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Interventions to improve retention in a surgical, clinical trial: a pragmatic, stakeholder driven approach.

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Abstract

Objective

To explore stakeholder perspectives upon participant retention in clinical trials, and to generate strategies to support retention in a surgical, clinical trial.

Study Design & Setting

The SWIFFT trial is a multi-centre study comparing treatments for the fracture of the waist of the scaphoid bone in adults. Here we report upon a multi-stage, iterative consultative process with SWIFFT stakeholders, these include workshops with members of the public, with nurses involved in data collection, and with consultant clinicians. Structured discussions were digitally recorded and transcribed, data were handled and analysed following a framework approach to qualitative data analysis.

Results

Removing practical barriers were identified as important factors in supporting retention. Stakeholders also identified that i) how well a study is understood and ii) how much it is valued are important factors in an individual's willingness to maintain their involvement. A number of strategies resulted from this consultation, these include: in-clinic data collection, co-ordinated clinical and research appointments, a SWIFFT website and newsletter.

Conclusion

A participatory approach to trial retention might engage all relevant stakeholders in the delivery of a clinical trial, it might also support the generation of specific and contextually relevant solutions to the challenge of participant retention.

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1. Background.

Difficulties in recruitment and retention as barriers to the successful conduct of a clinical trial are well documented. Multiple systematic reviews illustrate challenges to trial recruitment and point to varied and complex reasons for this (1-8). Issues of retention, however, have received less explicit attention despite being equally problematic as it can introduce bias and challenge the validity of inference (9, 10). Reasons for attrition have commonly been considered alongside recruitment (11-13) and are similarly presented as complex and difficult to categorize. Where attrition has been considered in isolation, practical difficulties of maintaining contact with participants over an extended period, especially if they change address or telephone number, and participants losing interest or commitment, are highlighted (14).

Evidence for the impact of strategies to support retention is uncertain, with limited systematic research focused upon retention strategies in clinical trials (12). Broader review, which include cohort and survey studies, point to the benefits of monetary incentives, teasers on envelopes, and recorded postal delivery (15), as well as reminder letters and shorter questionnaires (8). Where review is restricted to randomised evaluations embedded within host clinical trials, most strategies to improve retention are targeted at questionnaire response rates for which monetary incentives (the offer of, adding monetary incentives and increasing monetary incentives) are shown to be effective (14). Evidence from single trials might also suggest that specialized postal strategies, recorded delivery and open-trial design may be beneficial (14). It is recognized that there has been limited consideration of strategies focused upon in-person data collection at, for example, hospital clinics (in contrast to postal questionnaires) and that investigation of such strategies is required (14).

More general assessment suggests that trial context, research population and specific trial procedures significantly impact upon attrition (11, 16) and that qualitative investigation is important in the production of trial-specific retention strategies (11, 16). Elsewhere, others have pointed to the value of integrating qualitative research within clinical trials to further inform the research process (17, 18) and bodies such as INVOLVE (19, 20) and the James-Lind Alliance (www.lindalliance.org) point to the importance of engaging stakeholders in the generation, operation and management of clinical studies (21-25).

A growing body of work demonstrates the value of engaging stakeholders in this way (26-30) and highlights how qualitative investigation might: expose specific misunderstandings about trial processes (31); illuminate local organizational cultures and norms (11); map distinctive characteristics (32, 33); identify important environmental factors (16); and, expose researcher attitudes which are impacting upon trial operation (34).

Here we consider a stakeholder-consultative process to inform retention strategies in the Scaphoid Waist internal Fracture Fixation Trial (SWIFFT) (http://www.nets.nihr.ac.uk/projects/hta/113637). This is a multi-centre trial comparing surgical fixation versus plaster cast treatment for fracture of the scaphoid bone in adults (35). It is a trial with multiple data collection points that include both completion of standard research instruments via post and return visits to hospital clinic for additional clinical assessment and imaging. The study primary end-point is 1-year, with an additional 5-year clinic review to establish long-term consequence of fracture and treatment.

For SWIFFT, difficulties of retention may be exaggerated in two important ways. Previous review has identified that (amongst other characteristics) females are more likely to participate in research (36) and that younger people (amongst others) are more likely to drop out of research studies (37). The SWIFFT research population, most likely men under the age of the thirty, would seem vulnerable to both these trends.

Here we report upon measures taken in the SWIFFT trial to generate strategies to support retention amongst the research population which could also be used to inform retention strategies in future studies. The purpose of this commentary is two-fold: to outline an approach to stakeholder consultation, and to describe the strategies and mechanisms that it generated.

2. Methods.

2.1 A multi-stage, iterative stakeholder consultation.

To generate broader insight into issues of retention, and to generate strategies to support retention, a series of stakeholder consultations were held – events took place over a six month period spanning the end of year 1 and beginning of year 2 in a 3 year programme of patient recruitment. Patients with a previous wrist/scaphoid fracture, research nurses and orthopaedic surgeons (all of whom were Principal Investigators on the SWIFFT Trial) participated in these events.

An initial half-day workshop with members of the public explored how the trial is understood and perceived. Stakeholders were invited via mail-out to previous fracture clinic patients and via word of mouth recruitment in local clinic settings. Eight individuals volunteered to take part and all attended on the day; six (4 male, 2 female; all under 30 years old) had prior experience of a scaphoid fracture (all fully recovered), two had not experienced this fracture but were typical of the SWIFFT target population (i.e. male under 30). None of the individuals were currently eligible to participate in the SWIFFT trial.

Short presentations about the study were made by members of the SWIFFT team and a structured discussion was led by PL and JD. Topics reflected a pragmatic concern for the successful operation of

the trial and included: whether the purpose and design of SWIFFT was well understood; the acceptability of data collection instruments; and, strategies to encourage participation and retention. Participants were encouraged to discuss these topics amongst themselves and to introduce issues, ideas and suggestions that they felt pertinent. Notes were made by participants and by facilitators during the workshop; discussion was also digitally audio recorded. Audio recordings were transcribed in full and hand-written notes captured digitally (for ease of handling) by both photographing sheets and transcribing content into Microsoft Word format.

Research nurses at SWIFFT study sites were invited to a second half-day workshop; seventeen attended representing fourteen (of 26) different sites. PL, SB and JD facilitated the meeting introducing insight generated in the public meeting for discussion, once again participants were encouraged to discuss broadly and to raise additional topics and insight when relevant. Discussions were audio recorded and research nurses and facilitators invited to make notes during the workshop. Audio recordings were transcribed in full and again hand-written notes were digitized for ease of handling and analysis.

A third strand of consultation focused upon SWIFFT principal investigators. SB and JD discussed retention at a sub-group meeting (SWIFFT PIs only) of a British Society for Surgery of the Hand (BSSH) event. Insights generated in the previous workshops were shared and discussion considered strategies which might be easily incorporated into normal routines. A short online survey covering similar topics was subsequently circulated to all principal investigators (n=26) via the Survey Monkey website. Online responses (n=17) and meeting notes were transferred to Microsoft Word.

2.2 Analysis and development of the framework.

All data were handled using N'Vivo 10 software package for qualitative data, and a framework approach was adopted in data analysis (38, 39). PL led data analysis, generating and populating the analytic framework, with JD (primarily), SB and other members of the trial team verifying data interpretation and validating the form and content of the framework.

Taking what is already known about trial retention (and to a lesser degree trial recruitment) as a starting point an initial analytic framework consisting of three broad themes was created. Data from the public workshop was then mapped to this framework and used to refine it - generating higher level codes within each theme by grouping lower level codes found in the data (see Table 1).

Coding of data (transcripts and notes) was led by PL, with JD verifying the lower level coding, i.e. all data mapped to a specific lower level code would be reviewed to ensure coherence and consistency of coding. Where a lower level code incorporated inconsistent data (describing different factors or perspectives), data might be re-coded or the lower-level code revised or re-organised (e.g. with

distinct aspects disaggregated). The organization of lower level codes into higher level groupings (codes / sub-themes) was negotiated through discussion by the authors. Again all data organized within a higher level code would be reviewed to ensure coherence and consistency. Higher-level codes and analytic themes were presented to the SWIFFT trial management group as part of reporting progress.

Insert Table 1: Initial analytic template.

Data from subsequent phases of consultation were handled in a similar fashion: coded, organized within higher level codes, and situated within broader themes. At this point the framework might be amended or revised where new topics or different perspectives offered additional or different insight.

2.3 Routine trial data monitoring.

Strategies for improved retention generated from the stakeholder consultation were presented to the project oversight committees i.e. Trial Steering Committee (TSC) and Data Monitoring Ethics Committee (DMEC). Those that were subsequently approved by the Trial Management Group (TMG), and when necessary by the East Midlands (Derby) Research Ethics Committee (13/EM/0154), were incorporated into SWIFFT research procedures.

3. Results.

3.1 Multi-stage, iterative stakeholder consultation.

Almost two hundred data points were coded to the initial analytic framework. The data was consistent in scope and tone across the different stakeholder groups with similar barriers to retention perceived and similar solutions offered. Almost half of those data points recorded addressed *practical strategies to support involvement*; additionally, *barriers to participation* and *notional strategies to support involvement* each covered around one-quarter of all data presented.

Review of this data (by JD and PL) indicated that whilst practical solutions were perceived by stakeholders to be most important, other factors might be worthy of further investigation. Twenty-eight (of 53) *Barriers to Participation* were coded as either *Uncategorized* or as linked to *Perceptions of the study*, leading to an assessment that less tangible factors might significantly affect retention rates. Data generated in the research nurse workshop reinforces this point - that participants might feel like 'guinea pigs', might not fully understand research processes, or might want to cease participation as soon as they are well. These examples, with similar ones made by both members of the public and the SWIFFT PIs, suggest that a participants' conceptual engagement with a study is an important factor in retention.

This assessment informed a revision of the analytic framework to one which more clearly disaggregates practical from less tangible barriers and connects the practical and notional benefits associated with a range of general and targeted strategies to improve retention (see Table 2). That practical measure might be perceived to encourage, as much as enable, participation points to a broader concern that retention strategies may need to consider participants' commitment and connection to the SWIFFT study.

Insert Table 2: Revised analytic framework.

3.1.2 Understanding the study.

Both members of the public and SWIFFT PIs suggested that a lack of understanding about the study, both in its relevance and its processes; as well a lack of appreciation of its significance might be important factors in individuals dropping out of SWIFFT. Providing information about the study was considered an obvious response to this danger and the use of accessible formats (such as newsletters and websites) to provide exciting and/or enticing messages was considered important:

> *"if you can share background information about it … background to how the study is going so that they know that something is happening and they're not just filling in these forms and somebody's just sticking them in a box … I think the thing about keeping people informed is for me would make it more appealing is not just only having a questionnaire coming through the post but at some point a letter or some information saying this is what we've done this is what we're doing – so that you know that somebody is actually looking at these things and something's being done" (Sarah)*

> *"They need to appreciate the importance of follow-up and continued engagement with the study and the wider implications for managing this in the long term. It may be that they do not appreciate the contribution they are making and feel as individuals to be unimportant." (SWIFFT PI 5 – survey response)*

3.1.3 Valuing the study

Notes taken during the Research Nurse workshop similarly illustrate the importance of providing information to participants. In this session another form of information was also considered significant – "*remember personal information [about the participant], spend time with them make them feel special …. Remember personal details, communicate well, and thank them every time"*. Demonstrating an interest in the participant and their experience (of fracture, treatment, and research) was considered a way of helping a participant feel valued and involved in the study. More than this "*on-going personal contact with patients*", "*continuity of contact"*, "*being accessible*" and "*building relationships*" were commonly perceived to enable participation and encourage retention.

> "*A sense of involvement. Consultant at follow up - not palming it off to juniors. I see all of our patients on each follow up and reinforce how important it is*." *(SWIFFT PI 3 – survey response)*

Personalizing involvement in SWIFFT was also advocated by members of the public:

"making it personal to them is a big thing as well – making them feel like them in particular, they in person are going to help shape the study…

… or they could have their name on the paper [letter] so that when they read it – it's just to them as opposed to [anonymous communications] … it's worth doing – its making a difference and it needs to be personal" (James and Matthew in discussion)

Other mechanisms for making SWIFFT more personally engaging included generating a competitive element to it, including maps which show areas which are recruiting and retaining participants, "*you could do it geographically like a graph saying who's contributed most … there's the whole country pride then isn't there, kind of Manchester vs Liverpool vs…".* Similarly, a lottery-style prize draw was proposed as more exciting than standard inconvenience payments. Discussion of payments was otherwise inconclusive with the importance of rewarding participation recognized but the form of payment (money, voucher, gift, etc.) and amount and schedule inconclusive.

"18 years olds are often quite self-centered and certainly are resistant to being advised … they need to be engaged and they need to see some value for them. Financial incentive is one way, perhaps an itunes gift card or a gift card for a DVD if they attend their first few appointments." (SWIFFT PI 9 – survey response)

"Giving money might encourage people just to go yeah yeah yeah without really thinking about it but there's a hell of a lot of people who just wouldn't even touch it if there wasn't anything in it for them and that's what we've got to remember that there is a lot of people who are 'what's in it for me' so that is a big difference you know, £40 is a big incentive" (Peter)

"That's what I was thinking, what about 15, 30, 60 then you're doubling it each time." (Sarah)

"there's no point giving too much incentive at the end because you've got to keep them to the end and you've got to keep them from the start to the end" (Amanda)

Research nurses pointed to the danger of participation in SWIFFT being less attractive once a participant feels that their fracture has healed. Similar opinions were expressed by the SWIFFT PIs and in the public workshop where previous fracture patients indicated a desire to get back to normal as soon as their cast had been removed. Wider assertions of 'being too busy' reinforced the point that long-term commitment might be difficult to achieve with this population of generally active younger individuals.

"He's got no concerns, he's working full time, he said he's doing fine he don't see why I'd want him to come so he can't understand why he needs to come back because clinically they're getting better, they've got a full range of movement that's why I can't get them back" [Research Nurse]

"yeah – I think there's a lot of people - it could be an age thing [young] - but for me, my arm was in a cast [when it] came out of the cast and from that second of it coming out I'd healed – I'm done now – I don't need to go back to the hospital … the only way you're gonna get people in is by saying here's some money … you asked if my friends would do it, they wouldn't come back … (James)

"The patient who failed to attend three times for follow up was 18 years old. She is young, unreliable and enjoys partying and occasionally studies. She forgot the first time, the second time she couldn't be bothered as her wrist was not painful and did not see any gain for her to return. We persuaded her to come back at another clinic but had to remind her on the day." (SWIFFT PI 9 – survey response)

3.2 Trial management strategies & routine trial data monitoring.

Informed by this stakeholder consultation SWIFFT study processes have been developed in a number of ways that are designed to support improved participant retention.

Early adopted strategies have included: the collection of questionnaire data at hospital clinic appointments (in addition to their postal administration); the co-ordination of research appointments at the same time as clinic appointments; participants primed by being shown follow-up questionnaires at recruitment; and, on-going review of open-response comments recorded by patients on questionnaires.

Later measures that have been implemented include: the creation of a regular participant-targeted newsletter; the creation of a participant-targeted website which includes information about study progress (http://www.swifft.co.uk/); the creation of a patient video to provide information in a more user friendly fashion about why patients should continue to stay in the study, the video takes the form of a question and answer discussion with the SWIFFT PPI representative and is available on the website; the creation of a study tagline, "SWIFFT study: patients helping to improve healthcare through research", which is affixed as a label to all participant correspondence; and finally, instigating a "SWIFFT I-pad Lottery" where all participants who complete data collection are entered into a series of prize drawers (at 26 weeks, 52 weeks and 5 years).

A number of additional strategies proposed in the stakeholder consultation have been considered and rejected, these include: online data collection of questionnaire instruments; abandoning the SF-12 to reduce data collection burden; and, amending the participant payment schedule to increase the payment at 26 weeks.

4. Discussion.

Previous research has been inconclusive about how best to respond to difficulties in trial retention; multiple strategies have been offered but few are supported by a strong evidence base (14). The stakeholder driven approach that we employed is informed by this uncertainty and by a body of literature which points to the value of trial specific insight and strategies (11, 14, 16). Whilst the

insights discussed here were in the context of a surgical trial with a predominantly male and younger population, they could be potentially considered for trials in general.

4.1 General insight.

4.1.1 Stakeholder consultation to inform retention strategies.

Our consultative process offers a map for engagement and a model for handling data that others concerned about trial retention may wish to replicate.

We have demonstrated the value of a broader consultative net than concerns for public and patient involvement might normally advocate (20). Here we consulted with stakeholders from within our trial (local investigators and research nurses), from those outside of the trial (in our public workshop), and routinely incorporated this feedback into trial management systems that involved the TSC, DMEC and TMG. This combination of multiple perspectives and mechanisms has informed strategies to improve retention that are both meaningful to participants and practical within the conduct of the trial.

We have also, in handling the stakeholder data, made a strong analytic distinction between practical challenges, practical solutions, and additional (notional) benefits. This tripartite model, in part, reflects the nature of the SWIFFT trial population, but it also reflects the broadly held notion that some participants may simply lose interest in a study (14). The danger that trial participants may simply lose interest will vary by trial (where target population, trial duration and participant burden are likely to be factors), but we would argue that all triallists should be wary of this. Looking beyond the practical challenge of attending an appointment or completing a research instrument is consequently an important (although possibly less obvious) focus for stakeholder consultation and for those strategies generated to support retention.

Whilst our approach elicited and incorporated views from a variety of stakeholders, this did not include the perspective of trial participants themselves. We have, however, also been interviewing patients who took part in the SWIFFT trial and individuals who did not. We expect these interview data will help to generate further insights into the experiences and attitudes of patients towards surgical, clinic al research which may include how to enhance retention of trial participants (35).

4.1.2 Integrating consultation into trial operation & management strategies.

Stakeholder consultative processes like those described above risk being tokenistic if they are not fully integrated into both the conduct of a trial and its management systems and processes.

We would suggest that a concern for participant retention should be manifest from the earliest possible point, and here we initiated participant priming about the schedule of return visits and about other data collection during the recruitment process. Whilst this might feel like an added barrier to

recruitment it is pertinent to reflect that if a concern for retention only emerges when participants are not attending appointments (or returning instruments) then it may already be too late to remedy any difficulties.

We would also remind that retention should be fully integrated into trial management processes. Here we included both recruitment and retention as separate standing items on all meeting agendas so that specific attention is given to retention. The stakeholder consultation activities were presented as a part of these meetings (at the TMG in particular) and strategies for amending research processes in order to improve retention developed (in the TMG) and approved (in the TSC). More than this, monitoring retention and data completeness has been given equal weight alongside monitoring of recruitment statistics. Our general point remains that retention is as important as recruitment for clinical trials.

4.2 Specific insight.

4.2.1 Difficulties of retention in the SWIFFT population.

Our stakeholder consultation has demonstrated that many of the general points about trial retention are pertinent to our younger, trauma related research population. Moreover they point to some very specific selective attrition associated with a younger, active population. That such participants might be difficult to track due to changes to contact details was presented as *normal* and *almost unavoidable* in this group where frequent changes to electronic and mobile telephone contact details are common. That this population might be easily distracted and in transition in other parts of their lives (leaving home, entering work, entering university, etc.) were also perceived to exaggerate retention issues. That this population might also be more active in lifestyle and consequently impatient to regain normality once their injury has healed further contributes to the danger that they will lose interest and drop-out of longer term follow-up.

4.2.2 Solutions to retention difficulties in the SWIFFT population

Given these specific challenges our stakeholder consultation has generated a number of strategies which are concerned with communication and engaging this young, active population; some of these strategies are evident in the existing literature, some are new and novel.

Elsewhere studies have pointed to improved communication with participants as benefiting trial recruitment (3, 12); here a SWIFFT newsletter, website and patient video have been created to inform participants about study progress and processes. These mechanisms are designed to act both as a reminder about the study as well as containing information and messages which will generate enthusiasm. The study tagline is similarly intended to reinforce the purpose and importance of the research in a similar way that teasers on envelopes might offer benefit (15).

More distinctively our consultative process has generated suggestions that a prize-draw / lottery might be a *more exciting* mechanism for reimbursing participants for their inconvenience, and that *friendly* Research Nurses might generate a more enduring relationship with study participants. These strategies speak directly to a younger, more easily distracted study population. That *friendly nurses* might not formally be implemented is less significant than the insight it offers about the clinical population and how best to motivate their continued involvement.

In response to concerns about a research population which is active (in employment, study, lifestyle) and which might find multiple face-to-face appointments practically difficult to attend (and difficult to justify) our stakeholders proposed the coordination of clinical and research appointments, they also suggested greater flexibility in appointment timing and location which have both been implemented when possible.

Other strategies suggested in the literature have not been adopted for a variety of reasons such as shorter research instruments (8, 15), open trial design and opt-in trial design (5) and on-line data collection (14). It is possible that undertaking this consultation at an earlier stage (during a pilot study perhaps) might have informed more fundamental trial design amendments that have not been possible here.

Finally there is increasing awareness for the need to provide an evidence-base to address the uncertainties around the effective and efficient conduct of trials. Embedded methodological studies within a trial (SWAT) have been proposed to identify strategies that will improve recruitment and retention of participants in trials (40). The Northern Ireland Hub for Trials Methodology Research has created a repository that currently lists 54 protocols for SWAT's that includes interventions to improve retention such as timing and mode of delivery of self-competed questionnaires, questionnaire design, use of financial incentives, electronic prompts, newsletters and many more. Strategies identified from our stakeholder consultations could be evaluated as these SWAT's.

5. Conclusion.

Participant retention is a key factor in the success of any research study; it is also a complex matter which defies general assessment and single, simple strategies. This commentary reports upon a consultative exercise intended to generate strategies to support retention in a surgical, clinical trial. It draws upon the views of three distinct stakeholder groups (patients, research nurses and consultant clinicians) and suggests that motivational factors about the patient understanding and valuing of the study, such as newsletters, websites, patient video, are as important as practical measures such as collecting questionnaires in clinic and being flexible with the arrangement of appointments.

The participatory approach adopted offers benefit both in identifying strategies for amending trial processes, but also in engaging directly those who will be most affected by such changes (RN and consultants). It is limited by the inclusion of a relatively small number of stakeholders and by the limited amount of time taken to consult with them – more stakeholder events might generate further and more detailed insight. Given our target clinical population (younger) we might have thought more about social media and other electronic forms of consultation and contact. In a similar vein for more complex trials (with more varied populations, or incorporating more complex interventions) it may be that different types of stakeholder consultation might be required – reaching more broadly, generating multiple and varied forms of consultation. That our public stakeholders here are self-selected, and perhaps atypical in their willingness to support research management processes, also points to a need for broader and more extensive stakeholder consultation in this area.

Finally, it is too complex to examine which of the multiple strategies that were implemented in SWIFFT affected retention. Where possible, randomised evaluations embedded within host clinical trials to evaluate strategies identified here is recommended.

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Table 1: Initial analytic template.

THEME	***Higher level coding***	***Lower level coding.***
Barriers to Participation. ***[53 data points]***	Barriers to **completing survey**	○ Unnecessary questions. ○ Survey too long. ○ Other barriers to survey.
	Barriers to **follow-up appointment**	○ Time commitment.
	Perceptions of the study which might be a barrier	○ Relationship to clinical care. ○ Reverse psychology
	Other uncategorised barriers	○ Personal/personality factors. ○ Social/familial barriers.
Notional strategies to support involvement ***[47 data points]***	Focus upon **study detail**.	○ Emphasize significance of the study. ○ Provision of information.
	Focus upon **the person**.	○ Patient advocate for the study. ○ Personalise study. ○ *The study values your participation.*
	Other uncategorised strategies	
Practical strategies to support involvement. ***[93 data points]***	Practical support for **follow-up**.	○ Convenience of appointments. ○ Money as an incentive. ○ Non-money incentives. ○ SMS as reminder. ○ Vouchers as incentives.
	Practical support for **questionnaire**.	○ Collect in clinic. ○ Online or other mechanisms.
	Practical support for **study engagement**.	○ Individual personal contact details. ○ Study newsletter.

Table 2: Revised analytic framework.

1. Practical challenges:	***Practical solutions:***	***other benefits:***
Survey instrument looks long and intimidating.	A. Reduce/reformat survey, possibly for online delivery. B. Collect survey data at clinic appointments. C. Make follow-up appointments more convenient [not 9-5, not hospital]. D. Reminders about on-going participation.	1. Multiple mechanisms for completing surveys will reinforce that participation is important and valued. 2. Flexibility and responsiveness with appointment time/location will reinforce that participation is important and valued.
Follow-up appointments are inconvenient and time consuming.		
Economic and/or familial circumstances might get in the way.		
2. Understanding the study:	***Practical solutions:***	***other benefits:***
Not recognising the impact that the research might make.	A. A dedicated newsletter which provides detailed information about the study and its progress. B. A dedicated website which provides detailed information about the study and its progress.	1. Emphasise SWIFFT's size, significance and potential. 2. Demonstrate on-going progress in study milestones and achievements. 3. Provide detail about the study and its processes – about why elements are necessary
Not appreciating that the study is making progress.		
3. Valuing the study:	***Practical solutions:***	***other benefits:***
Once "I'm better" what benefit do I gain from taking part?	A. Personalised communications help to build connection to the study. B. A consistent, named contact helps to build connection to the study. C. 'Prizes' and internal competition – e.g. recruitment and retention rates by region/hospital. D. Personal testimonies from patients reinforcing benefit of being involved.	1. Generate attachment to the study beyond personal, clinical care. 2. Emphasise that participation is meaningful and valued. 3. Enable participants to position themselves with regard the whole study, i.e. how many other people, how many locally, how many at 6 months, etc. 4. Ensure that no-one is out of pocket. 5. Provide a variety of incentives to maintain involvement – money, 'goodies', 'meaning'.
Money might help retention in some cases, but not all (esp, small amounts).		