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Abstract

Although there is now an extensive international body of research and evidence about care and carers it is fragmented and disparate. Without synthesis, organisation and accessibility it cannot effectively inform and improve policy and practice with carers. This paper makes the case for a freely accessible knowledge exchange network that would provide relevant stakeholders with access to a regularly updated and coherent database of carer-related research and evidence; offer interactive opportunities to exchange and generate knowledge; facilitate links and information sharing; and disseminate innovative practice, interventions and services. It is proposed that this network is known as the 'Carer-related Knowledge Exchange Network' (CAREN) and that it is initially based in the United Kingdom. However, given the global relevance and reach of care and caring, it could then be extended and adapted for the international stage. In addition to outlining its dimensions, development and functionality, the challenges of establishing and sustaining CAREN are discussed. The cross-cutting importance of care and caring, and the number of stakeholders who need access to coherent, robust information and networking opportunities underscore the need to develop CAREN's potential to make a sustained and cost-effective contribution to addressing a critical global issue of the 21st Century.

Introduction

The worldwide increase in the number of family carers (carers) supporting a relative who is older, disabled or seriously ill is well-documented (OECD 2011; Pickard 2015). Recent reviews of the extensive body of national and international evidence around the role and contribution of carers have shown that, as strong as its separate elements may be, this body of work is highly fragmented and located in numerous spheres and places. It also takes many forms; there is a wide range of research articles, projects, reports, data sets, conference proceedings and digital resources produced by different bodies and sectors, such as carers third sector organisations, universities, research institutes/centres and government departments. In addition, there is a plethora of policy, practice and guidance documents, web-based advice/information sources, consultations and discussion forums (e.g. blogs) hosted by a range of organisations (e.g. charities, government departments and independent networks) (Larkin and Milne 2014; Greenwood and Smith 2016; Henwood, Larkin and Milne 2017).

Existing carer-related research and evidence can be credited for helping to raise carers' profile in public discourse; foregrounding caring as an important issue within social policy; driving forward carer research; and informing improvements in practice (Stalker 2003; Larkin and Milne 2015a). However, that research and evidence is widely distributed, and is not coherently synthesised in one place has significant implications for many stakeholder groups and knowledge and evidence syntheses.

A freely accessible knowledge exchange digital resource, known as the Carer-related research and evidence exchange network (CAREN) (www.open.ac.uk/caren/), has been recently developed. It is for all stakeholders who require any form of carer-related knowledge. Underpinning this network is a National Institute for Health Research School for Social Care Research (NIHR-SSCR) funded scoping review on carer-related evidence and knowledge (Henwood, Larkin and Milne 2017, Larkin, Henwood and Milne 2018). It took a broad approach to evidence and knowledge in order to and bring together a wide and disparate range of relevant sources. Not only did the review include traditional research evidence, but also what is often termed grey literature, namely resources beyond academic and peer-reviewed or scholarly articles. Examples are articles and reports in the professional trade press (e.g. Community Care); resources in multiple formats including digital, and audio visual (e.g. training materials, guides); and patient/user and carer generated knowledge and evidence (e.g. videos, bulletins). All materials were saved and coherently organised using EndNote data management software. The review was then written up into a report which uniquely, synthesised and mapped carer-related knowledge and evidence and offers an overview of its range and type alongside a coherent commentary of its content, dimensions and nature (Henwood, Larkin and Milne 2017).

This paper starts by making the case for an accessible carer-related research and evidence resource for stakeholders in carer-related domains across policy, practice and research. It then describes how CAREN was set up, its value to its users and issues pertaining to its future development. Whilst international literature is included in

this discussion, for reasons of consistency - and because it was developed in England - examples of policy and practice are drawn from the UK.

The need for carer- related research and evidence

With reference to carers themselves, access to well-organised and useable information is key to meeting their needs and facilitating choice and is associated with improved quality of life (Harland and Bath 2008; Rand and Malley 2014). Carers and service users having access to information and making informed choices is a core policy aim in many Western countries (Needham 2011; Larkin and Mitchell 2016). Furthermore, in the UK, the Care Act 2014 *legally* entitles carers to information and advice (HM Government 2014; Larkin and Mitchell 2016). It is therefore imperative that current challenges around utilising carer-related information are addressed to support the achievement of these policy aims.

Care, and meeting care needs, have become critical matters for governments, employers, policy makers, practitioners and researchers. The global drive towards evidence-based policy and practice has increased the requirement (often within a short timeframe) for coherently organised synthesis of evidence across a number of different policy arenas (including health and care, employment and workforce development, and welfare benefits) (Nutley et al. 2007; Sheets et al. 2014; Campbell et al. 2015; Fisher 2016). For example, this is increasingly apparent in the development of the series of cross-government carers strategies in the UK. These aim to increase carers' rights and

improve their lives through recognising, valuing and supporting them. The Carers team in the UK's Department of Health and Social Care was recently expeditiously required to bring together a distillation of contemporaneous evidence to underpin the forthcoming Carers Strategy for England and inform the future direction of carers' policy (Carers UK 2016).

Practitioners often need to make use of carer-related information and evidence quickly and effectively to help with assessments of need and service-related decisions in different contexts. This stakeholder group includes social and health care workers, social workers, carers' support workers, personal assistants, carers organisations, and service commissioners (Department of Health 2012; Hewison and Rowan 2016; Milne and Larkin 2015b).

The research community also needs to be able to readily access and make use of reliable information. The current fragmentation of research and evidence means that much of its additive benefit is lost, thereby limiting its capacity to inform future research (e.g. in terms of avoiding duplication) and reducing opportunities for researchers to maximise its value and impact (Barnes 2006; Larkin and Milne 2015a).

Additionally, issues relating to research funding are relevant. There is increasing emphasis on ensuring that research directly relates to the efficacious design and development of services and interventions. That messages about effectiveness are communicated clearly to decision-makers, service commissioners, practitioners,

carers, and third sector agencies is a key priority. More cost-effective ways of allocating research funding is a prerequisite to the realisation of these goals, particularly in an era of cuts in both research funding and health and care service provision (Sá et al. 2013; Burnett et al. 2016; Department for Business, Innovation and Skills 2016; Humphries et al. 2016; O'Dowd 2016; Sanders-McDonough et al. 2016; Muscio et al. 2016).

The importance of enhancing access to, and making use of, coherently organised information, research and evidence is increasingly recognised in the health and social care sector. Furthermore, it is now well-established that knowledge exchange between research, practice and policy stakeholders is central to the development of good quality care, and evidence-based practice (Department of Health, 2012; Matosevic et al. 2013; Rutter and Fisher, 2013; Campbell et al. 2015). Knowledge exchange between researchers and external stakeholders is also seen as critical to demonstrating impact (Department for Business, Energy and Industrial Strategy 2016; UKCIP and Cooper, 2016).

There are several examples of shifts to the more effective deployment of carer research and evidence in informing policy, services and interventions (Yeandle et al. 2017). An example is the international Carers Research collaborative network (using JISCmail). This now has a worldwide membership of 160+ and enables researchers, carers, service users, third sector organisations, practitioners and policy makers to share information on the evidence base for carer services, research and

policy. To date it has been used to disseminate information about events and publications and as a repository for resources e.g. reports and academic papers. However, this is not a comprehensive or systematically compiled up-to-date resource nor is it sophisticated in terms of interactivity, search functions or platforms for discussion. Further, it cannot facilitate the prompt sharing of information about innovative policies, practice and interventions through, for example the use of apps or social media. Rather it is the product of (mainly) one informed individual's regular trawling of relevant sources and networks.

The newly launched International Journal of Care and Caring is another example. In addition to publishing high quality academic peer-reviewed papers it includes two other sections; the innovative Debates and Issues section attracts shorter articles and commentaries from contributors outside academia, such as policy makers, carers, third sector organisations, practitioners and service providers¹. The Reviews section covers conferences, policy and practice publications as well as edited books, research monographs and digital resources. The journal reaches a wide audience including: academics researching or teaching on care and caring; care commissioners; carers organisations; carers and care recipients; care workers and their employers; funding bodies; health and social care practitioners and decision makers; human resources professionals; policy-makers; service users; social workers; trade unions and training organisations.

¹ This section is free to registered users

Other developments in the UK include the Royal College of General Practitioners(RCGP) Carers Hub. This is an online information platform for use by primary healthcare staff which aims to improve carer support in primary care. It has information about identifying and supporting carers, bringing together RCGP resources as well as signposting to external resources.

Although such developments represent progress, they separately and independently focus on different sources of information, research and evidence, have different aims and perspectives and (mainly) target particular stakeholder groups. At present, there is no coherent, co-ordinated, systematic or universal approach to the location, networking, utility and accessibility of carer-related knowledge. Nor is there is a platform for the effective orchestration of the sharing and exchange of carer-related research and evidence between different stakeholder groups.

Towards CAREN

Recognition of this deficit was the main driver for the establishment of CAREN. The project was steered by a team comprising of a carer researcher, website designers, IT support, software developers, technical architects and knowledge exchange experts. Regular consultations were undertaken with representatives from CAREN's key stakeholder groups (including carers). This team has now been superseded by an international management group made up of carers, service users, carers organisations, researchers, practitioners and policy makers.

The main foundation for CAREN was the aforementioned scoping review (Henwood, Larkin and Milne 2017, Larkin, Henwood and Milne 2018). CAREN's design, infrastructure and operation were informed by the design and functionality of existing models of knowledge exchange (Baxter et al.2008; Harland and Bath 2008; Murdock 2013).

Knowledge exchange is a process which forges connections between individuals, groups, networks and communities across sectors and disciplines to exchange ideas, evidence and expertise. It is associated with innovation, enterprise and entrepreneurship, and is often instrumental in the co-production and generation of knowledge (Nutley et al. 2007; Boaz et al. 2009; Ward et al. 2012). The concept of knowledge exchange has been adapted for use in many different contexts reflecting their particular characteristics, aims and needs. For instance, web-based information technology platforms have been developed in public health to meet the need for evidence-informed decision making in areas such as smoking cessation and encouraging healthy alcohol consumption. These platforms facilitate collaboration and exchange between different organisations and professions with the aim of aiding decision-making, supporting patients and other users, and planning effectively (Quinn et al. 2014).

The role played by the internet, digital platforms and information technology has significantly extended the reach and potential of knowledge exchange, most notably in relation to the development of networks. Although critics have focused on the way

knowledge exchange networks often assume a hierarchical model and lack strategies to manage their members' evolving needs, many have acquired international currency (Monti, and Soda 2014; Anderson and McLachlan 2016; Warren et al. 2016). These include networks that help to facilitate research leadership in health policy development (Graham et al. 2005; Best and Holmes 2010; Hall et al.2010; Murdock et al. 2013; Rutter and Fisher 2013; Redman et al. 2015). An example is the WHO EVIPNet (<http://www.who.int/evidence/en/>) which promotes the systematic use of research evidence in policy-making to strengthen health systems and ensure programmes, services and drugs are delivered to those who most need them. One of these programmes focused on tackling the double burden of communicable and non-communicable diseases in Africa.

These examples suggest that knowledge exchange models have potential for adoption within the carers field. Key features of knowledge exchange models that would work in the carers field included: the capacity to accommodate the needs of a wide range of stakeholders (e.g. policy makers, practitioners, carers); breadth of discipline (e.g. social work, health, social policy); and multi-disciplinarity of, and variations within, carer-related research and evidence (e.g. health based, carer-led, small scale evaluations). Models of knowledge exchange that are selective, chargeable and principally for the benefit of members of specifically defined groups (Dovey et al. 2016; UKCIP and Cooper 2016) were not deemed appropriate. It is essential that a knowledge exchange network suitable for the world of care and caring is inclusive and

free at the point of use; most carers and many carers' support services and charities do not have the funds for resources of this type.

The systematically gathered and organised data in the Endnote database produced as part of the scoping review was transferred onto a designated area on the Open University's website ². CAREN was subsequently developed to provide a comprehensive, regularly updated interactive web-based platform. It is free, has single point access and optimised for the search needs of all stakeholders, national and international. The interactive elements are based on features used in existing networks to facilitate knowledge exchange such as webinars, online forums, Facebook and twitter

Examples of CAREN's key roles include:

- supporting decision-making by *carers* and *social care and health care practitioners*
- the provision of information and evidence for *service commissioners* to support cost-effectiveness in decision-making
- the facilitation of informed exchanges between *carers, social care workers, social workers and social work students* in relation to innovative practice and effective assessments
- enabling discussions between *commissioners and policy makers* about co-designed services and commissioning decisions

² The lead author is employed by the Open University

- dissemination and facilitation of dialogues between *carers, researchers, PhD students, research funders, policymakers and practitioners* in relationship to evidence, policy and practice thereby facilitating evidence-based improvements in the quality and cost-effectiveness of care services and practice with carers
- acting as a source of information about policy consultations and policy development for *carers, government departments and third sector organisations*
- providing an information platform about research funding opportunities at no (or very little) cost *for researchers and research funders*
- acting as an *international noticeboard* for promoting conferences and events of interest to *CAREN's stakeholders* e.g. the 8th International Carers Conference
- the interactive facilities around carer research will help *researchers* reduce duplication of effort, develop multi-stakeholder research teams (which may include carers), acquire knowledge quickly about research activities, recruit for studies, post information about progress, explore new and innovative methods, discuss study findings, and make the most effective use of funding
- providing opportunities for the *University-based researchers* to maximise the impact of their research; the UK's Research Excellence Framework places considerable emphasis on impact.

Realising CAREN's potential

Ensuring that CAREN continues to meet the needs of its stakeholders and maximises its potential will be an ongoing and iterative process. Regular updating of the content based on the database of carer-related research and evidence is fundamental; the

pace of change in this area necessitates updates at a (minimum) of four monthly intervals. Essential too is further work to enhance CAREN's interactive features to extend its capacity for knowledge exchange. For instance, through the use of apps and synchronous video consultations. The latter have been used in other knowledge exchange networks to achieve real-time or simultaneous communication with people in different locations (Whitworth and Friedman 2008; Khuntia et al. 2015; Yan et al. 2016). The extension of social media applications within the platform may also be of value e.g. functionality to organise events (Miralbell 2015). In addition, moving available knowledge into active use (referred to as knowledge mobilisation strategies) are worthy of exploration, particularly in relation to the use of transmedia (e.g. a combination of on-line video, Facebook and blogging) to encourage communication between diverse groups and the communication of information in various formats (Anderson and McLachlan 2016; Nutley et al. 2016).

Interactive design features from other networks that could also be adapted for use in CAREN are non-competitive digital spaces for interactive exchanges around specific topics between different groups of, or individual, users (Lomas 2005; Morton et al. 2012; Nutley et al. 2016). For CAREN, these topics are likely to include commissioning decisions, research, policymaking, service development and practice issues. Interactive exchanges could be promoted and supported by a digital space which, for example, could host exchanges; create subject groups; share ideas, or papers; allows the tagging and downloading of documents and storage of materials in 'libraries.

Given CAREN's international reach, new ways of engaging with stakeholders beyond the UK need to be regularly revisited. Exploration of the capabilities of knowledge exchange approaches relating to care and caring utilised in other countries also feature in the CAREN development plans (Social Care Institute for Excellence 2012; Lam and Dearden 2015; Baker and Irving 2016; Ewert 2016; Sancino, 2016). Organisations such as Eurocarers and Carers Worldwide will be able to provide relevant advice.

As discussed above, there are other developments which focus on the effective use of carer research and evidence, namely the international Carers Research collaborative network and the RCGP Carers Hub. To capitalize on their contributions, such initiatives could be incorporated into CAREN via links and information feeds.

There is also an ongoing need to evaluate CAREN's impact on policy, practice and research. Evidence that could provide this information may include: information about hit rates, who uses CAREN and for what purpose, how materials accessed via CAREN have been deployed, which new links or networks have been established, and how commissioners have used CAREN's resources to develop new services in their area. User-centred design literature could be useful in ensuring a focus on user needs and requirements (Vredenburg et al. 2002; Ozok et al. 2017). In addition, surveys and online interviews with identified users could, for example, capture the impact of accessing CAREN's resources on carers' quality of life or explore how social workers have improved their practice with carers using information and evidence gleaned from CAREN. The facility to gather such data needs to be embedded into CAREN'S

functionality. Furthermore, mechanisms for using feedback to shape CAREN's development will be required in order to ensure that it is responsive to new demands and ideas.

The challenges of realising CAREN's potential

Realising the CAREN's potential is not without challenges. The most important challenge is ensuring its sustainability which necessitates addressing a number of structural issues. A primary issue relates to funding; long-term, dedicated investment of time and financial resources is critical to CAREN's success. Extending CAREN's infrastructure, regularly updating its content and systems, ensuring it operates effectively and maintains its credibility and currency for its wide variety of stakeholder groups in the ways described above is largely dependent on funding.

Staff costs will constitute a significant portion of CAREN's funding footprint. There is a need for staff with different skills including a network manager for ongoing oversight and to maintain CAREN's sustainability, coherence, effectiveness and value for money (Murdock et al. 2013). Other costs are likely to relate to bespoke IT software, rights clearances, broadband usage, supporting the consultation phase, fees for 'experts' and payments for panel members and other development activities. Securing such funding may be complicated as the network is essentially an interdisciplinary project, spanning communities, institutions, sectors and countries. Funding bodies who see inter-disciplinarity and multi-sectorality as important will need to be identified. Given

CAREN's magnitude and relative complexity, funding from a number of sources may need to be secured. The contribution from these sources may also change in proportion, significance and type over time as the network evolves.

A second structural requirement is long-term organisational commitment. The Open University is very willing to host CAREN and support its development and expansion. Most Universities already run and oversee interactive digital platforms. In comparison with third sector carers organisations and government departments, they also offer independence and (relative) permanence. A University host is therefore likely to be the best option, especially in relation to guaranteeing CARENs' sustainability.

Although existing knowledge exchange models can inform CAREN's development, there are challenges relating to its knowledge exchange functionality. Updating the broad and varied knowledge terrain, that characterises the carers' field, will demand commitment, creativity and technicality. Meeting and capturing the different needs, levels of knowledge, educational, professional and organisational backgrounds, requirements and priorities of CAREN's variety of users is another challenge. Addressing these will need to include the adoption of techniques that facilitate global and inclusive information exchange and that do not privilege those with more power or resources (Baxter et al. 2008; UKCIP and Cooper 2016).

CAREN also poses challenges for those staff with overall responsibility. For example, the network needs individuals who can cope with the well-documented problems of

managing relationships between disciplines and sectors in a multi-stakeholder environment, together with the inevitable conflicting organisational and individual priorities around the knowledge exchange process (Murdock et al. 2013). As CAREN will be a longstanding network, staff changes are likely. A great deal of tacit knowledge about the network will be held by staff. To ensure coherence and continuity, such people-embodied knowledge needs to be captured thereby creating organisational memory and supporting the sustainability of CAREN as both a concept and a network (Lyll et al. 2013). The value of using a task management tool (e.g. Asana) to track ongoing developments could be explored in relation to this particular challenge.

Conclusion

The establishment of CAREN addresses a significant systemic deficit in the carers field and represents a step change in the way carer-related evidence and knowledge is captured, addressed, shared and disseminated. When fully developed, it will provide a range of stakeholders with access to a regularly updated database of carer-related, materials, research and evidence and offer interactive opportunities to exchange, discuss and disseminate information, facilitate links, generate new knowledge and share innovative practice. This unique network has the potential to improve the lives of the ever-increasing number of carers, by significantly enhancing the relationship between carer research and evidence and policy and practice.

Although securing CAREN's potential in the future is relatively complex and costly, it is achievable; a number of key foundation stones are already in place and expertise in the required cognate disciplines and contributory fields exists. Given the importance of carers internationally it is a network whose time has come and whose capacity to address issues of worldwide significance can only be realised through the vehicle of knowledge exchange.

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