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| <div style="text-align: center;"> <b>CareSearch Project</b><br/> <b>Research Studies Register: Registration Proforma</b> </div>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                          |  |  |                                                   |     | <b>0131</b> |    |  |                |
| <b>Study Title: Who Grieves? The patient perspective</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                          |  |  |                                                   |     |             |    |  |                |
| <p><b>Brief description of the study</b> Bereavement support is an integral element of palliative care with families and caregivers having access both prior to and after the patient's death. Globally, specialist palliative care services potentially provide the most comprehensive bereavement support services. For the majority of people grief is a normal event with only a small proportion (10-20%) of people experiencing persisting grief-related symptoms requiring some sort of professional intervention or treatment.</p> <p><b>Aim:</b> This qualitative study aims to explore whether people with a life limiting illness, who are expected to die within the next six months, are concerned about the bereavement needs of people other than their next of kin.</p> <p><b>Objectives:</b> The objectives of this study are to: i) To establish the feasibility, acceptability, safety, and practicability of having prospective bereavement follow-up conversations with people nearing the end of life; ii) To gain insights into the patients' experience of the research; and iii) To determine the acceptability of the study, including recruitment rates and the degree to which these conversations could be integrated into clinical practice.</p> |                                                          |  |  |                                                   |     |             |    |  |                |
| <b>Study Methodology: (Please mark with an x which type of study methodology)</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                          |  |  |                                                   |     |             |    |  |                |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Epidemiology                                             |  |  |                                                   |     |             |    |  |                |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Health Services / Health Economics / Quality Improvement |  |  |                                                   |     |             |    |  |                |
| <b>x</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | <b>Qualitative, Observational or Descriptive</b>         |  |  |                                                   |     |             |    |  |                |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Mixed Method                                             |  |  |                                                   |     |             |    |  |                |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Systematic Review                                        |  |  |                                                   |     |             |    |  |                |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Intervention: RCT                                        |  |  |                                                   |     |             |    |  |                |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Intervention: Comparative or cohort study                |  |  |                                                   |     |             |    |  |                |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Intervention: Case series                                |  |  |                                                   |     |             |    |  |                |
| <b>Project details:</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                          |  |  |                                                   |     |             |    |  |                |
| Funding source (Optional): Internal                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                                          |  |  |                                                   |     |             |    |  |                |
| Has the study received ethics approval?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                          |  |  |                                                   | Yes | <b>x</b>    | No |  | Not applicable |
| Project starting date: February 2013                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |                                                          |  |  |                                                   |     |             |    |  |                |
| Project completion date: 31 January 2014                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                          |  |  |                                                   |     |             |    |  |                |
| Multi site:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                          |  |  |                                                   | Yes | <b>x</b>    | No |  | Not applicable |
| <b>RESEARCHERS</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                          |  |  |                                                   |     |             |    |  |                |
| Principal Investigator (name)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                          |  |  | <b>Prof. Jane Phillips</b>                        |     |             |    |  |                |
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| Investigator C (Name)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                          |  |  | Prof. Elizabeth Lobb                              |     |             |    |  |                |
| Investigator D (Name)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                          |  |  | Ms Penny West                                     |     |             |    |  |                |
| Investigator E (Name)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                          |  |  | Prof David Currow                                 |     |             |    |  |                |

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| <b>Associated publications / reports:</b>                        |
| <b>Topics (Admin only) Bereavement, Grief and loss, Patients</b> |