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Citation

Larkin, Mary (2016). Scoping Carer Research. In: 4th International Conference on Evidence-based Policy in Long-term Care, 4-7 Sep 2016, London School of Economics.

URL

https://oro.open.ac.uk/47276/

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SCOPING CARER RESEARCH

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Life-changing Learning

INTRODUCTION

- now a wealth of national and international material and research about carers

- currently fragmented and disparate

- lacks accessibility and utility which:

  - makes finding information about carer research problematic

  - impedes its capacity to reliably inform future research

NATIONAL INSTITUTE FOR HEALTH RESEARCH SCHOOL FOR SOCIAL CARE RESEARCH (NIHR SSCR) project

- entitled “Utilising Carer-Related Research and Knowledge: a scoping review and information resource”

- central to the project is a unique and comprehensive scoping review of carer-related knowledge which will:

  - for the first time provide an academically robust and detailed mapping of carer-related evidence and knowledge

  - contribute to the identification of future research priorities relating to carers and inform social care practice

  - underpin a fully accessible digital resource developed in partnership with, and hosted and updated by, the Social Care Institute for Excellence (SCIE) as part of their resources to support the implementation of the Care Act 2014.

PRESENTATION OUTLINE

- NATIONAL INSTITUTE FOR HEALTH RESEARCH SCHOOL FOR SOCIAL CARE RESEARCH (NIHR SSCR) project
- SCOPING.....
- METHODOLOGY 1
- METHODOLOGY 2
- METHODOLOGY 3
- INDICATIVE FINDINGS
- NEXT STEPS ……

SCOPING.....

- 10 month scoping review by experienced full-time research associate, started in March 2016

- scoping , capturing, organising and synthesising existing national and relevant international carer-related evidence and knowledge

- drawing on Arksey and O’Malley’s (2005) framework

- Project Advisory Group (PAG) central to the development and delivery of the project

- considerable breadth and depth of research evidence and knowledge

- iterative process

METHODOLOGY 1

- approach to the scoping is deliberately wide – attempting to map and delineate the landscape of knowledge and evidence in relation to informal carers

- initially focused on developing a framework that enabled management and structuring of the material based on on ‘vertical’ and ‘horizontal’ analysis

- developed a matrix that integrated both these dimensions of the analysis and allowed cross-reference between different elements

- national and international literature and material relating to care for adults published in English since the mid-1980s

- identified literature and other materials through a range of methods e.g. Electronic on-line library databases; searching and following up of reference lists; use of networks and organisational and personal networks

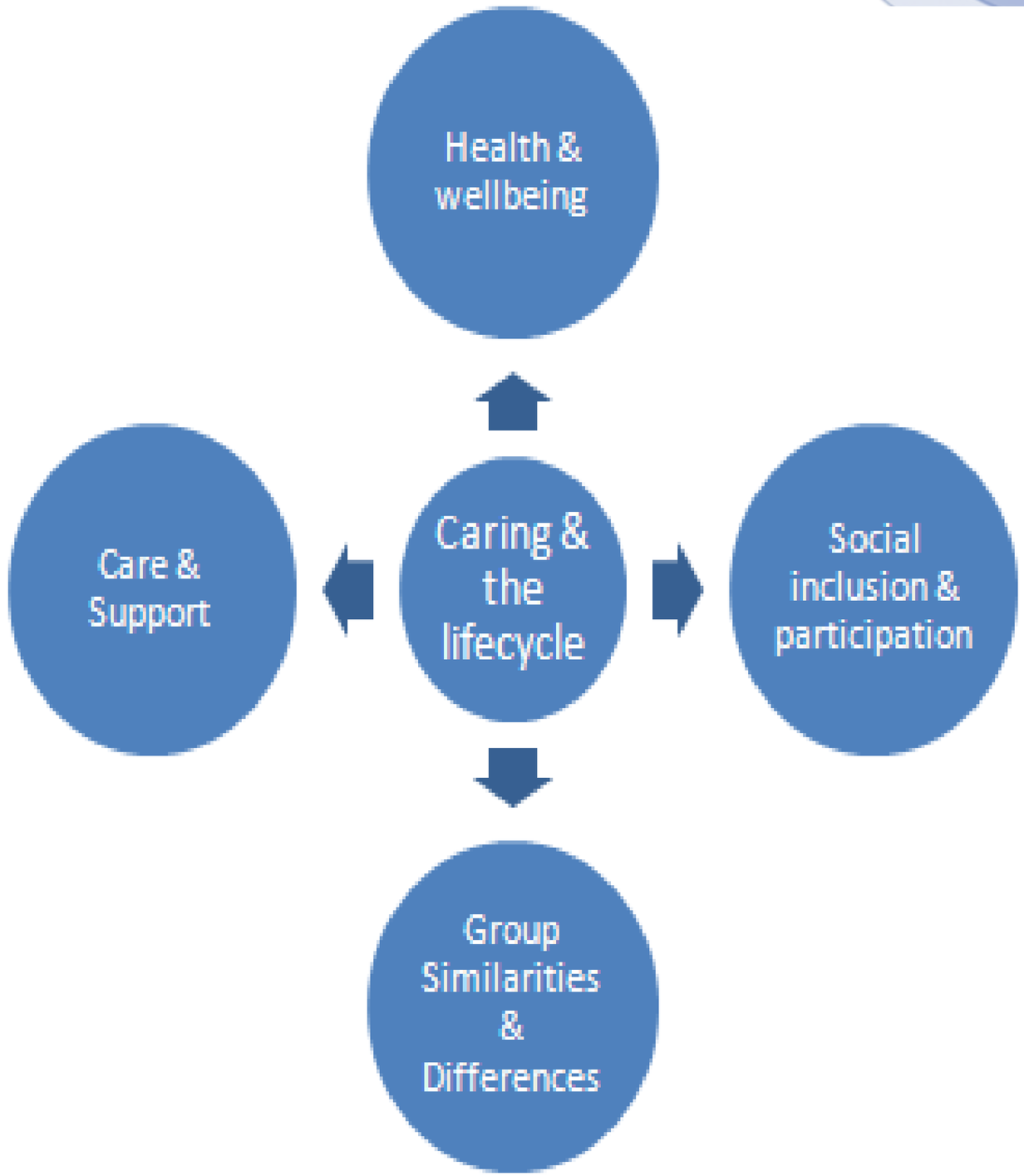
Matrix

Cross-cutting themes and issues from 2010 Carers Strategy	*Carer Characteristics*						
	Carer profile (gender, marital status etc.)	Ethnicity	Young carers	Working age carers	Older carers	Carers of different conditions	Intensity & duration
Identification & recognition	Identifying hidden carers. Barriers to identification. Access to services and support.	Identifying hidden carers. Barriers to identification. Access to services and support.	Identifying hidden carers. Barriers to identification. Access to services and support.	Identifying hidden carers. Barriers to identification. Access to services and support.	Older carers, particularly spouse carers often overlooked. Access to services and support.	Specific issues around mental health, learning disability, dementia etc. Access to services and support.	Particular issues around identifying carers providing high intensity care and/or support of long duration (or multiple episodes of care). Access to services and support.
Realising & releasing potential	Support to remain in or return to employment, education and training.	Assumptions about caring responsibilities and impact on education, training and employment.	Impact on education and training opportunities.	Support to remain in or return to employment, education and training.	Some older carers may want support to remain in or return to employment.	Specific issues around mental health, learning disability, dementia etc.	Long term impact and consequences of caring.
A life outside caring	Social and leisure activity; time off, family and community participation.	Social and leisure activity; time off, family and community participation.	Social and leisure activity; time off, family and community participation.	Social and leisure activity; time off, family and community participation.	Social and leisure activity; time off, family and community participation.	Social and leisure activity; time off, family and community participation.	Increased pressure on time reduces life outside caring.
Staying healthy	Differences between carers of different profiles.	Health and wellbeing (physical and mental).	Health and wellbeing (physical and mental).	Health and wellbeing (physical and mental).	Health and wellbeing (physical and mental).	Health and wellbeing (physical and mental).	Particular challenges for high intensity and long duration caring.

METHODOLOGY 2 (1)

- first framework was problematic in practice

- **a lifecycle approach** provided a framework that w both credible, practical still a covered a very wide territory but required fewer sub-categories to interrogate it



METHODOLOGY 2 (2)

- **refined the inclusion/exclusion criteria:** altered to work published since 2000

- **revised the electronic databases searched:** diminishing returns on using multiple databases - agreed a core set of databases to focus on

- use of **Endnote** to log and file references, facilitate management of material and identify overlaps and duplication

METHODOLOGY 3

- using the lifecycle framework had inherent limitations

- rather than using a framework now focusing on allowing themes to emerge from the material

- will evolve further but the richness, breadth and depth of the material that has been identified and catalogued is apparent in the emerging groupings

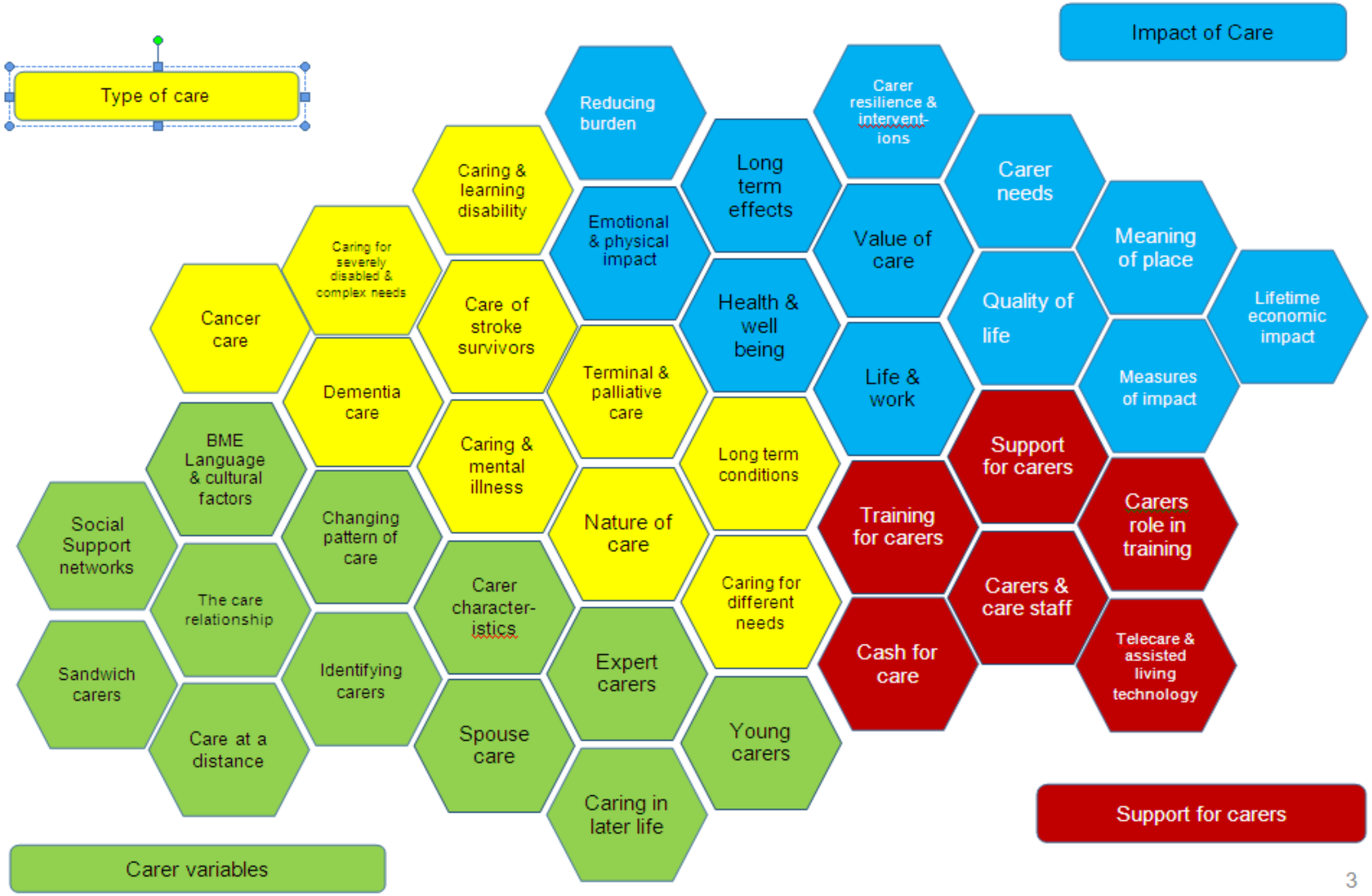
INDICATIVE FINDINGS

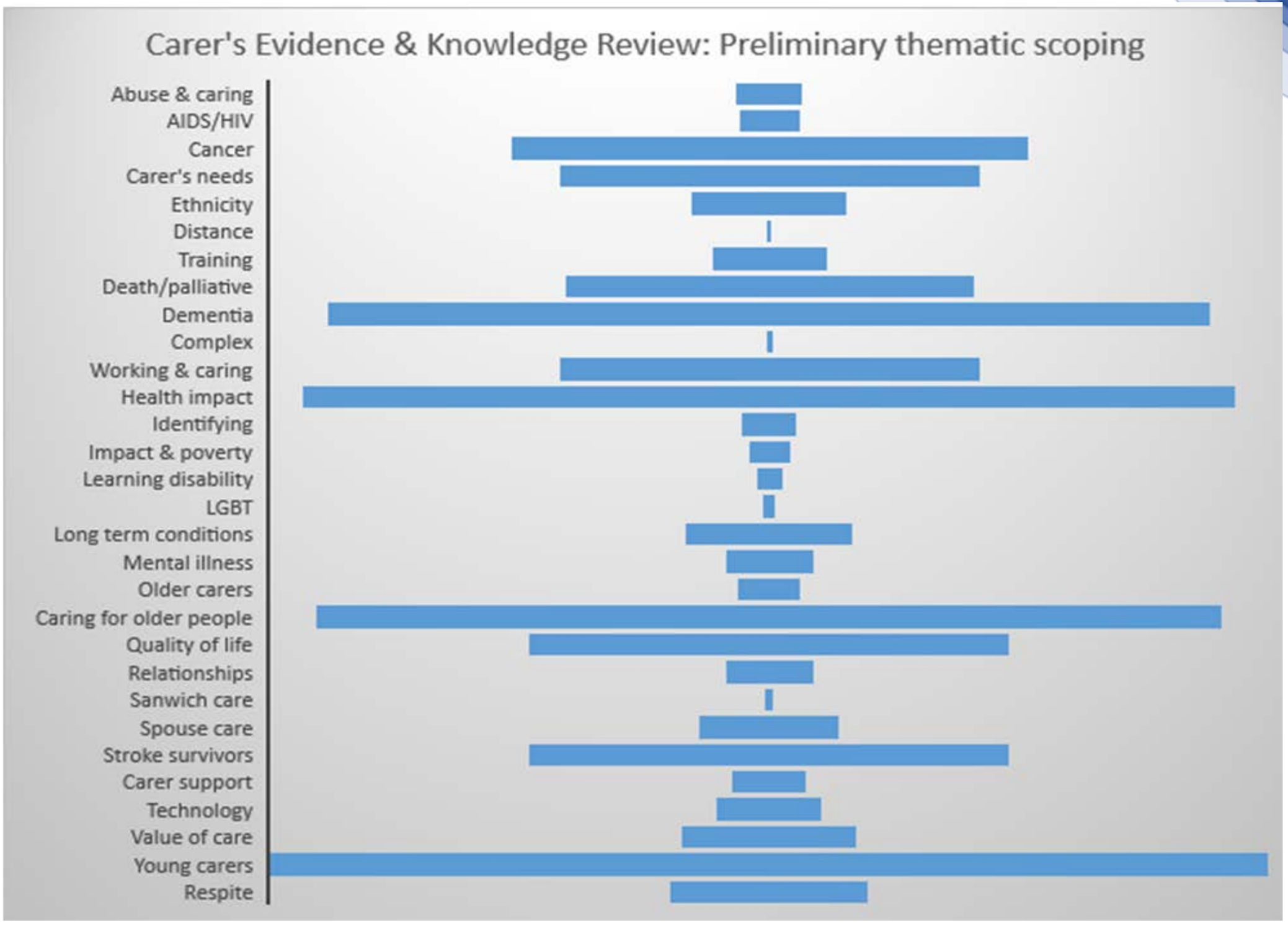
- to date more than 2,988 references have been identified, collated, annotated and saved to EndNote.

- grey literature has been more challenging to uncover in databases and a specific search using OpenGrey uncovered relatively little. Used/ using HMIC, JiscMail sources , the SCIE resource ‘Social care on-line’.

- 4 major themes have been identified through scanning titles, abstracts and keywords

- further analysis using ‘Smart Group’ classification through EndNote has allowed the frequency of major themes and topics to be identified


Type of care
Impact of Care
Reducing burden
Carer resilience & intervent-ions
Caring & learning disability
Long term effects
Carer needs
Emotional & physical impact
Value of care
Meaning of place
Caring for severely disabled & complex needs
Health & well being
Quality of life
Lifetime economic impact
Cancer care
Care of stroke survivors
Life & work
Measures of impact
Terminal & palliative care
Dementia care
Support for carers
BME Language & cultural factors
Caring & mental illness
Long term conditions
Carers role in training
Social Support networks
Changing pattern of care
Nature of care
Training for carers
Carers & care staff
The care relationship
Carer character-istics
Caring for different needs
Sandwich carers
Identifying carers
Expert carers
Cash for care
Telecare & assisted living technology
Care at a distance
Spouse care
Young carers
Caring in later life
Carer variables
Support for carers
3


Carer's Evidence & Knowledge Review: Preliminary thematic scoping
Abuse & caring
AIDS/HIV
Cancer
Carer's needs
Ethnicity
Distance
Training
Death/palliative
Dementia
Complex
Working & caring
Health impact
Identifying
Impact & poverty
Learning disability
LGBT
Long term conditions
Mental illness
Older carers
Caring for older people
Quality of life
Relationships
Sanwich care
Spouse care
Stroke survivors
Carer support
Technology
Value of care
Young carers
Respite

RELATIVE FREQUENCY OF THEMES

- largest number of studies and reports focus on ***types of carer***. The highest frequency is around young carers (370); caring for older people (336); care for people with dementia (327). A particular focus on black and minority ethnic carers (BAME) is less frequently identified (58), as is spouse care (52)

- ***the needs of the cared for person****:* and the most heavily researched and documented themes are: care for older people (336); care for people with dementia (327); care for people with cancer (192); care for stroke survivors (178); and palliative and end of life care (152). Less frequently identified needs include: long term conditions – e.g. Parkinson's Disease, Multiple Sclerosis – (62); with mental illness (33); AIDS/HIV (23), learning disabilities (10)

- **impact of caring on carers** e.g. health and wellbeing (346); quality of life (178); working and caring (156); impact on relationships (33); abuse and caring (25); and sandwich generation demands (4)

NEXT STEPS ……

- identification of discrete and interrelated themes will be followed by charting the material

- next stage of the scoping review will involve the collation, summarising and reporting of results

- interim overview report will be produced by January 2017

- Consultation Workshop in February 2017, involving the Project Advisory Group and a range of relevant stakeholders

- final version of the scoping review report for publication which will be disseminated through a variety of channels 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

- SCIE digital resource to be launched in June 2017