving optimal blood glucose levels. <sup>13,14</sup> However, distress and confusion at unexpected and unexplained blood glucose readings, leading in some cases to a sense of failure and self-blame, were also reported. <sup>13-15</sup> A progressive decline in monitoring was influenced by these experiences but also by primary healthcare professionals, who either disapproved of the monitoring method or showed little interest in the results. <sup>15</sup> However, a limitation of previous qualitative studies is that they have generally not acknowledged how participants were trained to use the different methods of monitoring or how these were incorporated into the overall approach to self management. <sup>10</sup>

We used a mixed methods approach in the DESMOND Self-Monitoring Trial, to explore the acceptability of the two monitoring methods (blood and urine) in people with newly diagnosed type 2 diabetes, who had experienced equivalent education in self-management and training in monitoring, and had been allocated randomly to one of the two methods. Our aim was to provide insight into the quantitative results of the DESMOND Self-Monitoring Trial, dentifying issues contributing to the differences found between arms in the continued use of, and satisfaction with, the two methods, and the level of threat perceived from diabetes.

## Methods

Ethical approval was granted (as part of the DESMOND Self-Monitoring Trial) by Cambridgeshire (UK) Research Ethics Committee (07/H0304/129). Local research governance approval was received from participating five Primary Care Trusts - public authorities in England which, at the time of this study, had responsibility for funding NHS services in a defined geographical area.

## **Participants**

A sample of participants in the DESMOND Self-Monitoring Trial<sup>11</sup> was invited to participate in a semi-structured individual interview approximately 12 months after attending the education sessions (i.e. 12 months into the trial). Purposive sampling guided recruitment to maximise diversity in age, gender, location, diabetes-specific well-being and treatment satisfaction (the latter two from participants' scores on returned questionnaires for the main trial). <sup>11,16,17</sup> Individuals were sent an invitation letter with an opt-in reply slip accompanied by a participant information leaflet. The interviewer telephoned each participant who returned a reply slip to check their willingness and arrange an interview.

#### Data collection

Interviews were conducted in the interviewees' homes. Written informed consent was taken prior to the interview. A semi-structured topic guide was used which covered: awareness, views, and experience of self-monitoring and monitoring method(s) – before, during and after the education session; perceptions of confidence in managing glucose levels; views about the education sessions; and views about the trial. Interviews were audio-recorded, transcribed in full and anonymised. Interview transcripts were reviewed (by HE) during the course of data collection in order to determine the point at which saturation had been reached; after completing 18 interviews, it was considered that new themes were no longer emerging and areas of interest had been adequately explored.

## Analysis

Analysis was informed by the constant comparative approach. Transcripts of the initial nine interviews were read (by HE) to develop preliminary codes, and categorise them into an initial coding framework. The remaining transcripts were read (by HE/SM) to develop existing codes and finalise the coding framework. NVivo software (QSR International) was then used (by SM) to facilitate systematic coding of all data. A second round of coding (by SM) focused in more detail on the two monitoring methods in terms of how participants used them and what they had learnt. Finally, once

the trial results were known, a third round of coding (by HE) focused on identifying any further data relating to the trial results (for example whether interviewees talked about diabetes as threatening / serious).

Quotations from interviewees are labelled by geographical area (A-E) and qualitative study ID number (1-18). Gender; age group (<50, 50-70, >70 years) and monitoring method are also noted to provide participant characteristics without identification.

#### **Results**

Eighteen adults with newly diagnosed type 2 diabetes who were participating in the DESMOND Self-Monitoring Trial took part in the interview study. Ten had been allocated to SMBG and eight to urine self-monitoring; seven were women, and the age range was 29-80 years. All interviewees had attended DESMOND structured group-based education, with equivalent training in monitoring for their allocated method. Interviewees were geographically located in five Primary Care Trusts.

We present the qualitative data under key themes that relate closely to the findings reported in the DESMOND Self-Monitoring Trial results paper.<sup>12</sup>

Use of allocated monitoring method and treatment satisfaction

The qualitative data support the trial's finding of higher treatment satisfaction and continued use of allocated monitoring method in the SMBG group. Most interviewees in this group reported perceiving the method as accurate, convenient, and useful in a practical sense for managing their diabetes and understanding their symptoms (Box 1, interviewee C1). To emphasise this point, some made a direct comparison with urine monitoring with regard to their understanding of how the two methods worked (Box 1, D5). Interviewees in this group gave examples of how they engaged with the process and the results. For example, some enjoyed tracking their levels over time, and in a couple of cases embraced technology that facilitated this (Box 1, D1). Most in the SMBG group described how they learnt about the effects of various foods and activities on their blood glucose and/or how to interpret symptoms by regular and timely monitoring, thus aiding behaviour change.

Associated with this learning, most interviewees in the SMBG group mentioned an improved sense of personal control and independence. The opportunity and ability to self-monitor was reported as a way to avoid unnecessary visits to primary healthcare practitioners, thus reported as benefiting both individuals and their practitioners (Box 1, E2). Furthermore, two interviewees talked about how SMBG facilitated their self-management by serving as a disciplinary device, acting as a visible reminder when blood glucose levels were higher than ideal (Box 1, D5).

Interviewees' accounts provide two predominant explanations for the gradual decline in frequency of SMBG reported in the trial findings.<sup>11</sup> Most of this group reported reducing self-monitoring to once or twice a week, with three monitoring daily. The most common explanation for this decline was that

SMBG was needed less frequently, having established a pattern of how to manage blood glucose following a period of monitoring and learning (Box 1, A1). A second explanation was due to perceived lack of support from their primary healthcare practitioners: lack of encouragement, lack of help interpreting results or disapproval about the method due to its purported futility or the cost of prescribing testing strips (Box 1, E1). Lack of support meant not acquiring information needed to interpret and act on their monitoring results, and for others it removed the incentive or "sense of purpose" (Box 1, D1). Only one participant in the qualitative study sample had swapped from SMBG to urine monitoring.

In the urine monitoring group, half of the interviewees were still regularly using their allocated method at 12 months, although all but one was monitoring less frequently than previously. This half had not questioned its accuracy and were content with its ease and convenience (Box 2, D2). The other half recalled finding it useful initially but, over time, had altered their views. After approximately one year into the trial, this sub-group considered urine monitoring to be inaccurate and of little value, reported only ever receiving "normal" results, and typically referred to it as a "waste of time" (Box 2, B1). These all mentioned how their healthcare practitioner had agreed, referring to it as inaccurate (Box 2, A2), not useful or expensive. This had triggered three interviewees to switch to SMBG (Box 2, A3); at least one case as a result of their practitioner's advice (Box 2, A2).

Perceived threat from diabetes and diabetes-specific concerns

Regarding the between-group difference in threat perception reported in the trial, <sup>11</sup> when asked directly about severity of diabetes, all interviewees in the urine monitoring group, and most in the SMBG group described their diabetes as "not too bad" or "borderline" (Box 3 D6). Interviewees across the two groups typically explained this perception by referring to a lack of symptoms, and due to currently controlling (or aiming to control) their diabetes using diet rather than medication. The urine monitoring group interviewees further explained this by referring to their consistently "normal" urine readings as evidence of this (Box 3, D4). This had led some in this group to conclude that their diabetes was well managed, and three interviewees to question their diagnosis altogether (Box 3, D4), supporting previous research.<sup>10</sup> There was little evidence of diabetes-related worry in these interviewees' accounts, which aligns with the trial's report of a less threatening view of diabetes in the urine monitoring group.<sup>12</sup>

In contrast, it was clear that SMBG provided visible evidence of having diabetes and of the effect of self-care behaviours - such as differing quantity/type of foods or levels of physical activity - on blood glucose levels. While a couple of interviewees in the SMBG group reported worry following a high blood glucose reading, most reported working out its cause (usually a case of having "slipped" from an otherwise healthy diet) and acknowledged how high readings served as a reminder of both the importance of maintaining optimal self-care and of the seriousness of the condition (Box 3, C1). More instances of diabetes-related concerns emerged in the interviews with the SMBG group, than those allocated to urine monitoring. For example, a few mentioned feeling low or that their diabetes was controlling them (Box 3, C2). Two interviewees in the SMBG group, who had reported diabetes to be more serious than others did, described how not having achieved as great a reduction in their blood glucose as they had wanted had led to lowering of their mood (Box 3, D1).

#### **Discussion**

The DESMOND Self-Monitoring Trial reported that people with newly diagnosed type 2 diabetes who attended structured education had comparable improvements over 18 months in glycaemic control regardless of being randomised to SMBG or urine monitoring. However, between-group differences were apparent in continued use of monitoring method, and perceived threat from diabetes and, in the per protocol analysis, in treatment satisfaction. 12 By exploring the experiences of participants in both trial arms, the current qualitative study contributes to our understanding of these differences. Interviewees reported SMBG as accurate, convenient and useful (in a practical sense) for managing their diabetes. Declining use of SMBG over time was explained by: a) having established sufficient insight from self-monitoring about the effects of routine foods and physical activity to enable management of blood glucose with less frequent monitoring; or b) discouragement and lack of support from primary healthcare professionals. The sharper decline in use of urine monitoring, and the substantial percentage switching to SMBG reported by the trial can also be explained; interviewees randomised to this method found it inaccurate and of little value. Overall, interviewees reported not perceiving their diabetes as serious due to managing it with diet only, lacking symptoms, and – for those urine monitoring – viewing consistently 'normal' glucose readings (i.e. below the renal threshold). SMBG provided more visible evidence of diabetes via the effect of self-care behaviours on blood glucose, and more diabetes-related concerns emerged in this group as a result.

## Explaining levels of engagement in self-monitoring

The trial reported that participants randomised to SMBG were significantly more likely to be continuing to use their allocated method at 6, 12 and 18 months, compared with the urine monitoring group. <sup>12</sup>
Our qualitative findings support and inform the trial results: interviewees reported SMBG as helpful for learning how to interpret symptoms and the effects of self-care behaviours (quantity/type of foods eaten and physical activity) on their blood glucose; the gradual decline in blood monitoring over time reflected a view of a reduced need for such frequent monitoring after this period of learning. This suggests that people with newly diagnosed type 2 diabetes had learned principles for self-care based on their blood glucose readings and then applied these in routine daily life. It might be useful to anticipate this decline by modifying self management education and encouraging the use of self-monitoring periodically to check these principles were still sound or to experiment with new self-care

behaviours. In contrast, the steep decline in urine monitoring was explained as resulting from dissatisfaction and perceived 'uselessness' by many individuals. Those who switched to blood monitoring reported being keen to engage in self-management and to have tools to facilitate this.

The trial reported a temporarily more threatening view of diabetes in the blood monitoring group. The qualitative findings indicate that SMBG provided a more visible reminder, both of having diabetes and the effect of activities on blood glucose, than urine monitoring. Such visibility, in combination with the education and tools to enable action, appeared to raise the threat enough to promote better awareness, yet was not sufficiently overwhelming to lead to hopelessness or undue anxiety. In contrast, the lack of visibility of diabetes from urine monitoring led some interviewees to question their diagnosis. However, with the trial reporting no difference between the arms on HbA1c reduction, this increased awareness does not seem to have translated to more effective blood glucose management, at least in those recently diagnosed.

## The potential influence of healthcare professionals on self-monitoring

Professionals at participating primary care practices received training about the aims and conduct of the trial and were asked to provide impartial advice about monitoring methods to their participating patients, 11 but, despite this, some of interviewees reported discouragement from professionals (consistent with previous research<sup>15</sup>). Indeed, lack of professional support and/or feedback about selfmonitoring results or lack of willingness to prescribe monitoring strips emerged as reasons for stopping self-monitoring. Some of this discouragement may relate to concerns about the associated prescription costs<sup>19</sup> or, since these were refunded in the DESMOND Self-Monitoring Trial, it may reflect the wider debate about clinical and cost-effectiveness of such self-monitoring in non-insulin treated type 2 diabetes. 8,9 Furthermore, while considerable efforts were made to ensure the impartiality of educators throughout the trial, 12,20 training for primary care staff was neither extensive nor continuous due to the multi-site design of the study and large number of practices involved. Thus, staff may have forgotten their instructions that their attitudes might influence the outcomes of the trial. Primary healthcare professionals may require additional training to ensure that they and their patients understand the value of 'structured' blood glucose monitoring, and are trained to interpret the results; which has been demonstrated to be both feasible and effective in a recent trial. <sup>21</sup> Furthermore, additional patient education on incorporating monitoring into self-management, perhaps via a followup session focused on interpreting results – after a sufficient period of time of monitoring and experimenting with it – might be useful.

#### Strengths and limitations

Our findings support those of previous qualitative research conducted in non-trial contexts. <sup>10,13,15</sup> Our interviewees received equivalent structured education in self-management of diabetes and training in their allocated self-monitoring method, thus controlling for effect of educator/education and enabling comparison of the two methods. This addressed a limitation with previous qualitative studies of self-monitoring in type 2 diabetes. Purposive sampling was used to ensure the qualitative study sample was diverse in age, gender, location, diabetes-specific well-being and treatment satisfaction (based on questionnaire scores from the main trial). Interviewing people approximately 12 months after education and the introduction of self-monitoring afforded them a good length of time to try their allocated method and choose to continue with it or not. Thus, our qualitative findings can be considered indicative of interviewees' considered experience and specifically did not capture their initial views during that potentially 'positive' phase immediately after education. One limitation of interviewing at 12 months, however, was that the findings of the main trial were not yet known, hence it was impossible to explore explanations for trial results *in situ*.

Diabetes services operate under different conditions in different countries; for example, in the UK, meters and monitoring strips have been provided free to patients but more recently, primary care teams are under pressure to reduce costs. This may lead them to discourage patients from testing their blood. These differences might limit the generalizability of these findings outside the UK. However, many of the findings of this study (for example the powerful influence of the attitudes of healthcare professionals) are relevant to care in other countries. Thus, awareness of patient acceptability of self-monitoring and the influence of professional views are relevant messages for all professionals involved in diabetes care.

## Conclusions

The findings from this qualitative study support the conclusion of the trial – that while there may be no differences in biomedical improvement between people with newly diagnosed T2DM allocated to self-monitoring blood or urine glucose as part of a structured education programme, the reported

differences in acceptability suggest that those who are actively using SMBG, and do not find urine monitoring useful, could be encouraged to continue by their primary care professionals. <sup>12</sup> However, it would also appear to be reasonable for professionals to support those for whom urine monitoring is perceived as both acceptable and valuable. Importantly, these qualitative findings highlight the influential role of primary healthcare practitioners, whose views are pivotal in encouraging or discouraging people with type 2 diabetes in their self-care behaviours. This work confirmed the strong opinions of some individuals about the benefits of SMBG versus urine monitoring (for example, on perceived seriousness of diabetes, perceived responsiveness to self-care behaviours, hygiene). Thus primary care teams should consider not only the cost of SMBG and urine strips but also the impact on the individual when expressing their own views about either method of monitoring. Finally, the finding that SMBG was needed less frequently once individuals had gained sufficient insight from a period of self-monitoring provides useful clinical guidance. It may help professionals to target support and advice during periods when patients find it most useful.

## **Declarations/Acknowledgments:**

- Ethical approval. Approval was granted (as part of the DESMOND SMBG trial) by Cambridgeshire (UK) Research Ethics Committee (07/H0304/129). Local research governance approval was received from participating Primary Care Trusts.
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- 2. Conflicts of interest. HCE, HMD and SM declare that they have no conflicts of interest. JS is a member of the Roche Diagnostics Australia (RDA) Accu-Chek Advisory Board. In the past 3 years, her research centre has received consultancy fees from RDA in respect of her attendance at advisory board meetings, as well as from Abbott Diabetes Care, Eli Lilly, Johnson & Johnson, Medtronic, Merck Sharp and Dohme, Novo Nordisk, RDA, and Sanofi Diabetes, for speaking engagements and/or unrestricted educational grants. KK has acted as consultant and speaker for . AstraZeneca, Boehringer Ingelheim, Janssen, Lilly, MSD, Novartis, Novo Nordisk and Sanofi. He has received grants in support of investigator initiated trials from AstraZeneca, Boehringer Ingelheim, Lilly, Novartis, Novo Nordisk, Roche and Sanofi. MJD has acted as consultant, advisory board member and speaker for Novo Nordisk, Sanofi-Aventis, Lilly, Merck Sharp & Dohme, Boehringer Ingelheim, Janssen and Astra Zeneca and as a speaker for Mitsubishi Tanabe Pharma Corporation. She has received grants in support of investigator and investigator initiated trials from Novo Nordisk, Sanofi-Aventis and Lilly. SRH reports personal fees from Lifescan.
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# Box 1: Views about self-monitoring of blood glucose (SMBG) of individuals allocated to SMBG in the DESMOND Self-Monitoring Trial

#### Perceived usefulness

## Accurate and useful in a practical sense

Interviewee C1 (male, <50, SMBG): "I prefer doing the blood to be honest ... to me it's less hassle, just get your box out, stick it in your finger ... easy-peasy, done, write it the book ... and you can do it anywhere."

Interviewee D5 (male, 50-70, SMBG): "Look at urine... you're looking at your average ... blood glucose level over the period that your bladder filled up ... but it's not quite the average because it depends how much fluid was going through your kidneys I guess ... whereas blood monitoring is a ... is an instantaneous measure ... direct correlation with what was going on at that time ... to me that's an extremely valuable way of understanding how your body's working with it" (D5-SMBG)

## A self-management tool

Interviewee D1 (male, <50, SMBG): "You know [device company] who ... make the machine... have got their own website and ... you can actually download your machine data onto their site ... and it can produce graphs to take into your doctor and it can sort of tell you pretty much daily what your sugar levels were and you can add to it and stuff like that"

Interviewee E2 (female, 50-70, SMBG): "I don't want there to be endless trips to the [GP], you know... I mean, it's such a simple test isn't it... You know, you're saving somebody else's time"

Interviewee D5 (male, 50-70, SMBG): "I thought, I'm starting to be naughty ...so I'll just monitor what I'm doing again, and that gives me the discipline because when I see it on the meter ... and you know two hours after a meal and I'm still above eight ... I'm thinking now come on, let's get serious again ... and bring it back down again."

## Explanations for decline in self-monitoring

#### Establishing a pattern

Interviewee A1 (female, >70, SMBG): "I must admit I sometimes ... I haven't been doing it all that much, I don't know whether I should be doing it more often ...[The educators] said the purpose of it was to find out our reactions to certain situations and I have tried to observe that so at first I was doing it very regularly to find out certain, you know, if certain foods were affecting me. Erm ... now that I have established a pattern I don't feel that I've got to do it so often ... I found out that I reacted very badly to some cereals in the morning ...so erm ... I've settled on one particular favourite cereal which er ... seems to work."

#### Perceived lack of encouragement from health professionals

Interviewee E1 (female, 50-70, SMBG): "[The nurse is] monitoring it less because you sort of put it to the back of your mind, which is why [nurse] said do it less. She said otherwise people can become overanxious about it. And she said your scores are so low, that there's no need to do it all the time."

Interviewee D1 (male, <50, SMBG): "There didn't seem to be any sort of feedback coming my way, so for example I had loads of those little DESMOND diaries, you know, [with] the date and the time and to record what the sugar level was, and then it had sort of a bit [...] 'What do you think caused it to be high, low or normal? What have you had to eat?' you know like I could say well I had two bits of toast and marmalade at nine o'clock and [...] the marmalade's high in sugar and that's what's caused me to have a reading of fourteen or something. ... But I sort of took them all ... well three or four of them down to the doctor's and. 'Oh yeah, thanks very much,' but you know it was one way traffic, there was no feedback... With me I ... I like to sort of have a sense of purpose [...] I just think that in some way you know having a bit of feedback would be good"

# Box 2: Views about urine self-monitoring of individuals allocated to this method in the DESMOND Self-Monitoring Trial

#### Perceived usefulness

## Accurate and useful in a practical sense

Interviewee D2 (male, 50-70, urine-monitoring): "I am still using them... about twice a week. (Okay. What sort of measurements are you getting?) Light green. (Which is ... What's that saying to you?) Phew! .. nothing there ... I will admit that it went dark brown the other night. I know I was a naughty boy! (What did you do?) I had a good plate of fish and chips ... No idea how accurate they are, but I take it they are perfectly accurate."

## Explanations for decline in self-monitoring

### Not useful for self-management

Interviewee B1 (female, >70, urine-monitoring): "I'm reasonably responsible, and if I know that something is going to be an improvement and is going to help me to be less of a nuisance to anybody else ... if I can manage myself then I will do all I can on my own to do that. ... The downside that I've discovered obviously is that I've never, ever had a positive result ...which means that to me it's a bit of a waste of time really because I don't change anything as a result of testing my urine ... I've had big meals and tested afterwards and tried ever so hard to get a result!"

## Perceived lack of encouragement from health professionals

Interviewee A2 (female, 50-70, urine-monitoring): "and I was disappointed in that because I thought well, if I was doing the urine tests and nothing was showing up ... then why is the doctor now saying I'm high. So I did go and talk to the nurse about it [...] about urine test ... and she said. 'Well it's not very accurate.' And she's actually given me a little blood test monitor now"

### Swapping from urine monitoring to SMBG

Interviewee A3 (female, 50-70, urine-monitoring): "I think once out of what- the hundred times I must have done it did I ever come above the normal ... and you think, 'What am I doing all this for? This is just ridiculous' ... And the [SMBG] one gave you an accurate sort of reading."

Box 3 Perceived threat from diabetes and diabetes-specific concerns – views expressed by interviewees using self-monitoring of blood or urine glucose in the DESMOND Self-Monitoring Trial

#### Minimal perceived severity of diabetes

Interviewee D6 (male, 50-70, SMBG): (How severe do you think your diabetes is?) "Erm ... absolute borderline. I would have thought on a good day I wouldn't have ... I wouldn't have registered."

#### Association between test results and threat

Interviewee D4 (male, >70, urine-monitoring): "I don't think it's severe at all, I have no symptoms [...] I take me er...diabetes as if it is mild and it's easily controlled by diet...because every time I've [...] tested it's always been normal...or within the normal bounds or range [...] As I say I haven't taken it too seriously because it er has not been a great problem...er I mean if I was really bad— if I went out there and tried my own sticks and it went "whoops"...then I'd be concerned, I'd be down the doctors...fairly quickly"

(later) "... and you think 'how have I got diabetes?' They said I have, but [the urine-monitoring result] has never been anything other than normal."

Interviewee C1 (male, <50, SMBG): "I overdid it at Christmas and that was a bit of a shock 'cause that's my first Christmas after [starting SMBG] and it [blood glucose level] went up. So this year it'll be no Christmas pudding and no Christmas cake."

#### Diabetes-specific concerns

Interviewee C2 (female, <50, SMBG): "Sometimes the diabetes will ruin my life ... Well it's sometimes when I see like people eating erm ... cakes and biscuits and sweets and like ... I feel ... I want to eat them but I can't.... It just gets me down a lot... sometimes I feel like the diabetes is controlling me."

Interviewee D1 (male, <50, SMBG): "Things aren't quite working out as planned and I'm not losing weight as much as or as quickly as I liked and my blood sugar levels aren't under control as much as I would like ... I felt like for the first time in my life I wasn't achieving anything and it was all going in the wrong direction and erm ... it was almost inevitable that I was going to have to have medication... You do go through peaks and troughs so one minute you think, yeah I've got this under control and everything's going nicely, the other minute you think God, my sugar level's sky high and I haven't really ate much today, you know what's going on and ... and it's little things like that which do affect your mood"