**The role of the Carer Support Needs Assessment Tool (CSNAT) in palliative home care: a qualitative study of practitioners' perspectives of its impact and mechanisms of action**

Dr Gail Ewing    (Corresponding Author)
BSc PhD RGN RHV
Senior Research Associate
University of Cambridge
Centre for Family Research
Free School Lane
Cambridge UK
CB2 3RF
Tel: 01223 334881
Fax: 01223 330574
 ge200@cam.ac.uk


Dr Lynn Austin
PhD MSc
School of Nursing, Midwifery & Social Work
The University of Manchester




Professor Gunn Grande
BA (Hons) MPhil PhD
School of Nursing, Midwifery & Social Work
The University of Manchester

## Abstract (248 words)

### Background

The importance of supporting family carers is well recognised in healthcare policy. The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based, comprehensive measure of carer support needs to facilitate carer support in palliative home-care.

### Aim

To examine practitioner perspectives of the role of the CSNAT intervention in palliative home-care to identify its impact and mechanisms of action.

### Design

Qualitative: practitioner accounts of implementation (interviews, focus groups, reflective audio-diaries) plus researcher field notes. Setting/participants: 29 staff members from two hospice home-care services: contrasting geographical locations, different service sizes and staff composition. A thematic analysis was conducted.

### Results

Existing approaches to identification of carer needs were informal and unstructured. Practitioners expressed some concerns, pre-implementation, about negative impacts of the CSNAT on carers and expectations raised about support available. In contrast, post-implementation, CSNAT provided positive impacts when used as part of a carer-led assessment and support process: it made support needs visible, legitimised support for carers and opened up different conversations with carers. The mechanisms of action that enabled the CSNAT to make a difference were creating space for the separate needs of carers, providing an opportunity for carers to express support needs and responding to carers' self-defined priorities.

### Conclusions

The CSNAT delivered benefits through a change in practice to an identifiable, separate assessment process for carers, facilitated by practitioners but carer-led. Used routinely with all carers, the CSNAT has the potential to normalise carer assessment and support, facilitate delivery of carer identified support and enable effective targeting of resources.

**What is already known about the topic**

- Caregiving at end-of-life has multiple impacts on carers
- The principle of supporting carers is well established in healthcare policy
- There has been little research on how carer assessment and support may best be achieved in practice

**What this paper adds**

- The Carer Support Needs Assessment Tool (CSNAT) provided positive impacts compared to existing approaches when used as part of an assessment and support process
- Impact of the CSNAT: made carer support needs visible, legitimised support for carers and opened up different supportive conversations
- What enabled the  CSNAT to make a difference was creation of a space to identify the separate needs of carers, providing an opportunity for carers to express support needs and responding to support needs prioritised by carers rather than those identified by practitioners

**Implications for practice**

- The CSNAT, used routinely with all carers, has the capacity to normalise carer assessment and support
- It allows practitioners to be more responsive to individual needs through delivery of carer identified support with potential to enable effective targeting of resources

**Background**

Caregiving at end-of-life entails considerable costs for carers and the wider family, including emotional, social, financial and physical cost[1] and even increased mortality.[2] Lack of perceived support from health services in the final months of caregiving has been found to impact negatively on carers' health and coping in bereavement.[3] Evidence from two recent systematic reviews[4;5] indicates that supportive interventions can help address some of these effects, reducing caregivers' psychological distress. In recognition of the impact of caregiving, the importance of supporting family carers is well established in healthcare policy both nationally and internationally.[6-9] Since 2004, UK guidance has stressed that carers needs should be assessed, acknowledged and addressed[6], with support for carers seen as an essential component of the End of Life Care Strategy[7] and identified as one of the Top Ten Quality Markers for healthcare providers.[10]

The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based, comprehensive measure of carer support needs intended for use as a practice tool in palliative home-care.[11] . It was developed in response to the absence of an existing direct measure of carer support needs. Fourteen broad domains of support, each encompassing a range of individual carer needs, were identified through interviews/focus groups (FGs) with 75 bereaved carers. The domains fall into two broad groupings, reflecting the dual role played by carers and support they may require both as co-workers and as co-clients in palliative home-care.[12] The 14 domains were used to structure a direct measure of carer support needs, enabling carers to indicate domains where they needed more support. The tool was subsequently validated with 225 adult carers providing support to palliative patients at home.[13] The CSNAT was found to be a valid tool for direct measurement of carer support needs, with good face, content and criterion validity. Further information and an inspection copy of the CSNAT can be obtained from the authors.

The CSNAT was designed to be incorporated into a process of assessment and support that is practitioner facilitated but carer-led. As such, it enables carers themselves to identify domains in which they require more support and prioritise those of most importance. Then a conversation can take place between carer and practitioner about the carer's specific support needs within prioritised domains and supportive input they would find helpful. This differs from usual practice in which identification of carer needs is more informal, professionally led and part of the patient assessment process. Thus for implementation in palliative care practice, the CSNAT represents a complex intervention, comprising a structured framework for a carer-led approach to assessment and support.

This paper addresses the next stage of work with the CSNAT: investigation of how it works in routine palliative care practice. This is in keeping with the MRC Framework [14] for evaluating complex interventions, which stresses the importance of understanding what makes interventions effective. This paper examines practitioner perspectives of carer assessment before and after implementation of the CSNAT intervention, in order to identify its impact and mechanisms of action that need to be part of the intervention process for the CSNAT to have a positive impact. A separate paper reports further on the implementation process, identifying factors affecting uptake of the CSNAT in palliative home-care practice.

**Methods**

**Design**

Implementation of the CSNAT was investigated within initial qualitative pilot work in one small hospice at home service in 2010 (Setting A) followed by a mixed methods feasibility study in a large hospice home care organisation with both a hospice at home service and a community-based specialist palliative care team in 2011-12 (Setting B). In both settings, the qualitative components of the studies aimed to explore practitioner perspectives of the impact of the CSNAT and to understand how the intervention worked in practice. COREQ guidelines have been followed for reporting qualitative studies.

This paper draws on qualitative data from both settings: practitioner accounts of implementation from interviews, FGs, dissemination discussion sessions and reflective audio-diaries. Researchers (GE/LA) made frequent visits to both settings to gain familiarity with each service and the process of implementation was recorded as field notes.

Ethics approval was received from The University of Manchester Committee on the Ethics of Research on Human Beings for the pilot study on 1 April 2010 (reference number 09356) and for the feasibility study on 6th January 2011 (reference number 10308).

**Setting**

The two hospice home-care services were in contrasting geographical locations (urban/rural) with different service sizes and staff composition, ensuring contextual diversity. Both services delivered care to patients and family carers at home. A summary description of each service is provided in Figure 1.

*Insert Figure 1 about here*

Each service implemented the CSNAT as a service development (see Figure 2). The research study ran in parallel to investigate staff experiences with CSNAT implementation in practice.

*Insert Figure 2 about here*

**Recruitment and study sample**

All staff were sent recruitment packs with an invitation letter, study information leaflet, reply form and freepost envelope for its return. The study researchers then contacted staff interested in taking part to provide any further details required about the study. The participants were aware that researchers (GE/GG) had developed the tool. It was made clear that the research team was seeking a full understanding of their experience of implementing the tool.  Each participant provided written consent and background details prior to data collection.

There were 26 participants from a total of 30 trained staff: service managers (2) clinical nurse specialists (14; another 4 did not take part), Hospice at Home (H@H) nurse coordinators (6), H@H nursing sisters (3) and one staff nurse. Three healthcare assistants who used the CSNAT also volunteered to take part.  Apart from the HCAs (two with NVQ training), all staff were general nurses, more than half of whom were educated to degree level in nursing or palliative care. Length of time in post ranged from 1-12 years. The roles of the H@H nurse co-ordinators and the H@H nursing sisters were different. The co-ordinator role involved in-depth first assessment of need for

both patient and carer(s) and agreeing a plan of further care including arranging and coordinating 'hands-on' input, both day and night, and referral onwards. Further contact and care was most often by telephone, but could include 'hands-on input' to review and crisis manage. In contrast the H@H nursing sisters were responsible for ensuring all necessary clinical details were known before the service provided care visits. Where this involved a visit from the Sisters themselves, they also provided any personal care.

**Data collection**

A total of nine FGs and discussion sessions were hosted in the two HHC services and facilitated by two researchers: GE and a senior colleague working within family research in Setting A; GE/LA in Setting B. Four FGs (17 participants) were held prior to CSNAT implementation: to discuss existing approaches to identifying carer needs, initial responses to the tool and how staff anticipated using the CSNAT in practice. A further three FGs (16 participants) were held post-implementation to explore actual experiences of using the tool. Two participants were unable to attend the post-CSNAT FG and completed interviews instead. A discussion session was held in each setting at the end of data collection (14 participants) which was also recorded with participants' consent.  In addition, 11 participants provided reflective audio-diaries of CSNAT use in practice (38 exemplars in total) either as self-recorded diaries or audio-recorded telephone contacts with the study researcher. Throughout both research studies both service managers and study researchers recorded reflections and field notes of the CSNAT implementation process.

**Data analysis**

Interviews, FGs, discussion sessions and audio diaries were digitally recorded, transcribed, anonymised and checked by the research team. A thematic analysis based on the Framework approach was conducted.[15] The process of analysis involved two researchers for each setting (GE/GG-Setting A; LA/GE-Setting B) and included initial reading and re-reading of transcripts to become familiar with the data. Then an indexing framework was developed, derived both from interview/FG questions and from themes arising from the data, and used to organise the data. Atlas/ti software was used to facilitate data management. Throughout the analysis memos were written. Analyses were discussed and compared, allowing clarification of themes and interpretations to be agreed.

**Findings**

In presenting the findings, italics indicate verbatim quotations, followed by the participant's study ID number (P__). Original IDs have been recoded to ensure anonymity. […] indicates omitted text.

**Pre-CSNAT implementation views of carer assessment**

Limitations of existing approaches

Practitioners stated they supported both patient and carer as part of their remit. However referrals were primarily for input for patients and it became apparent that their primary concern was addressing patients' needs. Before CSNAT implementation, both services already undertook detailed patient assessment and discussions with carers, if present, normally took place as part of this broad patient assessment process. Identification of carer needs was informal and unstructured and input for carers, where recorded, was documented within patients' records.

Practitioners favoured a conversational approach to assessment but as neither service was using an assessment tool or guiding framework, the range of carer needs assessed could be variable. It could be '*luck of the draw*' (P07) as to which support areas got picked up with carers with their existing approach. *'It's dependent on the skill, the bias, the expertise of the person doing the assessment'* (P12). Practitioners also reported that their supportive role was not always fully clear to carers. Reflecting on existing practice, they commented that carers may not have realised that an assessment was actually being undertaken: *'I think as well, what we've just said about, you are assessing the carer through the general conversation and chitchat and you're picking things up. They might not necessarily identify that'* (P14).

Perceptions of the CSNAT

On the whole, practitioners were positive about the 14 CSNAT domains, identifying them as familiar areas of support. The CSNAT was seen as *'comprehensive, so it covers everything'* (P06) with the advantage that the domains structured assessment for all carers, ensuring consistency. Nevertheless, in advance of implementing the CSNAT, practitioners expressed some concerns about the potential negative impact on carers and their expectations of support available.

The importance of building relationships with carers was seen as very important *'it's just getting to know them, getting a rapport with them'* (P24) and some viewed the tool as potentially blocking a relationship if too much was asked too soon. Related to this was a concern about the tool raising issues carers might not be ready to discuss: *'It might bring things up as well that maybe at that particular time the carer's not prepared to, or doesn't want to, identify, like 'knowing what to expect in the future in caring for your relative'*(P14). Needs were felt best discussed as they arose and presenting a set of support domains 'all in one go' viewed as potentially problematic. This related partly to burdening the carer, but also to worries about the CSNAT raising expectations of availability of certain aspects of support. *'And if you ask them about something that you know you can't do, you're raising an expectation and then letting them down.'*(P06) This view came about where practitioners associated particular supportive input with certain domains, such as respite care or practical help in the home, which the service might be expected to deliver.

**Post-implementation: CSNAT for carer-led assessment**

None of the anticipated concerns about the negative impact on carers of using the CSNAT was reported by practitioners using the CSNAT for carer-led assessment. Instead, they identified how using this approach enabled them to support carers in ways that were not possible in existing practice.

Visibility of carers' support needs

The tool, structured around 14 domains, enabled practitioners to show carers common areas of support they might need in a way their previous informal conversations did not. One practitioner described a typical conversation about carer support: *'And quite often in that kind of situation it is "oh I don't know what I want", you know, they can't focus, but the CSNAT allows them to focus on that because it is asking them specific questions.'* (P22)  The support domains presented allowed carers to see the range of areas in which others in their circumstances have needed support.

The tool was also a visible reminder of support needs to carers. One practitioner explained that a carer *'had had a look at our carer assessment form and he noted really that he needed extra support really around knowing what's going to happen at the end, and symptom management.'* (P04) It also enabled carers to consider whether their needs were changing, e.g. as the patient's condition deteriorated, this same carer had used a blank copy of the CSNAT to identify that his situation had changed and was able to discuss with the service at a subsequent visit that he now needed more support.

Legitimacy of support for carers

A particular difficulty faced by services was the reluctance of many carers to accept support for themselves: *'sometimes people brush it off, they, sort of, say, "oh, it's…I'm alright, I'll just get on with it" and "look after him."'* (P09)  Practitioners found that presentation of support domains on the tool itself helped with normalising concerns carers had: *'But I think what this does, it puts it in the minds of the carers that they are allowed to have needs and that it's okay to ask for help because we've made that introduction.'*(P22) A separate carer assessment tool acted to reinforce to carers practitioners' interest in them and the importance of them being supported.

Different types of conversations with carers

The CSNAT facilitated different conversations with carers, including wider family engagement. One practitioner had a visit where several family members were present including the patient: a difficult situation where they all felt that they wanted to be in charge, but the patient's daughter was being left to manage. The practitioner used the CSNAT with them as a group and described it as defusing the tension: *'I think because they were centring their care on dad and they couldn't think past that. So all your questions* [on the CSNAT] *brought it all out in the open and they all talked to each other with me.'* (P01) The CSNAT provided a focus: they were able to identify support needs the daughter had as the main carer which could be met by other family members and those where the family as a whole needed some external support.

Practitioners also found that the CSNAT also facilitated conversations with patients. It enabled them to demonstrate the capability of carers but also to highlight where they did need support for themselves: *'I've used it sometimes as a way of saying to a patient, "look this is what he does for you; he does all your medication, he does all of this, he does your washing, and the only thing he's*

*not doing is having a bit of time to himself in the day."'(P09).* In this instance the CSNAT provided a way to show both patient and carer the role played by the carer but also that support was needed to enable him to continue in a caring role.

**Mechanisms of action**

The impact of using the CSNAT, as compared to existing practice, came about when practitioners changed their approach to one that incorporated the CSNAT into a carer-led process of assessment and support. This section examines how this change in approach, that made positive impacts possible, was achieved in practice.

Creating a space for the separate needs of carers

Practitioners who found the CSNAT beneficial developed their own ways of introducing the tool during visits: planning ahead and adjusting their introductory 'spiel'. One simple method was to introduce the CSNAT as something for the carer along with the patient notes to be completed on visits: '"*BUT there is an assessment for YOU". And that's, as I say, that's when she burst into tears like no-one had really thought about her.'*(P04) The space created for carer needs did not have to be in a separate physical place, simply a separate focus on them: '*and then what I did when I first started using it was I said "now, can we have a few minutes to talk about […] what help that you need."'* (P16) Often practitioners had to make a leap of faith and try a different approach to realise its effect not just on carers but also on themselves. In this example the practitioner recognised that she had not been able to address the carer's situation in previous contacts: '*I let him have a look at it himself, I didn't read it out to him, because I think he needed to do that. And he did, he filled it all in and I did get stuff from that so it, it was very useful*.' (P05)

In some cases it was not always possible to create a separate space during the visit itself: '*I think you do just pick up on when it's the right time to go through it with them […] and when it's the right time to say, "look, this is for you and I want you to look through this when it's a bit quieter and I will phone you next week."'* (P22) With this approach some method of follow up CSNAT conversation was established, e.g. one practitioner left a CSNAT for a carer to complete even though she said: '*the previous two times I didn't feel as if there was any connection between us at all really, I always felt as if I was in the way.'* (P10) At a later visit the practitioner had a separate conversation to discuss the completed CSNAT and found it facilitated her contact with the carer: '*I found out about the daughter and I feel now that I actually know her, and I didn't know her, she hadn't opened up at all and I don't think she's opened up to anybody. But the CSNAT enabled her to open up and express lots of fears and concerns.'* (P10)

Providing an opportunity to express needs

Practitioners found that the CSNAT enabled engagement with carers to express their support needs not previously possible. One carer, who always left the room during practitioner visits, chose to complete and return the CSNAT: '*which was the first time really either I or the district nurse or the GP had had that face to face meeting with him. […] So it was just really helpful, because I think without the CSNAT form it would have been difficult to say, "look, shall we go and sit down", without him perhaps making an excuse*.' (P21) Practitioners also identified that contacts using their existing informal approach did not always reveal any needs whereas the CSNAT did, which was often

unexpected. Describing her contact with a carer, one nurse explained: '*She didn't seem to identify many concerns at all. Well no concerns in fact. So I left the CSNAT with her and asked her if she would post it back to me, and she was very happy to do that. When I received the CSNAT back in the post I was quite surprised at the amount of information that was on it, and the areas that had been identified.*' (P10)

Carer prioritised support needs

The areas in which carers needed more support were not always those practitioners anticipated: '*[the carer's support needs] funnily enough, were more about discussing his illness and finding out more about it […] rather than, "well I'm struggling to get round the house I could do with a bit of practical help in the home."*' (P14) Nor did practitioners always anticipate domains prioritised by carers: '*What I found particularly useful is the things that I thought she might not be able to cope with were the things she was coping with, and the things she wasn't able to cope with - I was quite surprised.*' (P26) Even though carers only wanted a little more support in some domains, these could be prioritised in terms of urgency of supportive input.

The change in approach to carer-identified needs not only meant that they were supporting carers in areas they wanted help with, it also benefitted their own practice: '*my assessments can be a bit long and long winded. I think sometimes I'm guilty of giving people too much information all at once. So what I've tried to do on a subsequent assessment was to do the CSNAT first before I told them anything about the service.*' (P09) This was followed up later in the study:

Interviewer*: So does that mean you're actually having to say less to them in total?*

P09*: 'Yeah, because you don't have to give them the whole spiel because […] you individualise it.*' By focusing on what the carer actually wanted help with, less time was spent on aspects of support either not needed currently or already met.

**Discussion**

This paper investigates practitioners' experiences of the CSNAT intervention, a carer-led approach to assessment and support using an evidence based, comprehensive measure of carer support needs in palliative home-care practice. Initial apprehensions of some practitioners about using the CSNAT did not manifest themselves in practice. Rather practitioners, who used the CSNAT within a carer-led process of assessment and support, identified positive impacts including providing greater visibility of support needs, legitimising support for carers and opening up different conversations with carers. These benefits were additional to what was achieved from existing approaches to identifying carer needs. Creating a space for the separate needs of carers, providing an opportunity for carers to express support needs and responding to carer–prioritised support needs were identified as mechanisms of action, enabling a positive impact when the CSNAT was used.

While positive benefits of the CSNAT have been demonstrated, the study's limitations should also be noted in that findings are practitioner-reported and come from two service provider organisations. In a UK context, subsequent work on the CSNAT seeks to address these limitations by reporting the impact of the CSNAT on outcomes for carers in bereavement in a stepped wedge cluster trial [16] and perspectives of carers themselves on the CSNAT collected as part of this trial. The CSNAT has also been used in a further cluster trial of its impact on current caregiving experiences in Western

Australia. The Australian study found positive effects: a significant reduction in carer strain through the caregiving period.[17]

Some of the difficulties practitioners describe in supporting carers are recurrent and long-standing themes within the palliative care literature: not only carers 'not knowing' what support might be available, but also not even being aware of what they 'don't know.'[11;18;19] Also well recognised is the reluctance of carers to accept support for themselves, preferring instead that care be provided for the patient.[11;20-22] This study has found that the CSNAT goes some way towards addressing these difficulties, an important step forward in the context of the substantial body of evidence of the impact that caregiving has on carers.[1;23-27] Incorporating the CSNAT in the assessment process was found to help carers with 'not knowing' through allowing visibility of support needs. It was also felt to normalise needs, allowing being supported to be seen as a normal part of taking on a caring role. In a recent study on barriers to identifying carers of people with advanced disease, Carduff et al [28] found that practitioners in primary care were not seen to legitimise carer needs and this was difficult for carers. In contrast in this study, where practitioners used the CSNAT, rather than their previous unstructured approach, they were able to demonstrate their interest in supporting carers and meeting their needs.

Crucially, what this qualitative study enabled was further understanding of the mechanisms of action of the CSNAT in terms of creating a space for the separate needs for carers and affording them the opportunity to express and prioritise their needs. Qualitative findings from a recent trial of the CSNAT in Western Australia reported similar results and that the CSNAT approach gave carers permission to ask for help, particularly in relation to emotional support needs.[29] This contrasts with 'doorstep conversations' that often typified practitioners previous informal contacts with carers,[11;28] where discussions were often limited. Some practitioners expressed surprise that carers, when using the CSNAT, identified support needs that would not have otherwise been uncovered. There may be different possible explanations for this positive effect, one of which is that the tool allowed carers the privacy to identify support needs without the need for a discussion front of the patient. Alternatively the CSNAT gave carers a chance to reflect on their situation and control the timing of accepting support. Nolan et al [30] have argued that the timing of support in relation to needs is a key factor in determining whether services are acceptable or not. In these instances, carers had time to reflect on their needs but also the opportunity to discuss support needed at a time when they felt ready.

The key finding of this study, however, is that a tool <u>alone</u> does not bring about benefits described; rather they resulted from a change in assessment approach to one that was facilitated by practitioners but carer-led. Creating space for carers to identify their separate support needs distinct from those of patients and providing an opportunity to focus on carer priorities were key changes in approach. Such changes in practice are always challenging, but these underlying principles are not new: simply to date they have not been applied within a carer assessment context. The current practice model for holistic needs assessment (HNA)[31] for patients identifies a very similar approach: engaging patients more fully, facilitating choice and supporting self-management, all of which contributes to enabling practitioners to better concentrate their efforts on meeting relevant needs.

**Implications for practice**

We already know that family carers are essential in palliative and end of life care but suffer considerable impacts from taking on a caring role. Only carers themselves know what they really need; and needs will be individual. This study identified limitations in existing approaches to identifying carer needs and positive impact where practitioners integrated the CSNAT into a carer-led process of assessment and support. The CSNAT used routinely with all carers has the potential to normalise support for carers, facilitate delivery of carer-identified support likely to improve carer outcomes, with the potential to enable targeting of resources in a more effective manner. Furthermore use of the CSNAT also offers added benefits to practitioners and provider organisations. The tool enables practitioners to evidence their assessment and support for carers in a way that was not previously possible. At an organisational level it has the potential to demonstrate the support provided for carers by palliative care services.

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| **Figure 1: Hospice Home-care Context** | | |
|---|---|---|
| | Setting A | Setting B |
| Service size (referrals per month) | 40-50 | around 100 |
| Average length of care before patient death | Four to six weeks | Six months |
| HHC teams participating | Hospice at Home service | (1) Community Specialist Team (2) Hospice at Home Team |
| Team composition | Dual role: Service Manager/lead practitioner Nurse co-ordinators (RGNs) (6) Health Care Assistants (18) | Single Service Manager for both teams. (1) Clinical Nurse Specialists (18) plus 1 staff nurse (2) Nursing Sisters (3) plus Health Care Assistants (15) |

**Figure 2: Service development components**

*(1) Staff training*
Service managers, who were leading on implementation, and the research team worked together to develop CSNAT training workshops. Thereafter the training was delivered by the service managers covering background and development of the tool and the process of using it as a practice tool. Each service also decided which staff members would use the tool (trained staff only or healthcare assistants (HCAs)). This was to promote 'ownership' of the CSNAT by the services.

Initial protocols for using the tool for both trained staff and HCAs were developed at Setting A. Training materials and these protocols were then shared with the service manager at Setting B together with feedback on experiences of implementation from Setting A. This enabled the training package at Setting B to be revised and updated based on initial implementation experiences.

*(2) The CSNAT as an assessment tool for use in practice*
Research work to date had resulted in a comprehensive assessment tool, comprising 14 support domains, a section on 'anything else' to allow the carer to add any needs not already covered and a simple system enabling carers to indicate whether more support was needed in each domain (no; a little more; quite a bit more; very much more).[13]

Each service then had to determine how the tool would fit within existing practice recording systems, either paper based or electronic. This included deciding which details to record about the carer, identifying priorities and an action plan for support to document input provided. Both services decided to adopt a simple A5 format customised with their own logo on the front.