Quality of Life Evaluation & Patient Report Outcomes (PROMs) in older people
WHO Definition of Quality of Life

“An individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns”
WHO Definition of Quality of Life

“An individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns”

No explicit mention of health
WHO Definition of Quality of Life

“**Health** is just one of a number of important domains of overall quality of life including employment, housing, access to education, local neighbourhood. Aspects of culture, values, and spirituality are also key aspects of overall quality of life that add to the complexity of its measurement.”
Reduce Complexity To Numbers

Inevitable loss of information
BUT
Potential gain in simplicity and ability for comparisons and benchmarking
Aggregate PROMs and Performance Data

Individual PROMs Data

IMPROVE PATIENT CARE
Patient Centered Care
Survey of 2040 adults >65

- 70% Self-manage
- 20% Co-manage
- 10% Delegate

- 85% prefer independent or shared role in decision making

- 40% experienced treatment burden

J Wolff, C Boyd  JGIM 2015 30 p1497-1504
Clustering of Symptoms

- Pain, Fatigue, Insomnia & Mood disturbance
- 30% have 2-3 of the list
- 31% have all 4

Cheng | Critical Reviews in Oncology 2011 78 p127-137
RECOMMENDATION

Patients 70+ for whom chemotherapy is being considered:

GERIATRIC ASSESSMENT (GA)
Ideally linked to Integrated Care Plan (ICP)

• Select appropriate treatment

• Identify health and functional status that may affect cancer treatment delivery
Key parameters for Geriatric Assessment in Oncology

- Functional status*
- Co-morbidity*
- Cognition*
- Nutritional Status
- Social situation
- Polypharmacy
- Psychological (Depression/Anxiety)

- Very heterogeneous population
- Age is not a good marker of adult health

*Donovan EJCC 2015  24 574-590
No consensus on instruments

- TUG
- VES-13
- 7DA
- MNA
- AS
- G8
- GDS
- I-ADL
- MMSE
No consensus on Health Professionals (MDT)
Patient Reported Outcome Measures (PROMS)

- Measure of aspect of patient’s health
- Direct from the patient (or ? Proxy)
- No interpretation by clinician

<table>
<thead>
<tr>
<th>Interpretation not valid</th>
<th>Verifiable by performance</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. rating of symptom or difficulty in carrying out activity</td>
<td>e.g. patient reports limitations in physical function. Can be verified by observed performance</td>
</tr>
</tbody>
</table>
Patient Reported Experience Measures (PREMS)

- Measure related to patient centered care
- Covers aspects of structure and process of care as experienced by patient
- Not interpreted by another person
Patient Reported Experience Measures (PREMS) include:

- Respect for patient values and preferences
- Information provision
- Communication and education
- Coordination of care
- Involvement of family
- Emotional and physical support
- Discharge preparation
- Continuity, transitions
What is the matter with you?

What matters to you?
• Does it bother you
• that you are unable
To climb stairs?
What QL instruments are used?

Quick literature search
• PubMed 2003 – 2017
• “Cancer”, “Elderly”, “Quality of Life” (Titles only)

68 references

Exclusions
• 4 Review papers
• 1 Carers
• 5 Duplicates
• 2 Qualitative interview studies

56 papers remaining
Findings

- EORTC QLQ-C30 + Modules (27)
- SF36 (7)
- I-ADL (4)
- FACT-G + Modules (3)
- EQ5D (3)
- HADS (2)
- (Excluded KPS, ECOG)

- SF12
- QL Index
- NHP
- Becks D
- CES-D
- SCNS
- EORTC PALC15
- BFI
- Hope
- ADL
- Interview for Social Interaction
- ZBI
Psychometric Properties Of Validated Questionnaires

- valid content
- reliable – test re-test
- sensitive - responsive to clinical change
- cross-cultural validity
EORTC QLQ-C30 + Modules

Phase I
Determining Issues

Phase II
Formulating the question / item

Phase III
Pilot Testing

Phase IV
Field Testing and Psychometrics

English + minimum of 3 European languages
## EORTC QLQ-C30

<table>
<thead>
<tr>
<th>Functioning Scales</th>
<th>No. of items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>5</td>
</tr>
<tr>
<td>Role</td>
<td>2</td>
</tr>
<tr>
<td>Emotional</td>
<td>4</td>
</tr>
<tr>
<td>Cognitive</td>
<td>2</td>
</tr>
<tr>
<td>Social</td>
<td>2</td>
</tr>
<tr>
<td>Quality of life</td>
<td>2</td>
</tr>
</tbody>
</table>
PHYSICAL FUNCTIONING SCALE

Items

Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?

Do you have any trouble taking a long walk?

Do you have any trouble taking a short walk outside of the house?

Do you have to stay in a bed or a chair for most of the day?

Do you need help with eating, dressing, washing yourself or using the toilet?
RESPONSE CHOICES

- Four point Likert-type
  1. Not at all
  2. A little
  3. Quite a bit
  4. Very much

- Scale range = 5 - 20  (5 x 1 - 5 x 4)
- Transforms to 100 - 0 (inverted)
- High Score - good functioning
## EORTC QLQ-C30

<table>
<thead>
<tr>
<th>Symptom Scales/Items</th>
<th>No of items</th>
</tr>
</thead>
<tbody>
<tr>
<td>fatigue</td>
<td>3</td>
</tr>
<tr>
<td>pain</td>
<td>2</td>
</tr>
<tr>
<td>nausea and vomiting</td>
<td>2</td>
</tr>
<tr>
<td>appetite loss</td>
<td>1</td>
</tr>
<tr>
<td>dyspnoea</td>
<td>1</td>
</tr>
<tr>
<td>sleep disturbance</td>
<td>1</td>
</tr>
<tr>
<td>constipation</td>
<td>1</td>
</tr>
<tr>
<td>diarrhoea</td>
<td>1</td>
</tr>
<tr>
<td>financial impact</td>
<td>1</td>
</tr>
</tbody>
</table>

*(High score - high symptom burden)*
**EORTC QLQ-ELD15**

Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

<table>
<thead>
<tr>
<th>During the past week:</th>
<th>Not at All</th>
<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. Have you had difficulty with steps or stairs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32. Have you had trouble with your joints (e.g., stiffness, pain)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33. Did you feel unsteady on your feet?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. Did you need help with household chores such as cleaning or shopping?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. Has your relationship with your family become closer?</td>
<td>Not applicable</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36. Have you felt able to talk to your family about your illness?</td>
<td>Not applicable</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
37. Have you worried about your family coping with your illness and treatment? 

Not applicable 1 2 3 4

38. Have you worried about the future of people who are important to you? 

1 2 3 4

39. Were you worried about your future health? 

1 2 3 4

40. Did you feel uncertain about the future? 

1 2 3 4

41. Have you worried about what might happen towards the end of your life? 

1 2 3 4

42. Have you had a positive outlook on life in the last week? 

1 2 3 4

43. Have you felt motivated to continue with your normal hobbies and activities? 

1 2 3 4

44. How much has your illness been a burden to you? 

1 2 3 4

45. How much has your treatment been a burden to you? 

1 2 3 4
EORTC QLQ-ELD14

- 5 Scales
  - Mobility
  - Worries about others
  - Worries about future
  - Maintaining purpose
  - Illness burden
Computer Adaptive Testing (CAT)

VERSUS

QUESTION (ITEM) LIBRARY
1. 2. 3. 4. 5. .................... 29. 30.

VERSUS

PF ITEM LIBRARY:

56 items, field tested on 1176 heterogeneous cancer patients from 6 countries.

Analysed using Item Response Theory

31 items could be included in a unidimensional IRT model

EORTC QLQ-C30 v. 5 Item PF Scale
Computer Adaptive Testing (CAT) (based on IRT)

VERSUS QUESTION (ITEM) LIBRARY
1.~  2.~~  3.~~  4.~~  5.~~~  ..................  29.~~~~  30.

~~  31

Score = 57
5 fixed items

Score = 57
Fewer questions, more precision

BGS Oncogeriatrics 2018
Emotional Functioning

Q1: Did you feel tense?     Q2: Did you worry?
Q3: Did you feel irritable?  Q4: Did you feel depressed?

Not at all (1), A little (2), Quite a bit (3), Very much (4)

Score = 5  \[ Q1=2, Q2=1, Q3=1, Q4=1 \]
  or  \[ Q1=1, Q2=2, Q3=1, Q4=1 \]
  or  \[ Q1=1, Q2=1, Q3=2, Q4=1 \]
  or  \[ Q1=1, Q2=1, Q3=1, Q4=2 \]

Score = 10  \[ Q1=1, Q2=4, Q3=1, Q4=4 \]
  or  \[ Q1=2, Q2=3, Q3=3, Q4=2 \]
  etc.....
Item 21 'Did you feel tense?'
Slope = 2.41
Threshold1 = -1.75
Threshold2 = -1.03
Threshold3 = 0.19

Item 23 'Did you feel irritable?'
Slope = 1.31
Threshold1 = -2.30
Threshold2 = -1.56
Threshold = -0.25
COMPUTER ADAPTIVE TESTING

- Use response to one question to choose next question to ask
- Ask questions until no improvement in precision by asking additional questions
- PROMIS Project
EORTC QLQ-C30 in practice

1) Thresholds for clinical importance
   ◦ Anchor items: Burden, limited daily activity or needed help

2) Patient and HCP understanding and preferences for graphical presentation styles for PROM results
   • 83/85% of patients/HCP rated graphs as easy
   • 59/78% of patients/HCP correct interpretation
Patients preferred coloured bar charts (39%) to heat maps (20%) and colour line charts (12%).

HCPs preferred Heat maps (46%).
PROMS are tin openers not dials
Don’t forget the carers

- 98 cancer patients >70 + carers.
- SF12 and Zarit Burden Interview 3 & 6 months

Role emotional and pain worsened over the 6 months

Key determinants were
  ◦ patient’s age,
  ◦ perceived burden
  ◦ patient’s functional independence.

Germain V. – JGO 2017 8 p220-228
2015 NHS England Independent Cancer Taskforce report

Achieving World-Class Cancer Outcomes

- Recommendation 64
- To develop a national metric on quality of life by 2017, which would enable better evaluation of long-term quality of life after treatment.
- PROMs should be rolled out across breast, colorectal and prostate cancer by 2020, with evaluation and further rollout across other cancer types.