

# How the public are involved in prioritising Health and Social Care research

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# Ensuring Value in Research Funders Forum

## Principle 1:

*Justifiable research priorities*

Health-related research agendas and priorities should be set with the **meaningful involvement** of those who will use and be affected by health-related research.

# HCRW Funding Streams

Responsive-mode / researcher-led grant schemes

Stage	PPI
<b>Applications</b>	Questions on PPI and broader collaborations during development of bid and project delivery
<b>Stage 1 assessments:</b>	All Wales Assessment Panel (5 public and practice reviews per application) Prioritisation Oversight Committee (public, practice and policy members)
<b>Stage 2 assessments:</b>	Peer reviews include public involvement and practitioner reviews
<b>Funding boards:</b>	At least 2 public member representatives
<b>Grant management:</b>	Reporting on PPI and engagement activities, including in ResearchFish

# Pilot project

- Trial a new approach - upfront meaningful engagement
- Joint with **Social Care Wales**

*“How can we best provide sustainable care and support to help older people live happier and more fulfilling lives?”*

- **End points** (i) clear priorities  
(ii) research on priority areas funded by a variety of funding bodies

## JLA Priority Setting Partnerships

- Tried and tested <https://www.jla.nihr.ac.uk/jla-guidebook/>
- Brings patient, carer and clinician groups together on an equal footing

## Adaptations – “*In association with JLA*”

- All online
- Faster
- Led by working group not stakeholder group
- Beyond Top 10

**Our advantages:**  
resources, networks,  
links to policy and  
implementation,  
funding body.

# Step 1 – Set up working group

## Step 2 – Initial survey

Older people receiving care and support

Unpaid carers

Social care practitioners

Across Wales

Black, Asian and Minority Ethnic communities

Across Wales

Range of job types

Range of settings– care home, domiciliary, nursing home

Gypsies and Travellers

Domiciliary, residential and community settings

Range of type of care received

Disabled people

Both frontline and senior

Range of age of carers

Refugees / asylum seekers

LGBTQ+

Public, private, 3<sup>rd</sup> sector, volunteer

People who are homeless

BAME

Range of client groups

# Setting priorities for social care research in Wales

**What  
you think  
matters**

How can we best provide sustainable care and support to help older people live happier and more fulfilling lives?

Complete the survey by 6 July



@ResearchWales &  
@SocialCareWales



Gofal Cymdeithasol Cymru  
Social Care Wales



Ymchwil Iechyd  
a Gofal Cymru  
Health and Care  
Research Wales

## Older people / unpaid carers

What has helped?

Anything else?

What could have been different or better?

What questions should research address to help people live independently?

What questions should research address to improve health and well-being?

Anything else?

## Social care practitioners

## Step 3 – Indicative questions

“Be aware that people are lonely before they are ill”

“More help to access social activities”

“How can the issue of loneliness be addressed and improved for older people in order to make a positive impact to their health and wellbeing?”

“I suppose lonely people need more help”

How can home and community-based social care enable older people to socialise, reducing loneliness and isolation?

“Company and help to get dressed and things”

“Regular phone calls and befriending schemes for older people”

“How is social care enabling people to form connections within their communities?”

“Activities for older people tend to be stereotyped, and there is not enough choice”



## Step 4 - Interim prioritisation survey

**\* Please tick the questions that you think are important for future research to answer** (you can tick as many as you like, but try not to choose all of them, as at the next stage you will be asked to narrow your selection down to 10):

- |  |  |
|--|--|
| <input checked="" type="checkbox"/> How could the expertise of carers of older people be better recognised and valued by staff in social care? (C4)  | <input checked="" type="checkbox"/> How can social care make better use of the potential of local communities to support older people, for the benefit of all? (O5)          |
| <input type="checkbox"/> How can older people be involved in the design and development of social care services? (P3)  | <input checked="" type="checkbox"/> Would regular contact by social care services with all older people, no matter whether they need support, help to prevent problems? (R2) |
| <input checked="" type="checkbox"/> What services or combination of services (e.g. support in the community, home-based care and use of technology) best enables older people to remain independent? (O11) | <input checked="" type="checkbox"/> How well do current assessments identify older people's needs? (S3)  |
| <input checked="" type="checkbox"/> What are the best ways for older people to get   | <input checked="" type="checkbox"/> How can social care for older people be funded in a sustainable way? (F1)  |

Qu code	Summary Question	% Older people and carers selecting this in Top 10	% Practitioners selecting this in Top 10	Equal weighting	# proposals by older people in Initial survey
C2	How can we reduce isolation and stress amongst carers of older people and prevent burn-out? (C2)	43%	28%	35%	3
O1	How can social care and health services, including the voluntary sector, work together more effectively to meet the needs of older people? (O1)	26%	46%	36%	0
R4	How can home and community-based social care enable older people to socialise, reducing loneliness and isolation? (R4)	26%	28%	27%	17
S5	What are the benefits to older people of receiving continuous support from the same paid carers? How can this best be achieved? (S5)	26%	19%	22%	7
P1	How can older people be better involved in decisions about their own care? (P1)	20%	30%	25%	2
P2	How can social care for older people be tailored to the interests and needs of individuals? (P2)	20%	20%	20%	9
O9	How can social care services better meet the needs of Gypsy, Roma and Traveller elders? (O9)	3%	9%	6%	0
P7	How can social care better meet the needs of black older people and older people of colour? (P7)	3%	7%	5%	4

# Step 5 - Workshop



Day 1 – Wednesday 16 <sup>th</sup> September	
Time	Session
12:30	Registration and virtual refreshments
13:00	Welcome and introduction <ul style="list-style-type: none"> <li>About the workshop: Katherine Cowan, James Lind Alliance, v chair</li> <li>About the social care priority setting project: Kristina Staley, I specialist</li> </ul>
13:45	Small group session 1 – comparing priorities <ul style="list-style-type: none"> <li>Participants divided into four small discussion groups</li> </ul>
14:30	Break – 30 minutes <i>Turn off your mic and video</i>

**Document B**

**Setting priorities for social care in Wales**

*How can we best provide sustainable care and support to help older people live happier and more fulfilling lives?*

**Participants' guide to the online workshop**

Thank you for agreeing to participate in the online workshop. The purpose of this guide is to help you prepare for, join and take part in the online workshop. It aims to answer the following questions about the workshop:

**Document C**

**Setting priorities for social care in Wales - Participant Worksheet – pre-workshop exercise**

**Individual ranking of questions for the workshop on 16<sup>th</sup> and 17<sup>th</sup> September 2020**

This is a list of 15 questions for future research on social care for older people. They have come from a survey we carried out with people aged 65+, carers and family, and social care professionals. The questions have been checked against current evidence to make sure they have not already been fully answered by research.

Please spend some time before the workshop reading this list of questions. We would like you to rank them from 1–15, 1 being the most important in your opinion and 15 being the least important, for research to answer.

If you find it too difficult to rank all the questions, please just choose 3 questions that are the most important to you and 3 questions that the least important to you. Please do still read all the questions as we will be discussing them together at the workshop.

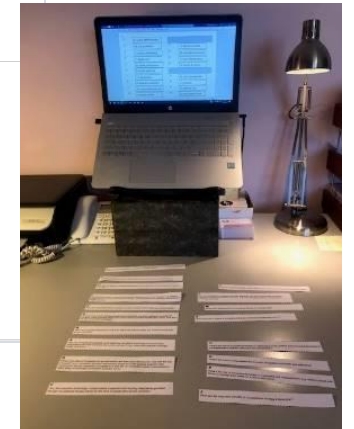
Make a note of any comments in the right-hand column. **Please have this with you when you join the online workshop.** You will not be asked to send it in. Everyone will discuss their choices in small groups.

Ref	Question	Your ranking (1-15)	Notes
A	Does early care planning and/or early or regular contact by social care services, help prevent problems and result in better experiences for older people than waiting until there is a crisis?		
B	How can home and community-based social care enable older people to socialise, reducing loneliness and isolation?		
C	How can respite for carers of older people be improved?		
D	How can social care and health services, including the voluntary sector, work together more effectively to meet the needs of older people?		

questions, please contact Emma at

	✓

search on social care for older



**1-10**

- I** Tailored to interests/needs of individuals
- G** Consistent high quality
- E** Support older people with complex needs
- H** Flexible to respond to changing needs/emergencies
- D** Social care and health services work together
- F** Funded in a sustainable way
- A** Early care planning and/or regular contact
- K** Reduce isolation and stress amongst carers
- J** Terms and conditions improved for staff
- N** Barriers in accessing services

**11-13**

- C** Respite for carers

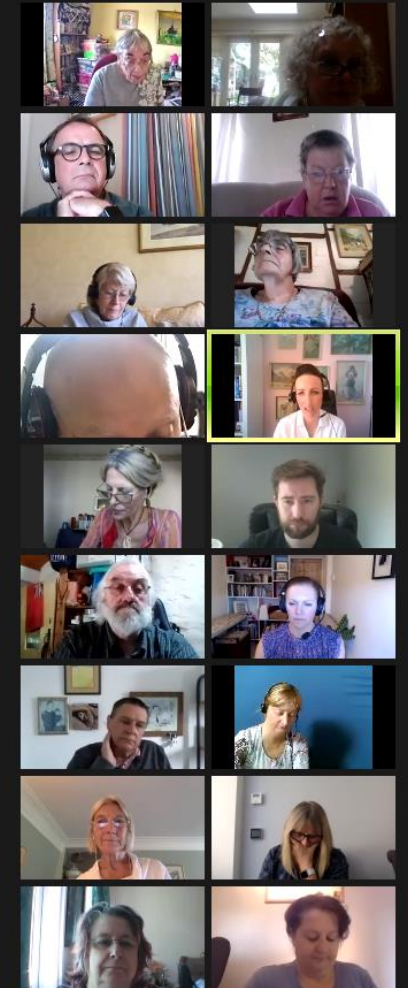
**14-15**

- B** Home and community-based social care
- L** The setting in different parts of Wales
- O** Support older people during Covid pandemic
- M** Continuous support from same paid care workers

Slide 1 of 1 English (United Kingdom) 123%

Participants in video conference: Sian Jones, Emma - Observer, Tricia - Facilitator, huw jones, Philip Bell, Glyn Williams, Holly

Rank	ID	Question	G1	G2	G3	G4	Combined score - sort lowest to highest
1	A	Early care planning and/or regular contact	1	1	1	4	7
2	K	Reduce isolation and stress amongst carers	2	2	2	5	11
3	D	Social care and health services work together	6	7	4	2	19
4	I	Tailored to interests/needs of individuals	5	4	12	3	24
5	E	Support older people with complex needs	9	5	5	9	28
6	F	Funded in a sustainable way	4	13	10	1	28
7	N	Barriers in accessing services	7	10	3	8	28
8	J	Terms and conditions improved for staff	8	3	14	6	31
9	G	Consistent high quality	3	14	8	7	32
10	B	Home and community-based social care	10	6	9	10	35
11	H	Flexible to respond to changing needs/emergencies	11	12	6	12	41
12	L	The setting in different parts of Wales	14	8	7	14	43
13	C	Respite for carers	13	11	11	11	46
14	M	Continuous support from same paid care workers	12	9	13	13	47
15	O	Support older people during Covid pandemic	15	15	15	15	60



# Narratives

#4 How can social care for older people be tailored to the interests and needs of individuals, including better involvement in decisions about their own care?

## The priority:

Older people said they wanted to be “*listened to and heard*” by care workers, so they can have an “*equal say in the care they receive*”. They wanted to be respected and understood as a unique, whole person with particular interests and needs, and to be supported to live their lives in the way they wish, “*such as being part of my church and playing music in a band*”. Some asked whether advocates add value by empowering individuals to understand their options and make choices. They wanted to know how best to make the individual’s needs central to the care they provide.

Practitioners asked how often older people’s needs aren’t being met because services are under-resourced: “*You can’t give people what they want, if you haven’t got the money to do it*”. This issue is discussed under Priority #6. Carers wanted social care services to better meet the older person’s needs, rather than them having to fit in with the service, for example, being able to get up and dressed at the time they wish, rather than during the only timeslot available.

Carers also wanted to have their say about the care package provided, when they may be impacted by the decision and have a good understanding of the older person’s needs.

## Stage 6 – Work with researchers

- Meetings on each of Top 10 (researchers, service users, practitioners, policy)
- **Narrative** as starting point
- 28 research suggestions, **actionable** research that will make a difference
  - New research evidence
  - New evidence synthesis;
  - Dissemination or Knowledge mobilisation;
  - Policy or audit
- **Feedback** to all who have participated in the project

# Stage 7 – work with funding bodies

- **Narratives** for Top 10 as starting point
- Have been working with:
  - National Institute for Health Research
  - Economic and Social Research Council
  - The Health Foundation
  - Wales Centre for Public Policy
  - Health and Care Research Wales
  - Welsh Government Policy Teams
- **Updates to researchers and participants**



1. Working Group
2. Initial survey
3. Indicative questions
4. Interim prioritisation survey
5. Workshop
6. Work with researchers
7. Work with funding bodies

Top 10 priorities after  
5 ½ months, £15k



Whole project is 18  
months, £15k



More information on the project:

- Public-facing project report (March 2020)
- Internal project report (November 2020 and 2021)

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