

Co-creation of video information stories to address information needs of carers of stroke survivors

Elizabeth Lynch, Annette McGrath,
Dominique Cadilhac, Gillian Harvey

 @E_A_Lynch

65% stroke survivors living in community require assistance¹

Early post-stroke, carers frequently overwhelmed by emotions²

3 years post-stroke, depression and anxiety high in carers³

Lack of information is an additional source of stress²

Best way of providing information is unclear

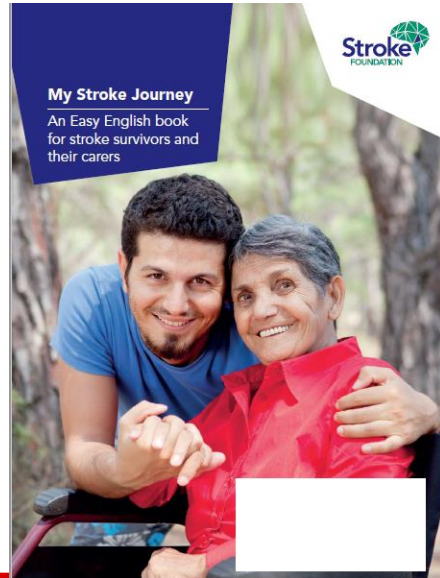


1. Deloitte Access Economics. *The economic impact of stroke in Australia*
2. Luker et al *Arch Phys Med Rehabil* 2017; 98: 1852-62
3. Cumming et al *Brain Impairment* 2008; 9:152-160

60% Australians struggle to find, understand & use health information & services¹

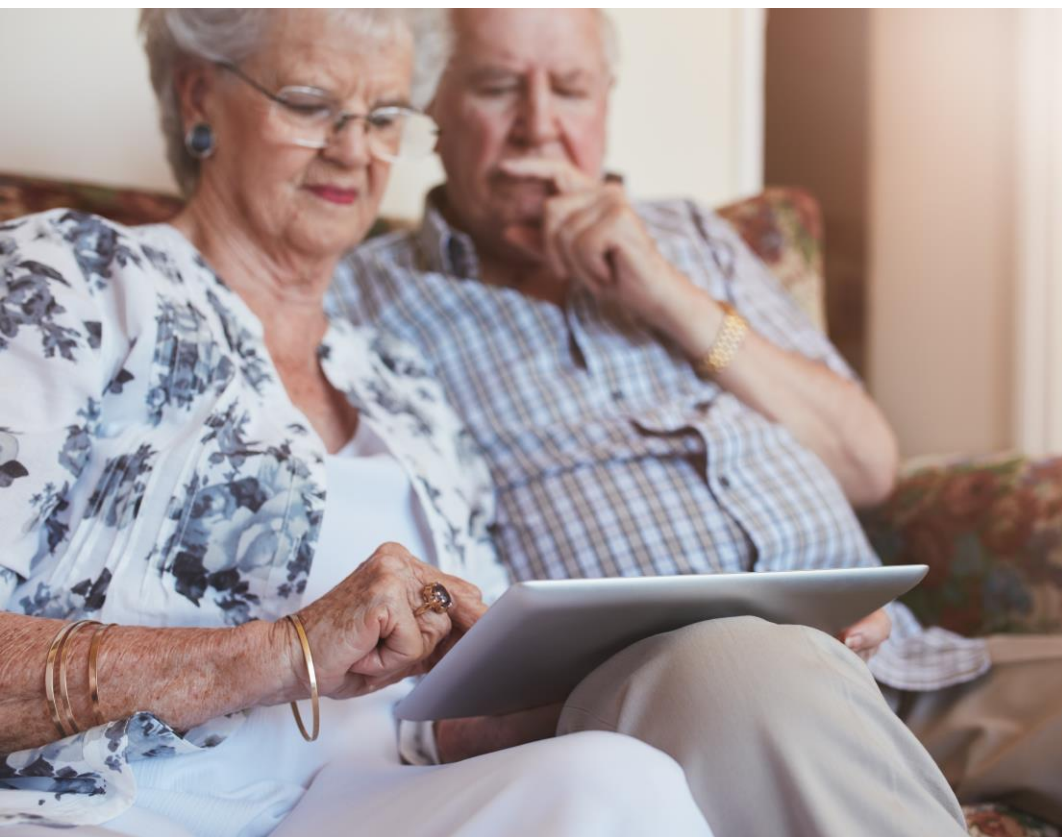
Recommendations regarding information provision:²

- Use a range of different communication strategies
- Share consumer stories
- Involve consumers to make sure information resources are easy to understand, use and act on



72% of adult internet users search online for health information¹

Carers search more commonly than rest of the population



Aim: To develop video stories to address information requirements of people new to the carer role

1. Fox S: *The Social life of health information 2014*

I

- Identify themes for information resources
- Interviews or focus groups

II

- Iterative development of video stories
- Video-recorded interviews

III

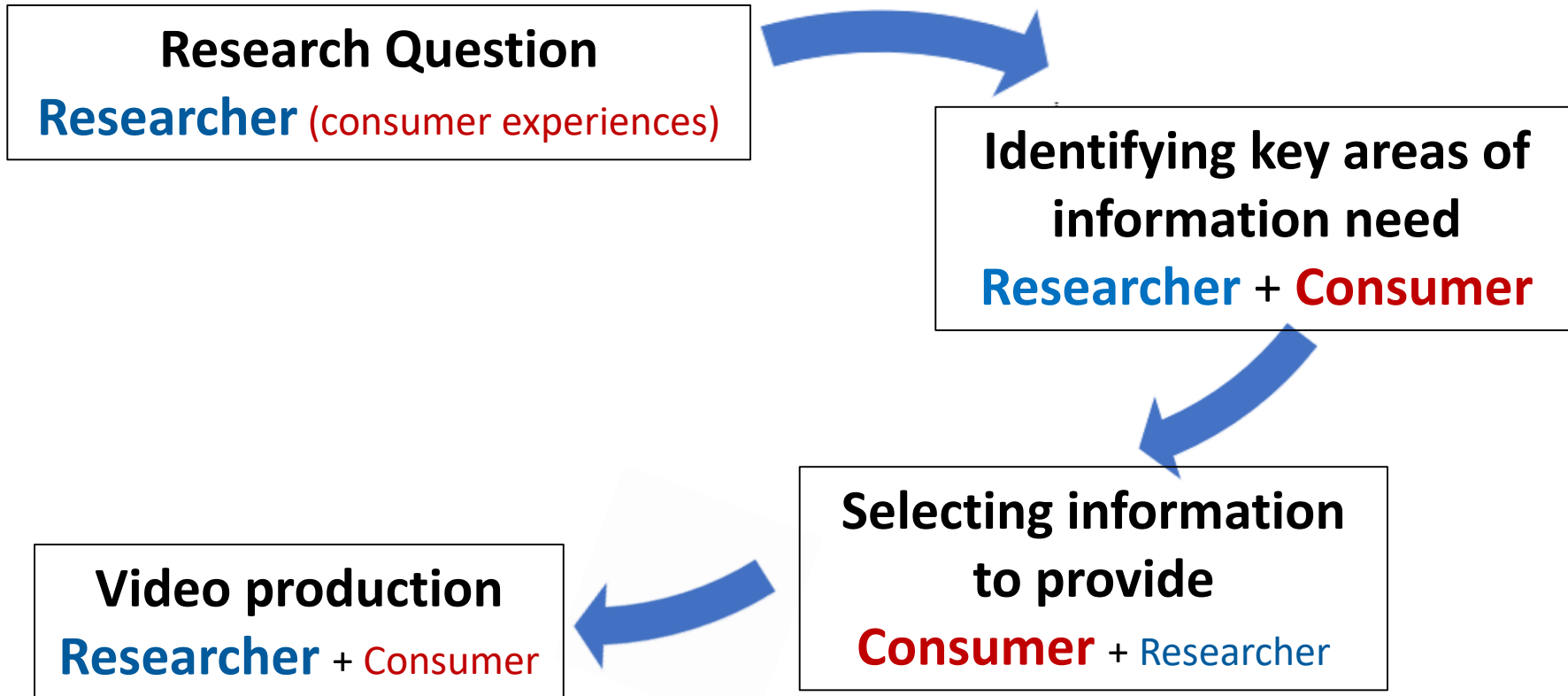
- (In planning stage)
- Dissemination: social media & websites

IV

- (In planning stage)
- Evaluation: interviews



Consumer involvement



Phase I. Themes for information

9 individual interviews

- 7 spouses/partners, 2 children
- 5 women, 4 men



What do you wish you had been told?

What was most important thing you have learned?

What should all carers of stroke survivors know?

Is caring for [partner/family member] like you anticipated?

Phase I. Themes for information

Some of the identified themes:

- Need to ask questions & get second opinions
- Stimulating brain recovery
- Aphasia
- Memory/cognitive/personality/mood/participation changes
- The importance of hope – ongoing recovery
- Learning new ways to do things
- “Letting go” and allowing stroke survivor to try new things
- Need for time to self
- Need for patience

Phase II. Development of video resources

4 video-recorded interviews: 2 husbands, 1 wife, 1 son

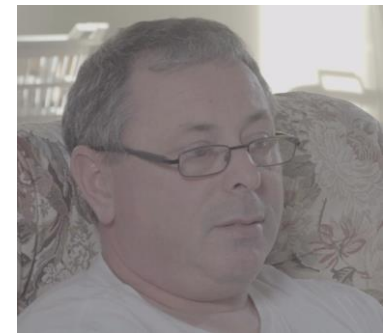
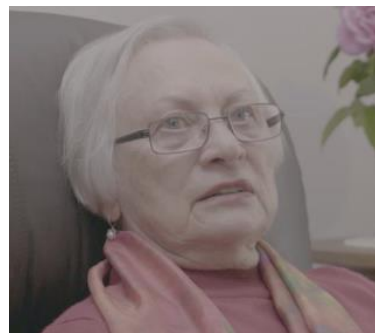
Time since stroke: 1-14 years

Participants discussed topics they considered important

Told in own words

97 minutes of raw footage

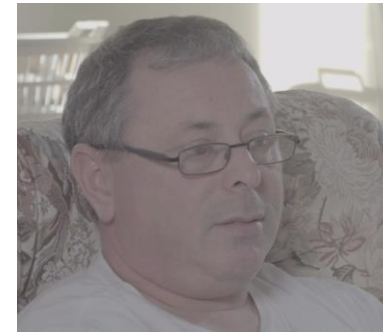
Option of taking extra video footage with stroke survivor



Phases III & IV. Next steps

Uploading final approved resources to Enableme, Youtube (Florey channel), Facebook, Twitter – September 2019

Evaluation via interviews with carers of stroke survivors participating in inpatient rehabilitation – October-Dec 2019



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