

# Panel Discussion

## **Are Existing Measurement Tools Accurately Measuring Health-Related Quality of Life of Informal Caregivers?**

**Moderator**



Anna Richards

**Speaker 1**



Fleur Chandler

**Speaker 2**



Jill Carlton

**Speaker 3**



Alice Biggane

# Disclosures



Fleur Chandler

- Parent of young adult with Duchenne Muscular Dystrophy
- Health Economist and Market Access Specialist
- Previously Head of Global Health Outcomes at GSK and Head of Market Access UK Ireland at Sanofi
- Parent Advisory Board Member Duchenne UK
- ISPOR Task Force on Paediatric Quality of Life
- Chair of Project HERCULES
- Stockholder in GSK, Haleon, Sanofi



Jill Carlton

- Professor in Health Outcomes Research at the University of Sheffield
- The opinions expressed are solely my own and do not express the views or opinions of my current employer (or any previous employer)



Alice Biggane

- Current employee of Pfizer UK
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# Issue being discussed

- As demands upon healthcare resources increase, informal caregiving has gained greater consideration in determining the impact of health conditions.
- Informal caregiving varies significantly across different health conditions

Three key areas of debate will be discussed:

- 1 conceptualising informal caregiver HRQoL for use within economic models
- 2 measurement of informal caregiver HRQoL
- 3 valuation and incorporation of informal caregiver HRQoL in economic evaluations

# Overview



Fleur Chandler

The lived experience and variability of being a caregiver, reflecting upon key domains of HRQoL affected



Jill Carlton

- a) the suitability of existing instruments to measure informal caregiver HRQoL
- b) the societal view of HRQoL impacts differing according to type and length of condition.



Alice Biggane

The need for wider conversations and collaboration between sponsors and payers to ensure alignment on how to capture HRQoL and the impact of potential treatments in HTA and cost-effectiveness analyses, without leaving value behind.

# Exploring the lived experiences and variability of being a caregiver



# Parent Caregiver Perspective

- My son Dom was diagnosed at 3 years old with Duchenne Muscular Dystrophy
- Progressive and fatal muscle wasting disease
- Constantly changing and worsening needs
- Impact on HRQOL is immense and far reaching at every stage
- Needs to be better recognised and represented in HTA



# Impact on Caregivers

# Measurement of informal caregiver HRQoL





# Measuring (HR)QoL: The problem



- Studies are using lots of PROs

Study	Condition	Measures
Algadeeb et al, 2024	ADHD	WHOQOL-BREF ZBI
Andres et al, 2024	Dementia	HADS
Bourissi et al, 2024	Cancer	SF-12
Ferrero-Sereno et al, 2024	Alzheimer's Disease	EQ-5D-3L Zarit caregiver burden scale Subjective Happiness Scale (SHS) Satisfaction with Life Scale (SWLS)
de Oliveira Tavares , 2024	Care-dependent patients	WHOQOL-BREF
Remor et al, 2024	Phenylketonuria	Phenylketonuria - Quality of Life (PKU-QoL) SF-36 TNO-AZL Questionnaire for Adult's Health-Related Quality of Life (TAAQOL) WHOQOL-100 WHOQOL-BREF Child Health Questionnaire - Children and Parent Form (CHQ-PF 50)

Instrument	N	Instrument	N	Instrument	N
Acceptance of Illness Scale	2	Existential Well-Being Subscale from the McGill Quality of Life Questionnaire	1	Rand 36-Item Health Survey	1
Beck Depression Inventory	3	Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale	1	Self-Rating Anxiety Scale	1
Beck Hopelessness Scale	1	The Duke-UNC Functional Social Support Questionnaire	1	Self-Rating Depression Scale	6
Coping Orientation to Problems Experienced Inventory	2	General Health Questionnaire	1	Short Form-12	3
Burden Scale for Family Caregivers	1	Hospital Anxiety & Depression Scale	27	Short Form-36	9
Carer Quality of Life	1	Life Satisfaction Checklist	1	Short Form-36 Mental Component Summary	1
Caregiver Burden Inventory	13	Metacognitive Questionnaire 30	1	Short Form-36 Version 2	2
Center for Epidemiology Studies Depression Scale	1	Multidimensional Scale of Perceived Social Support	2	State-Trait Anxiety Inventory-X	1
Chalder Fatigue Scale	1	McGill Quality of Life Questionnaire	10	State-Trait Anxiety Inventory-Y1	4
Chalder Fatigue Scale - Physical Fatigue Subscale	1	Positive and Negative Affect Schedule	1	State-Trait Anxiety Inventory-Y	2
Caregiver Network Scale	1	Patient Health Questionnaire-9	1	Satisfaction With Life Scale	2
Close Persons Questionnaire	1	Profile of Mood States - Short Form	1	World Health Organisation quality of life-BREF	5
Caregiver Strain Index	10	QoL Enjoyment & Satisfaction Questionnaire Short Form	1	Zarit Burden Interview	33
Dyadic Adjustment Scale - Dyadic Subscale	1	Quality of Life in Life-Threatening Illness Family Carer Version	4		
EuroQoL-5 Dimensions	3	Quality of Life at the End of Life	1		

# Measuring (HR)QoL: The problem



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# Content validity

- Current guidelines advocate
  - Relevance
  - Comprehensibility
  - Comprehensiveness
- Evidence is required to support use of any instrument
- Legacy measures can fair badly
- Does NOT necessarily mean they are not fit-for-purpose





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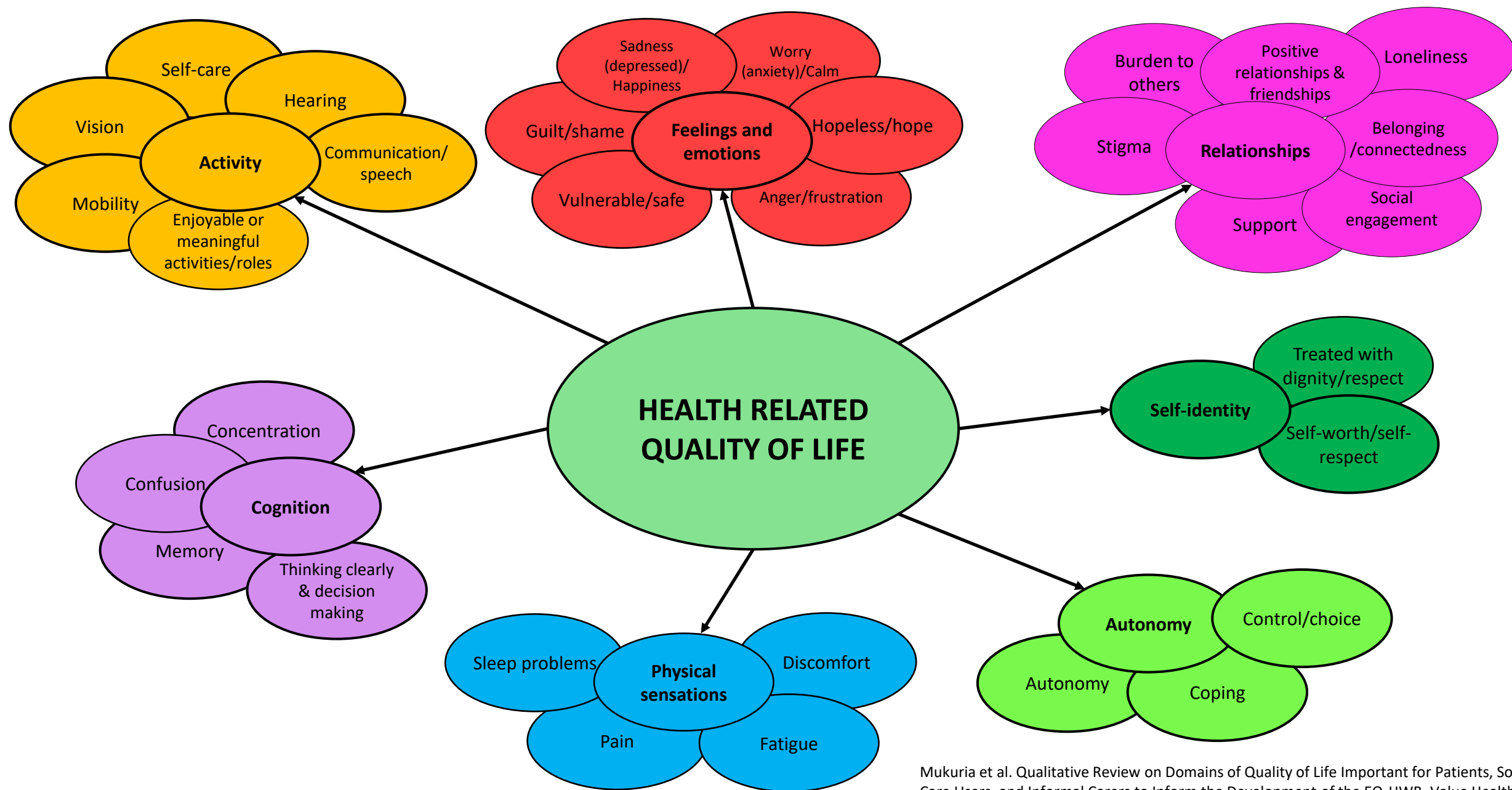


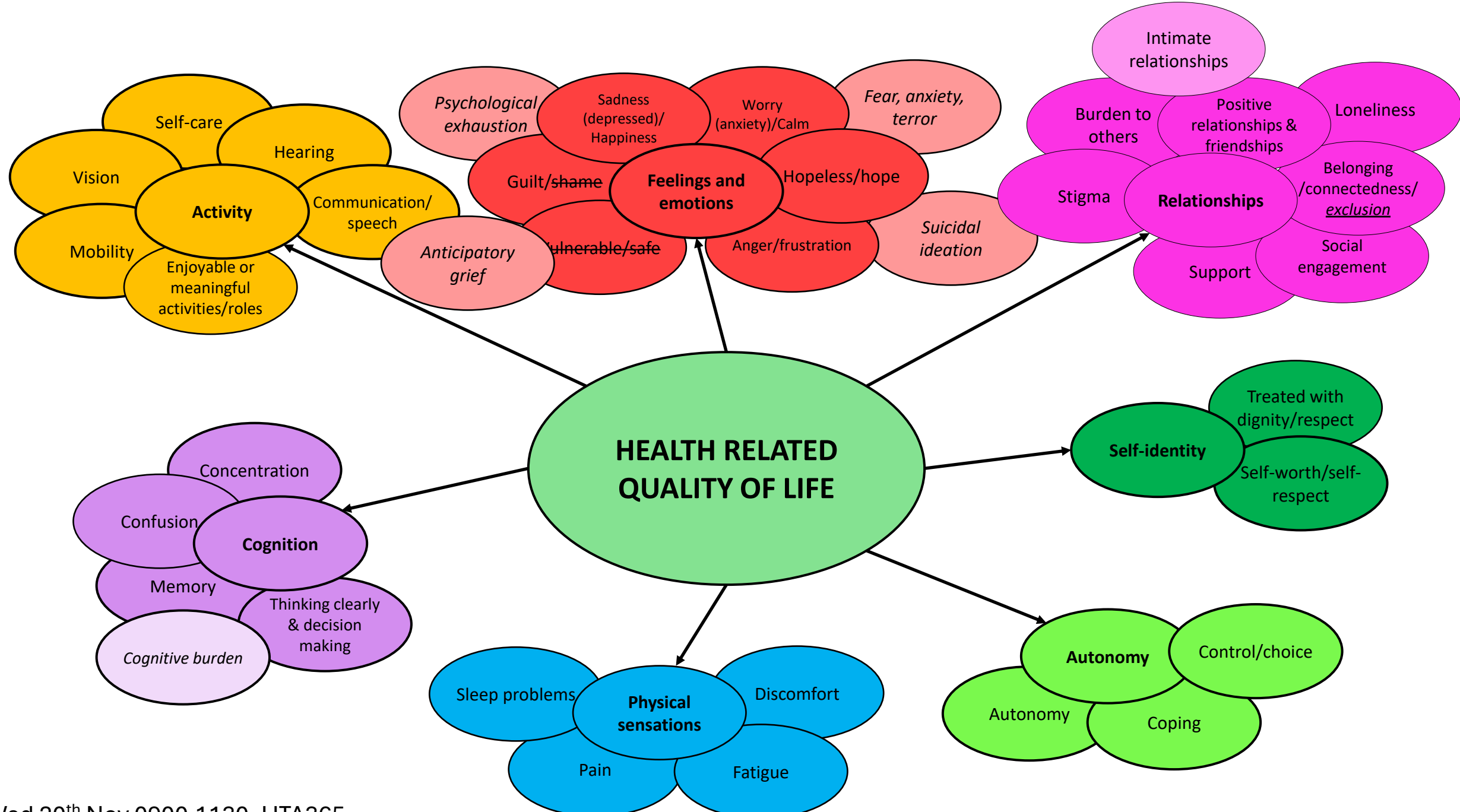


# Measuring (HR)QoL: The problem



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- Limited evidence to support their use
  - Content validity
  - Psychometric properties
- Measuring what matters?





# Acceptability

- Questions
  - Too many – respondent burden
  - Compromise with comprehensiveness
  - Too personal – missing data, low response rate
- Who?
- What?
- When?
- Where?
- How?







Should we care about  
who the care is for?

Caring for a partner







Caring for a partner







Caring for a child





Caring for a child







Caring for a child





Caring for a child





Caring for a child







Caring for a child





Caring for a child





# Summary

- Measuring the impact of being an informal carer is complex
- Differences exist across different characteristics (e.g., gender, sociodemographics, etc.)
- Caregiver burden and caregiver HRQoL are NOT the same BUT they are linked
- A generic approach to measurement work may not work
  - Akin to rationale for disease-specific measures
- Does society view caring differently if it is:
  - Caring for an **adult** with a progressive, life-limiting condition? (e.g., MND)
  - Caring for a **child** with a progressive, life-limiting condition? (e.g., DMD)

# Incorporating caregiver HRQoL in HTA submissions



# Declarations

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# Setting the scene

- Long-established relationship between the health/wellbeing of carers, the health of the patient they care for, and the volume of care provided



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- Caregiver health/ wellbeing can be impacted by emerging new health technologies



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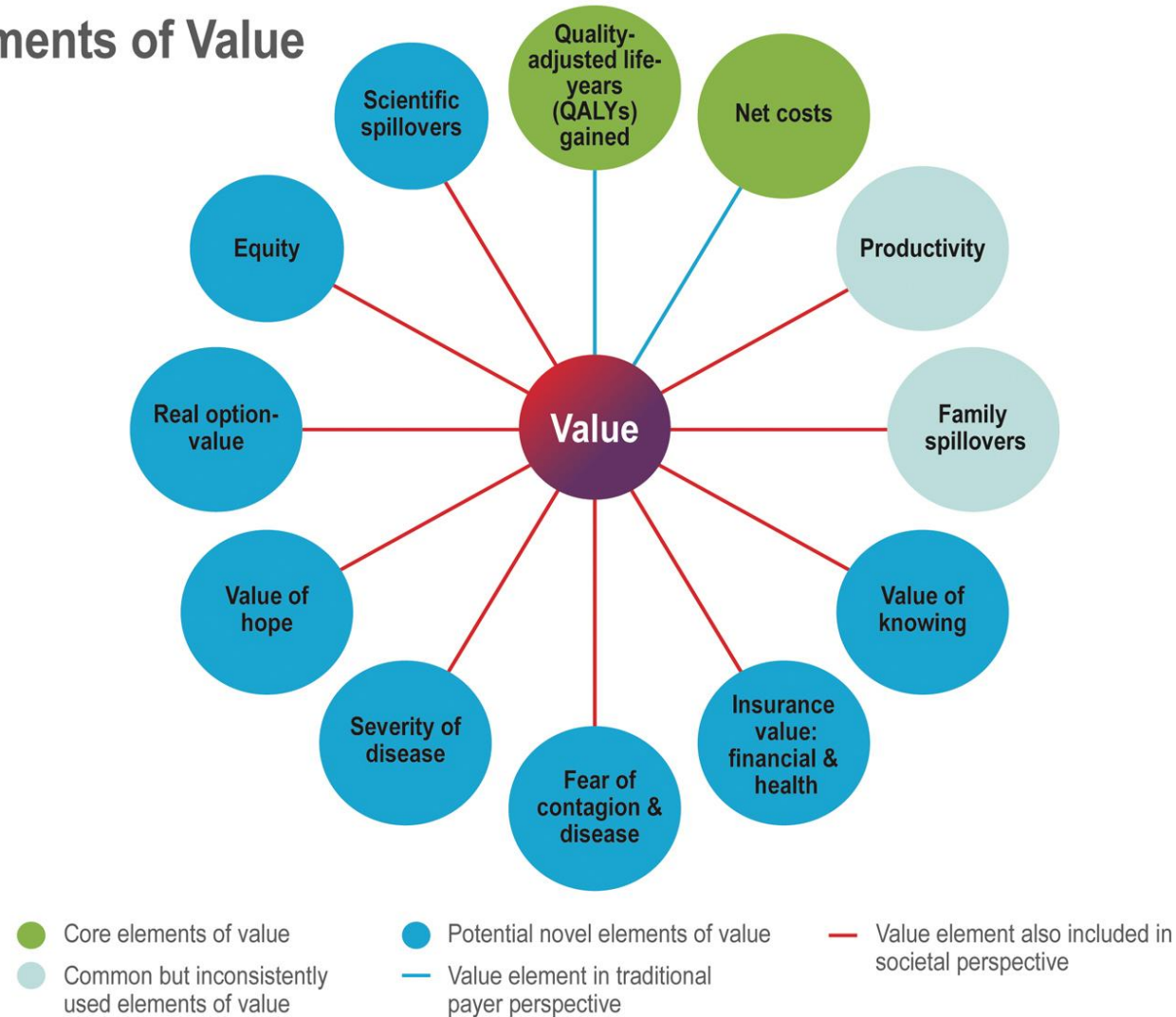
- Long-established relationship between the health/wellbeing of carers, the health of the patient they care for, and the volume of care provided
- Caregiver health/ wellbeing can be impacted by emerging new health technologies
- Caregiver inclusion in economic evaluations of new health technologies is an increasingly important consideration



# A growing consensus

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## Elements of Value






# A growing consensus

Pharmacoeconomics (2024) 42:343–362  
<https://doi.org/10.1007/s40273-023-01321-3>

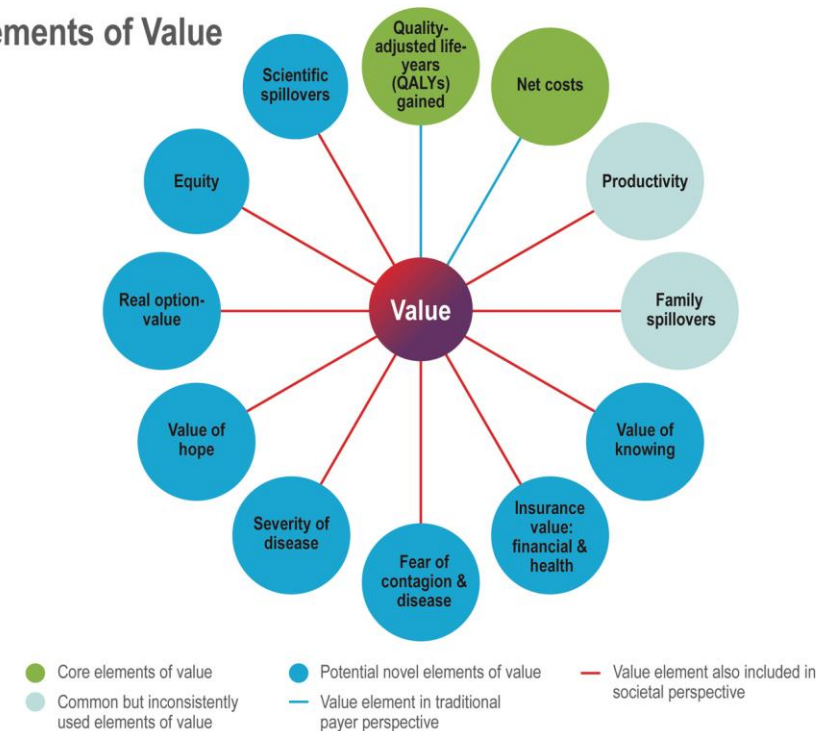
## ORIGINAL RESEARCH ARTICLE



## Recommendations for Emerging Good Practice and Future Research in Relation to Family and Caregiver Health Spillovers in Health Economic Evaluations: A Report of the SHEER Task Force

Edward Henry<sup>1</sup>  · Hareth Al-Janabi<sup>2</sup> · Werner Brouwer<sup>3</sup> · John Cullinan<sup>1</sup> · Lidia Engel<sup>4</sup> · Susan Griffin<sup>5</sup> · Claire Hulme<sup>6</sup> · Pritaporn Kingkaew<sup>7</sup> · Andrew Lloyd<sup>8</sup> · Nalin Payakachat<sup>9</sup> · Becky Pennington<sup>10</sup> · Luz María Peña-Longobardo<sup>11</sup> · Lisa A. Prosser<sup>12</sup> · Koonal Shah<sup>13</sup> · Wendy J. Ungar<sup>14</sup> · Thomas Wilkinson<sup>15</sup> · Eve Wittenberg<sup>16</sup>

### Elements of Value



Adapted from ISPOR STF (2018)


# A growing consensus

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Canada's Drug Agency  
L'Agence des médicaments du Canada  
Drugs, Health Technologies and Systems. Médicaments, technologies de la santé et systèmes.

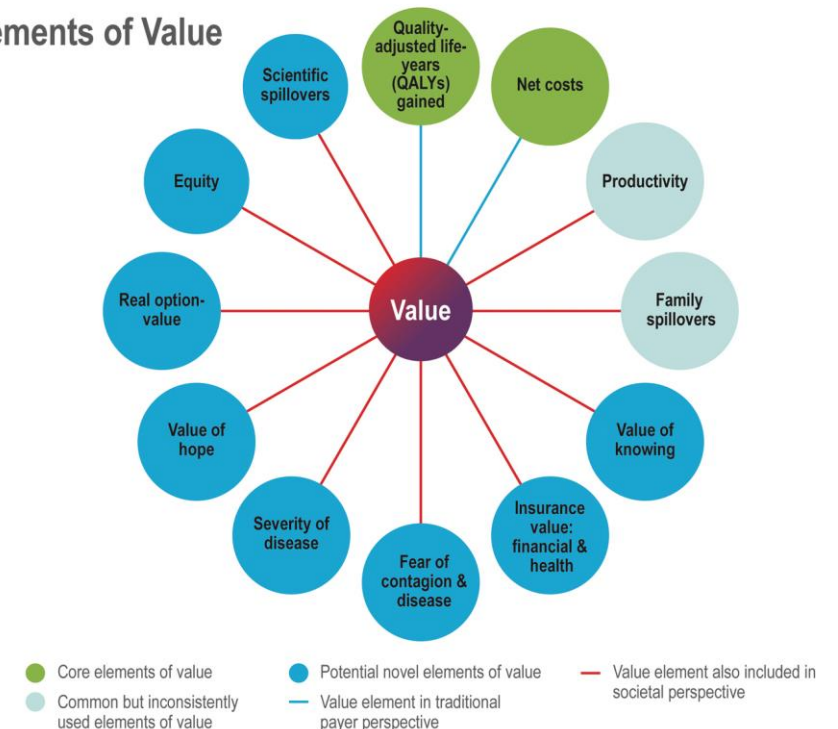


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National Institute for  
Health and Care Excellence



Zorginstituut Nederland

## Elements of Value



Adapted from ISPOR STF (2018)

# The current reality

- Recommendations to include caregiver HRQOL exist
  - including from the HTA bodies themselves!



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  - who, where, what, when, why and how?



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- Very few technology appraisals include caregiver HRQOL in cost utility analyses
  - what are the reasons? what are the implications?



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  - including from the HTA bodies themselves!
- **BUT** very little methodological direction is provided
  - who, where, what, when, why and how?
- Very few technology appraisals include caregiver HRQOL in cost utility analyses
  - what are the reasons? what are the implications?
- **Opportunity to collaborate and innovate?**





# So where do we go from here?

*"As with any emerging field,  
there is a need to define new  
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Prosser et al. 2019

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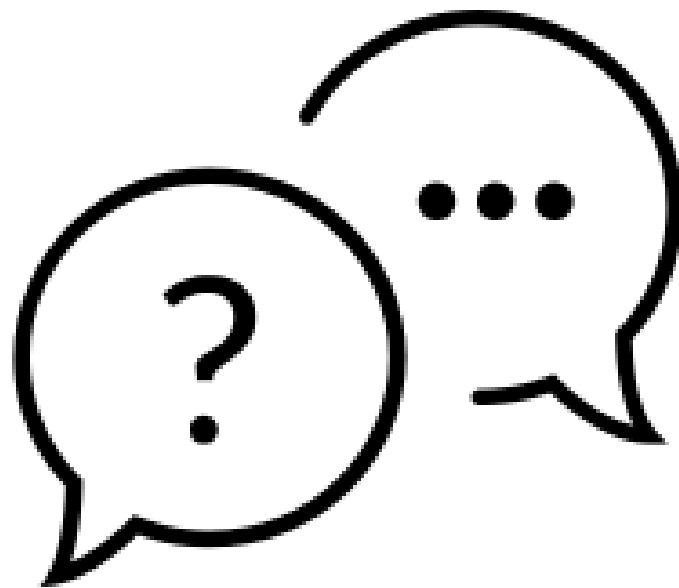


**Collaboration is key**

# Summary

- A growing consensus
  - *This is an important topic*
- Lots to figure out
  - *6Ws*
- Lessons learned from the past
  - *What can we use?*
  - *What can we improve?*
- Innovate for the future
  - *Think big and wide*
- Work together
  - *Equal, multistakeholder environment*







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