The Impact Report should be completed and submitted using the **grant reference** as the email subject to, reportsofficer@esrc.ac.uk on or before the due date.

Please complete each box as fully as possible, adhering to the word counts, please do not include images within the text. Appendices are not accepted.

Principal Investigators are expected to consult with co-investigators on the content of this report.

<table>
<thead>
<tr>
<th>Grant Reference:</th>
<th>ES/J021229/1</th>
</tr>
</thead>
</table>
| Investigator/s:  | Dr Mary Larkin (PI)  
|                  | CIs  
|                  | Professor Alisoun Milne (lead CI)  
|                  | Dr Anne Arber  
|                  | Professor Catherine Robinson  
|                  | Dr Diane Seddon  
|                  | Dr Julia Tabreham |
| Project Title:   | CARERS IN THE 21ST CENTURY: DEVELOPING THE EVIDENCE BASE |

**Description**

Please include a short overview of the projects impacts *(max 2000 characters with spaces)*

This carers seminar series has already had a wide range of scientific, economic and societal impacts, which will continue into the foreseeable future. These impacts have been achieved through careful attention to the planning, organisation, publicity, dissemination of seminars’ findings and the active pursuit of follow-on activities to ensure that the unique knowledge exchange which took place is used to empower and benefit carers and those they support.

The seminars were successful in raising awareness of carers issues and value of carer research across the UK. They also facilitated the identification of ways of developing a much-needed coherent and sustainable evidence base about policy, services and interventions that can be used to effect improvements in carers’ quality of life and those they support.
In addition, the impacts of the seminars mean that their other beneficiaries- namely, practitioners, academics, policy makers and commissioners at local and national levels - are better equipped to effect such improvements. Activities and outputs emanating from the seminars that will underpin their progress include national, Conferences, conference presentations, carer and carer support awareness raising activities, practice and policy (local and national) developments, the establishment of a Carers Research Jiscmail, academic journal papers, practitioner articles, a Special Issue of Health and Social care in the Community Special on carers and caring based on outputs from the seminar series, the submission of a proposal for international Journal of Care and Caring, and the establishment Special Interest Group for Carer Research.

Future research plans centre around the establishment of a national carers research network as the modus operandi for lasting impact of the seminar series. The carer Research JISCmail is seen as laying the foundation for this and funding options are currently being explored.

1. Scientific impact

A Please summarise below the scientific impact(s) your project has had. [Max 2000 Characters with spaces]

The overarching aim of the seminar series was to make a timely contribution to the development of a coherent evidence base about policy, services and interventions that improve carers’ quality of life and those they support. The four seminars drew together key stakeholders in the highly disparate field of caring for the very first time. The participants and presenters included researchers (e.g. leading academic researchers, early career researchers and postgraduate students), carers, service users, practitioners, policy makers and representatives from third sector organisations and government departments. The scientific impacts of the seminars were primarily achieved through the unique knowledge exchange that occurred, both formally and informally. Such engagement led to:

- the exploration and identification of issues that need to be addressed in carer research in the 21st Century
- the identification of issues that need to be addressed by policy makers
- challenges to existing carer-related research and methodologies
- increased profile for carer research
- deeper understandings about carers and the nature of carer research
- a rethinking of existing evidence and knowledge
- the development of collaborations and partnerships
Please outline the findings and outputs from your project which have had the scientific impact(s) outlined in 1A. [Max 2000 Characters with spaces]

It was concluded there is a need to:
- capture the outcomes of existing research effectively and sustainably
- identify research deficits and areas that need new, or additional, research
- prevent unnecessary duplication of research
- take forward research findings in a way that informs policy and practice development more effectively and contributes to the design of support services for carers and those they care for
- continue to develop the carers’ research agenda so that it is fit for 21st Century challenges

Dr Larkin and Professor Milne gave conference presentations at the:
- Social Services Research Group and the School for Social Care Research
- British Society of Gerontology
- Joint Universities Social Work Research.

Dr Larkin co-organised a national conference on carer and service user perspectives at which both Dr Larkin and Professor Milne presented.

The Carers Research Jiscmail has a worldwide membership of 50+. It disseminates information and serves as a repository for resources for carer researchers.

Academic journal papers:

A Special Issue of *Health and Social care in the Community on carers and caring* based on the seminar series with an editorial by Dr Larkin and Professor Milne will be published in January 2015.

Professor Yeandle (Leeds University) has agreed to be Editor for the proposed *International Journal of Care and Caring*. The proposal is being progressed following a meeting with Sage Publications.

Dr Larkin is External Examiner for 4 PhDs. She has appointed a Full-Bursary student –to undertake a PhD entitled “Carers, careers and Employment “

A Special Interest Group for Carer Research has been established at De Montfort University.
C. Please outline how these impacts were achieved. [Max 2000 Characters with spaces]

- Seminar topics were chosen to maximise the achievement of the seminars’ objectives.
- The presenters and participants were from a wide range of backgrounds and disciplines and were all carefully chosen to facilitate the cross-fertilisation of ideas necessary to achieve the seminars’ objectives and the generation of new knowledge. The presenters included 6 carers, 5 TSO members, 23 academics, 3 Standing Commission for Carers members (1 of whom was the SCOC Chair) 1 PhD student and the Director of a research and evaluation service. The seminars were by invitation only and were always full. Participants included researchers, carers, service users, practitioners, policy makers and representatives from third sector organisations.

- A variety of interactive presentation styles were adopted to increase opportunities for active participation and networking, such as breakout sessions, debates and interviews (e.g. one academic interviewing another). Time for questions and discussions was built into the seminar programme. Each seminar ended with a roundtable discussion which focused on identifying ‘Research Gaps and Priorities’ that had emerged during the day.

- An open access seminar website provides presentation ppts, discussion notes, videoed interviews with the speakers, briefing papers detailing the conclusions for each seminar and relevant publications and reports. The website also has blog to encourage further discussion. This website not only leaves a lasting legacy but also offers an invaluable source of information about carer research.

- The Expert reference group met after each seminar to reflect on progress to date and make any amendments needed to the following seminars. Seminar content was also altered in light of current developments where appropriate.

- Dr Larkin and Professor Milne actively pursued the follow-on activities identified, maintaining regular contact.

- Professor Milne reported back to each (3 monthly) SCOC meeting on the seminars’ progress.

D. Please outline who the findings and outputs outlined above had an impact upon. This can include specific academics/researchers through to broader academic groups. [Max 2000 Characters with spaces]

The findings and outputs impact on many academic groups across a range of disciplines in UK universities as well as the applied research audience engaged in carers research. These are:

- established researchers with an interest in carer research.
• early career researchers with an interest in carer research
• post graduate students (most notably, PhD students)
• research staff in Third sector organisations such as Carers UK, Carers Trust and Care Alliance Ireland
• researchers working in independent research and evaluation services e.g. Firefly

The seminars also provided opportunities for such individuals across the UK to:

• deepen their understanding of carer –related research
• broaden their understanding of carer –related research through the exploration of this research through a number of different lenses
• develop their research potential
• develop their understanding of theoretical, conceptual and methodological issues relevant to the emerging carers research agenda
• network, thereby enhancing their research profiles
• be beneficiaries of the knowledge dissemination the carers seminar facilitated

Future research plans centre around the establishment of a national carers research network as the modus operandi for lasting impact of the seminar series. The carer Research JISCmail is seen as laying the foundation for this and funding options are currently being explored. This network will therefore sustain the above impacts and secure the knowledge exchange required to develop a coherent evidence base about policy, services and interventions within health and social care that improve carers quality of life and those they support.

2. Economic and societal impact

A Please summarise below the economic and societal impact(s) your project has had. (Max 2000 Characters with spaces)

1. The seminars contributed to the development of a coherent and sustainable evidence base that can be used to:
   • provide a steer for and increase the effectiveness and integration of public services and policy around carers
   • potentially increase the cost – effectiveness of public services and policy in an era of austerity
   • inform the future carer research agenda, simultaneously reducing unnecessary duplication and fragmentation
   • can be used to enhance carers quality of life and those they support

2. At a societal level, the seminars raised awareness of carers issues and value of carer research across the UK

3. The presence of the Head of Carer Policy at the Department of Health and
members of Standing Commission for Carers members, including the Chair of the Standing Commission for Carers resulted in the seminars informing the forthcoming Care Act (2014)

4. Dr Larkin is working with 2 GP Carer Champions in the development of good practice to ensure carers needs are met within primary care more effectively (see NHS Commitment to Carers. http://www.england.nhs.uk/ourwork/pe/commitment-to-carers)

Please outline the findings and outputs from your project which have had the economic and societal impact(s) outlined in 2A. [Max 2000 Characters with spaces]

See A above and ........

Promoting awareness of carers support at De Montfort University
Dr Larkin organised a De Montfort University-wide showcase event of support for all staff and students with caring responsibilities was held in Carers week on 10th June. It operated on a 'drop-in basis' Information and advice was available from representatives from the following: Occupational Health Equality and Diversity Committee UNISON The Carers Centre (Leicestershire and Rutland) De Montfort Students Union SUCRAN (Service User and Carer Research Audit Network) University and Colleges Union Student services POD (People & Organisational Development) Student Welfare

National conference
Dr Larkin co-organised a national conference entitled “What Works? User and Carer Perspectives on Mental Health and Disability Services” on 11th June 2014. User and carer perspectives are central to the planning and commissioning of mental health and disability services. In this conference users and carers presented their experiences of what works for them and their involvement in planning and developing services. - people came from far and wide and included academics, commissioner, managers and members of the Standing Commission for Carers

Employers for carers membership
Dr Larkin is working with De Montfort University s People & Organisational Development to identify funding for the University to join Employers for carers
• The seminars were by invitation only. Participants were carefully chosen by the Expert Management Group so that they reflected a wide range of backgrounds & disciplines. They included researchers, carers, service users, practitioners, policy makers & representatives from third sector organisations.

• Even though the seminars were by invitation only, throughout the seminar series, we received many requests to attend. A ‘reserve list’ was therefore set up and any spare places were offered on a ‘first come, first serve’ basis to those on this ‘waiting list’. Every effort was made to ensure the participants at each seminar were drawn from a wide range of backgrounds and all the places available for each seminar were filled.

• Financial support for 4 PhD students and 10 carers to attend 1 or more of the seminars was provided. Replacement care for care was also funded.

• The seminars were held in 4 different locations. This was to achieve some parity in travelling time for participants and increase the chances of a number of them feeling they could attend by removing challenging journeys for at least some of the seminars. Carers who attended were appreciative of this organisational feature because of the logistics of finding replacement care for a whole day.

• Carers were panel members for 2 of the roundtable discussions

• There was full recognition of the role of carers as co-researchers and the need to embed carer into the whole research process; a particular project that included carer researchers was showcased too.

• The seminars were well publicised. For example, the PI gave local radio and newspaper interviews for the third and fourth seminars. Radio Leicester, Eagle Radio, the Leicester Mercury and Surrey Advertiser all ran features.

• Articles about the seminars were submitted to and published in Community Care, National Family Carer Network bulletin, De Montfort University Research bulletins and NIHR SSCR blog posts about carers research for Carers Week 2013
Please outline who the findings and outputs outlined above had an impact upon. This can be at a broad societal level through to specific individuals or groups. [Max 2000 Characters with spaces]

- The primary beneficiaries of this seminar series are CARERS. The evidence base to which the seminars contributed should help to improve outcomes for carers. These improvements are also likely to benefit those whom carers support.

- The carer presenters reported being empowered by their participation

- All of the seminar participants benefited from the forum for knowledge exchange, networking and collaboration. Other mutually beneficial outcomes were: increased critical awareness of contemporary and future issues for carers as well as relevant policy and health and social care interventions.

- The information made available as a result of the seminars, the seminar website and the Carers Research Jiscmail is advantageous to TSOs. This information informs their research and campaigning for improvements to carers lives and the lives of those they support.

- DMU employees and students with caring responsibilities

- Professor Milne participated in a panel devising guidelines on ‘training on conducting carers’ assessments’ for health and social care workers who have contact with carers in Kent. These were used by Kent County Council in their guide for TSOs tendering for carers assessment work

- Professor Milne was invited to Roundtable discussion on the New Government Framework on Extending Working Life - Carers (Dec 2013), Department of Health & Department for Work & Pensions event. The discussions at this event influenced the development of the Care Bill regarding working carers

- The close involvement of Department of Health (Head of Carer Policy) and Chair of SCOC in the seminar planning, pre-seminar and post–seminar events provided policy makers with a comprehensive overview of current and future issues for carers and carer policy. This knowledge can be used to inform future initiatives at local, regional and national levels.

- The articles and blog posts benefitted practitioners, policy makers and commissioners at local and national levels.
3. **Unexpected and potential future impacts**

### A Unexpected Impacts

Please note which, if any, of the impacts that your research has had were *unexpected* at the outset of the project, explaining where possible why you think this was the case. *[Max 2000 Characters with spaces]*

- After hearing the 2 carer co-researchers present in seminar 4, Dr Larkin invited them to present at the National conference she co-organised entitled “What Works? User and Carer Perspectives on Mental Health and Disability Services” on 11th June 2014. Their presentations stimulated much further discussion and debate at this conference.

- Following the seminars, Dr Larkin and Professor Milne were invited to give presentations on knowledge generation in carer research at the Joint Social Services Research Group, the School for Social Care Research event, the British Society of Gerontology conference and the Joint Universities Social Work Research Conference.

- Dr Larkin has been contacted by people from all over the world about the content of the paper that she and Professor Milne wrote to ‘launch’ the seminars. namely, Larkin, M and Milne, A. (2014). “Carer empowerment in the 21st century – a critical reflection”. Journal of Social Policy and Society, 13 (1) 25-38

- Dr Larkin secured a new post at the Open University with a remit to develop carer research and contribute to courses in their Faculty of Health and Social care.

- Dr Larkin has been invited to be a blogger on carers issues for Mental ELF and the Social care ELF which is being developed. The intention is that there will eventually be a separate Carers ELF. This has the support of the RCGPs and Dr Larkin is currently in negotiation with 2 GP Carers Champions about its development.

### B Potential Future Impacts

If you have a clear idea of the impact your project is likely to have in the future please detail these below. *[Max 2000 Characters with spaces]*

Dr Larkin and Professor Milne are submitting a proposal to the NIHR SSCR to secure funding for a sustainable UK wide carers research and knowledge exchange network. This will act as an interactive repository and resource for carers, those they support, practitioners, service providers, commissioners, policy makers, researchers, lecturers and other stakeholders. The more specific aims are to ensure the effective
use and exchange of existing - and the generation of new – carer-related knowledge, information and research evidence; improve services and care practice; enhance carers' capacity to make informed choices and evidenced-based decisions. The project's key objectives are to:

- Effectively capture, organise and synthesise 'all things carer' on an interactive and accessible website - this will include policy and practice documents, research findings/summaries, data sets, events, consultations, relevant website links, and academic materials;
- Provide a routinely up-dated network (CAREN) through which carer-related information can be easily accessed by a wide range of stakeholders (see above);
- Ensure that CAREN facilitates inclusive information and knowledge exchange, debate, cross-fertilisation of ideas, new partnerships, research links, and contributions to consultations and events for all those with an interest in carers and caring;
- Use CAREN to enhance carers’ and service users’ access to information and resources to help facilitate decision making and choice, and encourage carer involvement in research, policy and service related issues and practice discourse;
- Once established, to develop and extend CAREN’s activities and role, drawing on the findings of a systematic evaluation of its aims, impact and benefits.

At the moment, no such network exists. Given the importance accorded carers in policy and practice and their prominence as a cross-cutting research priority, this is a proposal that is both timely and important.

4. Impact limitations

A Limited scientific impact

Please state below any major scientific difficulties that have limited the scientific impact of your project. The statement should refer to an effect on impact rather than simply detail research difficulties or other project activity problems. [Max 2000 Characters with spaces]

- Due to a misunderstanding over the actual date of the end of the award, we were unable to use the £700 originally allocated for dissemination activities. An extension was discussed with the ESRC but unfortunately permission could not be granted to make this change.
B Limited economic and societal impact

ESRC recognises that some of the research it funds will not have an economic or societal impact in the short term. Please explain briefly below if this is the case for your project, and refer to your grant application where relevant. [Max 2000 Characters with spaces]