

# Adapting the Prostate Care Questionnaire to measure men's experiences of prostate cancer care in Ireland

Marita Hennessy, Eamonn O' Leary, Harry Comber,  
Frances J. Drummond, Linda Sharp

National Cancer Registry, Ireland

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# Overview



# Background

## Irish health system

- Mixed public/private healthcare system
  - ~32% have medical cards: qualify for certain health services free-of-charge, including free primary healthcare
  - ~50% have private health insurance
- Reorganisation of cancer services, 2006
  - National Cancer Control Programme
  - 8 designated specialist cancer centres
    - 8 Rapid Access Prostate Clinics
    - 6 surgical centres

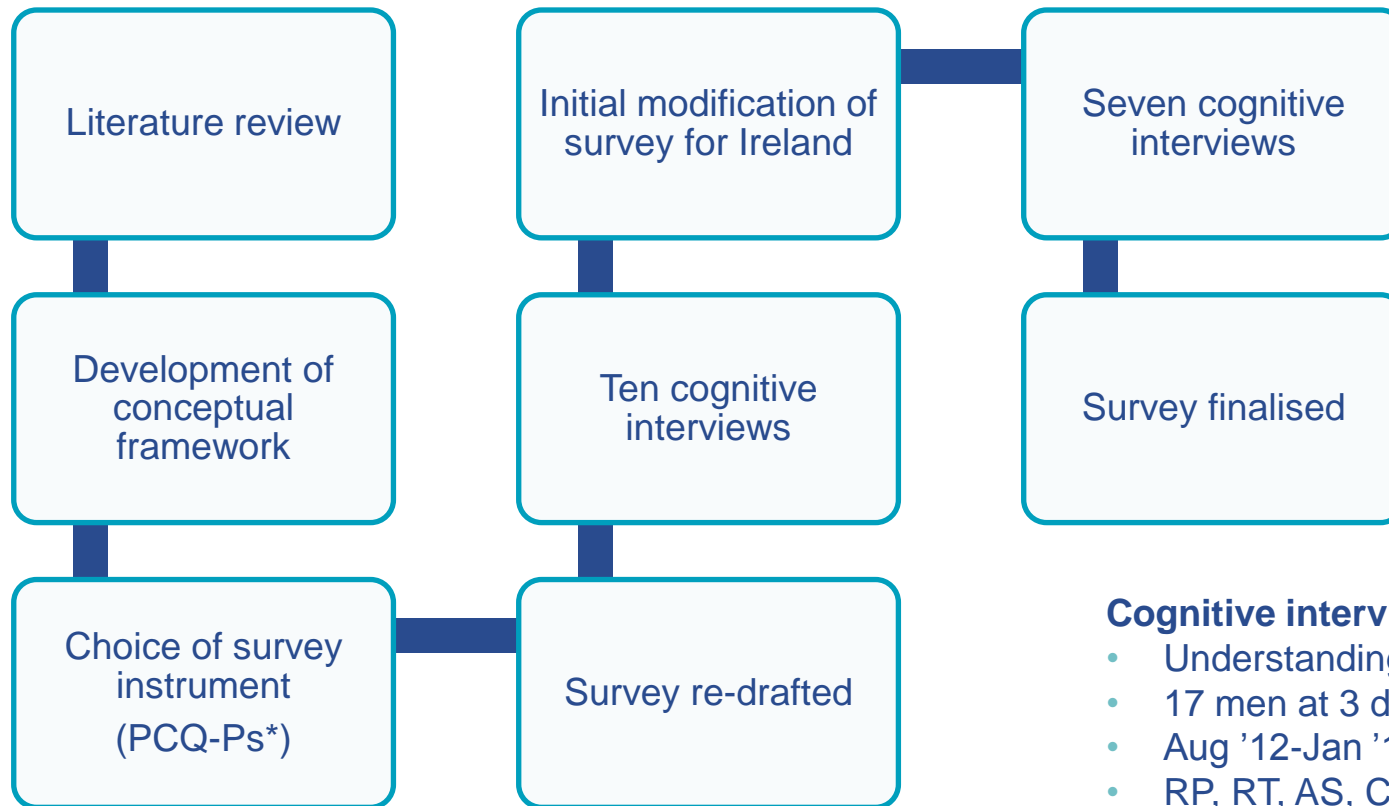
# Patient experience

- Important measure of quality of care
- In other cancers, patients who report higher satisfaction with care:
  - report higher quality-of-life; lower levels of anxiety & depression
  - more likely to cooperate with treatment
- Under-researched in Ireland
- First nationwide study of the care experiences of men with prostate cancer

# Aims and objectives

- To assess the care experiences of men recently diagnosed with prostate cancer in Ireland.
- Objectives:
  1. measure patient experiences and describe variations
  2. identify factors associated with good/poor experiences
  3. investigate associations between experiences and health-related quality-of-life and psychological wellbeing.

# Survey development

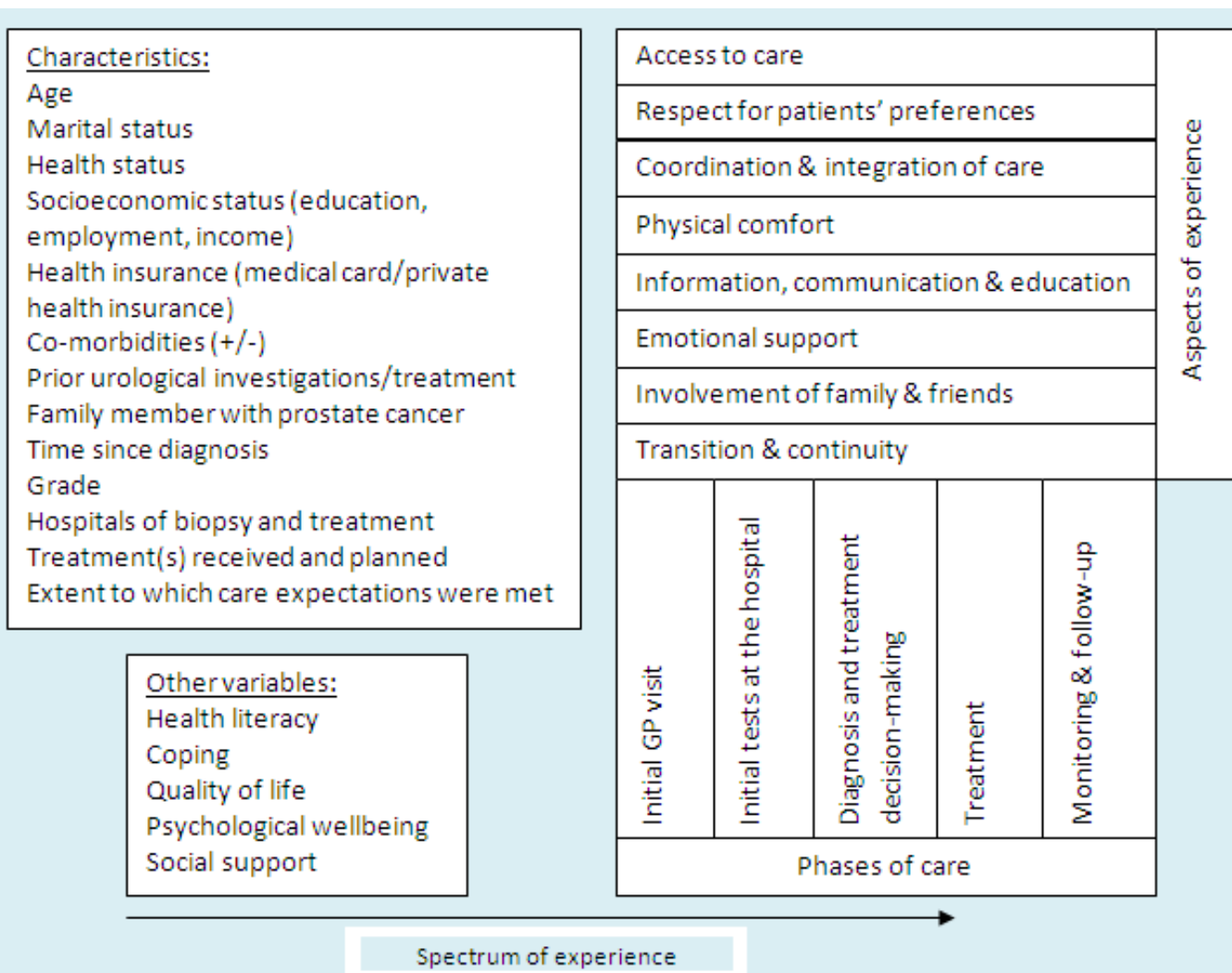


\*Baker et al. (2007)

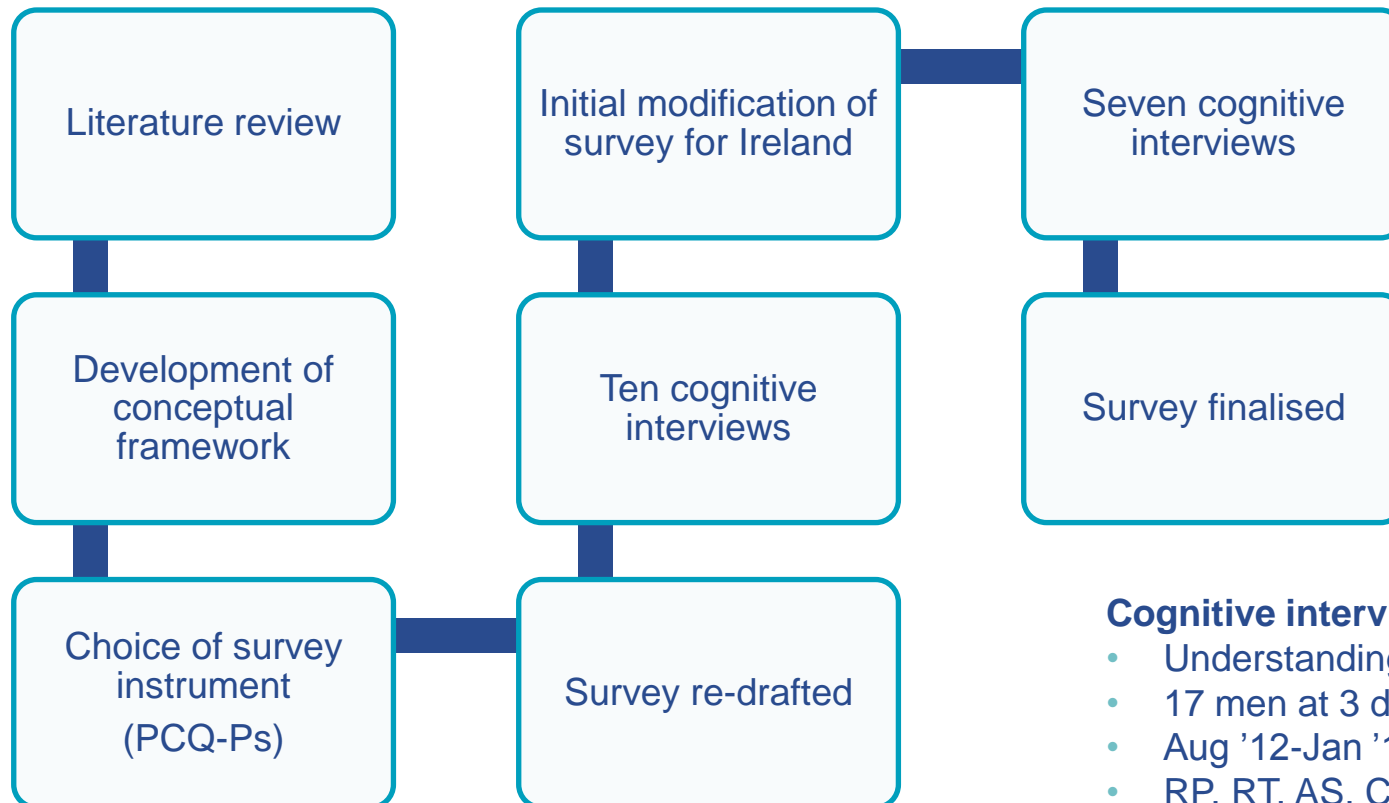
## Cognitive interviews:

- Understanding + insight
- 17 men at 3 different hospitals
- Aug '12-Jan '13
- RP, RT, AS, Comb; various ages
- Think aloud' + probes
- 20-90mins

# Conceptual framework



# Survey development



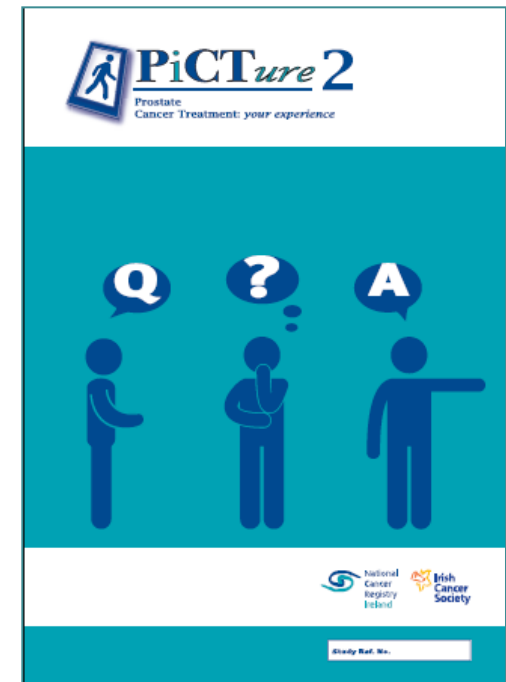
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# Areas that needed attention

1. Reasons for undergoing PSA testing
2. Routes for initial presentation, investigation and diagnosis
3. Waiting times
4. Treatments received – specifics
5. Routing of men on ‘active surveillance’
6. Questions not understood



## 1. Information & support

- Varied throughout cancer journey and by perceived need
- Some felt more emotional support needed although many 'get on with it'

## 2. Involvement

- Knowledge/information impacts on ability to participate care
- Reliance on 'experts' at the outset v some more critical/questioning
- Self efficacy increased with time and experience
- Involvement in decision-making - preferences

## 3. Overall perceptions

- Most = better than expected
- Some: reluctant to 'criticise' experts; post-treatment more critical of care/information provision; poor experiences reported

## 4. Altruism

- Advocates

# Survey methodology

## Selection

- Cases selected from Registry records (n=3,850), 5-20 months from diagnosis

## Screening

- Patient lists 'screened' by treating clinicians

## Survey admin

- All eligible men sent postal survey (n=2,180)

# Snapshot of survey results

- Very positive overall:

Adjusted RR = 71.4%

  - 49.1%: overall care 10/10; 83.2%: 8+/10
  - 68.9% overall care somewhat/much better than expected
- But some problems reported:
  - Waiting times
  - Information about side effects and what to do about them
  - Follow-up care
- Better experiences reported by those:
  - With access to a CNS (but only half had access to one)
  - Who had care in a designated cancer centre (except waiting times)

# Summary

- Patient experiences of care have rarely been assessed in Ireland, which had a mixed public-private healthcare system
- Patient experience questionnaires need to be modified appropriately for the settings in which they are applied
- Cognitive interviewing informs questionnaire development and revision and provides rich qualitative data which complements survey findings.

# Acknowledgements

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- Nurses, urologists and staff who facilitated interviews/recruited patients
- Clinical leads at participating hospitals
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- Study Advisory Group
- Colleagues at NCR

Further information: [m.hennessy@ncri.ie](mailto:m.hennessy@ncri.ie) or [www.ncri.ie](http://www.ncri.ie)



@IrishCancerReg