Institution: University of Cambridge		
Unit of Assessment: 4		
Title of case study: The Carer Support Needs Assessment Tool intervention (CSNAT-I): enabling comprehensive, tailored support for family carers		
Period when the underpinning research was undertaken: January 2008 – present		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Dr Gail Ewing	Research Associate, then Senior Research Associate	2005 – March 2020
Period when the claimed impact occurred: August 2013 - present		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact

At any given time more than half a million people in the UK are providing care to someone who is in their last year of life, with significant effects on all aspects of carer health and well-being. The Carer Support Needs Assessment Tool intervention (CSNAT-I) is a comprehensive, person-centred approach for supporting family carers which meet the need for evidence-based practice in end-of-life care (EOLC). The UK Royal College of General Practitioners (RCGP) and health departments in Australia and Norway recommend CSNAT-I. Training in its use has been delivered face to face to 134 UK organisations, and to teams in eight countries. Development of an online CSNAT Approach Training and Implementation Toolkit now enables practitioners nationally and internationally to implement CSNAT-I. As of July 2020, 168 organisations in 12 countries are licensed to use CSNAT as a practice intervention, and another 73 research licences have been issued for 58 organisations to use in 26 countries. The tool has been translated into 15 languages, allowing delivery of targeted, tailored support to carers worldwide.

2. Underpinning research

In England it is estimated that over half a million people at any given time are providing EOLC (NHS England: Actions for End of Life Care: 2014-16). These carers play a vital role in enabling patients to be cared for at home and die there if that is their preference (Gomes & Higginson, 2006; Turner & Fleming, 2019). But this role has a significant impact on carers' own health: 83% of cancer carers suffer clinically significant psychological morbidity in patients' last three months of life (Grande et al, 2018), affecting over 400,000 UK carers annually. High levels of caregiver burden result in social isolation, work difficulties and financial hardships (Stajduhar et al, 2010; Funk et al, 2010). A common reason for costly hospital admission of patients at end of life is breakdown of informal care at home (Gott et al, 2013), Reyniers et al, 2016).

Development of CSNAT-I

The research programme resulting in CSNAT-I was a measured response to acknowledgement in the UK EOLC Strategy (2008) of the key role of family carers, the impacts on them, and their need for assessment and support. CSNAT-I represents a fundamental change from the pre-existing practitioner-led, informal approach to supporting carers, often little more than asking a carer 'How are you?' within the patient assessment. CSNAT-I comprises an evidence based, comprehensive assessment tool which is integrated into a defined five stage person-centred approach. This enables a holistic and systematic process of assessment that is practitioner facilitated but carer-led, that is tailored to the carer's individual support needs. The programme throughout represents joint work by Dr Gail Ewing (University of Cambridge) and Professor Gunn Grande at the University of Manchester.

The initial CSNAT studies [1,2] involved 300 carers in the development and validation of a tool encompassing assessment of physical, practical, social, financial, psychological and spiritual support needs that policy indicates should be delivered to carers during EOL care. The initial study obtained 75 carers' perspectives of key aspects of support they needed during EOLC to structure the tool. Then a further 225 carers were surveyed to assess the tool's face, content and criterion validity. Results confirmed that CSNAT is valid tool for direct identification of carers' support needs. The tool uses a simple question and answer

format to address 14 broad domains of support needs with the carer. It is therefore comprehensive but concise for practice use. However, the CSNAT (the tool itself) is only one component of an intervention for practice. Further research identified delivery of the evidence-based tool within a person-centred approach as the mechanism of action of the intervention, CSNAT-I [5].

Demonstrating and enabling improved outcomes for carers

Two cluster trials of CSNAT-I involving 1003 carers demonstrated improved outcomes for carers. In an Australian study [3], the intervention group showed a significant reduction in caregiver strain in current carers compared with the control group. In the UK [4], CSNAT-I carers had significantly lower levels of early grief and better psychological and physical health in bereavement.

Understanding factors influencing intervention use in practice

The ultimate goal of the CSNAT-I research, i.e. to achieve better carer outcomes, depends on successful, consistent embedding of the intervention in routine practice. Comprehensive, carer led assessment and support is a significant change from existing practice. Ewing's research has therefore also included a focus on understanding factors affecting its initial adoption [6] and it being sustained in practice through studies of implementation of CSNAT-I at scale across 36 UK palliative care services [7,8], as well as an in-depth case study in a large hospice [K].

Facilitating implementation on a global scale

Lessons learned across the implementation studies [4-8] and the in-depth hospice case study informed training packages used to support intervention delivery. The CSNAT team have subsequently refined, expanded and updated their training materials to provide an essential adjunct to implementation: an online CSNAT Approach Training and Implementation Toolkit. Launched in February 2019, it enables practitioners nationally and internationally to undertake training at both the individual and organisational level to effectively implement CSNAT-I (http://csnat.org/training/). The dedicated website provides additional resources and support.

3. References to the research

All references listed below have been published in peer-review journals. The research is supported by competitively won grants.

1. Ewing G, Grande G. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. *Palliative Medicine* 2013; *27*(3): 244-256. DOI: 10.1177/0269216312440607.
2. Ewing G., Brundle C., Payne S., Grande G. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study. *Journal of Pain and Symptom Management* 2013; 46(3): 395-405. DOI: 10.1016/j.jpainsymman.2012.09.008.
3. Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L, Stajduhar K, Ewing G. The impact of the Carer Support Needs Assessment Tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLoS One* 2015; *10*(4): e0123012. 10.1371/journal.pone.0123012.
4. Grande GE, Austin L., Ewing G, O'Leary N, Roberts C. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: A stepped wedge cluster trial. *BMJ Supportive & Palliative Care* 2017; *7*(3): 326-334. DOI: 10.1136/bmjspcare-2014-000829.
5. Ewing G, Austin L and Grande G. The role of the Carer Support Needs Assessment Tool (CSNAT) in palliative home care: qualitative study of practitioners' perspectives of its impact and mechanisms of action. Palliat Med. 2016; 30(4):392-400. *
6. Austin L, Ewing G, Grande G. Factors influencing practitioner adoption of carer-led assessment in palliative homecare: A qualitative study of the use of the Carer Support Needs Assessment Tool (CSNAT). *PLoS ONE* 2017; *12*(6): e0179287. DOI: 10.1371/journal.pone.0179287.
7. Diffin J, Ewing G, Harvey G, Grande G. The influence of context and practitioner attitudes on implementation of person-centred assessment and support for family carers within palliative care. *Worldviews on Evidence-Based Nursing* 2018; *15*(5): 377-385. DOI: 10.1111/wvn.12323.

8. Diffin J, Ewing G, Harvey G, Grande G. Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: A qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. *BMC Palliative Care* 2018; *17*(129). DOI: 10.1186/s12904-018-0382-5.

Key competitive funding received

- Ewing G (PI), Grande G, Payne S on behalf of NFFH@H. Identification of key components of end- of-life care for development of a measure to improve nursing support to family carers of dying patients. Burdett Trust (GBP43,633: 15 months), Jan 2008
- Ewing G (PI), Grande G, Payne S. Development of a 'what matters to family carers' assessment tool for evaluation of care and support at end of life. Dimbleby Cancer Care (GBP38,859: 15 months), Feb 2009.
- Grande G (PI), Ewing G, Booth G, Todd C, Payne S. Piloting a carer support needs assessment tool to facilitate communication in palliative home care practice, BUPA Foundation (GBP19,946), May 2010- Jan 2011.Grande G (PI), Ewing G, Greene K, Todd C, Payne S. Evaluating the impact of a Carer Support Needs Assessment Tool in Hospice at Home care: a feasibility trial. Dimbleby Cancer Care (GBP78,395), Sept 2010-June 2013.
- Grande G (PI), Ewing G, Greene K, Moore J, Payne S, Todd C. Trial to evaluate the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in hospice home care. NIHR Research for Patient Benefit Programme. (GBP240,140), 01/05/2012 – 30/4/2014.

4. Details of the impact

In 2014, the World Health Organisation (WHO) estimated that the number of people in need of palliative care at the end of life is 20.4 million (WHO: Global Atlas of Palliative Care at the End of Life, 2014) of whom many will be looked after by family members. Cambridge University research (in collaboration with the University of Manchester) has had a significant impact on policy guidelines for carer support and on the practice of carer assessment and support both nationally and internationally.

Impact on practice guidelines and recommendations

Although the importance of supporting carers is widely recognised, there was a need for a systematic mechanism to identify and assess carers' needs in the last year of life. In August 2016, Hospice UK commissioned Ewing and Grande to undertake a study to develop national recommendations to achieve comprehensive, person-centred assessment and support for family carers towards EOLC. The 2018 report included 10 guidelines on structures and processes for the organisational change needed to achieve this NHS England policy ambition [A]. Hospice UK also commissioned a national survey of UK hospice providers, to benchmark current provision against the guidelines (survey report published in November 2019). To support hospices to develop carer assessment and support strategies in line with the recommendations, Ewing and Grande are now working in conjunction with Hospice UK to develop a knowledge network entitled 'Hospice Support for Family Carers'.

In February 2019, the RCGP and Marie Curie published new "Daffodil Standards" for EOLC. Standard 3 (Carer Support before and after death) identifies the CSNAT for assessment of carers' needs providing a link to the CSNAT Toolkit [B]. A total of 1369 GP practices have signed up to the Standards across the UK (18% sign up rate in England). RCGP website analytics (up to November 2019) further indicate reach: Standard 3 had 1485 unique visitors and 1810 page views.

In Australia, the government of New South Wales has developed a 'Blueprint for Improvement' to provide a flexible guide for health services to meet the needs of people approaching and reaching the end of life, their families and carers. 'Essential Component 5: Care' is based on the assessed needs of the patient, carer and family, and identifies the CSNAT as a core palliative care tool [C]. This complements the guidance still in place from the Department of Health in the state of Victoria for the CSNAT as the only recommended

clinical tool for assessment of family carers in EOLC [C]. In 2017, the Norwegian Government's guidelines recommended the implementation of the CSNAT within patient pathways [D], then in May 2020, use of CSNAT-I for all carers*. "4 of 10 Health Trusts have signed the license on behalf of their 9 palliative centers, another 4 have decided to so (8 centers)"* [D]. Ewing and Grande provided a training workshop in February 2019 for practitioner leads in three of the four Norwegian palliative care regions and are collaborating with regional leads on a protocol to manage CSNAT licence requests and practitioner training.

Stakeholder engagement and uptake

The impact of the CSNAT research on practice was recognised by the award of the first Practice-Changing Research Study Prize by the NIHR and Charities Consortium for Hospice and Community Research in April 2018, for uptake in practice detailed below [E].

As a result of stakeholder engagement by CSNAT team (nationally at key end-of-life care conferences, two successful CSNAT conferences and networking events for impact; and internationally through two CSNAT workshops for international teams and at the European Association for Palliative Care Conference, CSNAT interest group meetings) there is a continual demand from provider organisations to use CSNAT-I to provide tailored support within palliative care. The tool itself (CSNAT) is protected by copyright but made available free of charge to health services and not-for-profit organisations through a licensing process: the licence database held at the University of Manchester has enabled us to gauge the intervention's impact.

Uptake of CSNAT

85 organisations now hold practice licences in the UK and have adopted the tool in routine practice [F]. The CSNAT-I has been built into the Carer Strategy of hospices including the leading London hospice of St Christopher's [G] and St Barnabas Hospice in Worthing. Both hospices created new appointments specifically to facilitate CSNAT-I implementation across the organisation, measuring changes, understanding carers' needs and widening support for carers. CSNAT-I is also being used to demonstrate hospice impact on nurturing compassionate communities [G] and improved service quality and commitment in supporting carers of people with dementia [G].

Outside the UK, 83 organisations hold practice licences in 11 countries, including Australia (42 licences), Canada (regional umbrella license), China, Denmark, Germany, Ireland, New Zealand, Norway, Sweden, Taiwan ROC and USA. CSNAT has also been translated into 15 languages and culturally adapted for local implementation to better assess and address carers' needs [F].

A further 73 licences have been issued to 58 organisations to use the CSNAT in research studies to identify carers' unmet needs, including in Australia, Austria, Belgium, Brazil, Canada, Denmark, France, Germany, Greenland, Iceland, India, Ireland, Italy, Lebanon, Netherlands, Norway, Philippines, Portugal, Rwanda, Singapore, South Korea, Sweden, Thailand, Turkey, UK and USA [F].

Impact on practitioners through training

Successfully implementing the CSNAT in practice requires practitioners to learn about CSNAT-I and how it can fit within their practice. The CSNAT team has delivered face-to-face training to 134 UK healthcare organisations to date, initially to 44 as part of their research studies, and then as 'train the trainer' workshops to teams from a further 90 organisations who wished to use the intervention in practice. Overall, 538 practitioners and managers from hospice, hospital, community and primary care teams attended workshops hosted in Scotland [H], Wales, and throughout England. Ewing and Grande were also commissioned by NHS England and the RCGP to co-produce a Masterclass for GPs on carer identification, assessment and support. Launched in February 2020, these educational resources (Powerpoint and podcast) are part of the quality improvement programme for EOLC in general practice [I]: with 1000 podcast 'listens' to June 2020. Ewing and Grande were also

able to extend training to leads in 16 international teams (from Canada, Australia, Austria, Denmark, the Netherlands, Sweden, Portugal and Norway) as part of research collaborations, through opportunistic visits and through planned international training workshops. For example, in September 2019 they delivered workshops to 57 practitioners and managers in Edmonton and Calgary, Canada following Alberta Health Services' decision to implement the CSNAT intervention province-wide [J].

Since February 2019, the reach of the CSNAT intervention has extended considerably with the launch of the online CSNAT Approach Training and Implementation Toolkit. Now all UK and international teams who wish to use the intervention in practice have access to a full training programme that can be self-completed. To July 2020 there have been 586 toolkit registrations. 235 certificates of completion were downloaded by users prior to Continuing Professional Development (CPD) registration.

Impact on carers

The benefits of CSNAT-I to carers were demonstrated in two trials [3, 4]. Carers reported that using the CSNAT helped them express their needs and gain support, validation, reassurance and empowerment: *"The reassurance that you're not the only one, it's not selfish to ask for help for yourself. If you see other people doing it then it's okay to do it yourself sort of thing."* [K]. *"I found it a very useful exercise. It was very helpful in focusing my mind on what was happening, on those areas where I needed help and what help might be. It helped me acknowledge, and not be embarrassed by the fact, I was a little at sea over some of the implications of H's condition and the changing role that I found myself playing in relation to his illness. It provided a framework whereby some objectives, however small, could be set"* [K]. CSNAT-I has been increasingly integrated into assessment of carers in palliative care services through the licensing process. Where organisations have provided figures for carer assessments undertaken monthly, an estimate of 75,000-120,000 carers will have been supported by CSNAT-I. Based on implementation study statistics (7,8), the estimate is 16,500-26,500 between 36 organisations. These figures do not include region wide licences such as in Alberta, Canada and in Norway.

5. Sources to corroborate the impact

A. Hospice UK **(i)** Testimonial from Chief Clinical Officer and Head of Research & Innovation page 1 **(ii)** Report: Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. page 5

B. (i) RCGP and Marie Curie "Daffodil Standards" for End of Life Care. page 2 **(ii)** RCGP page analytics data

C. Uptake of CSNAT in Australia **(i)** Palliative and End of Life Care: A Blueprint for Improvement. page 4 **(ii)** Report for the Department of Health (Victoria) Core palliative care tool for use by clinicians to assess carers' needs, page 24

D. Norwegian implementation of CSNAT **(i)** Testimonial from Regional Lead in Norway. page 1 **(ii)** Norwegian recommendations. NOU 2017: 16 *På liv og død— Palliasjon til alvorlig syke og døende* (translating to "On life and death: palliation for the seriously ill and dying") pages 123, 127 (*language: Norwegian*).

E. Award certificate of Practice-Changing Research Study Prize by the NIHR and Charities Consortium for Hospice and Community Research in April 2018

F. Who is using CSNAT. Available from: http://csnat.org/current-users.

G. Examples of CSNAT usage in practice**: (i)** Testimonial from St Christopher's Hospice **(ii)**Princess Alice Hospice Surrey 2019 Trustees annual report. page 9 **(iii)** Royal Trinity Hospice Quality Account 2018-19. page 6.

H. Testimonial from Ayrshire Hospice

I. Testimonial from National Clinical Director for End of Life Care NHS England

J. Testimonial from Alberta Health Services, Canada

K. Reports from carers: (i) Using the CSNAT in Hospice – presentations from four hospices. pages 9, 10.(ii) What carers have told us about the CSNAT (page 13)