Carer Research and Knowledge Scoping Review

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INTRODUCTION

- SSCR Project: "Utilising Carer-Related Research and Knowledge: a scoping review and information resource"

- in partnership with Social Care Institute for Excellence (SCIE)

- now a wealth of national and international material and research about carers BUT it is fragmented, disparate, lacks accessibility and utility which in turn:
  - ➢ makes finding information about carer research problematic
  - ➢ impedes its capacity to reliably inform future research

- a unique and comprehensive scoping review of carer-related knowledge

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PRESENTATION OUTLINE

- **METHODOLOGY**

- **MAPPING THE TERRITORY**

- **THEMES AND ISSUES**

- **KEY MESSAGES**

- **IMPLICATIONS FOR POLICY**

- **IMPLICATIONS FOR RESEARCH**

- **NEXT STEPS ……**

METHODOLOGY

- 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

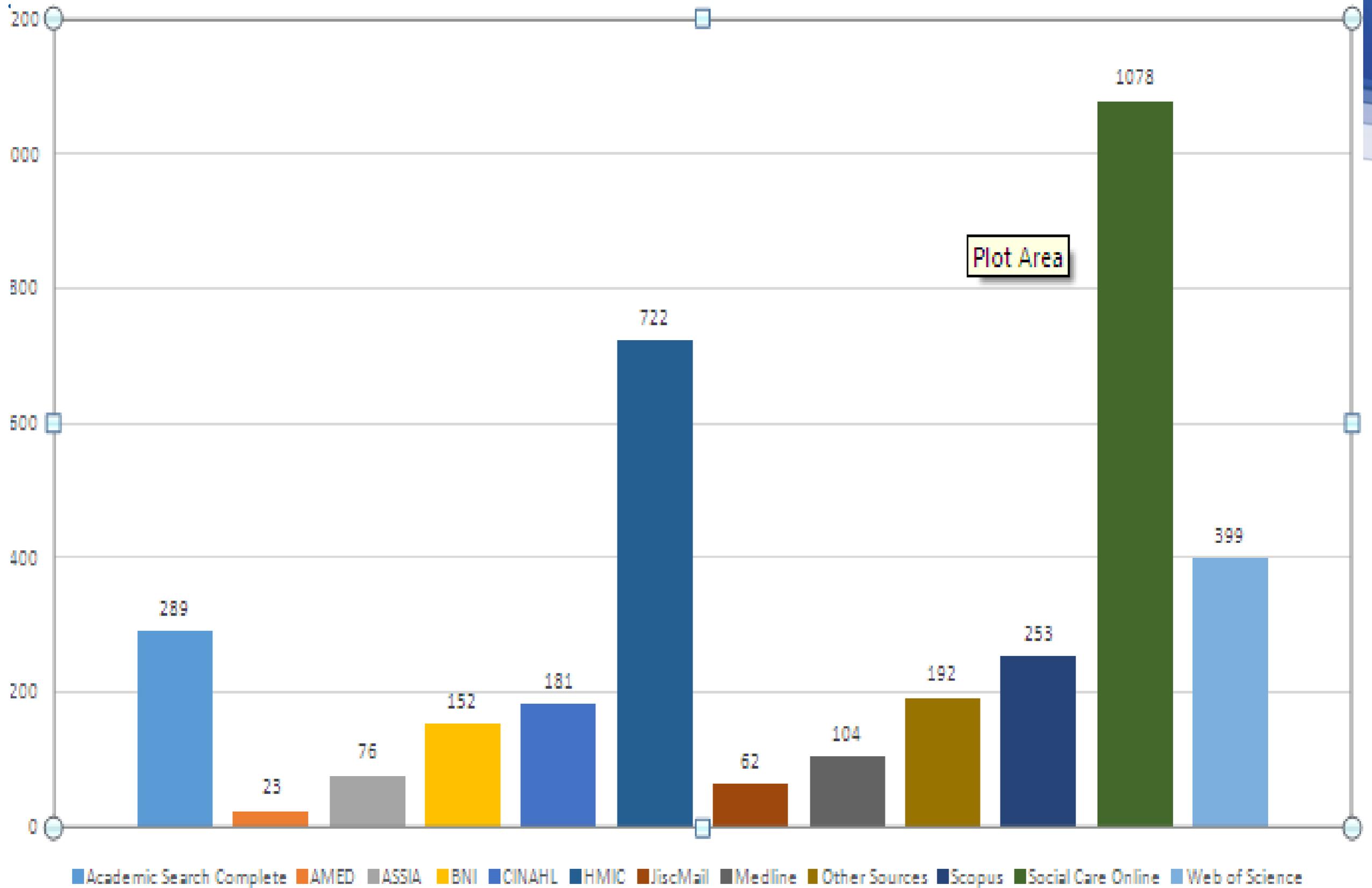- all materials were captured and saved using EndNote

SOAP & Narrative Reports

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MAPPING THE TERRITORY

- 3,535 references!

- databases varied in terms of their productivity

- materials were classified into 17 'types'

References by database

Reference types

22	8	51	33	15	25	63	275	41	2442	5	318	10	193	4	5	25

Book, Book Review, Book Section, Briefing, Bulletin, Conference proceedings, Film or broadcast, Government document, Guide, Journal article, Letter, Magazine article, Press Release, Report, Standard, Thesis, Toolkits, training & multimedia
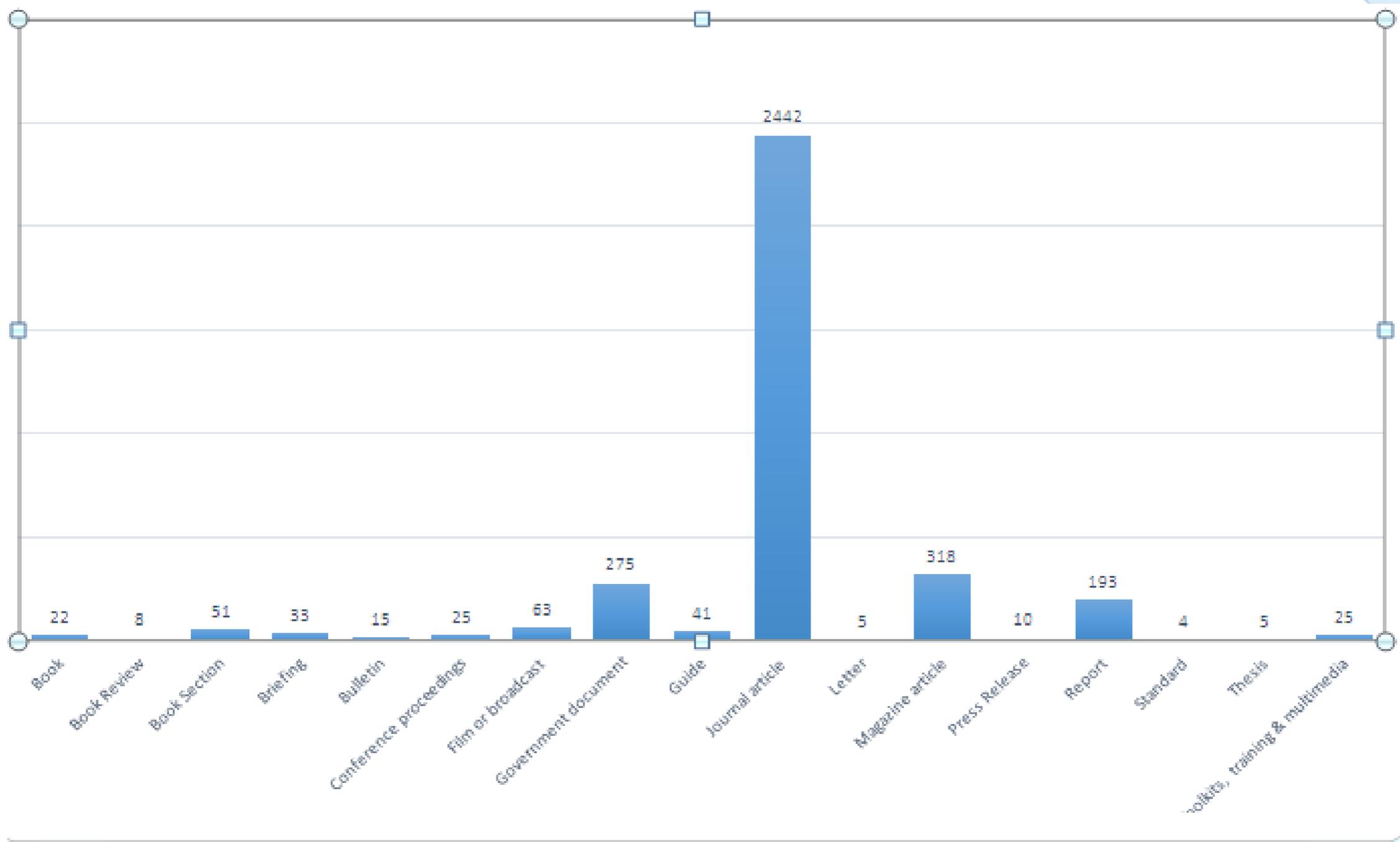
THEMES AND ISSUES

- 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 themes frequency

Themes classified by category
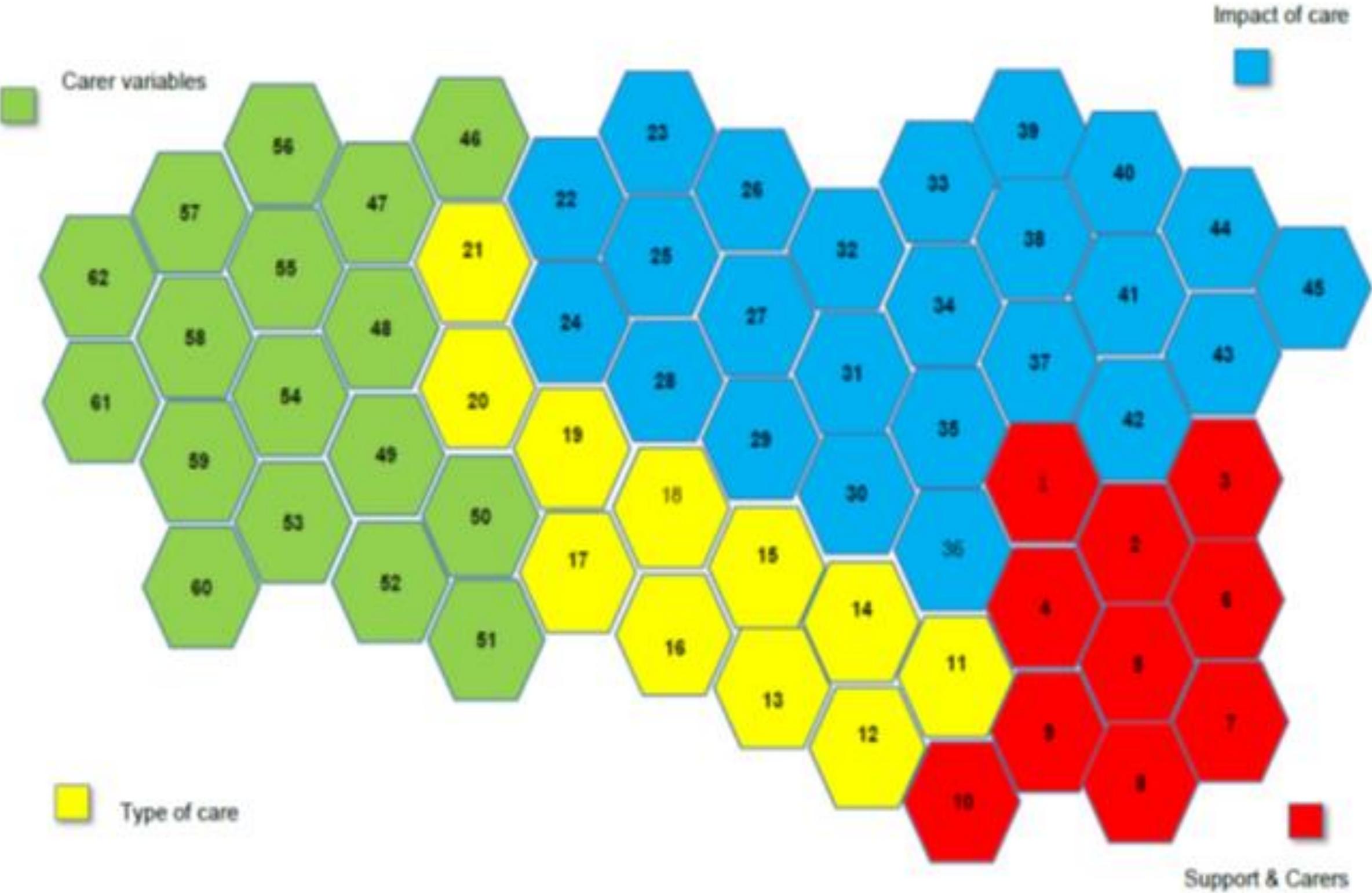
Defining the categories and themes

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 been 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

NEXT STEPS ......

- final version of the scoping review report to be disseminated with the aim of:
  - ➢ contributing to the identification of future research priorities
  - ➢ supporting the improvement and evidence-based nature of social care policy and practice with carers and those they support

- HEIF project - to transform the scoping review of carer research and knowledge into a freely accessible knowledge exchange digital resource on the Open University's intranet site for ALL national and international *stakeholders* who require any form of carer-related knowledge

- SCIE digital resource to be launched in June 2017

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SCIE CARERS HUB

SCIE Carers Hub

Google search ⇨ SCIE home page

SCIE/OU content: ⇨ hub ⇦ news feed
other dynamic 3rd party content

Scoping review: online, download, print, link to OU
Selected findings and themes explored
SCIE Care Act related content

⇩ regular updates

Disclaimer

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