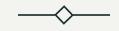# IMPROVING THE LIVES OF STROKE SURVIVORS WITH DATA

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Stakeholder Engagement Group Meeting

October 2022

Welcome and introductions

At today's meeting we will:

- Update you on research progress
- Describe the changes we are making as a result of the last SEG meeting
- Discuss findings from a systematic literature review - how we cost and measure informal care
- Help us to consider ideas for future 'Policy Labs'

Summary of last meeting, and what we've done since

- Recruited 132 new participants to the study (since 1 April 2022)
- Reduced meeting lengths to 1 hour
- Chosen the Fatigue Severity Scale to incorporate in our questionnaires
- Revised questionnaires to remove duplicate or unnecessary questions
- Working to make 'service use' questions more meaningful

Quantifying and costing informal stroke care: systematic review

Review team: Carina Bektur, Sophie Rowland-Coomber, David Wyatt, Julia Fox-Rushby, Ian Marshall, Charles Wolfe.

Background

- Informal care = paid and unpaid care provided to the stroke survivor by *non-professional carers*, usually by people with whom the care recipient has a social relationship, such as:
  - spouse, parent, child, other relatives, neighbour, friend, or other non-kin.

Aim

- To improve survey questions in the SLSR on informal care received by stroke survivors we conducted a systematic review aiming to:
  - systematically review methods of measuring and costing informal care;
  - identify the types and size of informal care time and costs and evidence explaining their variation;
  - to ascertain the range of definitions of informal care and informal carers used, areas of informal care covered, and informal care activities considered.

Methods

- Full protocol of systematic review is available on PROSPERO (CRD42022315466).
- We searched for peer-reviewed original empirical studies on the measurement and/or valuation of informal care received by stroke survivors in high-income countries published in the last decade.

Provisional Results

- 46 papers were included.
- 27 papers that reported quantification of informal care time, among which 7 imposed the limit of 16 hours per day.
- Mean daily estimates of informal care time: range from 0.9 to 13.2 hours.
- An increased informal care time was reported to be associated with:
  - higher level of dependency of the stroke survivor;
  - presence or a number of comorbidities.

Discussion

Q1: Are there any areas of informal care not covered in the literature?

Q2: Are there any people involved in informal care that are not covered in the literature?

Q3: Where do we draw a line in costing informal care?

Q4: Are there any (new/forthcoming) guidelines, working groups or studies on informal care we should be aware of?

Informal care activities reported in studies (n=46)

Personal Activities of Daily Living (ADLs):

- dressing (n=16)
- bathing (n=15)
- toileting (n=12)
- feeding (n=11)
- transferring (n=10)
- incontinence (n=5)

Household ADLs:

- housecleaning (n=5)
- laundry (n=5)
- ironing (n=2),
- gardening (n=2)

Instrumental ADLs:

- managing medications (n=11)
- cooking or preparing hot meals (n=10)
- driving and/or using private or public transport (n=10)
- shopping (n=9)
- tracking finance (n=9)
- writing letters or using the phone (n=2)

Other

- helping at the hospital or medical appointments (n=6)
- contact with healthcare services on behalf of the care recipient (n=4)
- supervision or surveillance of care recipient (n=3),
- companionship or socialising (n=3)
- provision of non-specific medical care or minor healthcare activities (n=2),
- emotional support (n=1)
- being available (n=1)

Q1: Are there any areas of informal care not covered in the literature?

Informal carers defined in studies (n=21)

- spouse/partner/significant other (n=21)
- children or children-in-law (n = 18)
- friends (n=6)
- siblings (n=3)
- paid non-professionals (n=2)

- neighbours (n=1)
- grandchildren (n= 1)
- parent(s) (n=1)
- others (other family members or other relatives or unspecified other option) (n=5)

Q2: Are there any people involved in informal care that are not covered in the literature?

Informal care costs defined in studies (n=21)

- Informal care time (n=21)
- Loss of income by carer(s) (n=6)
- Cost of caring equipment (n=3)
- Cost of travel for carer(s) (n=2)

- Out-of-pocket costs (e.g., medical care, adult day care/respite care, food delivery, caregiver support services) (n=1)
- Household changes/adaptions (n=0)

Q3: Where do we draw a line in costing informal care?

Discussion

Q4: Are there any (new/ forthcoming) guidelines, working groups or studies on informal care we should be aware of?

Maximising the potential for stroke data to improve care

Policy labs as an approach to getting evidence into policy and practice

What is a 'Policy Lab'?

A focused, collaborative workshop bringing together stakeholders around a particular challenge to…

- Assess the evidence
- Understand barriers and constraints to change
- Develop new ideas/approaches to improve outcomes

Participants might include policymakers, researchers, practitioners, interest groups, charities, industry and those with personal experience of the issues being addressed.

What do we mean by using "data to improve care"?

- Different types of evidence:
  - Clinical outcomes
  - Wider data on eg quality of life, impacts on carers
  - Lived experience
  - Economic data
  - Epidemiological data – understanding trends, multiple conditions, etc

- Used for different purposes:
  - Individual care planning – tailoring of care
  - Developing clinical guidance/care pathways at a system level
  - Informing planning – eg future service delivery and workforce needs

- By different people:
  - Clinicians
  - Patients, family/carers
  - Policymakers

What should the policy labs focus on?

To fully understand the data landscape and how the project can contribute, we need to develop some understanding of the below areas.

Within this we can identify questions where a policy lab approach might be useful (eg What types/standards of evidence are needed for different purposes? How can we use data to personalise longer term care?)

What does the current data landscape look like?

- What's currently collected?
- How is it used?
- Where do we need more/better data?
- What are the challenges in collecting data?

What are the data needs of different stakeholders?

- Who needs what data?
- What are the benefits/costs of this?
- Are there potential future uses that could be beneficial?
- Are these uses acceptable to all stakeholders?

How can we best collect and use data?

- How can we overcome barriers/challenges to data collection and/or use?
- What processes need to be in place to ensure good quality data?
- Who is responsible for collecting data?

How can we design good tools for collecting data and making it accessible?

- What features should a data 'portal' have?
- How do we make it useful/accessible to all?
- How can we encourage use in practice and/or scale-up collection?

A few questions to think about...

- Is there anything major we are missing?

- We will convene a (mostly) different group for each policy lab, depending on the question it addresses. Who might be the key people/groups to involve in different areas?,
  - What is the perspective they would bring?

- Are there particular routes to impact/change that we should focus on in the series of policy labs?
  - eg ways to influence clinical guidance, organisational policies or service planning

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