IPOS-Dem: a measure to assess symptoms and other concerns in advanced dementia

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Objectives of this presentation:

To understand some of the challenges (**and solutions**) in trying to systematically assess and measure – at individual person-level – changes in health status of those with advanced dementia

To consider an example of an holistic, person-centred outcome measure, <u>IPOS-Dem</u>, and how it meets some of these challenges

What is an 'outcome' measure?

'Outcome' is often used in a lay sense to mean 'the result or consequence of something'

In health care, 'outcome' and 'output' are often either confused or conflated

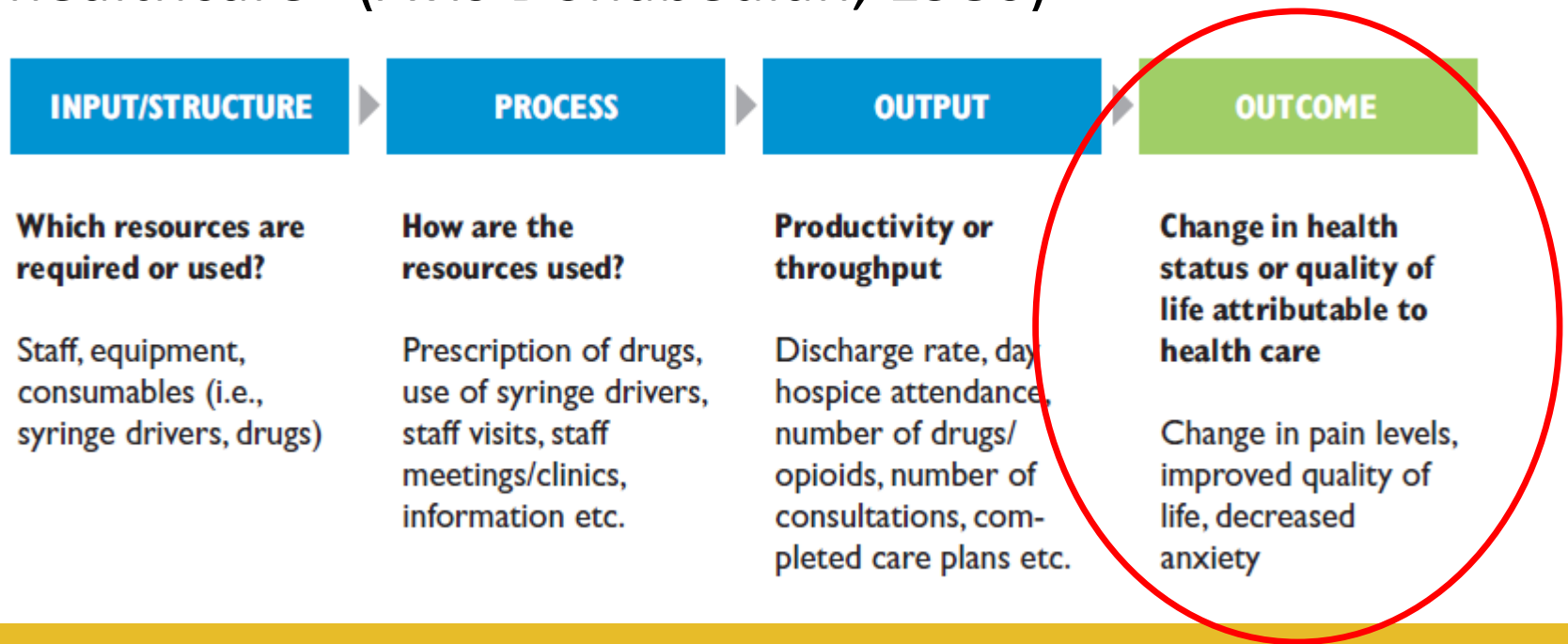'Outcome' derives from a systematic understanding of quality of care; asking

'what is needed to deliver high quality care?'

'what is the impact of care for the individual?'

i.e. what *is maintained* or *has changed* for an individual because of (hopefully high quality) care?'

What is an outcome measure?

- Way of measuring changes in a person's health or health-related wellbeing over time

- Outcome = "change in a person's current and future health status that can be attributed to preceding healthcare" (Avis Donabedian, 1980)

INPUT/STRUCTURE	PROCESS	OUTPUT	OUTCOME
Which resources are required or used? Staff, equipment, consumables (i.e., syringe drivers, drugs)	**How are the resources used?** Prescription of drugs, use of syringe drivers, staff visits, staff meetings/clinics, information etc.	**Productivity or throughput** Discharge rate, day hospice attendance, number of drugs/ opioids, number of consultations, com-pleted care plans etc.	**Change in health status or quality of life attributable to health care** Change in pain levels, improved quality of life, decreased anxiety

What is the challenge?

- People with dementia have high levels of comorbidities, symptom burden, and care needs [1]
- It is challenging to assess symptoms and other concerns in this population group [2]
- Untreated symptoms lead to avoidable distress and behavioural changes [3], poorer wellbeing, and reduced quality of life
- Results in challenges to clinical management and staff burden [4]

1. Mitchell et al NEJM (2009)
2. Kovach et al JAN (2006)
3. Husebo et al BMJ (2011)
4. Sourial et al Int Psychogeriatr (2001)

What is the challenge?

Very few measures exist which are suitable and well-validated for use among those with advanced dementia:

- Harrison et al. Alzheimer's Research & Therapy (2016) 8:48 – very few measures which consider the broader health outcomes; health status, wellbeing, quality of life
- Ellis-Smith et al. BMC Medicine (2016) 14:38 Doi: 10.1186/s12916-016-0582-x Measures for pain are best developed; all other measures require further validation. A multi-symptom measure for comprehensive assessment and monitoring is required.
- Webster L, Groskreutz D, Grinbergs-Saull A, *et al.* Development of a core outcome set for disease modification trials in mild to moderate dementia. *Health Technol Assess* 2017;21(26) Aimed to appraise existing research into outcome sets; underpinned by what is most important to patients.

Why use an outcome measure in advanced illness: Results of an international online survey of clinicians

Purposes of current/previous outcome measure use? (multiple answers possible)	N = 195 %
To **assess individual**'s symptoms / needs / concerns	92
As a **routine** part of clinical care	81
To **monitor changes** in a person's health status or wellbeing	71
To **evaluate the effect** of an intervention / care / service	68
To **document** individual characteristics and care needs	46
To **facilitate communication** within the team	46
To **assess families**' needs / concerns	43
To **facilitate communication** with people affected / their families	33
To **assess** the care given against audit standards	23

What is IPOS-Dem?

IPOS-Dem is a proxy-completed measure for use with people with advanced dementia living in care homes, developed at Cicely Saunders Institute, King's College London
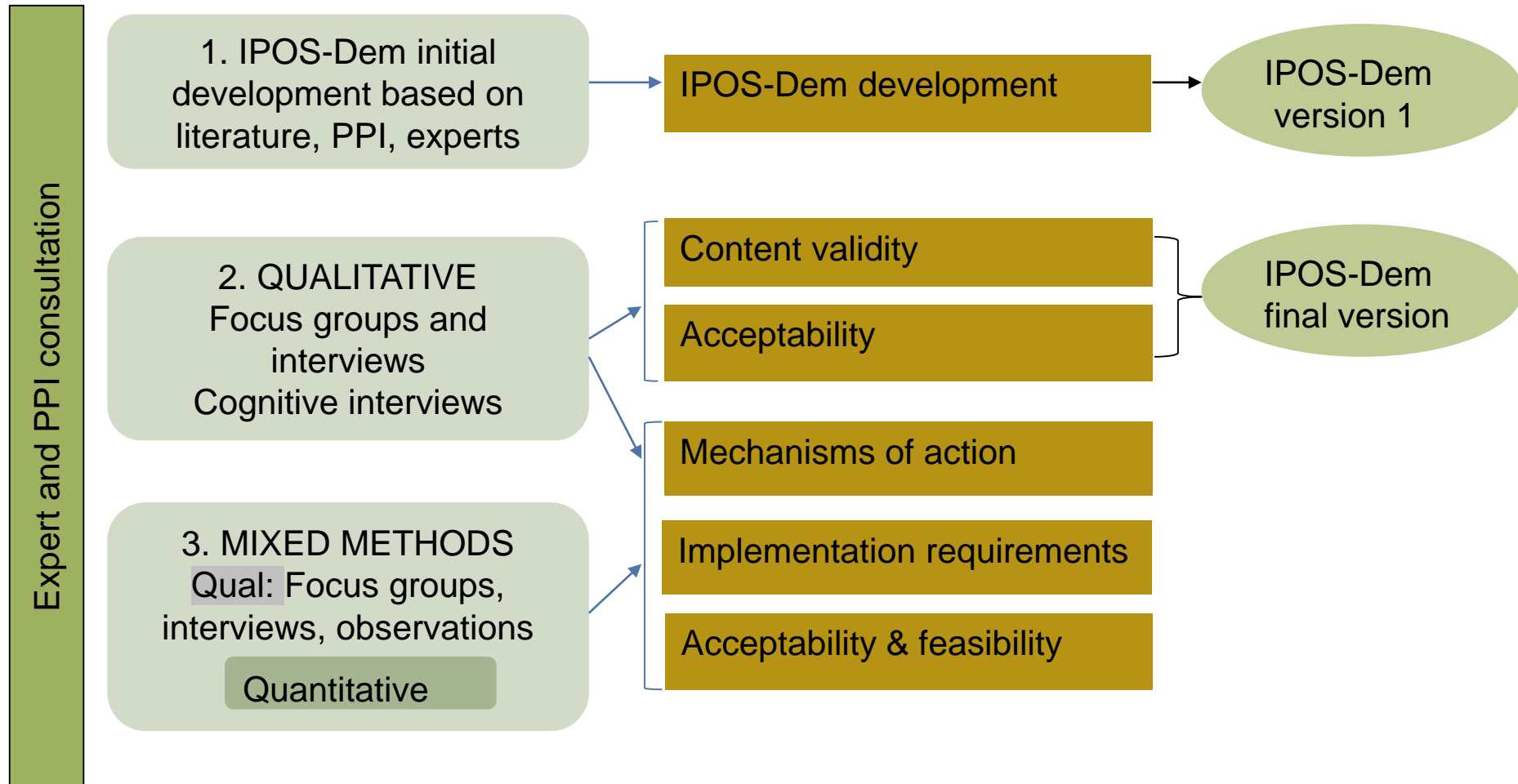
- Designed for both assessment and outcome measurement
- Derived from the Integrated Palliative care Outcome Scale (IPOS); for advanced illness
- Developed for use by staff in residential and nursing facilities; to improve assessment and monitoring of symptoms and other concerns important in advanced dementia
- Also used in advanced dementia research

An outcome measure needs to be …

- Valid and reliable [1]

- Acceptable (ease of use, value of information, clear language, flexibility for clinical use) [1,2]

- Feasible (brief, simple training, low burden) [1,2]

- Suited to assessment through observation and from knowledge about the person with dementia

1. Higginson and Carr BMJ (2001)
2. Slade et al Soc Psych Psych Epid (1999),

Overview of IPOS-Dem development

Expert and PPI consultation

1. IPOS-Dem initial development based on literature, PPI, experts → IPOS-Dem development → IPOS-Dem version 1

2. QUALITATIVE
Focus groups and interviews
Cognitive interviews →
- Content validity
- Acceptability
→ IPOS-Dem final version

3. MIXED METHODS
Qual: Focus groups, interviews, observations
Quantitative →
- Mechanisms of action
- Implementation requirements
- Acceptability & feasibility

designed for use in residential/nursing care facilities

Phase one: drafting of IPOS-Dem

Integrated Palliative care Outcome Scale adapted based on previous studies in this population and setting[1], symptom scoping review:

- Less applicable items modified to reflect population and setting: ≥40% missing

- Symptoms added

1. Brandt et al Pall Med (2005)

IPOS-Dem version 1

For instance, items added:

- Symptoms: swallowing problems, skin breakdown, delusions or hallucinations

- *Has s/he experienced a loss of interest in things or activities s/he would normally enjoy[1]*

- *Does s/he have the opportunity to engage in enjoyable or pleasurable activities?*

- *Have hearing (aids), foot care, dental care, vision (glasses) concerns been addressed?*

- *Weight loss*

1. Payne et al Pall Med (2007)

Phase 2: IPOS-Dem development

Aim: To explore content validity, comprehensibility and acceptability of IPOS-Dem

Clare Ellis-Smith, Catherine J Evans, Fliss EM Murtagh, Lesley A Henson, Alice M Firth, Irene J Higginson and Barbara A Daveson; on behalf of BuildCARE

IPOS-Dem development: results

- Four focus groups, 3 semi-structured interviews, with 26 participants (15 residential and nursing facility staff, 3 general practitioners, 2 community nurses, and 6 family/friends)

- Two rounds of 5 cognitive interviews (n=10) with residential and nursing facility staff

Final IPOS-Dem

Additional items: dental problems, difficulty communicating, poor sleep, diarrhoea, agitation, and wandering

Provision of lay terms and item descriptors

- *Drowsiness (sleepiness)*

- *Skin breakdown (redness, skin tearing, pressure damage)*

Provision of video training instructions

Final IPOS-Dem: 12 question measure

Phase 3: study design and methods

- Mixed methods study
- Two residential aged care facilities
- IPOS-Dem introduced into routine care of residents with dementia or cognitive impairment for 12 weeks
- Participants: residents, family, care staff, visiting health professionals

Phase 3: methods

Qualitative data collection:

- Observation: GP/ community nurse consultations
- Focus groups/ interviews with family/friends, facility staff, GP/community nurses

Quantitative data collection:

- IPOS-Dem scores and missing data
- Functional and behavioural measures
- Utility questionnaire for each IPOS-Dem
- Case note data extraction

Analysis: content analysis, descriptive statistics

Phase 3: results

- 2 focus groups, 7 semi-structured interviews, 3 non-participant observations with 18 participants (7 family, 10 staff, 1 GP)

- 36 residents recruited, 4 died before baseline

- Mean age (SD, range): 87.2 (8.3 67-102)

- Female: 24, Male: 8

- (Moderately) severe dementia: 25, severe cognitive impairment : 7

Phase 3 results: mechanisms of action

Facilitating communication:

- Between staff and family

'If the staff were completing this on a weekly basis, can I come down and say, can I see what [they've] said about my mum? (Family A1006) ... So would that be useful? (CES) ... Oh God, yes (Family A1006) ... Yeah (Family A1007)   (Family focus group)

- Between staff and managers

'I've had more staff come to me regarding residents having difficulty swallowing in the last 2 months than I think I've had in the last 2 years ...'
(Manager B3001.1)

- Between staff and external professionals

Phase 3 results: resident/ family outcomes

Comprehensive care needs addressed

'If you're finding things out from this ... you're making the lives of clients better, whether it be in a health way, or whether it be mentally, physically, in whatever way, then that's a good thing, something that you might not have picked up on without this'   *(Manager C1005)*

Improved symptom management

'Yeah I mean I can certainly think of a resident who has recently started to suffer with constipation and that was highlighted in this and now they're on a laxative ...'   *(Staff B3001.2)*

Increased family empowerment / engagement

'Yeah I do because she had diarrhoea for – then I could pick up on it you know and say to them have you done anything about this?'
                      (Family A3002)

Phase 3 results: Implementation requirements

- Leadership essential to implement well
- Needs to be embedded into care processes
- Is valued by care staff

'And I know it's more work, but even if it's only a little bit, it's still more work regardless of a little or a lot but I think things like this which, I don't mean this selfishly, doesn't just look after the clients, it promotes us, it promotes the care we're giving, it promotes the way in which we work, so you know, [...] I think it something that all [facilities] should do'

(Manager C1005)

IPOS-Dem:

Q1. What have been the person's main problems <u>over the past week</u>?

1...

2...

3...

IPOS-Dem:

Q2. Please select one box that best describes how the person has been affected by each of the following symptoms <u>over the past week</u>.

	Not at all	Slightly	Moderately	Severely	Over-whelmingly	Cannot assess
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Other symptoms include: poor appetite, dental problems, swallowing difficulties, skin breakdown, etc

IPOS-Dem:

Concerns about anxiety and worry, loss of interest, either the person affected by dementia themselves, or their family:

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always	Cannot assess
Q4. Have any of his/her family been anxious or worried about the person?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q5b. Lost interest in things things s/he would normally enjoy?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

IPOS-Dem:

Ability to interact positively, and ability to enjoy activities:

Over the past week:

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*	*Cannot assess*
Q7. Has s/he been able to interact positively with others (e.g. staff, family, residents)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q7b. Can s/he enjoy activities appropriate for his/her level of interests and abilities?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

IPOS-Dem:

Whether practical problems have been addressed, including hearing, foot care, glasses etc:

Over the past week:

	Problems addressed/ No problems	*Problems mostly addressed*	*Problems partly addressed*	*Problems hardly addressed*	*Problems not addressed*	*Cannot assess*
Q9. Have all practical problems been addressed? [e.g. hearing aids, foot care, glasses, diet]	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Study outputs:

- **Final version of IPOS-Dem**, with written & video instructions
- A person-centred assessment and outcome measure which focuses on overall health status in advanced dementia, from a very practical perspective
- Can be downloaded for free from www.pos-pal.org
- Evidence of good content validity
- Good acceptability and feasibility
- Some insights into the mechanisms of action
- Outline of implementation requirements
- Importance of tailoring to caregiver expertise: assessment needs to be based on their knowledge and observations of residents, with consideration of language and training

Next steps

- Further psychometric testing: different settings, and including a full scale validation study

- Testing effectiveness of IPOS-Dem as an intervention across settings

Useful resources:

See www.pos-pal.org to download the IPOS-Dem measure and manual

The main paper is at:

http://journals.sagepub.com/doi/abs/10.1177/0269216316675096

https://www.researchgate.net/publication/296194059 provides the systematic review of measures

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