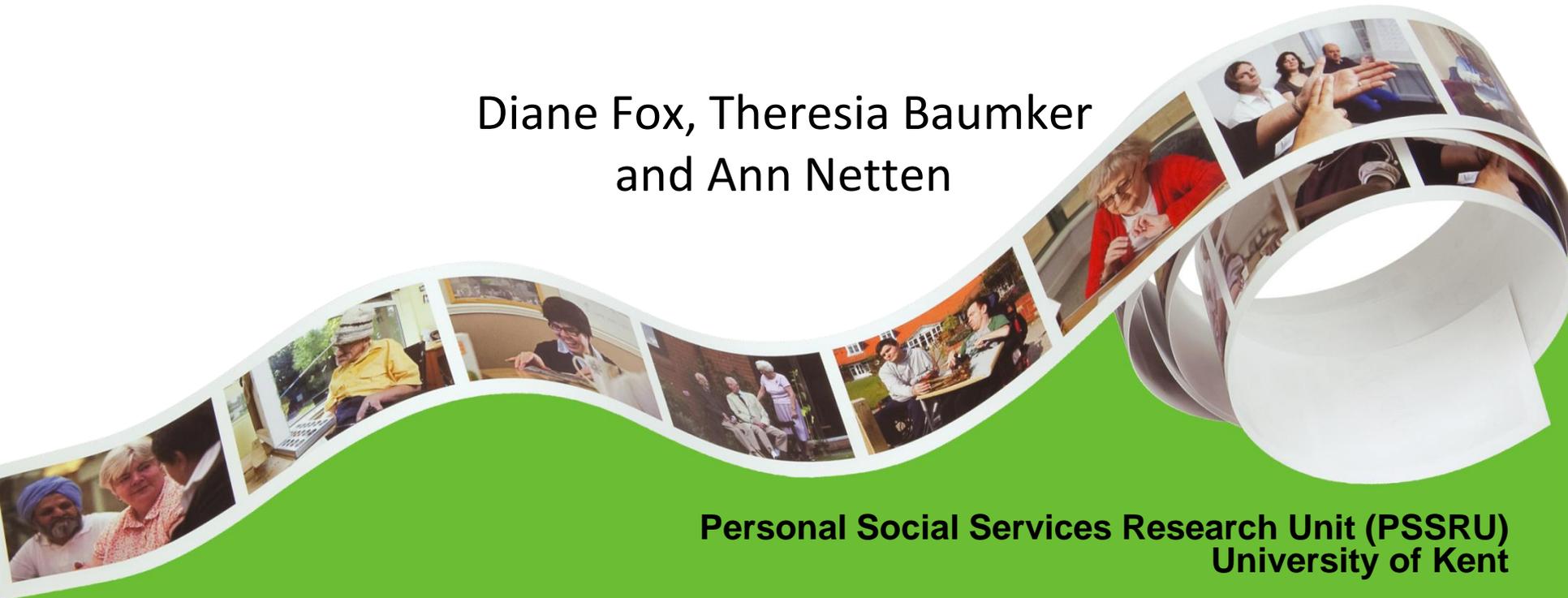


## School for Social Care Research

# Informing service development through analysis of survey data: Improving carer's quality of life?

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## Background 1: The starting point

### The development of 2008 Kent Carers' Survey

In 2008, Kent County Council and the Department of Health commissioned PSSRU colleagues, Dr Jacquetta Holder and Nick Smith and Professor Ann Netten to develop a postal self-completion carers survey.

#### The survey development had four stages

- Four group interviews with adult carers (n=20) recruited via support groups and two group interviews with care managers (n=10).
- Appraisal of existing research on carers' needs and outcomes
- Design of survey questions
- Cognitive testing of survey questions with carers (n=25)

## Background 2: Sample and content of 2008 Kent Carers Survey

The sample included 3 different groups which influenced questionnaire design.

- Carers identified by social service records as having an assessment or review in the last 12 months.
- Carers named on records of a service user who has had an assessment or review in the last 12 months.
- Carers identified by 18 voluntary organisations in Kent.

The broad topic areas covered were:

- Carer's characteristics
- Characteristics of the person being cared for
- Use of social care services by the carer and cared for person
- Satisfaction with social services, and social care support and services
- Views about the impact of services and aspects of service quality
- Views about quality of life outcomes.

## Background 3: Policy drives further survey development

Previous Labour government publish the 2008 Carers Strategy- “*Carers at the heart of 21st-century families and communities*”

The Department of Health fund the development of a carers survey for national use via the ‘user experience survey programme’. A programme of surveys of people using social care services which are collected by Councils with Adult Social Services Responsibilities (CASSRs) managed, collated and analysed by the Health & Social Care Information Centre (HSCIC). The user experience survey programme is overseen by the Social Service User Survey Group (SSUSG).

## Background 4: The development of the 2009/10 Personal Social Services Survey of Adult Carers in England (PSS SACE)

The 2009/10 Personal Social Services Survey of Adult Carers in England (PSS SACE) built upon the 2008 Kent Carers Survey.

### Additional five stages of development

- Response analysis of Kent Carers Survey 2008 led to some question amendments.
- Engagement with stakeholders to identify priority topic areas for potential inclusion.
- New questions on carers' experiences of healthcare settings and employer support were developed.
- Further 30 cognitive testing interviews conducted with carers in two areas (one in the North of England, one in the South).
- SSUSG agree final questionnaire within guidance from
- Association of Directors of Adult Social Services (ADASS).

## Background 5: 2009/10 Personal Social Services Survey of Adult Carers in England (PSS SACE)

Not mandatory -carried out by 90 out of 152 CASSRs (59%).

The questionnaire included 39 mandatory & 19 optional questions (total=58)

Questionnaires sent by post to

- Carers who had undergone an assessment or review in the last 12 months
- Some CASSRs included carers of service users who had an assessment or review in the last 12 months

Sent to 88,000 carers, returned by over 35,000 = a response rate of 40%.

## Project funded by the School for Social Care Research

Part of a collaborative project with PSSRU colleagues at London School of Economics (LSE).

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## PSSRU at LSE work: The 'visibility' of carers

Building upon previous analysis carried out by the HSCIC, our colleagues, Dr Linda Pickard and Dr Derek King compared a sample of carers who responded to the 2009/10 PSS SACE and carers completing an interview survey for the 2009/10 Survey of Carers in Households.

### Objectives

- identify characteristics of unpaid carers 'visible' to councils.
- examine variations between councils in the extent to which they are in contact with carers.

## PSSRU at Kent work: Exploring variation in carers' quality of life

### Objectives

- Explore what is already known about factors influencing carers' quality of life (QoL).
- Explore extent to which individual-level factors of carer & person they care for account for variations in carers' QoL.
- Explore extent to which CASSR-level factors account for variations in carers' QoL.

## Methods 1: Overview

- Undertook a rapid review of the literature with the help of a colleague, Stacey Rand.
- Carried out descriptive and bi-variate analyses to understand the structure of the sample of the 2009/10 PSS SACE.
- Used multi-level modelling to separate-out individual and LA-level factors.

## Methods 2: Social Care-related Quality of Life - Carers

Domain	Response Categories
<b>Occupation</b> (anything valued or enjoyed, including formal employment, voluntary or unpaid work, caring for others and leisure activities)	I am able to spend my time as I want, doing things I value or enjoy I do some of the things I value or enjoy with my time but not enough I don't do anything I value or enjoy with my time
<b>Space and Time to be yourself *</b> <i>*This was an optional question</i>	I have the space and time I need to be myself I have some of the space or time I need to be myself but not enough I do not have any space or time to be myself
<b>Control over daily life</b>	I have as much control over my daily life as I want I have some control over my daily life but not enough I have no control over my daily life
<b>Self-care</b> (in terms of getting enough sleep or eating well)	I look after myself Sometimes I can't look after myself well enough I feel I am neglecting myself
<b>Personal safety</b> (feeling safe from fear of abuse, being attacked or other physical harm)	I have no worries about my personal safety I have some worries about my personal safety I am extremely worried about my personal safety
<b>Social participation</b>	I have as much social contact as I want with people I like I have some social contact with people but not enough I have little social contact with people and feel socially isolated
<b>Encouragement and support in caring role</b>	I feel I have encouragement and support I feel I have some encouragement and support but not enough I feel I have no encouragement and support

## Methods 3: Multi-level modelling

### Estimation

- QoL based on sum of responses to six (3-level) questions
- Type of model took account of
  - distribution of the QoL measure and
  - the possibility that carers experiences within a CASSR may be more similar than between different CASSR.
- Hypothesised predictors based on literature

## Results 1: Multi-level modelling results

- Multi-level
  - Level-2: CASSR
  - Level-1: Individual carers
- most variation in observed QoL associated with individual factors (over 95%), and not differences between CASSRs

## Results 2: Significant associations with lower QoL:

- non-white ethnic background
- poor self-perceived health
- caring for person with dementia
- co-habiting with cared for person
- high intensity of caring (20+ hours caring per week)
- in full-time employment
- female
- age <65

## Results 3: What is associated with good QoL?

Controlling for effects of factors in the previous slide, probability of reporting good QoL increased with any more *positive* experience of support/services.

In particular,

- Easy access to, and helpful, information and advice services
- Easy access to services

When taking into account carers' experiences of services, the association with QoL with other individual level factors weakened

## Results 4: What else is associated with good QoL?

- Also significantly associated with QoL, but to a slightly lesser extent than access and helpfulness of information and services:
  - Less wait for receipt of services for service user
  - More contact with care manager of service user
  - Better consulted about services received by service user
  - Better timing of services received by service user
  - More flexibility in services for carer
  - Better informed of changes to services
  - More respectfully treated by service provider

## Impact of these findings on policy and practice

- Through the SSUSG, this work will be fed into decision-making about future versions of the PSS SACE.
- Alongside other research, these findings contribute to the growing evidence base on the most effective ways to support carers.
- From 2012, contributes to four of the Adult Social Care Outcomes Framework measures.
- Helps to interpret the quality of life outcome measures contained within the PSS SACE which could support decision-making and improve practice within CASSRs.

## Maximising the value of survey data in adult social care (MAX project)

Project within a programme of the Department of Health-funded Quality and Outcomes of person-centred care Research Unit (QORU)

### Aim

In partnership with CASSR staff, providers, service users and carers produce two toolkits (one for the Adult Social Care Survey and one for the PSS SACE) to support the analysis, interpretation and communication of survey findings.

### Approximate timetable

Jan 2013-Dec 2014 – Fact-finding phase

Jan 2014-Dec 2014 – Toolkit development

Jan 2015-Dec 2015 – Toolkit testing and dissemination

## Further analysis of the PSS SACE

The SSCR has extended funding for further analysis. With the permission of the HSCIC we are:

1. Exploring the relationship between satisfaction and carers' experiences of service quality.
2. Exploring in more detail the variations between different groups of carers.
3. Comparison the data from the 2009/10 and 2012/13 surveys.

## Further information

The development of the 2008 Kent Carers Survey

Contact Dr Jacquetta Holder: [j.m.holder@kent.ac.uk](mailto:j.m.holder@kent.ac.uk)

The development of the 2009/10 PSS SACE

[http://www.pssru.ac.uk/archive/pdf/dp2643\\_2.pdf](http://www.pssru.ac.uk/archive/pdf/dp2643_2.pdf)

The HSCIC analysis of 2009/10 PSS SACE

<http://www.hscic.gov.uk/pubs/psscscarersurvey0910>

**Thank you for your attention!**

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