

# Palliative and End of Life Care Group

## Research studies November 2018



UNIVERSITY OF  
CAMBRIDGE

Public Health and Primary Care  
The Primary Care Unit



<http://www.phpc.cam.ac.uk/pcu/research/research-groups/end-of-life-care/>

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# **1. Current and recent research studies**

## **1a. Care provision**

### **a) Data Sharing in End of Life Care: “Prepared to Share?”**

*Dr Mila Petrova, Post-Doctoral Research Associate [mp686@medschl.cam.ac.uk](mailto:mp686@medschl.cam.ac.uk)*

An evaluation of the Cambridgeshire and Peterborough Clinical Commissioning Group initiative for Data Sharing in End of Life Care nested in broader research on patient data sharing, health information technology and EPaCCS (Electronic Palliative Care Coordination Systems). A mixed methods study including interviews (40), survey of local GPs and Practice Managers (64% response rate), comparison with four existing systematic reviews (135 studies), case study comparisons (with London’s “Coordinate My Care” and the South West EPaCCS) and ethnographic observations. We found that challenges outnumber drivers in the development and use of EPaCCS and patient data sharing, which calls into question the policy steer that EPaCCS become available in all areas of England by 2020. <sup>1 2 3</sup>

### **b) Optimum ‘Hospice at Home’ Services for End of Life Care**

*Dr Brooke Swash, Post-Doctoral Research Associate [bes25@medschl.cam.ac.uk](mailto:bes25@medschl.cam.ac.uk)*

What are the features of Hospice at Home models that work, for whom, and under what circumstances? Building on our previous hospice at home research <sup>4</sup> this national study is undertaking:

- a) National survey of hospice at home services
- b) Measurement of service use
- c) Post-bereavement interviews with carers to assess quality of dying and death
- d) In depth interviews with carers, commissioners and providers to explore barriers and enablers to hospice at home service provision

Study protocol published. <sup>5</sup>

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<sup>1</sup> Petrova M, Riley J, Abel J, Barclay S (2016). “A crash course in EPaCCS (Electronic Palliative Care Coordination Systems): eight years of successes and failures in patient data sharing to learn from”. *BMJ Supportive and Palliative Care*: published online DOI:10.1136/bmjspcare-2015-001059

<sup>2</sup> Petrova M, Barclay M, Barclay SS, Barclay S (2017). “Between “the best way to deliver patient care” and “chaos and low clinical value”: General Practitioners’ and Practice Managers’ views on data sharing”. *International Journal of Medical Informatics*: 104: 74 - 83 doi.org/10.1016/j.ijmedinf.2017.05.009

<sup>3</sup> Petrova M, Barclay S. Something’s awry (again) in the debate on patient data sharing. (2018) *British Journal of General Practice*, 68 (668): 133. DOI: <https://doi.org/10.3399/bjgp18X695081>

<sup>4</sup> Buck J, Webb W, Moth L, Morgan L, Barclay S (2018). “Persistent inequalities in Hospice at Home provision: findings from a service evaluation”. *BMJ Supportive and Palliative Care*: e-pub Feb 2018 doi.10.1136/bmjspcare-2017-001367

<sup>5</sup> Butler C, Brigden C, Gage H, Williams P, Holdsworth L, Greene K, Wee B, Barclay S, Wilson P. (2018) “Optimum hospice at home services for end of life care; protocol of a mixed methods study employing realist evaluation”. *BMJ Open* 2018; 8: e021192. doi:10.1136/bmjopen-2017-021192

### **c) Bereavement Support Study.**

*Dr Pia Thiemann, Post-Doctoral Research Associate [pt350@medschl.cam.ac.uk](mailto:pt350@medschl.cam.ac.uk)*

- a) Systematic literature review of bereaved peoples' expectations for and experiences of support from Primary Care.
- b) Survey and in-depth interviews with recently bereaved people concerning their experience of and preference for Primary Care bereavement support
- c) Exploration of the feasibility and acceptability of a novel recruitment approach for recently bereaved people in the community. Recently bereaved people were invited to take part when attending Registrars' offices to register the death.

*Analysis currently underway.*

### **d) The prevalence of disrupted grief in adults aged 65 and over**

*Dr Pia Thiemann, Post-Doctoral Research Associate [pt350@medschl.cam.ac.uk](mailto:pt350@medschl.cam.ac.uk)*

Systematic literature review of the prevalence of Prolonged Grief and Persistent Complex Bereavement in older adults.

*Analysis currently underway.*

### **e) Marie Curie “Design to Care”.**

*Dr Sarah Hoare, Post-Doctoral Research Associate [seh91@medschl.cam.ac.uk](mailto:seh91@medschl.cam.ac.uk)*

Collaboration with Marie Curie Care, the Cambridge Engineering Design Centre and the Sheffield Hallam University Art Design Centre to design a new “toolkit” to enable the design of better palliative and end of life care services.

- a) Literature review of “experience-based co-design” in palliative care <sup>6</sup>
- b) Focus groups and interviews with community members and clinicians.
- c) Analysis of Marie Curie patient surveys to explore patients' and carers' views of specialist palliative care provision.
- d) Review of measurement approaches in palliative and end of life care: discussion paper in preparation

### **f) Fatigue in teenagers and young adults treated for cancer**

*Dr Anna Spathis, Consultant in Palliative Medicine, Associate Speciality Director for Palliative Care Teaching and MD student [anna.spathis@addenbrookes.nhs.uk](mailto:anna.spathis@addenbrookes.nhs.uk)*

Funded by Macmillan Cancer Support, this doctoral research is investigating fatigue in teenagers and young adults treated for cancer.

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<sup>6</sup> Borgstrom E, Barclay S. (2016) “Experience Based Design, Co-Design and Experience-based Co-Design in Palliative and End of Life Care” *BMJ Supportive and Palliative Care: e-pub DOI: 10.1136/bmjspcare-2016-001117*

- a) Systematic literature review published <sup>7</sup>
- b) Multicentre electronic survey completed <sup>8</sup>
- c) Qualitative intervention co-design study (*papers in preparation*).

Once the thesis has been submitted, funding will be sought for a feasibility trial of the non-pharmacological intervention developed.

### **g) Realist Review of End of Life Care in the Community**

*Dr Mila Petrova, Post-Doctoral Research Associate* [mp686@medschl.cam.ac.uk](mailto:mp686@medschl.cam.ac.uk) and Ian Wellwood  
Post-Doctoral Senior Research Associate [ian.wellwood@medschl.cam.ac.uk](mailto:ian.wellwood@medschl.cam.ac.uk)

Recently started, this NIHR School for Primary Care Research study uses realist methods to bring together studies on end of life care in the community. The assumption of the realist approach, in the tradition of Pawson and Tilley (1997), is that all programmes work, but for some people, in some contexts and on some occasions. We need this nuanced knowledge of programme effectiveness in order to apply them in the right circumstances, adapt and improve them. Our review will aim to specify the “mechanisms” which bring about good outcomes in end of life care in the community and the contexts which trigger, support or block those mechanisms.

### **h) Realist review of the management of complicated grief in primary care and community settings**

*Dr Mila Petrova, Post-Doctoral Research Associate* [mp686@medschl.cam.ac.uk](mailto:mp686@medschl.cam.ac.uk) and Ian Wellwood  
Post-Doctoral Senior Research Associate [ian.wellwood@medschl.cam.ac.uk](mailto:ian.wellwood@medschl.cam.ac.uk)

Taking a similar approach to the above study, this realist review focuses on the care of people experiencing complicated grief. It will identify what helps, for whom, under what circumstances and how the bereavement support helps.

*Work to commence early 2019*

### **h) Oldest-old spouses' experiences of providing end-of-life care: an intersectional approach**

*Tessa Morgan, PhD student* [t1m32@medschl.cam.ac.uk](mailto:t1m32@medschl.cam.ac.uk)

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<sup>7</sup> Spathis A, Booth S, Grove S, Hatcher H, Kuhn I, Barclay S (2015). “Teenage and young adult cancer-related fatigue is prevalent, distressing and neglected: it is time to intervene.” A systematic literature review and narrative synthesis. *Journal of Adolescent and Young Adult Oncology*; 4(1): 3 – 17.

<sup>8</sup> Spathis A, Hatcher H, Booth S, Gibson F, Stone P, ... Barclay S. (2017). “Cancer-related fatigue in adolescents and young adults after cancer treatment: persistent and poorly managed.” *Journal of Adolescent and Young Adult Oncology*; 6(3); 1 – 5 doi.org/10.1089/jayao.2017.0037

Multi-methods study examining the experiences of older carers living with their spouse with a life-limiting condition.

a) In-depth qualitative interviews with people aged 75 and over whose partner is receiving palliative care

b) Longitudinal analysis of the Cambridge City over-75 cohort data examining older peoples' caregiving trajectories over time.

*Field work underway*

#### **i) Does medically assisted hydration improve quality of life in the final days of life?**

*Dr Arjun Kingdon, Palliative Medicine Academic Clinical Fellow [adnk2@medschl.cam.ac.uk](mailto:adnk2@medschl.cam.ac.uk)*

Decisions concerning whether to start intravenous fluids in the final days of life are a frequent cause for concern among family members, with insufficient evidence available to guide clinicians.

*Systematic literature review recently started. Subsequent field-work is planned, for which doctoral fellowship funding will be sought.*

#### **j) CAPE: Community Care Pathways at End of Life**

*Dr Brooke Swash, Post-Doctoral Research Associate [bes25@medschl.cam.ac.uk](mailto:bes25@medschl.cam.ac.uk)*

Investigation of the patterns and pathways of care experienced by people approaching the end of life.

a) Quantitative data extracted from the GP and District Nurse records of 400 recently deceased patients.

b) Focus groups with General Practitioners and Community Nurses

c) Individual interviews with bereaved carers, GPs and Community Nurses exploring cases in greater depth.

*Paper under review<sup>9</sup> and in preparation*

#### **k) Patterns of prescribing in end of life using Clinical Practice Research Datalink**

*Amelia Harshfield, Research Associate [ah842@medschl.cam.ac.uk](mailto:ah842@medschl.cam.ac.uk)*

Retrospective cohort analysis of prescribing in final 12 months of life for CPRD patients who died between 2010 and 2015. Descriptive analyses of temporal trends in polypharmacy and drug classes specific to symptom management and End of Life Care. <sup>10</sup>

*Further paper in preparation*

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<sup>9</sup> Barclay, S, Moran, E, Johnson, M, Lovick, R, Graffy, J, White, P, Deboys, B, Harrison, K, Swash, B (2018) Opportunities and challenges in Primary Palliative Care research: the experience of the CAPE study. *BMJ Supportive & Palliative Care*: under review.

<sup>10</sup> Harshfield A, Abel G, Barclay S, Payne R (2018). "Do GPs accurately record date of death? A UK observational analysis". *BMJ Supportive and Palliative Care*: e-pub July 2018 doi:10.1136/bmjspcare-2018-001514

### **k) “Older Old” People near the End of Life**

Dr Jane Fleming, Post-Doctoral Senior Research Associate [jane.fleming@phpc.cam.ac.uk](mailto:jane.fleming@phpc.cam.ac.uk)

Qualitative and quantitative methods examining end-of-life care issues from the perspective of very old people and their carers. In-depth interviews with the surviving study participants, by then all in their late 90s or past 100, and with their relatives and other carers, including post-bereavement interviews.<sup>11 12 13 14 15</sup>

### **l) Who does (not) access hospice services, and why?**

Jake Tobin, Sebastian Tullie and Alice Rogers, medical students

Systematic review of the literature concerning inequalities in access to hospices and community-based specialist palliative care services in the United Kingdom, Australia, Canada and New Zealand.

*Analysis complete and paper in preparation.*

### **m) Hypothalamic-pituitary-adrenal axis function in patients with chronic breathlessness**

Dr Richella Ryan, [rcr41@medschl.cam.ac.uk](mailto:rcr41@medschl.cam.ac.uk) Clinical Lecturer in Palliative Medicine

PhD study of the hypothalamic-pituitary-adrenal (HPA) axis in patients with chronic breathlessness receiving palliative and supportive care services.<sup>16</sup>

*Further paper in preparation.*

### **n) Medical education research**

Dr Stephen Barclay, University Senior Lecturer [sigb2@medschl.cam.ac.uk](mailto:sigb2@medschl.cam.ac.uk)

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<sup>11</sup> Zhao J, Barclay S, Farquhar M, Kinmonth A-L, Brayne C, Fleming J and the Cambridge City over-75s Cohort (CC75C) study collaboration (2010). “The “oldest old” in the last year of life: population-based findings from CC75C study participants aged at least 85 at death”. *Journal of the American Geriatric Society*; 58: 1 – 11.

<sup>12</sup> Fleming J, Zhao J, Farquhar M, Brayne C, Barclay S and the Cambridge City over-75s Cohort (CC75C) study collaboration (2010). “Place of death for the “oldest old”: >= 85 year olds in the CC75C population-based cohort. *British Journal of General Practice*; 60: 275 – 282.

<sup>13</sup> Perrels A, Fleming J, Zhao J, Barclay S, Farquhar M, Buiting H, Brayne C and Cambridge City over-75s Cohort (CC75C) study collaboration (2013). “Place of death and end-of-life transitions experienced by very old people of different cognitive status. Retrospective analysis of a population-based cohort aged 85 and older”. *Palliative Medicine*: 28 (3); 220 - 233. DOI: 10.1177/0269216313510341

<sup>14</sup> Fleming J, Farquhar M, Cambridge City over-75s Cohort (CC75C) study collaboration, Brayne C, Barclay S. (2016). “Death and the oldest old: attitudes and preferences for End-of-Life Care. Qualitative research within a population-based cohort study” *PLOS ONE*: 11(4): e0150686. doi:10.1371/journal.pone.0150686

<sup>15</sup> Fleming J, Calloway R, Perrels A, Barclay S, Farquhar M, Brayne C on behalf of the CC75C study collaboration. Dying comfortably in very old age with or without dementia in different care settings – a representative “older old” population study. *BMC Geriatrics*: 2017 17/222. DOI 10.1186/s12877-017-0605-2

<sup>16</sup> Ryan R, Clow A, Spathis A, Smyth N, Barclay S, Fallon M, Booth S (2017). “Salivary diurnal cortisol profiles in patients suffering from chronic breathlessness receiving supportive and palliative care services: a cross-sectional study”. *Psycho-Neuro Endocrinology*: 79: 134 - 145 DOI:10.1016/j.psyneuen.2017.01.025

A longstanding programme of research with colleagues across the Medical School, investigating medical students' attitudes towards and experiences of palliative care

a) **Cambridge DIME study:** longitudinal cohort study of Cambridge medical students, investigating Cambridge medical students' personal experience of bereavement <sup>17</sup>, their anxieties concerning encountering death <sup>18</sup>, their experiences of meeting patients approaching the end of their lives <sup>19 20</sup>, the value of reflective practice in palliative care teaching <sup>21</sup> and their expectations of their future role in palliative care provision <sup>22</sup>

b) **Experience of the Dissecting Room:** a set of research studies concerning first year medical students' experience of the Dissecting Room, from which new approaches to supporting students during this experience is under development <sup>23 24 25 26</sup>

## **1b. Care planning**

### **a) Where do most people prefer to die?**

Dr Sarah Hoare, Post-Doctoral Research Associate [seh91@medschl.cam.ac.uk](mailto:seh91@medschl.cam.ac.uk)

This major systematic literature review of patient preferences for place of death concluded that we should be cautious about stating that most patients want to die at home, as is widely asserted. The review identified significant missing data because in many cases patients' preferences were not recorded: when this data was included in analyses it was not known where most patients wanted to

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<sup>17</sup> Whyte R, Quince T, Benson J, Wood D, Barclay S. (2013) "Medical students' experience of personal loss: incidence and implications". *BMC Medical Education*: 13; 36. DOI:10.1186/1472-6920-13-36

<sup>18</sup> Thiemann P, Quince T, Benson J, Wood D, Barclay S. (2015) "Medical students' death anxiety: severity and association with psychological health and attitudes toward palliative care". *Journal of Pain and Symptom Management*; 50 (3): 335 – 342. doi:10.1016/j.jpainsymman.2015.03.014

<sup>19</sup> Borgstrom E, Barclay S, Cohn S (2012) "Constructing denial as a disease object: accounts by medical students meeting dying patients". *Sociology of Health and Illness*: 35 (3); 391 – 404. DOI: 10.1111/j.1467-9566.2012.01487

<sup>20</sup> Barclay S, Whyte R, Thiemann P, Benson J, Wood D, Parker R, Quince T (2014). "An important but stressful part of my future work". Medical students' attitudes to End of Life Care throughout their course". *Journal of Pain and Symptom Management*: 49 (2): 231 – 242. doi.org/10.1016/j.jpainsymman.2014.06.004.

<sup>21</sup> Borgstrom E, Morris R, Wood D, Cohn S, Barclay S. (2016) "Learning to care: medical students' reported value and evaluation of palliative care teaching involving meeting patients and reflective writing". *BMC Medical Education*: 16: 306. DOI 10.1186/s12909-016-0827-6

<sup>22</sup> Diver R, Quince T, Barclay S, Benson J, Brimicombe J, Wood D, Thiemann P (2018). "Palliative care in medical practice: medical students' expectations". *BMJ Supportive and Palliative Care*; 8: 285 – 288 doi:10.1136/bmjspcare-2017-001486

<sup>23</sup> Quince T, Barclay S, Spear M, Parker R, Wood D (2011). "Student Attitudes towards cadaveric dissection at a UK medical school". *Anatomical Sciences Education*: 4(4); 200 – 207. DOI 10.1002/ase.237

<sup>24</sup> Bamber A, Quince T, Barclay S, Siklos P, Clark J, Wood D. (2013) "Medical student attitudes to the autopsy and its utility in medical education. A qualitative phenomenological study at one UK medical school". *Anatomical Sciences Education*: 7(2); 87 – 96. DOI 10.1002/ase.1384

<sup>25</sup> Gamlin C, Womersley K, Taylor H, Fay I, Brassett C, Barclay S (2017). "Can you be a doctor, even if you faint?" the tacit lessons of cadaveric dissection. *Psychiatry Danubina*, 2017; Vol. 29, Suppl. 3, pp 247-253

<sup>26</sup> Foreman J, Morley V, Brassett C, Taylor H, Lillicrap M, Barclay S (2018). "Anxiety mixed with anticipation: medical students' feelings prior to entry into the Dissecting Room". *Anatomical Sciences Education*: submitted Sept 2018

die.<sup>27</sup> Despite these findings and research of others, where patients die continues to be used in policy and practice as a metric of quality in end-of-life care.

### **b) Anticipatory prescribing in community end of life care.**

*Ben Bowers, PhD student and Queen's Nurse [bb527@medschl.cam.ac.uk](mailto:bb527@medschl.cam.ac.uk)*

a) Systematic review of the literature concerning anticipatory prescribing in adult end of life care in the community. *Paper submitted*<sup>28</sup>

b) Qualitative study of General Practitioners' decision-making concerning anticipatory prescribing for adults at home in their last days of life. *Fieldwork completed*

c) PhD project investigating current practice and patient, family carer and healthcare professionals' perspectives towards Anticipatory Prescribing in community End of Life Care.

*Fieldwork to commence shortly*

*Dr. Richella Ryan, Clinical Lecturer in Palliative Medicine [rccr41@medschl.cam.ac.uk](mailto:rccr41@medschl.cam.ac.uk)*

a) UK-wide mixed-methods study of local anticipatory prescribing policies and procedures

b) Anticipatory prescribing process modelling study: collaboration with the Cambridge Engineering Design Centre which seeks to clarify the processes and safety-critical stages.

### **c) Future Care Study. Decision-making concerning eating and drinking for people with progressive neurological disease with and without decision-making capacity.**

*Dr Gemma Clarke, Post-Doctoral Research Associate [gcc29@medschl.cam.ac.uk](mailto:gcc29@medschl.cam.ac.uk)*

a) Survey of public attitudes in GB and the US ( $N=2016$ ) examining public preferences for care at the end of life, as decision-making capacity and swallowing ability deteriorate due to progressive neurological disease, with a focus on measures to sustain or end life.<sup>29 30</sup>

b) "Cluster" based interviews with a patient, family member, healthcare professional and a paid carer, investigating decision-making and care surrounding mealtime difficulties and loss of swallowing.<sup>31</sup>

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<sup>27</sup> Hoare, S., Morris, Z. S., Kelly, M. P., Kuhn, I., & Barclay, S. (2015). Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. *PLoS One*, 10(11), e0142723. doi:10.1371/journal.pone.0142723

<sup>28</sup> Bowers B, Ryan R, Kuhn I, Barclay S (2018). "Anticipatory prescribing of injectable medications for adults at the end of life in the community: a systematic review". *Palliative Medicine*: submitted post reviews Oct 2018

<sup>29</sup> Clarke G, Fistein E, Holland A, Barclay M, Thiemann P, Barclay S (2017). "Preferences for care towards the end of life when decision-making capacity may be impaired: a large scale cross-sectional survey of public attitudes in Great Britain and the United States". *PLoS ONE* 12(4):e0172104 DOI:10.1371/journal.pone.0172104

<sup>30</sup> Fistein E, Clarke G, Holland A, Barclay S. (2018). "This Condition isn't going to get any better so I can't see why we're prolonging it". Risks and benefits of using empirical research to inform normative decisions concerning end of life care. *Journal of Disability and Religion*: paper in press.

<sup>31</sup> Clarke G, Fistein E, Holland A, Tobin J, Barclay SS, Barclay S (August 2018). "Planning for an uncertain future in progressive neurological disease: a qualitative study of patient and family decision-making with a focus on nutrition and hydration interventions". *BMC Neurology*; 18: 115 doi.org/10.1186/s12883-018-1112-6

The study was developed from previous research including a systematic review of the international literature on artificial nutrition,<sup>32</sup> an observational study of decision-making by a hospital based multidisciplinary team concerning tube feeding<sup>33</sup>, and a one-year retrospective study of clinical records.<sup>34</sup>

**d) Advance Care Planning in hospitalised frail elderly patients.**

*Dr Sarah Hopkins, Registrar in Geriatric and General Internal Medicine, Addenbrooke's Charitable Trust Clinical Research Fellow [s.hopkins@cantab.net](mailto:s.hopkins@cantab.net)*

Clinical audit has identified that when older people are admitted to hospital they are given the opportunity to discuss their longer-term care plans.

a) Systematic literature review under review<sup>35</sup>

b) Interview study of hospital healthcare professionals to understand their views of the benefits and barriers of ACP with this group. *Fieldwork starting shortly*

**e) Systematic literature review of end of life care conversations with cancer patients.**

*Dr Karen Petchey, NIHR GP Academic Clinical Fellow [kp393@medschl.cam.ac.uk](mailto:kp393@medschl.cam.ac.uk)*

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<sup>32</sup> Clarke G, Harrison K, Holland A, Kuhn I, Barclay S (2013). "How are treatment decisions made about artificial nutrition for individuals at risk of lacking capacity? A systematic review and qualitative synthesis". PLOS ONE: 8(4): e61475. doi:10.1371/journal.pone.0061475

<sup>33</sup> Clarke G, Galbraith S, Woodward J, Holland A, Barclay S (2014). "Should they have a Percutaneous Endoscopic Gastrostomy? The importance of assessing decision-making capacity and the central role of a multidisciplinary team". *Clinical Medicine*: 14 (3): 245 - 249

<sup>34</sup> Clarke G, Holland A, Woodward J, Galbraith S, Barclay S (2015) "Eating and drinking interventions for people at risk of lacking decision-making capacity: Who decides and how?" *BMC Medical Ethics*; 16:41. doi.org/10.1186/s12910-015-0034-8

<sup>35</sup> Hopkins S, Bentley A, Phillips V, Barclay S (2018). "Advance Care Planning in hospitalised frail older patients: a missed opportunity? A systematic review and narrative synthesis". *Age and Ageing*: submitted August 2018

Systematic review currently underway concerning patient and clinician views of and preferences for End of Life Care conversations. Builds on the group's suite of systematic reviews of End of Life Care conversations in a range of medical conditions <sup>36 37 38 39 40 41</sup>

#### **f) Advance Care Planning with frail and older people**

Dr Tim Sharp, NIHR GP Academic Clinical Fellow [timsharp@nhs.net](mailto:timsharp@nhs.net)

a) Systematic literature review of patient and professional attitudes to Advance Care Planning with frail & elderly individuals. <sup>42</sup>

b) Focus group study with GPs in Cambridgeshire investigating their attitudes to ACP with frail and elderly individuals. <sup>43</sup>

This research is being developed further in a School for Primary Care Research collaborative study on predictive value of the Electronic Frailty Index. <sup>44</sup>

#### **g) Advance Care Planning for the End of Life in Neuromuscular Disease**

Andy Hiscock, Physiotherapist and Regional Neuromuscular Disease Coordinator, NIHR CLAHRC Fellow 2016 [andrew.hiscock@nhs.net](mailto:andrew.hiscock@nhs.net)

a) Systematic Literature Review. The literature has rarely addressed discussions concerning the end of life in Duchenne Muscular Dystrophy and related conditions that affect teenagers and young adults. <sup>45</sup>

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<sup>36</sup> Barclay S, Momen N, Case-Upton S, Kuhn I, Smith E. (2011). "The conversation that rarely happens". End of life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *British Journal of General Practice*: 61; 59 – 60

<sup>37</sup> Momen N, Barclay S (2011). "Barriers to end of life care conversations in heart failure: addressing "The elephant on the table". A literature review and narrative synthesis". *Current Opinion in Supportive and Palliative Care*: 5; 312 - 316.

<sup>38</sup> Momen N, Hadfield P, Kuhn I, Smith E, Barclay S. (2012) "Discussing an uncertain future: End of Life Care conversations in COPD. A systematic literature review and narrative synthesis". *Thorax*: 67; 777 – 780

<sup>39</sup> Badrakalimuthu R, Barclay S. (2013) "Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis". *Age and Ageing*: 43 (1); 13 – 19.

<sup>40</sup> Sharp T, Moran E, Kuhn I, Barclay S. (2013) "Do the elderly have a voice? End of life care discussions with frail & elderly individuals: a systematic literature review & narrative synthesis". *British Journal of General Practice*: 63; 657 – 668.

<sup>41</sup> Hiscock A, Kuhn I, Barclay S. (Jan 2017) "Advance care discussions with young people affected by life-limiting neuromuscular diseases: a systematic literature review and narrative synthesis". *Neuromuscular Disorders*: 27: 115 – 119.

<sup>42</sup> Sharp T, Moran E, Kuhn I, Barclay S (2013). "Do the elderly have a voice? End of life care discussions with frail & elderly individuals: a systematic literature review & narrative synthesis". *British Journal of General Practice*: 63; 657 – 668. DOI: 10.3399/bjgp13X673667

<sup>43</sup> Sharp T, Malyon A, Barclay S (2017). "GPs' perceptions of advance care planning with frail and older people." *British Journal of General Practice*: 68; 44 – 53. DOI/10.3399/bjgp17X694145

<sup>44</sup> Stow D, Matthews F, Barclay S, Iliffe S, Clegg A, De Biase S, Robinson L, Hanratty B (2018). "Frailty scores to predict mortality in older adults using data from population based electronic health records: case control study". *Age and Ageing*: epub 10.1093/ageing/afy022

<sup>45</sup> Hiscock A, Kuhn I, Barclay S (2017). "Advance care discussions with young people affected by life-limiting neuromuscular diseases: a systematic literature review and narrative synthesis". *Neuromuscular Disorders*: 27: 115 – 119. DOI:10.1016/j.nmd.2016.11.011

b) Qualitative interview study with health and social care professionals about conversations concerning the end of life in Duchenne Muscular Dystrophy and related conditions. End of life care is rarely addressed until severe illness intervenes, at which point the young person's views cannot be elicited. <sup>46</sup>

#### **h) Advance Care Planning in heart failure: a feasibility trial**

Markus Schichtel, Post-Doctoral Research Fellow, [ms2591@medschl.cam.ac.uk](mailto:ms2591@medschl.cam.ac.uk)

Building on recent doctoral research developing an intervention to support ACP in heart failure, an application is to be submitted shortly for a feasibility trial of this intervention

### **1c. Care transitions**

#### **a) Admissions Close to the End of Life (ACE) Study**

Dr Sarah Hoare, Post-Doctoral Research Associate [seh91@medschl.cam.ac.uk](mailto:seh91@medschl.cam.ac.uk)

Study of hospital admissions by interviewing healthcare staff and next-of-kin about the admission of patients who died within three days of entering hospital. <sup>47</sup> The terms 'inappropriate' and 'avoidable' were found not to be useful descriptors of these admissions because they presume dichotomies that did not fit the situations of the patients. <sup>48</sup>

A recent publication from this study outlines the challenges for ambulance staff when called to patients close to the end of life <sup>49</sup>. A paper concerning home care has been submitted <sup>50</sup> with further papers in preparation.

#### **b) Patient transfers from hospice or hospital to care home at the end of life**

Dr Tabitha Thomas, Consultant Palliative Medicine, Arthur Rank Hospice, NIHR CLAHRC Fellow  
2016 [Tabitha.Thomas@ARHC.org.uk](mailto:Tabitha.Thomas@ARHC.org.uk)

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<sup>46</sup> Hiscock A, Barclay S (2017). "It's a hard conversation to have". Healthcare professionals' views concerning advance care discussions with young people affected by life-limiting neuromuscular diseases: an interview study. *BMJ Supportive and Palliative Care*; published online July 2017 doi.org/10.1136/bmjspcare-2017-001369

<sup>47</sup> Morris Z, Fyfe M, Momen N, Hoare S, Barclay S. (2013) 'Understanding Hospital Admissions Close to the End of Life (ACE) Study' *BMC Health Services Research* 13 (89)

<sup>48</sup> Hoare, S. (2017). Understanding end-of-life admissions: an interview study of patients admitted to a large English hospital shortly before death (Doctoral thesis). <https://doi.org/10.17863/CAM.22232>

<sup>49</sup> Hoare S, Kelly M, Prothero L, Barclay S. (2018) "Ambulance practitioners and end-of-life hospital admissions: an interview study". *Palliative Medicine*; 32(9): 1465 – 2473 DOI: 10.1177/0269216318779238

<sup>50</sup> Hoare S, Kelly M, Barclay S (2018). "Home care and end-of-life hospital admissions: a retrospective interview study". *British Journal of General Practice*: submitted Oct 2018

- i) Systematic literature review <sup>51</sup> revealed a very limited literature with no direct evidence from patients themselves.
- ii) Focus group study with five hospice inpatient teams in the Eastern region found staff find moving patients at the end of life from hospice to care homes extremely challenging. <sup>52</sup>

**c) Admissions from care home to hospital in the last week of life.**

*Dr Rebecca Farndale, NIHR School for Primary Care Research GP Academic Clinical Fellow*  
[rebecca-farndale@doctors.org.uk](mailto:rebecca-farndale@doctors.org.uk)

Study of 10 years' national data from Hospital Episode Statistics and Office for National Statistics Mortality Dataset of care home residents admitted to hospital within the last week of life. *Paper in preparation*

**d) Fast-track hospital discharge in end of life care**

*Dr Caroline Barry, Consultant in Palliative Medicine, Norwich. 2016 NIHR CLAHRC Fellow*  
[carolinebarry@hotmail.com](mailto:carolinebarry@hotmail.com)

Service evaluation of fast track discharge to examine association and outcomes between those with and without capacity to consent to discharge planning for end of life care. <sup>53</sup> *Further paper in preparation.*

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<sup>51</sup> Thomas T, Kuhn I, Barclay S (2016). "Transferring to a nursing home for end of life care: what are the views and experiences of patients and their relatives? A systematic literature review and narrative synthesis". *Palliative Medicine*; 31(2): 102 – 108 DOI: 10.1177/0269216316648068

<sup>52</sup> Thomas T, Clarke G, Barclay S (2018). "The difficulties of discharging hospice patients to care homes at the end of life. A focus group study". *Palliative Medicine*: 32 (7): 1267 - 1274 DOI: 10.1177/0269216318772735

<sup>53</sup> Barry C, Spathis A, Carding S, Treadell S, Barclay S (2017) "Palliative Care clinicians' knowledge of the law regarding the use of the Deprivation of Liberty Safeguards". *BMJ Supportive and Palliative Care*: 0:1–7. doi:10.1136/bmjspcare-2016-001186

## 2. Publications with medical students

Stephen Barclay co-leads the Association for Palliative Medicine's national Special Interest Forum on undergraduate medical education <http://www.apmuesif.phpc.cam.ac.uk/> and has a research programme investigating UK medical student teaching in Palliative Care <sup>54 55 56</sup>

Publications with medical students have included:

- a) An Editorial following the 2012 withdrawal of the Liverpool Care Pathway for the Dying <sup>57</sup>
- b) An Editorial concerning the recent Gosport Hospital scandal <sup>58</sup>
- c) Papers concerning students' experiences of the dissecting room <sup>59 60 61</sup>
- d) Twelve top tips for developing medical school teaching <sup>62</sup>

## 3) Future and planned research studies include:

### **a) Developing an intervention to optimise bereavement care in Primary Care.**

A National Institute for Health Research (NIHR) School for Primary Care Research collaboration led by our research group.

### **b) Who is (not) referred to hospice?**

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<sup>54</sup> Walker S, Gibbins J, Barclay S, Adams A, Paes P, Chandratilake M, Gishen F, Lodge P, Wee B (2016). "Progress and divergence in palliative care education for medical students: a comparative survey of UK course structure, content, delivery, contact with patients and assessment of learning." *Palliative Medicine*: 30(9): 834-842. DOI: 10.1177/0269216315627125

<sup>55</sup> Walker S, Gibbins J, Paes P, Barclay S, Adams A, Chandratilake M, Gishen F, Lodge P, Wee B (2017). "What do palliative care course organisers think of their course and institution, are they adequately preparing future doctors and what are the barriers to delivery? A survey of all UK medical schools." *British Medical Journal Supportive and Palliative Care*: e-pub doi:10.1136/bmjspcare-2017-001319

<sup>56</sup> Walker S, Gibbins J, Paes P, Adams A, Chandratilake M, Gishen F, Lodge P, Wee B, Barclay S (2016). "Palliative care education for medical students: differences in course development, organisation, evaluation and funding. A survey of all UK medical schools". *Palliative Medicine*: 31(6); 575 – 581 DOI: 10.1177/0269216316671279

<sup>57</sup> Knights D, Wood D, Barclay S. (2013) "The Liverpool Care Pathway for the Dying: what went wrong?" *British Journal of General Practice*: 63; 509 – 510. DOI: 10.3399/bjgp13X673559

<sup>58</sup> Knights D, Knights F, Barclay S (2018) " 'Please make comfortable': prescribing and communicating opioids in the wake of Gosport". *British Journal of General Practice*: 68 (674): 462 – 3. doi.org/10.3399/bjgp18X698705

<sup>59</sup> Gamlin C, Womersley K, Taylor H, Fay I, Brassett C, Barclay S (2017). "Can you be a doctor, even if you faint?" the tacit lessons of cadaveric dissection. *Psychiatria Danubina*, 2017; Vol. 29, Suppl. 3, pp 247-253

<sup>60</sup> Foreman J, Morley V, Brassett C, Taylor H, Lillicrap M, Barclay S (2018). "Anxiety mixed with anticipation: medical students' feelings prior to entry into the Dissecting Room". *Anatomical Sciences Education*: submitted Sept 2018

<sup>61</sup> Kassam C, Duschinsky R, Brassett C, Barclay S (2018). "Knowing everything and yet nothing about her". *Medical students' reflections on the experience of the Dissection Room*. *BMJ Medical Humanities*: submitted paper

<sup>62</sup> Boland J, Gibbins J, Barclay S (2018). "Twelve tips for developing palliative care teaching in an undergraduate curriculum for medical students". *Medical Teacher*: paper in press.

Building on our systematic review of hospice service referrals we are planning a collaborative study with seven hospices in the region, investigating who is not referred to hospice services and why.

**c) Stopping cancer treatments towards the End of Life**

Building on our published systematic literature review,<sup>63</sup> we are planning a study investigating decision-making concerning the stopping of cancer treatment as disease progresses.

**d) Optimising palliative and end of life care in care homes**

A recently awarded clinical PhD studentship, starting autumn 2018, to be undertaken with Dr Charles Daniels and colleagues in St Luke's Hospice North London

**e) Foundation year doctors' experience of and attitudes towards Palliative Care.**

Dr Aamena Bharmal, Academic Foundation Year doctor.

Systematic literature review underway and new study planned for 2019 in collaboration with colleagues in the General Medical Council

**f) Anticipatory Prescribing in End of Life Care in Nursing Homes**

This recently awarded Abbeyfield PhD studentship will further develop the group's research on anticipatory prescribing: due to start autumn 2019

**g) Continuity of care in General Practitioner Palliative Care.**

Dr Emilie Green, a GP Academic Clinical Fellow in London is developing proposal for a PhD study of continuity of care in GP Palliative Care, building on our recent literature review<sup>64</sup>

**h) National Institute for Health Research Applied Research Collaboration (NIHR ARC)**

We are currently awaiting the outcome of a major grant application to establish an ARC in the East of England, building on the previous ten years of NIHR CLAHRC funding. We will lead the Palliative and End of Life Care research themes in that proposal, if funded.

We are also seeking second-stage ARC funding to co-lead a national cross-ARC collaborative group in Palliative and end of Life Care with Prof Irene Higginson in London. If successful, this will establish Cambridge as a major national centre for collaborative Palliative and End of Life Care research.

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<sup>63</sup> Clarke G, Johnson S, Corrie P, Kuhn I, Barclay S (2015). "Withdrawal of anticancer therapy in advanced disease: a systematic literature review". *BMC Cancer*: 15: 892. DOI: 10.1186/s12885-015-1862-0

<sup>64</sup> Green E, Knight S, Gott M, Barclay S, White P (2018). "Patients' and carers' perspectives of palliative care in general practice: a systematic review and narrative synthesis of the literature". *Palliative Medicine*: 32 (4); 838 – 850 doi/10.1177/0269216317748862

## **4) Research studies of colleagues associated with group**

### **a) Perspectives on End of Life Care: caring for Muslim patients**

*Mehrunisha Suleman, Post-Doctoral Research Associate, Centre of Islamic Studies, University of Cambridge* [mehrunisha.suleman@gmail.com](mailto:mehrunisha.suleman@gmail.com)

A qualitative study of extent to which Islam and the beliefs, values and practices of Muslims influence decision making within End of Life Care in the UK. To date, 72 interviews have been completed with healthcare professionals, chaplains, community based Islamic scholars, patients and families. The aim is to collate evidence that can better inform practitioners and policy makers about the values, beliefs, processes and practices that Muslim patients and families rely on when making end of life decisions and to what extent these are informed by their faith commitments. The study also aims to highlight examples of good practice as well as challenges and gaps underlined by care providers when meeting the needs of Muslim patients and families. *Fieldwork underway.*

### **b) Support Needs Approach for Patients (SNAP)**

*Carole Gardener, PhD student Clinical Nursing Research Group* [acq68@medschl.cam.ac.uk](mailto:acq68@medschl.cam.ac.uk)

The development and testing of an intervention to enable delivery of person-centred care to patients with advanced COPD, using qualitative and quantitative methods to test the validity of the SNAP tool and explore barriers and facilitators to adopting and delivering the intervention within a clinical context. A systematic review has been published<sup>65</sup> identifying the comprehensive set of domains of support need for patients with COPD.

### **c) Addenbrooke's Hospital Gynae Psycho-Oncology Service.**

*Dr Annabel Price, Consultant Liaison Psychiatrist and Associate Speciality Director for Palliative Care Teaching* [ap806@medschl.cam.ac.uk](mailto:ap806@medschl.cam.ac.uk)

A two-year pilot service funded by Macmillan Cancer Support, which provides integrated psychological assessment, support and treatment alongside and beyond treatment for gynaecological cancer. Individual and group treatment is offered including the "Moving forward with Gynaecological Cancer" psychotherapy group, an 8-week course co-designed with patients to help women recapture their lives and identities after cancer and its treatment

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<sup>65</sup> Gardener AC, Ewing G, Kuhn I, Farquhar M. Support needs of patients with COPD: a systematic literature search and narrative review. *International Journal of Chronic Obstructive Pulmonary Disease*. 2018; 13: 1021-1035. doi:10.2147/COPD.S155622.

## Core group members November 2018

University Senior Lecturer	Dr Stephen Barclay
Senior Research Associate	Dr Ian Wellwood
Research Associates	Dr Mila Petrova
	Dr Brooke Swash
	Dr Pia Thiemann
	Dr Sarah Hoare
Clinical Lecturer	Dr Richella Ryan
Academic Clinical Fellows	Dr Becky Farndale
	Dr Karen Petchey
	Dr Arjun Kingdon
Academic FY doctor	Dr Aamena Bharmal
PhD / MD students	Dr Anna Spathis
	Tessa Morgan
	Ben Bowers
Clinical Research Fellow	Dr Sarah Hopkins
PA Research	Angela Harper
PA teaching	Angela Murphy
Admin Assistant	Sam Barclay
Visiting Fellows	Prof Mike Kelly
	Dr Markus Schichtel
Teaching Specialty Directors	Dr Anna Spathis
	Dr Annabel Price

**Dr Stephen Barclay**

**[sigb2@medschl.cam.ac.uk](mailto:sigb2@medschl.cam.ac.uk)**

**01.11.2018**