

## Marie Curie Research Grants Scheme

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Rapid Response Service Models in End of Life Care: What Works for Whom and in Which Circumstances?

**Abstract:**

**Background:** End of life care (EoLC) policies are closely aligned to the *Five Year Forward View* and the need to lead and deliver care with a primary care focus; recognising the importance of integrating health and social care systems, accessibility of services and care delivery based on local decision-making and the facilitation of patient choice. Such policies are seen as an effort to respond to the increasing incidence of chronic disease and frailty; a challenge which requires significant resources, planning of care and a shift to acknowledge when patients are reaching the end of their lives. Central Government also highlight the challenge of achieving cost improvements and restricted funding for quality care at the EoL. Research identifies that EoLC should be person-centred rather than disease specific; but, for patients and their families, there is a chronic under-representation of services to support people as they reach the end of life, particularly a shortage of out-of-hours services. Indeed, Marie Curie identifies the need for significant improvement in community services. Whilst innovative multi-agency community services are emerging, research to date on different service models is limited. One such service is the Marie Curie Rapid Response Service (RRS) based in primary care; aiming to enable patient choice to maximise their days at home for as long as it feels right, to help reduce pressure on primary health care teams and services, cut the risk of unplanned hospital admissions and minimise delayed discharges. There is little UK evidence about the contextual conditions that enable RRSs to work to enhance EoL experiences and outcomes for patients and their families living in the community nor on the economic impact of the different models of RRSs on individuals and society. The existing evidence about the resource implications of RRSs for health and social care providers is sparse, making it particularly difficult for policy makers who are charged with developing agile and responsive services. Moreover, data on disparities in the risk and outcomes from Covid-19 reveal that the virus does not affect individuals equally; existing health and social inequalities have persisted or been exacerbated during the Pandemic.\* The largest disparity is amongst people over the age of 80 but men, people living in deprived areas, ethnicity and occupation also impact negatively on Covid-19 outcomes. We will therefore bring the proposal up-to-date by exploring how the Pandemic has impacted (positively or negatively) on the different RRS models, for whom, and in what way. This will help us better understand RRSs during Covid-19 and beyond as EoLC is commissioned, planned and delivered.

**Our aim** is to undertake a realist evaluation of Rapid Response models in EoLC to uncover what works, for whom, and in which circumstances and to estimate their relative resource consequences through the 'new normal' context of Covid-19.

**Methodology:** Realist evaluation acknowledges that interventions take place within complex social systems and is well-suited to studying interventions, such as the RRS models, which operate at the nexus where a variety of practice, policy, resource and experiential forces operate. Realist evaluations base explanation of outcomes on the fact that interventions (RRSs) are implemented in different contexts (e.g. personal, familial, care). This combination of intervention and context triggers the activation of a mechanism (e.g. attitudinal, behavioural) which leads to the outcomes observed.

**Design:** The project will be undertaken in three phases (P1-3) across two NHS Foundation Trusts in North East England which operationalise two contrasting RRS models. **P1** will develop initial programme theories to guide data collection; including scoping the literature and system mapping to detail who is reached by the different RRS models across the sites. This will identify the key contexts (geographical, cultural, political, societal, economic/financial conditions) within which RRSs operate, and explain how outcomes occur. **P2** will test these initial programme theories with empirical data and investigate the outcomes (both intended and unintended) of the RRSs for stakeholders from a realist perspective. **P3** will conduct a realist economic evaluation to inform decision makers about the relative effectiveness of the RRS models, depending on context and how context impacts cost-effectiveness. In all phases, **Purposive Sampling** of RRS stakeholders will be used; e.g. bereaved carers, RRS staff, other health and social care professionals who interact with the services, and commissioners (number up to 100). We arrived at these numbers following discussion with practice partners about the feasibility of achieving these.

**Mixed Methods** will be used to gather data via focus groups, interviews, (either face-to-face or online, according to Covid-19 requirements/participants' preferences at the time), questionnaire and pre-existing outcome data from Clinical Commissioning Groups (CCGs).

**Findings** are intended to elucidate outcomes at a variety of levels – the individual level (e.g. people living with terminal illness, their carers and health professionals; age, gender, location, ethnicity, occupation) and the broader service landscape level (e.g. enabling capacity in primary care, capitalising on resources) for wider societal benefit). The resulting theory will aid in understanding the direct/indirect contribution of the different RRS models on stakeholders (whether intended or unintended).