MAXIMISING THE POTENTIAL OF CARER RESEARCH AND KNOWLEDGE

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Life-changing Learning

INTRODUCTION

- now a wealth of national and international knowledge around the role and contribution of family carers BUT it is fragmented, disparate, lacks accessibility and utility

- accessing and exchanging relevant information, research and evidence is challenging for all those who need it

- this has significant implications e.g. in relation to supporting carers' capacity to make informed decisions; achieving policy goals; maximising the value and impact of research

- MY PERSONAL MISSION!

PRESENTATION OUTLINE

1. **ECONOMIC AND SOCIAL RESEARCH COUNCIL (ESRC) CARERS SEMINAR SERIES**

2. **CARERS RESEARCH COLLABORATIVE NETWORK**

3. **INTERNATIONAL JOURNAL OF CARE AND CARING**

4. **SCOPING REVIEW OF NATIONAL AND INTERNATIONAL CARER-RELATED KNOWLEDEGE**

5. **CARER KNOWLEDGE EXCHANGE NETWORK (CAREN)**

1. ECONOMIC AND SOCIAL RESEARCH COUNCIL (ESRC) CARERS SEMINAR SERIES

- 2012-13 - ESRC funded carers seminar series to review the evidence base

- contribute to the development of 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. CARERS RESEARCH COLLABORATIVE NETWORK

- worldwide membership of 200+ comprising researchers, carers, service users, third sector organisations, NGOs, practitioners and policy makers to share information on the evidence base for carer services, research and policy

- anyone can ask to join but membership requests have to be accepted

- enables members to share and disseminate information about events and publications

- repository for research relevant resources, including academic papers

- members can post messages e.g. requests for research partners or collaboration

Carers Research collaborative network

Explore » Advice

Logged in as: mary.larkin@open.ac.uk (Owner)

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Latest Messages

Latest books and a new journal in Health & Social Care	Jessica Miles <Jessica.Miles@BRISTOL.AC.UK>	Thu, 13 Apr 2017 14:30:10 +0100
Short Course at University of Oxford - Practice of Evidence-Based Health Care	University of Oxford CPD Centre <cpdhealth@CONTED.OX.AC.UK>	Thu, 13 Apr 2017 12:14:19 +0100
Supporting adult carers - NICE guideline scope consultation	Mary Larkin <mary.larkin@OPEN.AC.UK>	Tue, 11 Apr 2017 11:35:53 +0100

CARER-RES

Carers Research collaborative network — Hide Latest Messages

A place for researchers, carers, service users, third sector organisations, practitioners and policy makers to share and exchange information on the evidence base for carer services, research and policy

- April 2017
- March 2017
- February 2017
- January 2017
- December 2016
- November 2016
- October 2016
- September 2016
- August 2016
- July 2016
- June 2016
- May 2016
- April 2016
- March 2016
- February 2016
- January 2016
- December 2015
- November 2015
- October 2015

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3. INTERNATIONAL JOURNAL OF CARE AND CARING

- high quality academic peer-reviewed articles
- 'Debates and Issues' section aims to attract shorter articles from contributors outside academia, such as policy makers, carers, NGOs, practitioners and service providers.
- 'Reviews' section which covers conferences, policy and practice publications as well as edited books and research monographs.
- the IJCC reaches a very wide audience within and outside academia

International Journal of Care and Caring

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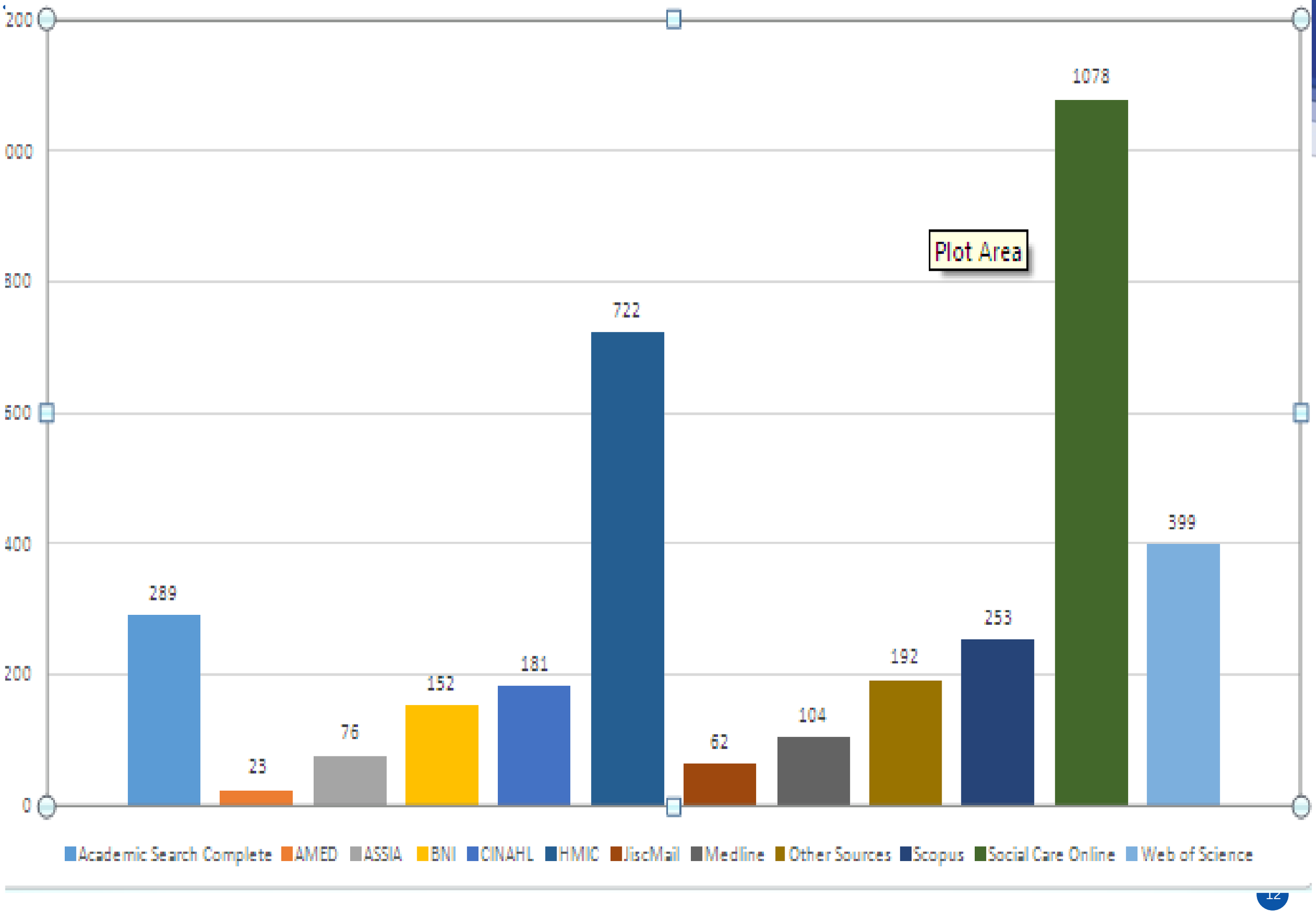
4.SCOPING REVIEW OF NATIONAL AND INTERNATIONAL CARER-RELATED KNOWLEDGE

- used Arksey and O'Malley's (2005) framework
- Project Advisory Group (PAG) central to the project
- approach was deliberately wide and both developmental and iterative
- inclusion criteria:
  -published since 2000
  -available in the English language
  - focused on the care of adults
- searches were undertaken between June and December 2016
- agreed a core set of 10 electronic databases, supplemented by additional web searches
- all materials were captured and saved using EndNote
- Report: Henwood M., Larkin M. & Milne, A. (2017) *Seeing the wood for the trees. Carer related research and knowledge: A scoping review.* https://www.scie-socialcareonline.org.uk/seeing-the-wood-for-the-trees-carer-related-research-and-knowledge-a-scoping-review/r/a110f00000RCtCnAAL

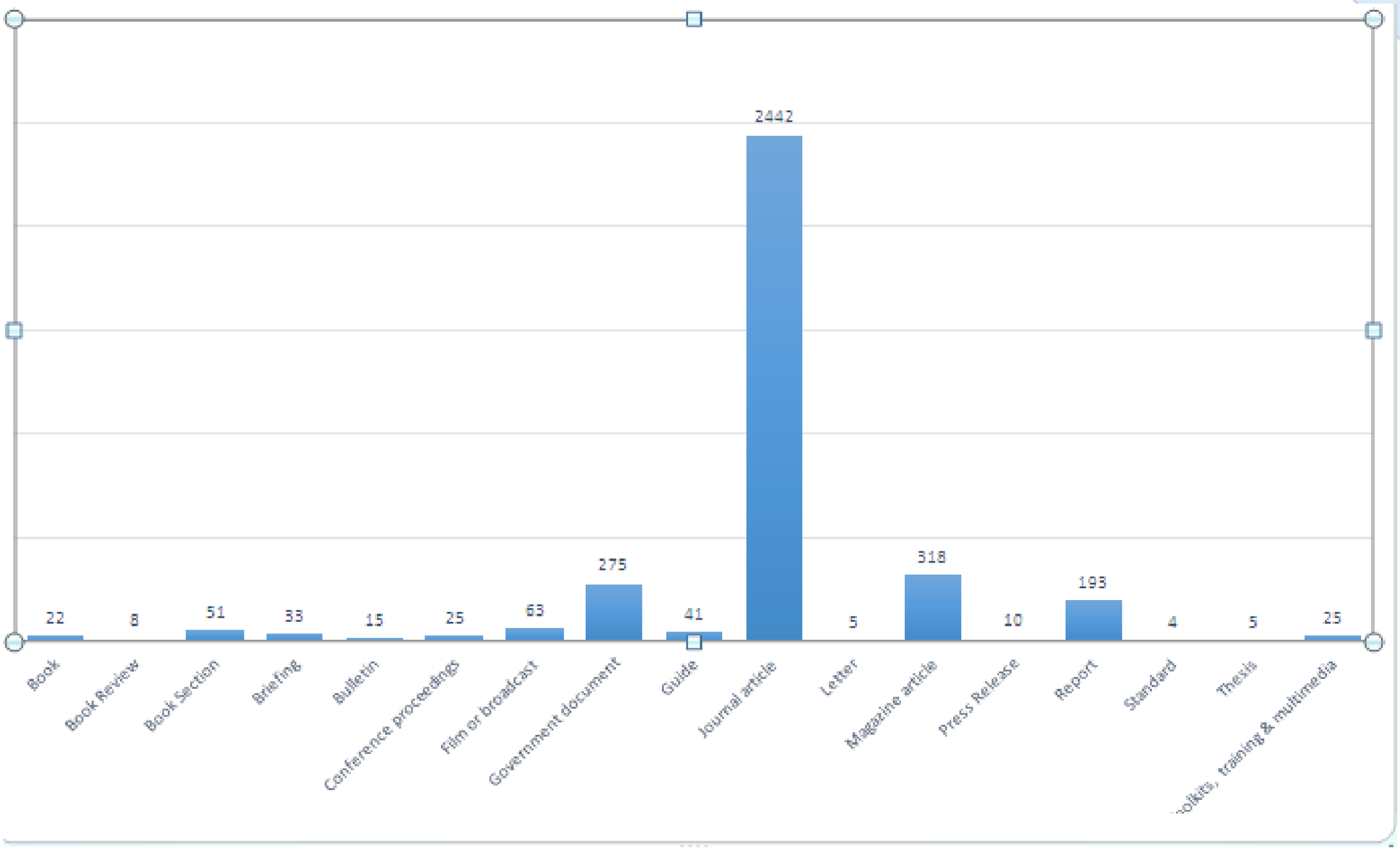
Mapping the territory

- 3,535 references!
- databases varied in terms of their productivity
- materials were classified into 17 ‘types’

References by database



Reference types



Themes and issues

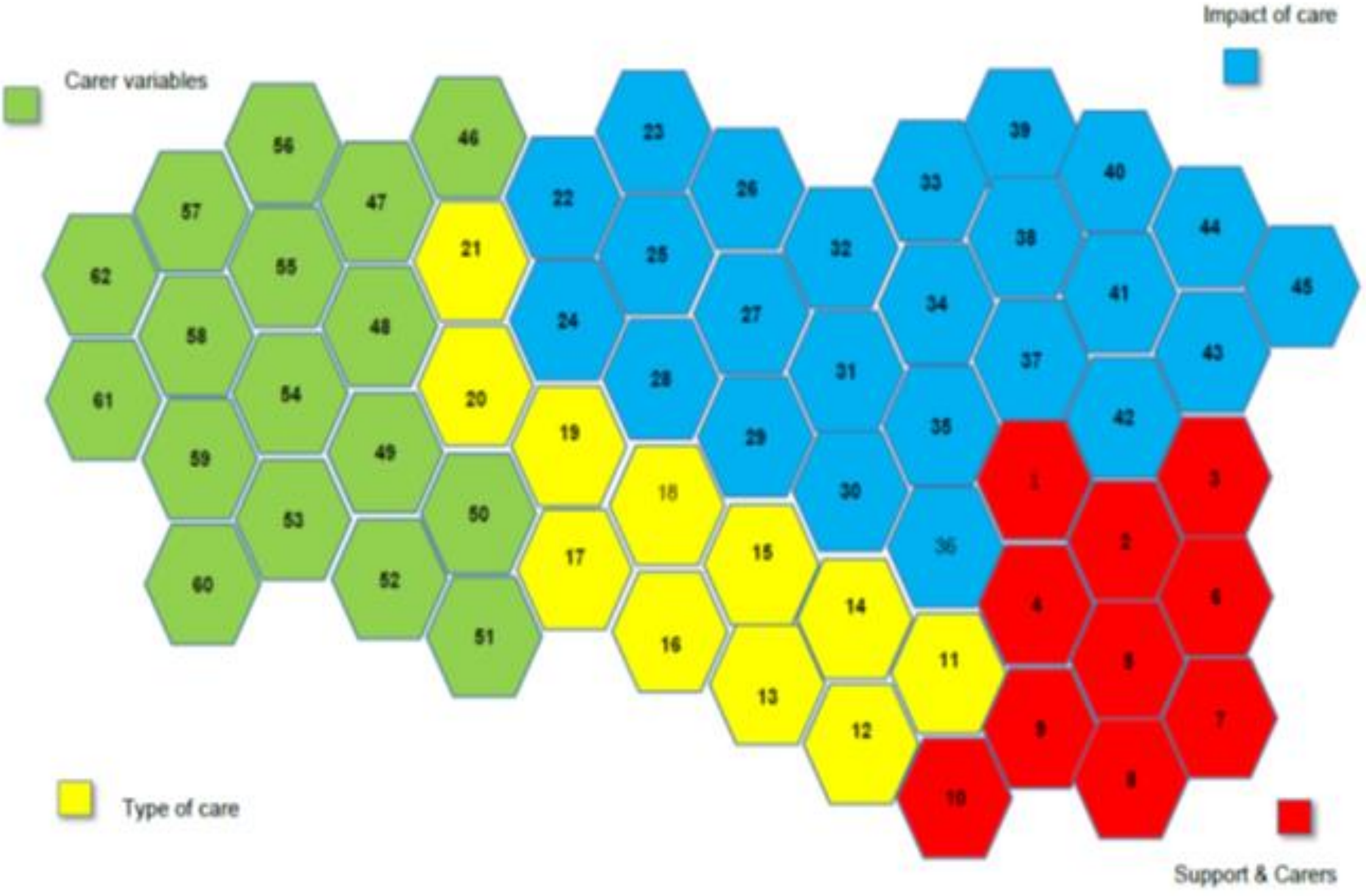
- the resources were coded and categorised into 62 themes

- the themes were classified within four major categories:
  - ***Impact of Care:*** the consequences and sequela of caring (39%)
  - ***Carer Variables:*** the characteristics and features of different types of carer and caring situations (27%)
  - ***Type of Care:*** the nature of needs of the cared for person, and the features of the care situation (18%)
  - ***Support and Carers:*** the provision and impact of general and specific help and support (16%)

- defined each of the themes within the categories

- analysis of frequency of themes

Themes classified by category



Defining the categories and themes

Support & carers	
1. Assessment	Assessment of carers' needs.
2. Care Act evaluation	Focusing on the implementation of the 2014 Care Act and considering the impact on and implications for carers.
3. Carer Support	Addressing carers' needs for support, or specific services/interventions intended to support carers.
4. Cash for care	Refers to Direct Payments, personal budgets and similar arrangements that provide cash to the carer to organise support on their own behalf and/or that of the person cared for.
5. Respite	Services and interventions intended to provide respite or a break for the carer and/or the person cared for.
6. Social support & networks	The nature of family, friends and wider community networks able to support carers.
7. Social Work Education	The involvement of carers in shaping social work education and training, and the importance of carers issues being reflected in course content.
8. Technology & telecare	Use of telecare, technology, telematics, robotics, electronic tracking etc. and applications for carers and those they support.
9. Training & carers	Training for carers, and involvement of carers in training of care providers and others.
10. Value of care	The notional value of care provided by carers, and the value attributed to caring (monetary and other).

The highest and lowest frequencies…….

Highest

- Carers and health (1,992)
- Carer support (1,596)
- Carers' needs (874)
- Caring for older people (627)
- Dementia care (618)
- Emotional and physical impact (467)
- Mental health (446)
- Burden of care (409)
- Relationships (336)
- Quality of life (333)
- Measuring and evaluation (323)
- Psychological impact (306)

Lowest

- Expert carers (35)
- Cash for care (35)
- Social work education (33)
- AIDS/HIV (32)
- Dual and sandwich carers (28)
- Friends, neighbours and sibling carers (25)
- Caring and the lifecycle (24)
- Projections (19)
- LGBT (18)
- The Care Act and carers (16)
- Caring at a distance (12)
- Post-caring (8)

Key messages

- carers and caring are extremely diverse
- similarities in the experiences of carers but at the same time all caring is unique
- attention to both parties in the caring dyadic relationship is vital in understanding where interests coincide and where they diverge
- little knowledge about ‘hard to reach’ carers - particularly BAME and LGBT carers
- the profile of and research about ‘young carers’ has grown considerably in recent years but they remain a small proportion of the carer population
- most care is provided for older people
- older carers are relatively invisible in policy, practice and research and are less likely to identify themselves as carers
- newly emerging ‘sandwich care’ generation
- the mental health of carers attracts considerable attention
- ‘burden of care’ discourse
- more attention is now being given to how carers cope
- high profile for balancing the demands of work, life and caring, and supporting working carers
- evidence about effectiveness of services and support for carers is equivocal and contradictory. Psychosocial interventions most likely to make a difference
- support has to be tailored. Sometimes it is the *process* of support and interventions that may be valued even if the end outcomes do not indicate positive effects

Implications for policy

- existing knowledge is able to identify critical points and to identify to groups of carers that are likely to be under particular strain and pressure and where attention should be prioritised
- building carers' resilience and enabling them to develop strategies to manage the stress and pressure they experience appears to be an important area to develop further

Implications for research

- knowledge about carers' lived experiences should be maintained and extended

- address the deficits in existing knowledge and direct attention towards expanding the evidence base

- evaluations of pilot programmes for interventions need to be more rigorously designed

- more longitudinal data is needed

5. CARER KNOWLEDGE EXCHANGE NETWORK (CAREN)

Welcome to the Carer Research and Knowledge Exchange Network (CAREN)

- www.open.ac.uk/caren

- a freely accessible knowledge exchange resource for all those across the globe who require any form of carer-related knowledge e.g. governments, carers, employers, policy makers, practitioners, researchers, third sector organisations and research funders around the world

Establishing CAREN

adapted existing knowledge exchange models

- transferred the items captured and coherently organised on Endnote during the review

- used same organisation system as the review i.e. 62 themes classified into four major categories :
  - *Impact of care*
  - *Carer variables*
  - *Type of care*
  - *Support and carers*

- **DEMO -** www.open.ac.uk/caren

- twitter, links to other relevant sites, Facebook blog and podcasts webinars

Examples of CAREN's roles

- a reliable and independent database for carer research and knowledge
- translation of research and evidence into evidence-based improvements in the quality and cost-effectiveness of both health and social care services and practice with carers (researchers, policymakers and practitioners)
- a source of information about policy development and evidence for government departments and NGOs
- the provision of information and evidence for carers, service commissioners, NGOs, policymakers and practitioners to support cost-effectiveness in decision-making and service development
- the facilitation of informed exchanges in relation to consultations and innovative practice (e.g. carers, NGOs and government departments)
- help researchers reduce duplication of effort, quickly acquire knowledge about existing research
- an 'international noticeboard' for promoting conferences and events

Future development

- led by international management team
- regular updating of resources
- extend knowledge exchange and search facility
- feedback and evaluation
- sponsorship

In sum…..

- CAREN addresses a significant systemic deficit in the carers field

- step change in the way carer-related issues are captured, disseminated and addressed

- has the ongoing potential to improve the lives of the ever-increasing number of carers, by considerably enhancing the relationship between carer research and evidence and policy and practice

- it is a network whose time has come!

CONCLUSION

- these steps represent significant progress in maximising the value and impact of carer research, evidence and knowledge.

- BUT the journey has not ended!

- still need more ideas about ideas about how we make the best use of the carer-related knowledge base that we have got and to develop it is a way that really does improve outcomes for carers

QUESTIONS and SUGGESTIONS?