

# The Patient Roles and Responsibilities Scale (PRRS): a psychometrically robust and useful tool to measure what matters most to patients

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## Lay summary

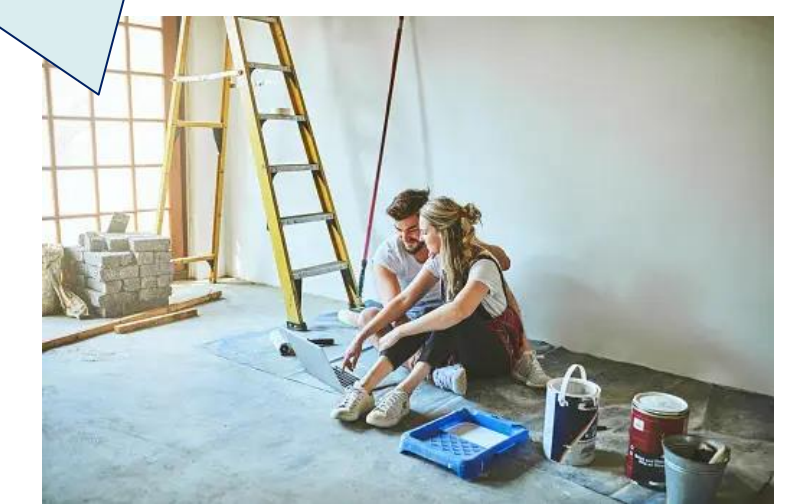
- More people are living longer with cancer. This can impact broad aspects of life, such as caregiving responsibilities for children or others, financial wellbeing, and the ability to continue or return to work.
- With PPI input, we developed and validated the Patient Roles and Responsibilities Scale (PRRS) to measure these impacts. The scale has three core subscales completed by all respondents: responsibilities and social life, family wellbeing, and financial wellbeing.
- The 16 core item PRRS was first validated in 2017 in 135 people with cancer and was shown to be a reliable and valid measure. Here we present further validation using the data from five studies with breast cancer patients.
- 352 people completed the PRRS and found the items to be acceptable (items were not often missed).
- We also looked at the proportion of people who chose the worst response to each item (called floor effects) and the proportion who chose the best response (ceiling effects). If too many people select the answer at either end of the scale, this tells us that the item isn't working. No items had floor effects and only one showed ceiling effects.
- Finally we checked that the items in the subscales are measuring the same underlying ideas. This is called internal consistency which was found to be good for the overall scale and for the separate subscales.
- We are happy with how the PRRS performed in these studies. These results mean that the PRRS is a good questionnaire to use in future breast cancer studies.

## Example items

I worry about the impact of my illness on my children and/or other family members

My illness interferes with performing my responsibilities at home (e.g. cooking, cleaning, gardening, DIY)

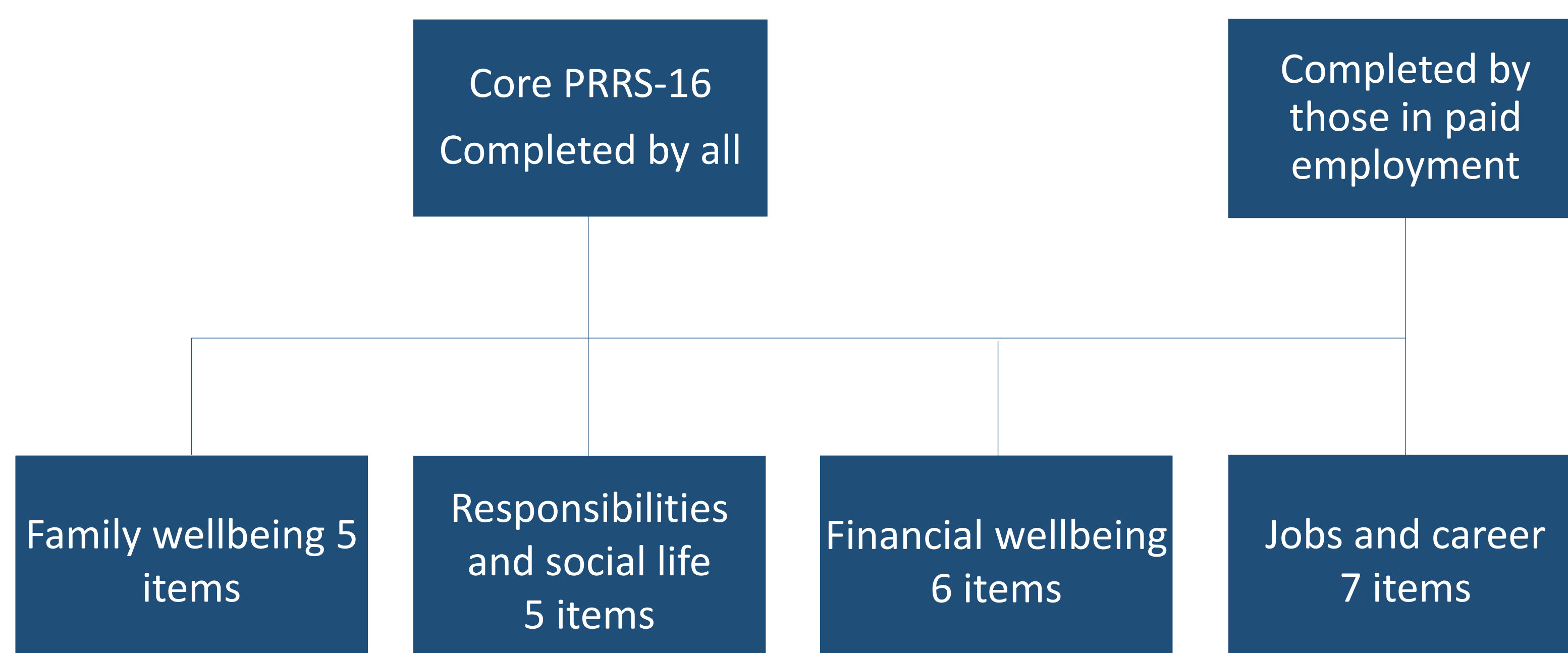
I worry that my illness will impact my employment in the future (including return to work)



I have difficulty meeting the additional costs of my illness



## Questionnaire structure



## Validation in breast cancer

- PRRS was administered to breast cancer patients participating in one of five studies between 2017-2022.
- 352 patients completed the scale: 92 (26%) <50yrs old, 132 (38%) 50-60yrs, 92 (26%) 61-70yrs and 36 (10%) >70yrs.
- 122 (35%) were early stage disease, 230 (65%) were locally advanced or metastatic cancer.
- Acceptability and precision were assessed by missing data rates (threshold set at >15%) and floor/ceiling effects (threshold set as exceeding 70% minimum or maximum score, per item). Internal consistency was assessed using Cronbach's alpha for total score and individual subscales.
- Missing data rate was extremely low (0.4% overall, maximum 0.6% for any individual item).
- No items demonstrated floor effects. One item showed above threshold ceiling effects - 70.3% responded 'not at all' to the item *my family gives up things because of the financial impact of my illness*.
- Cronbach's alpha was 0.93 for PRRS-16 total score, 0.88 for responsibilities and social life subscale (five items), 0.91 for the family well-being subscale (five items) and 0.84 for financial wellbeing (6 items).

## Initial validation

- 135 people with stage III/IV breast, lung or gynaecological cancer or melanoma completed PRRS alongside other questionnaires for validation.
- Principal component analysis of 16 core items identified three subscales accounting for 61.5% of the total variance.
- Cronbach's alpha was 0.9 for PRRS-16; and ranged from 0.79–0.87 for the subscales.
- The scale has good test–retest reliability (ICC-0.86), sensitivity to change and the predicted pattern of correlation with validation measures  $r = |0.65-0.77|$ .

## Summary

- The PRRS is a psychometrically robust measure of the wider QoL impacts of cancer and treatment.
- This additional data demonstrates its validity specifically in breast cancer.
- The scale is acceptable to patients and has good face validity, covering broader aspects of well-being such as caregiving, family life, and finances which are highly valued by patients.
- The PRRS is suitable for use with breast cancer patients in clinical trials, real-world studies and as an aid to clinical conversations around treatment and intervention.
- Work is ongoing to further refine and validate the jobs and career subscale.

## References and acknowledgement

Shilling et al doi: 10.1007/s11764-017-0628-x

Shilling et al doi:10.1007/s11136-018-1940-2

Catt et al doi:10.1007/s11764-016-0580-1

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Photographs by numerous artists on Unsplash.

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