

<b>Institution:</b> The University of Manchester		
<b>Unit of Assessment:</b> 3 (Allied Health Professions, Dentistry, Nursing and Pharmacy)		
<b>Title of case study:</b> Improving health service support for family carers during end-of-life care: implementing a Carer Support Needs Assessment Tool Intervention (CSNAT-I) and principles for organisation change		
<b>Period when the underpinning research was undertaken:</b> January 2008 - January 2018		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name:</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Gunn Grande	Professor of Palliative Care Reader Senior Lecturer	2011 - date 2009 - 2011 2007 - 2009
Lynn Austin	Research Associate	2010 - 2015
Janet Diffin	Research Fellow Research Associate	2016 - 2017 2013 - 2015
<b>Period when the claimed impact occurred:</b> August 2013 - July 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<b>1. Summary of the impact</b>		
<p>Family carers provide essential end-of-life care worldwide, with detrimental consequences to their health. In the UK approximately 500,000 provide such care annually, with 83% suffering significant mental health impact. The University of Manchester (UoM), in collaboration with the University of Cambridge, developed and trialled an effective, evidence-based intervention (CSNAT-I) that improves carer health, a CSNAT-I training programme, and provided national recommendations for organisational implementation of carer support. UK and worldwide the research team trained over 830 healthcare practitioners in CSNAT-I. 85 healthcare organisations across the UK and 83 organisations across 11 other nations use CSNAT-I, benefitting up to 120,000 carers. NHS England's carer Masterclass for general practice and Hospice UK's carer strategy are based on CSNAT-I and the group's recommendations. CSNAT-I is currently being rolled out within a structured implementation strategy across Norway and Alberta Province, Canada.</p>		
<b>2. Underpinning research</b>		
<p>Family carers are lynchpins in enabling end-of-life care at home and relieving hospital pressures, in accord with patient preferences and government policy. In the UK alone this involves an estimated 500,000 carers annually, 83% (400,000 plus) of whom suffer likely significant psychological morbidity, representing a substantial public health problem. Although the Department of Health End of Life Care Strategy (2008) stressed that carers' support needs should be assessed and addressed, evidence and guidance for achieving this in practice were missing.</p> <p>The research underpinning this impact case addressed this gap by providing 1) an evidence-based, person-centred carer assessment and support intervention consisting of an evidence-based assessment tool and a five-stage support process (CSNAT-I) that improves carer outcomes; 2) healthcare practitioner CSNAT-I training; 3) organisational implementation principles, described in points a.-i. below.</p> <p>The research conducted 2008-2018 benefitted from a strong and equal collaboration between the Universities of Manchester and Cambridge (Dr Gail Ewing). The grants, Principal Investigator or Co-Principal Investigator and Research Associates/Research</p>		

Fellows were all based at UoM, but programme development, execution, analysis and publication was fully joint with Cambridge. Training development was led by Cambridge. Training and support websites are hosted by UoM and NIHR CLAHRC/ ARC (Collaboration for Leadership in Applied Health Research and Care/ Applied Research Collaboration) Greater Manchester (GM). The research team:

- a. Developed a comprehensive **Carer Support Needs Assessment Tool (CSNAT)©** with N=75 carers across 5 UK hospice home care (HHC) services [1].
- b. Demonstrated the content validity, criterion validity and comprehensiveness of the **CSNAT©** through testing with carers across UK (N=225 from 6 HHC services) [2].
- c. Identified principles for effective use of CSNAT in healthcare practice (**CSNAT-Intervention**) via feasibility testing with practitioners at 2 HHC services [3].
- d. Demonstrated the benefits of **CSNAT-I** to carers through pragmatic cluster RCTs with 3 Australian [4] and 6 UK HHC services [5]. **Carers who received CSNAT-I had significantly reduced strain during caregiving (effect size 0.35) [4] and significantly reduced grief, improved mental and physical health post-bereavement [5].**
- e. Identified the key factors for successful implementation of **CSNAT-I** through an implementation study with 36 UK hospice/palliative services [6] and one case study.
- f. Established the most effective training principles for **CSNAT-I** through an iterative process of training delivery, feedback and refinement over 5 years [4-6].
- g. Developed, tested and refined a CSNAT-I **online Training and Implementation Toolkit** based on lessons learnt from c., e. and f.
- h. Developed **Hospice UK National Recommendations** on core principles for implementing comprehensive, person-centred carer assessment and support in healthcare organisations, from secondary analysis of data from e. combined with stakeholder consultation (100+ contributors) (Hospice UK/NIHR CLAHRC GM funded).
- i. Benchmarked current performance of UK hospices against national recommendations from h. through a national survey of all Hospice UK member organisations (Hospice UK/NIHR CLAHRC GM funded).

Further research has shown benefits of CSNAT-I beyond palliative care, including improved preparedness and reduced strain in carers of older people after discharge from hospital (Australian RCT by Toye et al. *Int J Nurs Stud* 2016; 64: 32-61) and suitability of CSNAT© for carers of patients with motor neurone disease (qualitative study, Ewing et al., in press).

### 3. References to the research

1. Ewing G, **Grande GE**. Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. *Palliat Med* 2013; 27: 244-256. doi: [10.1177/0269216312440607](https://doi.org/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. *J Pain Symptom Manage* 2013; 46: 395-405. doi: [10.1016/j.jpainsymman.2012.09.008](https://doi.org/10.1016/j.jpainsymman.2012.09.008)
3. Ewing G, **Austin L, Grande G**. The role of the Carer Support Needs Assessment Tool in palliative home care: a qualitative study of practitioners' perspectives of its impact and mechanisms of action. *Palliat Med* 2015; 30 (4); 392-400. doi: [10.1177/0269216315596662](https://doi.org/10.1177/0269216315596662)
4. 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. doi: [10.1371/journal.pone.0123012](https://doi.org/10.1371/journal.pone.0123012)

5. **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 Support Palliat Care* 2017; 7 (3): 326-334. doi: [10.1136/bmjspcare-2014-000829](https://doi.org/10.1136/bmjspcare-2014-000829)
6. **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 Palliat Care* 2018; 17:129. doi: [10.1186/s12904-018-0382-5](https://doi.org/10.1186/s12904-018-0382-5)

#### 4. Details of the impact

##### Context

Prior to this work there was a lack of an evidence-base, tools, implementation strategy and principles for consistent end-of-life carer assessment and support. The research team has implemented evidence-based carer assessment and support in healthcare practice via:

- 1) "pathways" of training development and collaboration;
- 2) broad reaching national and international roll-out within healthcare organisations;
- 3) national and international guidelines;
- 4) direct impact on carers assessed and supported by practitioners.

##### Pathways to impact

###### Face-to-Face (F2F) CSNAT-I training for practitioners

From autumn 2013, F2F training used a train-the-trainer model to cascade CSNAT-I to a wide range of healthcare organisations by training practitioner 'champions' to train others within their teams. Added user support was provided by two national conferences (2016, N=100; 2019, N=80) and online group meetings. Some teams further adapted the training materials to deliver CSNAT-I training throughout their region in the UK (Carers Trust/ Peterborough & Cambridge CCGs) and abroad (Canada; Austria). CSNAT has been translated into 15 languages [A].

###### Online CSNAT-I training for practitioners via Toolkit and support platform

The free online CSNAT-I Training and Implementation Toolkit was launched 11.02.2019 to extend national and international training delivery, further supported by information and resources on the CSNAT website. Organisations obtain a free CSNAT-I practice license following completion of practitioner training, and training is Continuing Professional Development (CPD) accredited. NIHR CLAHRC/ ARC Greater Manchester supported Toolkit development and now hosts the Toolkit.

###### NHS England Masterclass training of general practitioners 2020

NHS-E commissioned the research team to provide an online four-module Masterclass on improving carer support for general practice to support the Quality Improvement Programme for GPs, fully based on the team's CSNAT-I training and national recommendations for implementation [B].

###### Hospice UK collaboration to improve hospice carer provision

The research team worked with the largest UK hospice member organisation to guide, assess and improve hospice support for carers nationally (Hospice UK/ NIHR CLAHRC GM funded) [C].

###### International drivers for spread

International implementation has been spearheaded by feasibility studies and trials in Australia, Denmark, Netherlands, Austria/Germany, Canada to date (Sweden and Portugal setting up); supported by the research team via e-mail, Skype/ Zoom meetings, annual

CSNAT-I network meetings at European Association for Palliative Care Annual Congress (2016, 2017, 2018, 2019) and UK international workshops (2018, 2019).

### **Reach and significance of the impact**

#### Practitioners trained in CSNAT-I

Face-to-face training in CSNAT-I delivery has been provided to 538 UK practitioners from 134 organisations and to 57 practitioners abroad for cascading within their organisations. The Online Training and Implementation Toolkit has had 586 registrations and issued 235 certificates from launch 11.02.19 to 31.05.20.

#### Spread within UK to deliver CSNAT- I to carers within hospices, hospitals, community teams

- 85 UK healthcare organisations hold CSNAT-I Practice Licences [A], including:
  - an estimated 20% of Hospice UK member organisations.
  - Carers Trust/ Cambs & Peterborough CCG licence for 70 GP practices [D].
  - UK's flagship hospice, St Christopher's, where CSNAT-I is a central component of their Carer Strategy 2018: *"The person centred focus of CSNAT and the conversations around the 14 domains has transformed social work practice... The questions are empowering for carers... It emphasises what's strong with people rather than what's wrong with them... within the very diverse community of South London CSNAT has proven to be culturally relevant and sensitive"* [E].

#### Spread internationally to deliver CSNAT-I to carers within regions or individual healthcare organisations

- 83 healthcare organisations outside the UK hold CSNAT-I Practice Licences (in Australia, Canada, China, Denmark, Germany, Gibraltar, Ireland, New Zealand, Norway, Sweden, Taiwan, USA) [A].
- Canada: Alberta Health Services roll-out of CSNAT-I [F].
- Australia: 42 healthcare organisations have a CSNAT-I license following local trials [3] and Department of Health Victoria State recommendation (2010).
- Austria: roll-out across Austria/ Germany following adaptation of CSNAT-I which won an award from the German Society of Palliative Medicine.
- Denmark: successful trial of CSNAT-I in nine services.
- Netherlands: feasibility testing ongoing.

#### National and international guidelines promoting carer support/CSNAT-I, with added follow up

- The Royal College of General Practitioners (RCGP)/ Marie Curie recommend CSNAT-I for carer support in their guidelines for end-of-life care in general practice ("Daffodil Standards", 13.02.19) [D]. Standards provide prominent links to the CSNAT-I Training and Implementation Toolkit and website. 18% of GP practices in England have signed up to the Daffodil Standards.
- The research team's NHS England carer Masterclass is available to all GP practices nationally and has had nearly 1,000 podcast listeners since February 2020 [B]. The Masterclass coordinates with the Daffodil standards for wider impact.
- Hospice UK promoted to all members the research team's National Recommendations (2018) for organisational implementation of carer support, and the team's survey report (2019) on hospices' performance against national recommendations and launched a Project ECHO (online community of practice network teaching platform) for improvement of carer support (February 2020) [C].
- The Norwegian Government's May 2020 guidelines for national end-of-life care provision recommend CSNAT-I for all carers: implemented in three of the four Norwegian palliative care regions following the research team's workshops (February 2019) with regional leads to agree a national CSNAT-I implementation strategy [G, H].

National recognition for the impact of the research awards

The CSNAT-I team received the first NIHR and Charities Consortium Award for practice changing research 2018 and its impact [I].

Impact on carers

Based on implementation data and trial evidence [3, 4] tens of thousands of carers will have had reduced caregiver strain and improved outcomes in bereavement from CSNAT-I. Up to 120,000 carers have been supported through CSNAT-I based on CSNAT-I licensee's own estimates. Feedback from carers attests to the benefits of CSNAT-I, including being able to reflect on and express their own needs, and gaining reassurance and support *"It formalised what I probably knew I needed, but it's difficult to articulate when you're going through it...so yes it was very good"*; *"It gave me the reassurance I needed. It does make you feel less isolated, knowing if anything goes wrong, I'm not the only one making decisions"* [J].

**5. Sources to corroborate the impact**

- A. Access Database of CSNAT Licences and anonymised data from licence Permission Request forms available upon request. Electronic copies of permission forms and licences also held.
- B. Letter from National Clinical Director for End of Life Care NHS England and NHS Improvement (dated 17 July 2020), on value of CSNAT-I work, its commissioning into a carer support Masterclass for the Quality Improvement programme, web statistics on Masterclass use.
- C. Joint letter from Hospice UK Chief Clinical Officer/ Head of Research & Clinical Innovation from 2020, noting importance of the research team's work in helping them achieving Hospice UK strategic aims in supporting carers.
- D. RCGP/ Marie Curie Daffodil Standards recommendation of CSNAT- I for support of carers: <https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards/the-daffodil-standards/standard-3-carer-support-before-and-after-death.aspx>. which contains a link to the Carers Trust/ Peterborough & Cambridge CCGs GP Prescription Leaflet for carers incorporating CSNAT-I.
- E. Letter from Consultant Social Worker Patient and Family Support, St Christopher's Hospice from 2020 on how CSNAT-I has transformed their social work practice.
- F. Letter from Medical Lead, Alberta Health Services, Edmonton Zone (dated 19 March 2020), detailing the joint collaboration and the roll out to date of CSNAT-I within Alberta Province, Canada.
- G. Norwegian Parliament approval of recommendation from Department for Health & Care 7 May 2020 that CSNAT-I should be used for end-of-life care nationally, p. 55 <https://www.regjeringen.no/no/dokumenter/meld.-st.-24-20192020/id2700942/>
- H. Letter from Regional Advisory Unit for Palliative Care, Department of Oncology, Oslo University Hospital from 2020, on the value of CSNAT-I and roll-out within Norway to date.
- I. Award certificate: The CSNAT-I team received the first NIHR and Charities Consortium Award (2018) for practice changing research, encompassing work in publications [1- 5].
- J. Aoun S, Deas K, Toye C, Ewing E, Grande G, Stajduhar K (2015). Supporting family caregivers to identify their own needs in end-of-life care: qualitative findings from a stepped wedge cluster trial. Palliative Medicine; 29(6): 508-517: on the value placed on CSNAT-I by carers.