REVIEW ADVISORY PANEL (RAP)

Project: Addressing psychological morbidity in informal carers of patients at the end of life (EOL): evidence synthesis and stakeholder consultation to produce tailored, evidence-based information and priorities (Helping people stay in good health when looking after someone at end of life)

Introduction

This document provides an overview of the Project's Aims and Objectives and its Governance and Management arrangements. It also details the Terms of Reference for the Review Advisory Panel.

1. Aims and Objectives of the Project

This project will summarise and communicate what is known about factors affecting poor psychological health for carers during end of life care giving. Its aim is to help reduce psychological morbidity among EOL carers by:

(1) conducting a synthesis of the research evidence on factors that increase or decrease carer psychological morbidity during end of life care giving, and integrating findings into a coherent framework

(2) translating these findings into accessible, bespoke information for key stakeholders to help them better target current and future efforts to reduce psychological morbidity and its impacts.

To meet its aim the Project has the following objectives:

1.1 To synthesise evidence from observational quantitative studies – to identify factors associated with psychological morbidity during EOL caregiving

1.2 To synthesise evidence from qualitative studies – to explore factors carers themselves feel have an impact on their psychological health

1.3 To synthesise evidence from intervention studies – to examine which of the factors above influence the effectiveness of existing interventions to improve carers' psychological morbidity

1.4 To integrate these syntheses into a coherent framework of factors affecting psychological morbidity during EOL caregiving - to provide a coherent, accessible and evidence-based model of psychological morbidity during EOL care giving that is meaningful and relevant to carers

2.1 To translate synthesised evidence into tailored materials - to provide different stakeholder groups with bespoke, accessible and evidence-based summaries relevant to their needs and sphere of influence to enable them to make better use of resources and improve interventions to support carers

2.2 To explore how project outputs can be translated into primary care procedures in order to form the basis for further development and testing of a future intervention in primary care

2. Governance & Management of the Project

1. The **Principal Investigator (PI)** has overall responsibility for the delivery and financial management of the project.
2. Two Research Associates **(RAs)** will run the project on a day to day basis**.**.
3. The **Principal Investigator** will have weekly review and problem solving meetings with the **RAs.**
4. The **Core Research Team (CRT)** will consist of the PI, RAs and the four project co-applicants based at the University of Manchester (PB, MP, AW and CR). The CRT will undertake overall management of project processes. This team will have monthly meetings to review progress against milestones, advise on procedures and materials, and agree project actions for the coming month.
5. The **Research Management Group (RMG)** will consist of the Core Research Team and the four remaining co-applicants (JF-PPI lead, MF, CMS and SAB). The RMG is the executive (decision making) group for the project and will have 3-monthly meetings (7 in total) to oversee project progress against evidence synthesis and stakeholder engagement objectives.
6. The **Study Steering Committee** (SSC) will consist of two experts on evidence-synthesis, one statistician, one expert on family carer research, and two PPI representatives. The SSC will meet the RMG 6-monthly to provide overall supervision on behalf of the Project Sponsor (University of Manchester) and Project Funder (NIHR) and to ensure that the project is conducted to rigorous standards.
7. The **Review Advisory Panel (RAP)** will consist of 10 members representing stakeholder groups. The RAP will scrutinise and advise on the work of the RMG (see Terms of Reference below).

3.Terms and Reference for the Review Advisory Panel (RAP)

3.1 Role of the Review Advisory Panel (RAP)

The **Review Advisory Panel** will be an advisory group responsible for providing independent scrutiny and advice on the project to the RMG.

Its work will involve:

- Reviewing the project procedures and materials
- Providing advice on:
    - How we search the research literature to make sure we do not miss anything that is relevant to carers
    - How we summarise and organise findings from the literature to make sure these make sense to carers
    - How we go about recruiting further carers as co-analysts and stakeholder participants and how we conduct analysis, stakeholder workshops and focus groups to ensure carers feel comfortable to express their views
    - How we communicate final findings to stakeholders, including review of dissemination materials and advice on dissemination.

- Raising any concerns related to any aspect of the project in a timely fashion to the PPI Lead or Principal Investigator.

3.2 Membership of the RAP

The RAP will consist of 5 carer members, 1 patient, 1 researcher, 1 clinician, 1 service commissioner and 1 policy maker.

RAP members need to be aged 18, be able to contribute to meetings and live within reasonable travelling distance of the University of Manchester. They further need to have good command of written and spoken English; be able to read, scrutinise and comment on documents; be able to work effectively as part of a group; and be able to give advice from their perspective to researchers.

Carer members of the RAP also need to be people who have current or past experience of supporting a family member, friend or neighbour at the end of their life who feel able to reflect on their views and personal experiences as carers to a group. This will ensure that the views of the wider carer community are represented.

3.3 Meetings of the RAP

- The group will meet approx 6 times during the 18 month period of the project at important project time points
- Meetings will be attended by at least two members of the RMG, including the PPI Lead.
- Meetings will last 3-4 hours, including lunch.
- Meetings will take place at the University of Manchester.
- Meeting dates, times and venues will be communicated well in advance.
- Agenda items and reading materials will be circulated well in advance
- When necessary we will organise smaller, more flexible meetings to get views from as many RAP members as possible.
- If members have occasionally have difficulty attending in person, we will arrange for them to dial in by phone or internet (conference call).
- Whilst we are aware that not everyone will be able to attend all meetings, there is an expectation that everyone should make the majority of meetings
- We will fund respite care if RAP members need someone to look after a family member, friend or neighbour while they attend a meeting.
- The Chair of the RAP will be the Project's PPI Lead. The RAP will further nominate someone from amongst its members to be Deputy Chair should the need arise.
- The Chair, 1 research team representative, 2 Carer members, and 1 other stakeholder member are required to be present for a meeting to proceed, and decisions will not be able to be taken if this is not the case.
- Decisions will be arrived at by group consensus in the main; however a majority decision is permitted if unanimity cannot be reached. The Chair will usually have the casting vote.
- Care/Patient members will be offered the necessary support to enable them to contribute effectively to the RAP.

The first meeting of the RAP will be held with just the carer/patient members present to introduce them to the project and each other; to ensure they are comfortable with

the role of research team members; and to ensure that they understand their role and responsibilities.

3.4 Requirements of RAP Members

- that they attend RAP meetings or provide apologies in advance
- that they treat information shared within the group confidentially
- that they respect the opinions and experiences of other people in the group
- that they respect the opinions and experiences of the wider research team
- that they provide input appropriate to the research aims, RAP remit and study funding budget
- that they share any issues or concerns directly with the Principal Investigator, Gunn Grande or the PPI Lead, Jackie Flynn.

Members will be unable to continue being a members of the RAP if they:

- Resign from the group
- Breach confidentiality
- Do not adhere to the Terms of Reference of the Group
- Act in a manner which is not conducive to wider group working

If RAP members leave before the end of the programme, or if numbers fall below ten for any other reason, new membership opportunities will be publicly advertised and additional members appointed.

New members will be able to join the group if there is a vacancy and they have expressed an interest to join; meet the RAP membership criteria, and if the PI, PPI Lead and RAP members agree to their involvement.

RAP membership will be reviewed annually.

3.5 Requirements of RMG Members in Working with the RAP

- To provide regular updates to the RAP about project progress
- To try to use lay summaries and avoid jargon
- To share opportunities for involvement
- To respect the opinions and experiences of the RAP
- To clarify payment for involvement in advance
- To provide any training, related to the project, which is required
- To address any concerns raised by the group in a timely manner

3.6 Remuneration for RAP activities

RAP Carer/Patient members will be paid for their time spent attending meetings, and reviewing project materials/documentation. Payments will be in accord with hourly rates recommended by INVOLVE (£12.50-£20 depending on the task – see separate document on Payment Policy for PPI contributors). We will also reimburse travel expenses for regular public transport/ car journeys, and for any respite care required for Carers to attend meetings.

3.7 Accountability

Any concerns that RAP members have with regard to the structure, organisation or conduct of the Research Advisory Group, which cannot be resolved internally, may be raised by members with the Principal Investigator (PI), Gunn Grande, or the Public/Patient Involvement representative on the Research Management Group, Jackie Flynn.

3.8 Changes to the Terms of Reference

The Terms of Reference may exceptionally need to be amended, varied, or modified from time to time following full consultation with the PI and RMG, and the agreement of RAP group members.