



**JOURNEE SCIENTIFIQUE du 1<sup>er</sup> juin 2010 :**  
**L'EVALUATION DE LA QUALITE DE VIE DES PERSONNES ATTEINTES DE CANCER**

**L'évaluation de la qualité de vie et des difficultés  
sociales des patients en pratique clinique**

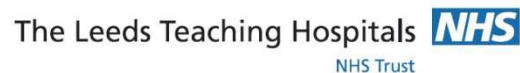
**(assessment of quality of life and social difficulties patients in clinical practice)**

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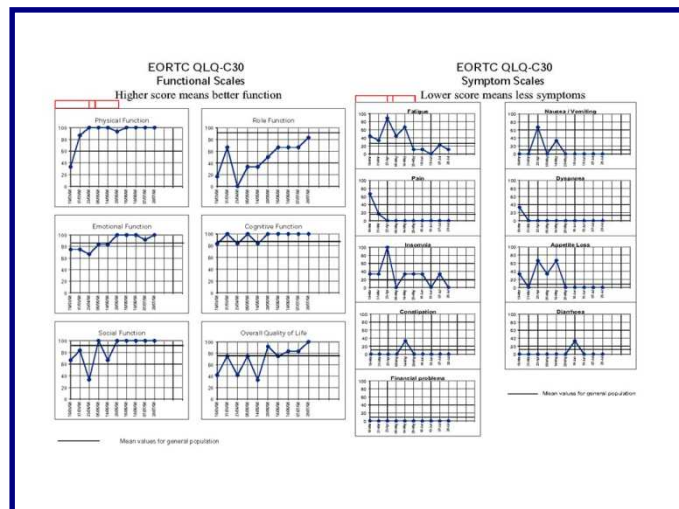
University of Leeds





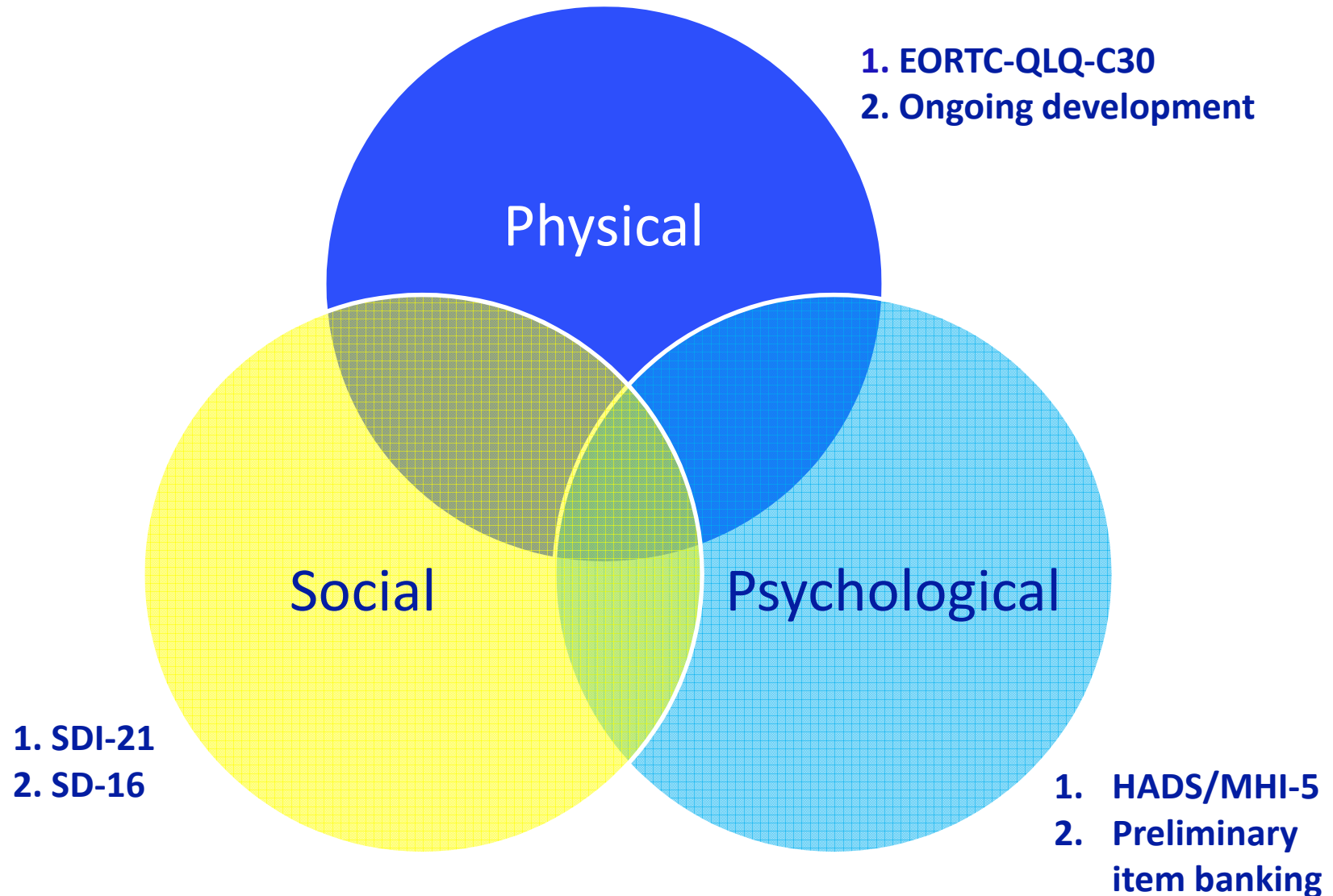
# Logistics

- Touch-screen data collection
- Integrated in to clinical practice
- Easy for patients to use
- Acceptable



- Immediate print-out with historical comparisons
- Easy scoring
- Moving to web-enabled systems

# Patient Centred Assessment: domains



# Social Difficulties Inventory: item generation

	1	2	3	4	5
A					
B					
C					
D					
E					
F					
G					
H					
I					
J					
K					
L					
M					
N					
O					
P					
Q					
R					
S					
T					
U					
V					
W					
X					
Y					
Z					



*“..I’ve got used to his cooking – at first (laughs) it were shocking, but he’s done his best..”*



Thomas Faed 1861 Faults on both sides, Tate Gallery Collection, London

*“I think he just shut himself off in his own little shell.”*

*“The business is faltering in all honesty, down to the illness....and how can I get out of the business without getting into a load of debt?”*



# Social Difficulties Inventory SDI-21 Psychometrics

- Pre-testing
- Frequency of endorsement

- Validity
- Reliability
- Factor analysis

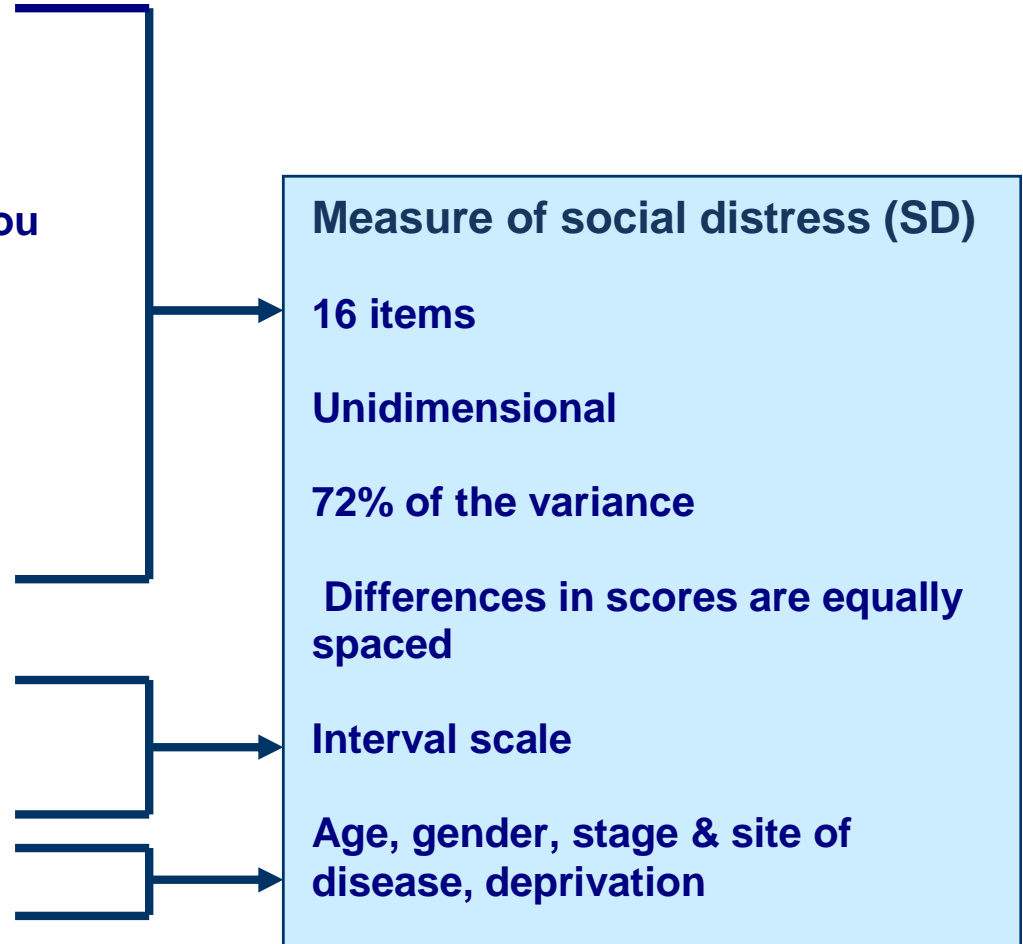
During the past month	No difficulty	A little	Quite a bit	Very much
1. Have you had any difficulty in maintaining your independence?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Have you had any financial difficulties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Have you had any difficulty concerning your work? (or education if you are a student)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the past month	No difficulty	A little	Quite a bit	Very much
12. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Have you had any difficulty concerning sexual matters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Have you had any difficulty concerning plans to have a family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Have you had any difficulty concerning your appearance or body image?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Have you felt isolated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Have you had any difficulty with your plans to travel or take a holiday?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Have you had any difficulty with any other area of your everyday life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Social Distress SD-16 Rasch analysis



- Independence
- Domestic chores
- Personal care
- Care of dependents
- Support for those close to you
- Welfare benefits
- Finances
- Financial services
- Work
- Planning the future
- Communication with close
- Communication with others
- Sexual matters**
- Plans to have a family**
- Body image
- Isolation
- Getting around
- Where you live**
- Recreation
- Holidays**
- Other**

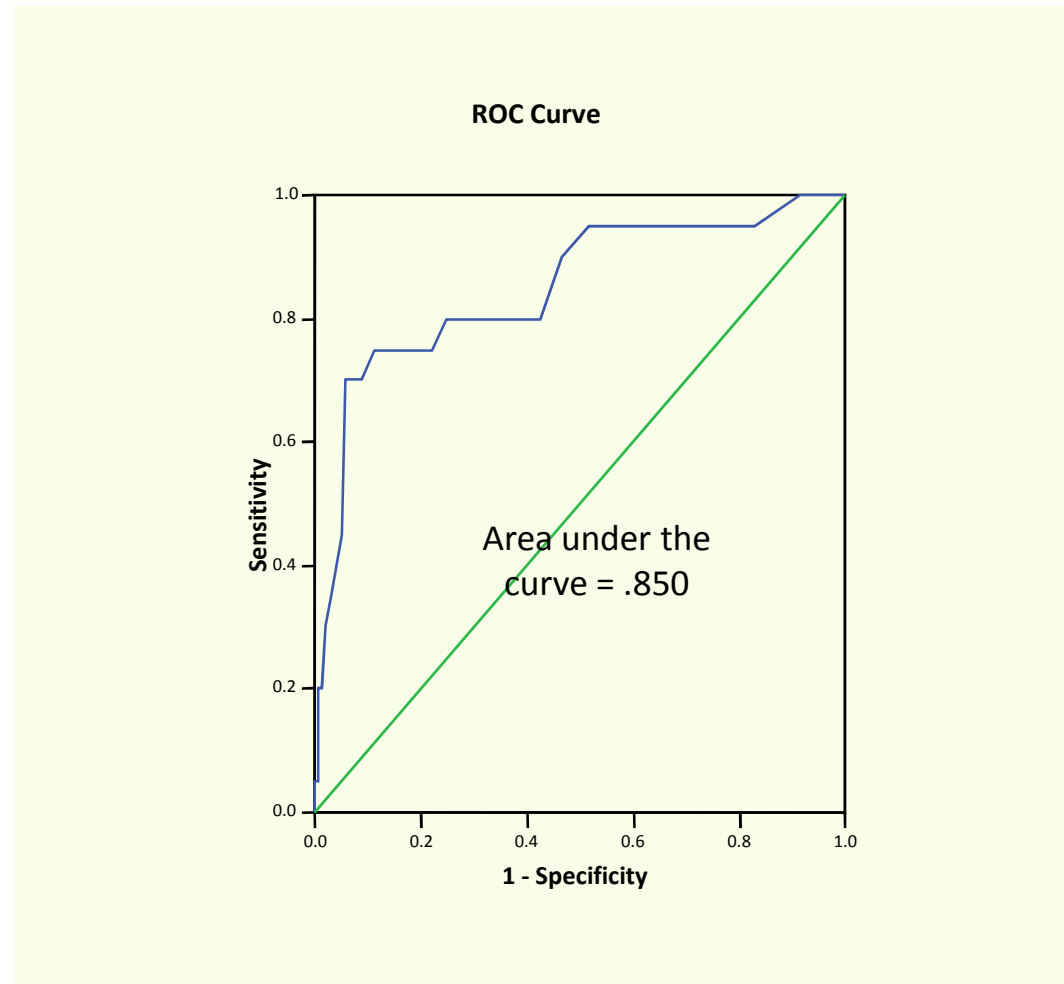


# Clinical meaning: cut point for SD-16

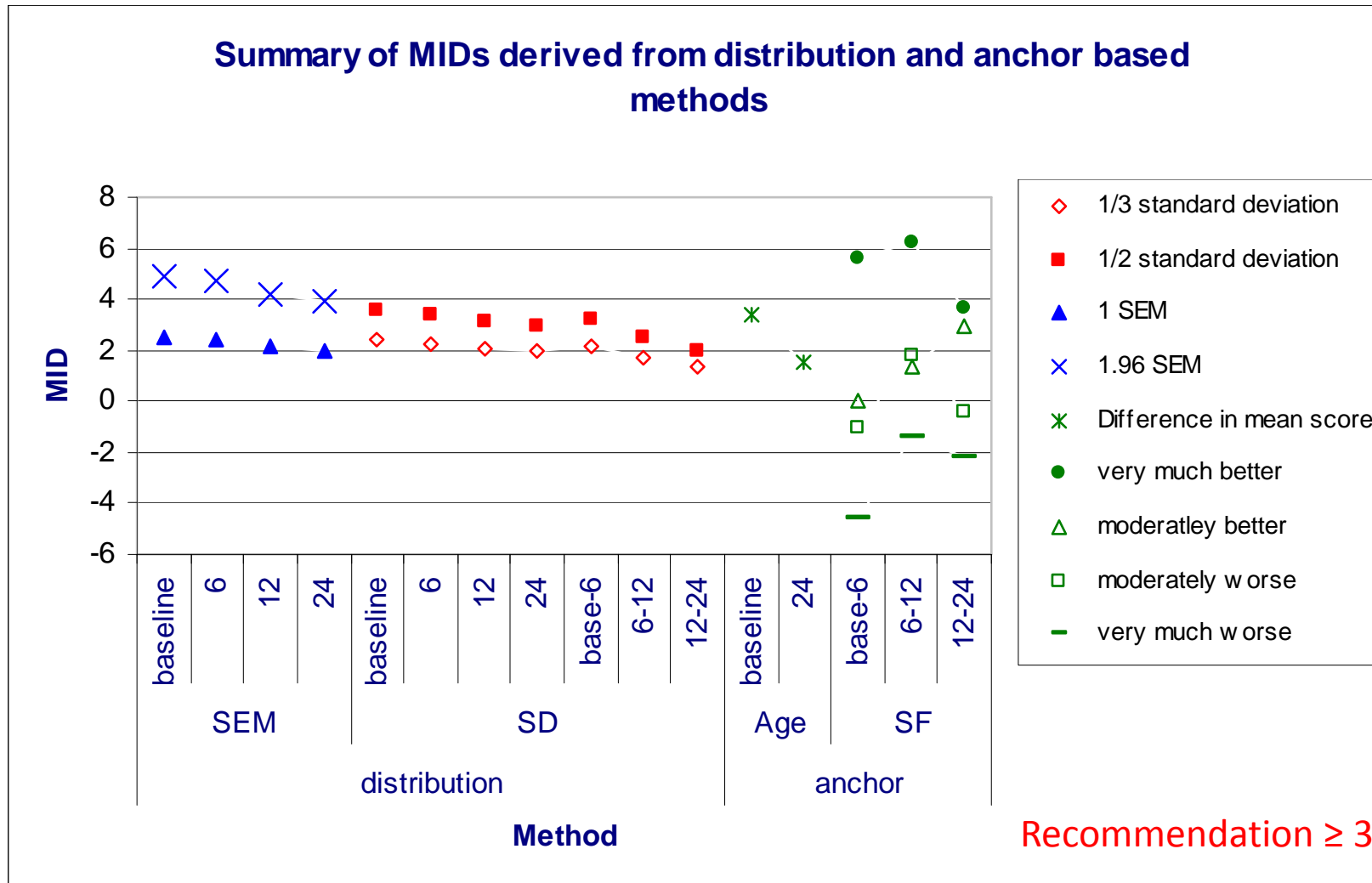


## Social Distress (SD) (16 Rasch items)

- Researcher interview (gold standard)
- Top 10% of researcher scores  $SD \geq 14$
- Using this gold standard the best 'cut-point' for patients was patient  $SD \geq 10$

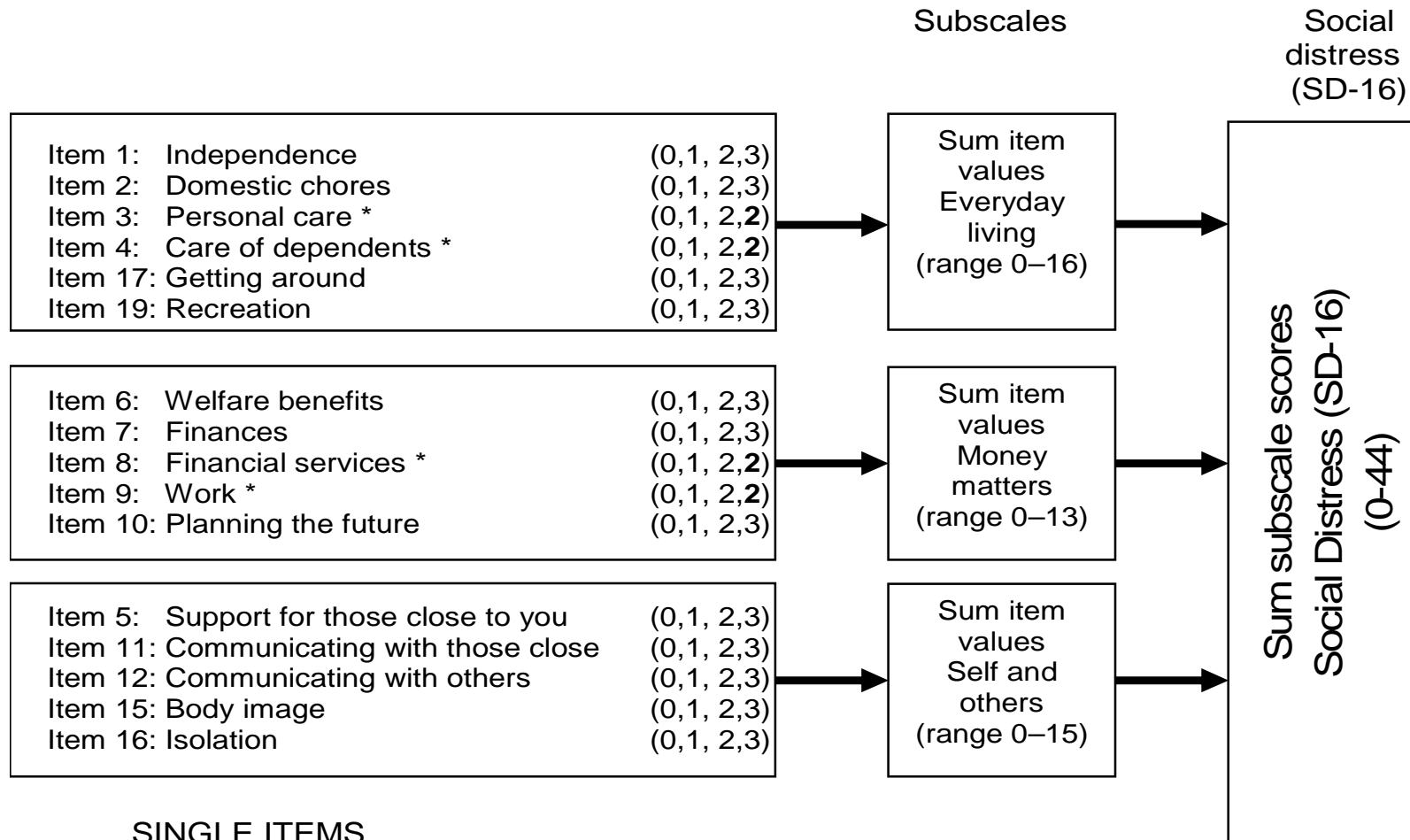


# Clinical meaning: SD-16 change



# Clinical meaning: SD-16 subscales

Item	Scale
1	1
2	1
3	1
4	1
5	1
6	1
7	1
8	1
9	1
10	1
11	1
12	1
13	1
14	1
15	1
16	1
17	1
18	1
19	1
20	1
21	1



## SINGLE ITEMS

Item 13: Sexual matters	(0,1, 2,3)
Item 14: Plans to have a family	(0,1, 2,3)
Item 18: Where you live	(0,1, 2,3)
Item 20: Holidays	(0,1, 2,3)
Item 21: Other	(0,1, 2,3)

Change in subscale score  $\geq 2$  meaningful (group level)

# Discussion Triggers following SDI-21 administration



Single Assessment

Additionally on Follow-Up

SD-16  
Score

5 single non  
SD-16 items

SD-16  
Change Score

SD-16 Subscale  
Change Score

$\geq 10$

High  
Scores

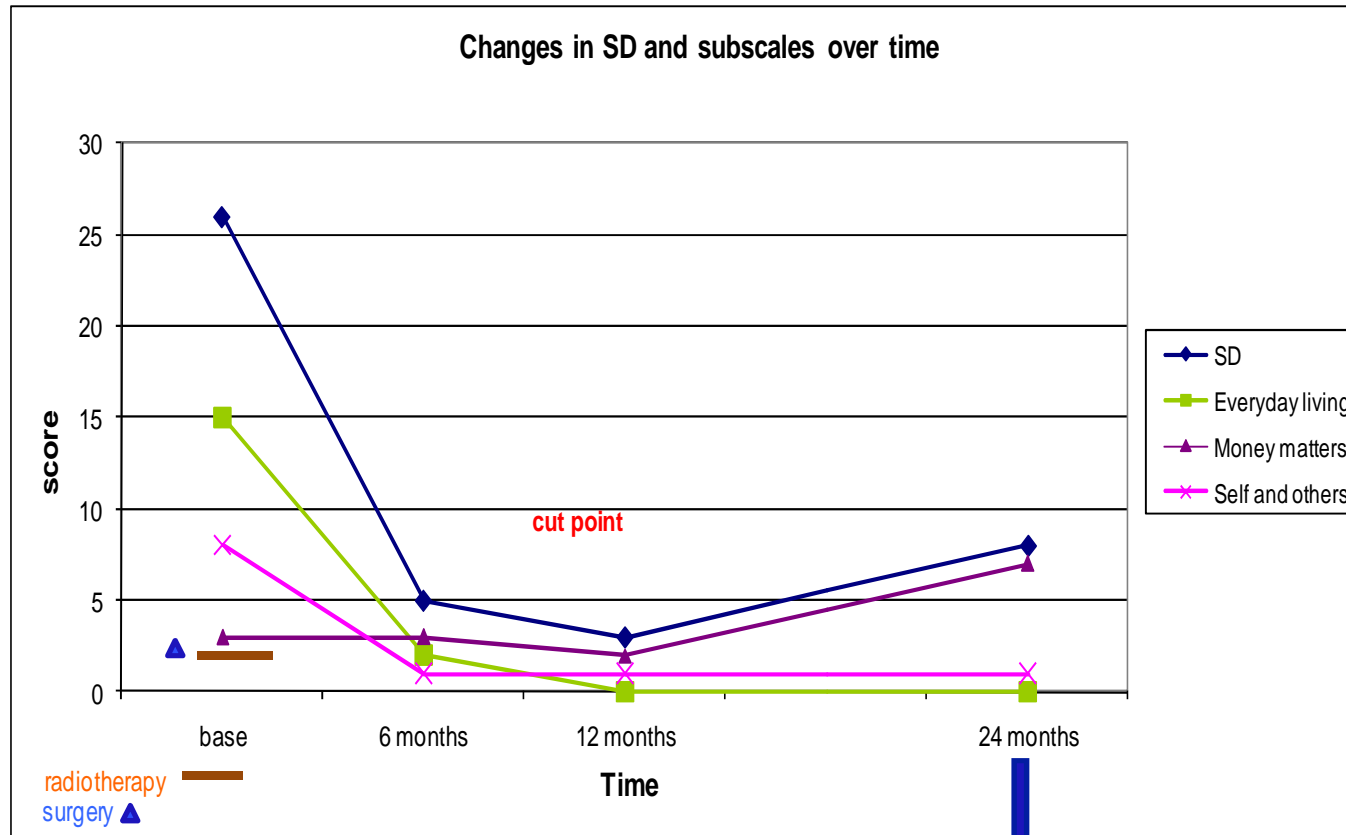
$\geq 3$

$\geq 2$

Identify and discuss  
areas of difficulty from  
subscales

Discuss areas of difficulty where  
scores above threshold

# Individual measurement of social difficulties over time



- 35 year old man with testicular cancer

- Treatment: surgery and radiotherapy at baseline

- Disease free, on routine review

- Married, living with wife

- Became unemployed between 12-24 months

<p><b>Individual items</b></p> <ul style="list-style-type: none"> <li>• Plans to have a family (quite a bit)</li> </ul>	<p><b>Social distress items</b></p> <ul style="list-style-type: none"> <li>• Work (very much)</li> <li>• Planning the future (quite a bit)</li> </ul>
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# Roles and responsibilities: patients



- 41 patients completed SDI-21, interviewed
- Coded using SD-16 subscales and single item framework

## Everyday living

- Would like
  - Simple advice
  - Practical solutions
  - Access to services

## Money Matters

- Would like
  - Information early
  - Leaflets for basic information
  - Help with form filling
  - Someone available to speak to for specific advice

## Self and others

- Would like
  - Exploration by staff
  - Reassurance
  - Information leaflets
  - Advice
  - Support groups
  - Patient mentor
  - Referral for more complex problems

# Roles and responsibilities: staff



- 17 doctors and 16 nurses interviewed using patient scenarios, completed questionnaire
- Coded using SD-16 subscales and single item framework

## Everyday living

- Assessment and intervention within remit
- Doctors – clinical approach
  - i.e. blood transfusion
- Nurses- holistic approach
  - i.e. asking partner to take on new role
- ‘Caring for dependents’
  - less confidence
  - lacked expertise

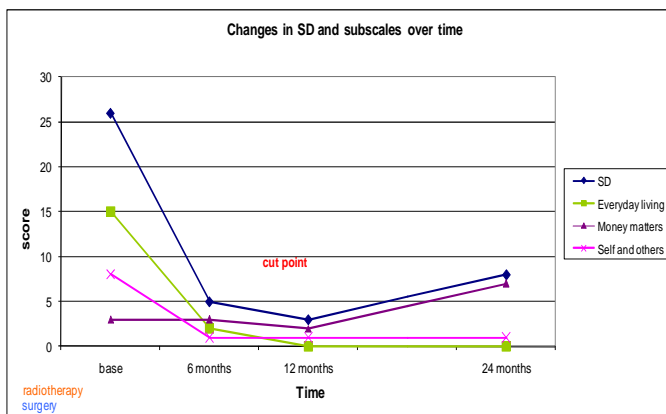
## Money Matters

- Limited knowledge
- Doctors -marginal activity
- Interventions doctors
  - completion of medical forms
  - writing letters for insurance or employment
- Interventions nurses
  - linking
  - referral

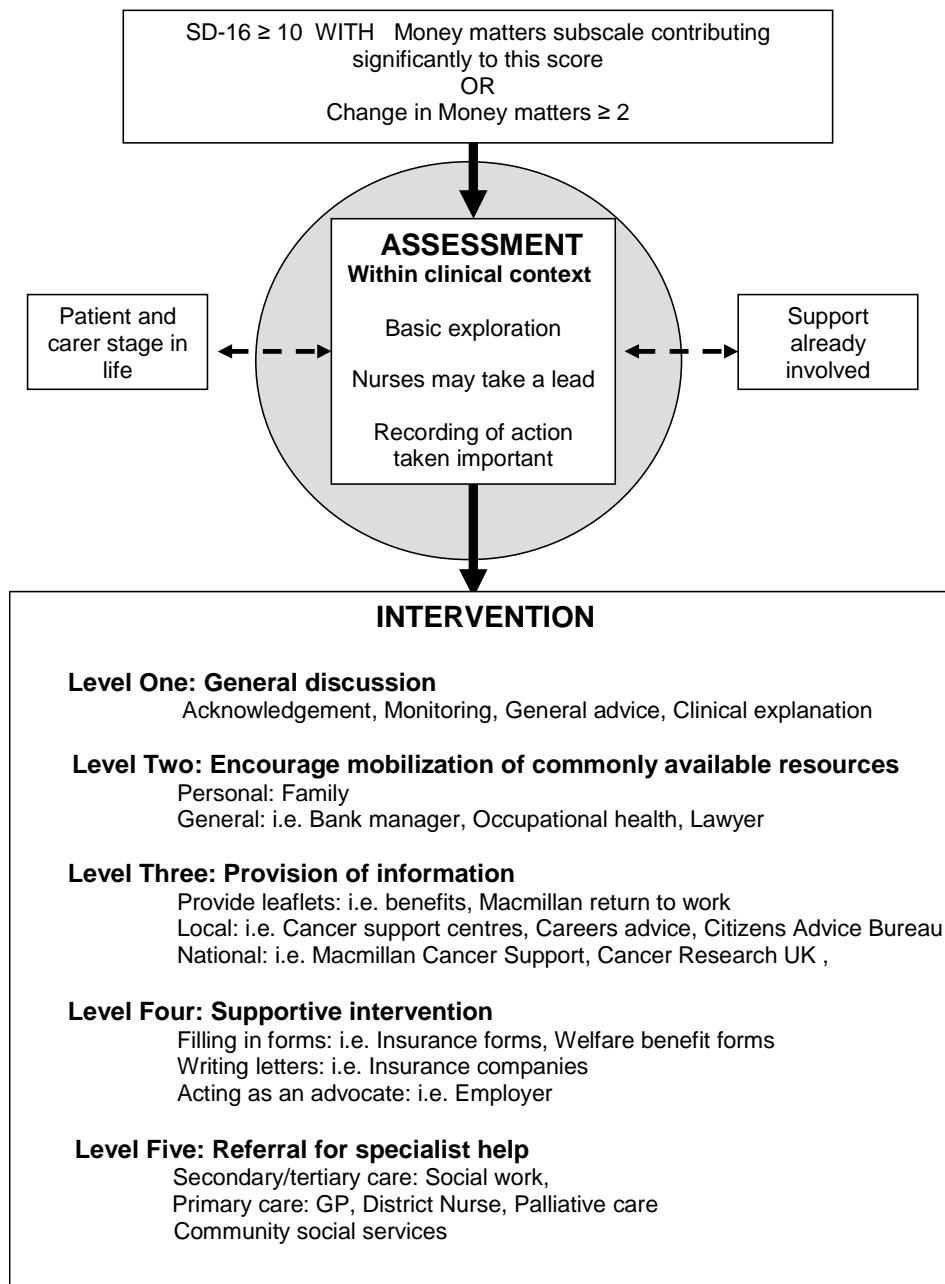
## Self and others

- Staff cautious
- Perceived as complicated
- Nurses more involved
- Interventions:
  - brief exploration
  - acknowledgement
  - information
  - advice
  - complex problems referred to appropriate specialist services

# Staff training



- Score interpretation
- Context
- Intervention
- Recording



# Resources



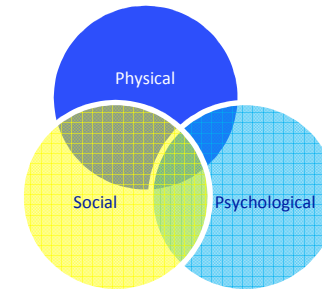
Michele Angelo Petrone

## Hospital based

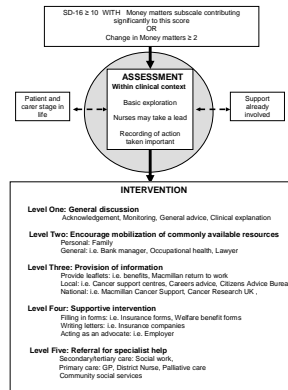
- Professions Allied to Medicine
- Social work
- Psychosocial
  - Psychiatry
  - Psychology
- Specialist
  - Palliative
  - Fertility
  - Clinical nurse specialists
  - Psychosexual

## Community based

- Clinical
  - Primary care
  - District nursing
  - Palliative care
- Local authority services
  - Social work
  - Home care
  - Housing
- Financial and employment
  - Citizens Advice Bureau
  - Careers advice
  - Welfare Benefits help line
- Voluntary organisations
  - Support centres
  - Web resources



# Patient Centred Assessment



Thanks to

The patients and staff who have  
participated in the social difficulties work

Prof Galina Velikova &  
Psychosocial and Clinical Practice Research Group

Cancer Research UK & Macmillan Cancer Support