Literacy levels in Prostate Cancer Patients: the Relationship between Health Literacy Level, Understanding of Cancer Information and Decision-Making -Results from Phase 1

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Overview

- Background
  - Health Literacy
 - Prostate Cancer
- Study outline
- Phase 1
  - Methods and Results

1	WHO (1998)	"The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" [31]
2	American Medical Association's (1999)	"The constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment" [12]
3	Nutbeam	...in access to,
4	Institute	...d services needed
5	Kickbusch	...n the community, at ...tical empowerment ...on and their ability
6	Zarcadoo (2003, 20)	...nd, evaluate and ...increase quality of
7	Paasche-(	...neans that health ...ccomplished. The
8	EU (2007)	"The ability to read, filter and understand health information in order to form sound judgments" [30]
9	Pavlekovic (2008)	"The capacity to obtain, interpret and understand basic health information and services and the competence to use such information to enhance health" [41]
10	Rootman & Gordon-Elbihbety (2008)	"The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course" [42]
11	Ishikawa & Yano (2008)	"The knowledge, skills and abilities that pertain to interactions with the healthcare system" [14]
12	Ma	...rehension, and ...kills, strategies,
13	Au (20)	...es such as ...l, emergencies,
14	Yo	...print material, ...nd perform
15	Ad	...n or digital
16	Ad	...kills to
17	Freedman et al. (2009)	"The degree to which individuals and groups can obtain process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community" [35]

focus on one's ability to
obtain, **process** and **understand**
health information and services
necessary to make appropriate health
decisions

Considered as a
quality of
the individual
but also **the interaction** of the individual
with the society in which they live.

Sørensen *et al.*, 2012
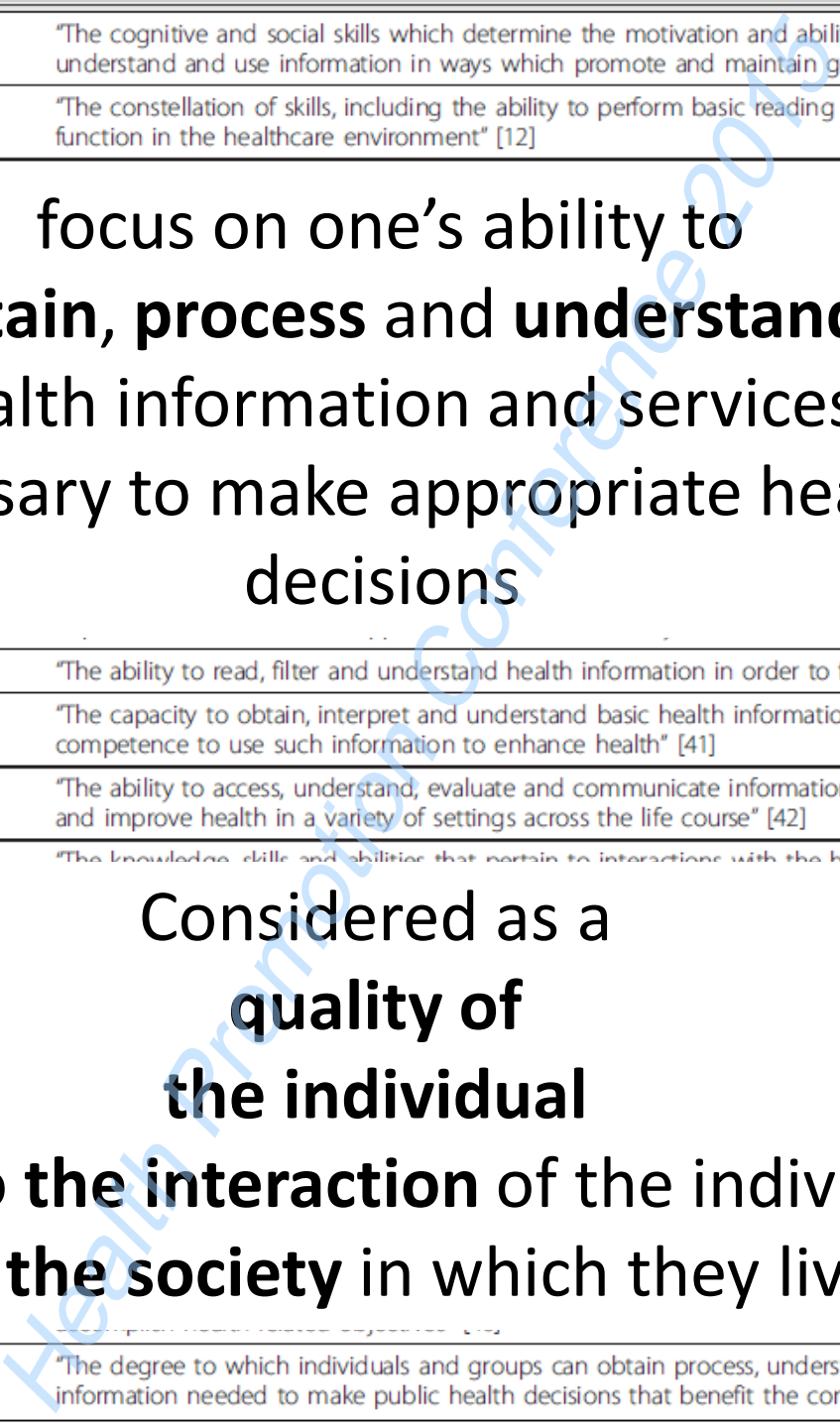
Factors that Influence HL level

Personal Factors

- General literacy levels
- Cognitive skills
- Motivation
- Physical and emotional health
- Experience with health care
- Specific health condition
- Beliefs about health
- Socioeconomic status
- Social Supports

System Factors

- HCP 's communication skills
- Complexity of health information
- Characteristics of healthcare setting
- System demands and expectations upon patients
- Time pressures upon health care professionals

Health Literacy and Cancer

- Research in HL

  – Has focused on general population and other areas within medicine rather than oncology.

  – Prevention: Attendance for screening programmes

  – Research on HL in the cancer population is *"suboptimal, using less robust measurement tools"*

  Koay *et al*. 2012

Cancer Factsheet

Prostate

National Cancer Registry Ireland

Key facts

1 in 8 men in Ireland

	Females	Males	Total
Number of new cases per year	-	3,384	-
Incidence rate (cases per 100,000 per year)	-	157.3	-
Cumulative lifetime risk of diagnosis (to age 74)	-	13.8%	-
Percentage of all invasive cancers	-	31.5	-
Ranking amongst most common cancers diagnosed*	-	1st	-
Number of deaths per year	-	519	-
Mortality rate (deaths per 100,000 per year)	-	22.9	-
Cumulative lifetime risk of death (to age 74)	-	0.9%	-
Percentage of all cancer deaths	-	11.1	-
Ranking amongst most common invasive cancer deaths	-	3rd	-
Number of people with this cancer still alive in 2012	-	26,358	-
Number alive per 100,000	-	1,161	-

invasive cancers only, excluding non-melanoma skin cancer

Trends in incidence rate 1994-2012
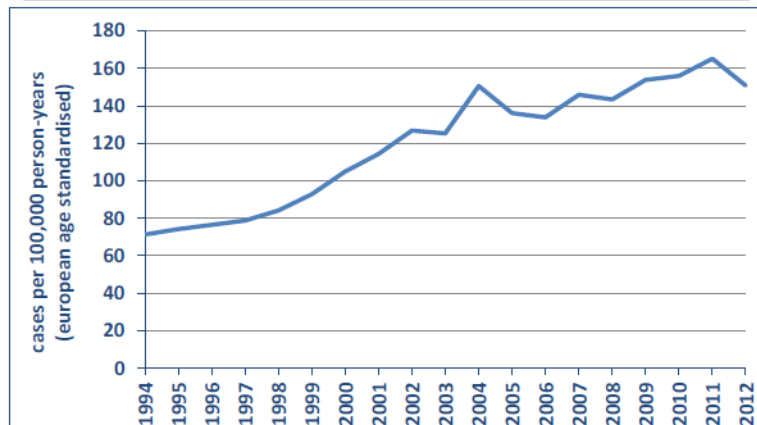
Age profile at Diagnosis

Cases

median age=67

- <50 yrs 2.3%
- 50-64 yrs 38.0%
- 65-74 yrs 40.1%
- 75+ yrs 19.6%
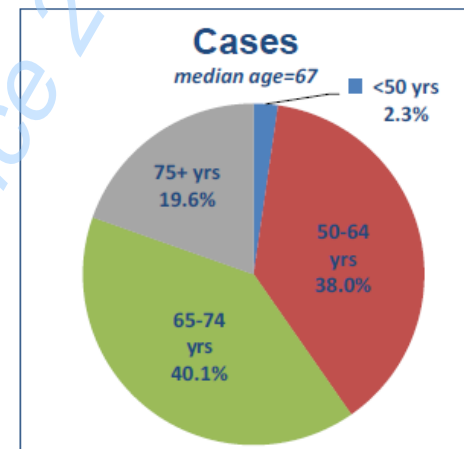
5 year net survival

Years	Net Survival (age standardised)	95% confidence intervals
1994-1999	69.4%	(67.5 - 71.4%)
2000-2005	86.1%	(85.0 - 87.2%)
2006-2011	90.8%	(89.8 - 91.9%)
2008-2012*	91.0%	(90.0 - 92.0%)

Treatment

- **Treatment options**
  - Surgery
  - Radiotherapy
    - External Beam
    - Brachytherapy
  - Hormone Therapy
  - Active surveillance

- **Treatment Outcome**
  - Overall Survival
  - Side effects
  - Possible Side Effects
    - Urinary Dysfunction
    - Sexual Dysfunction
    - Bowel Dysfunction

Prostate Cancer
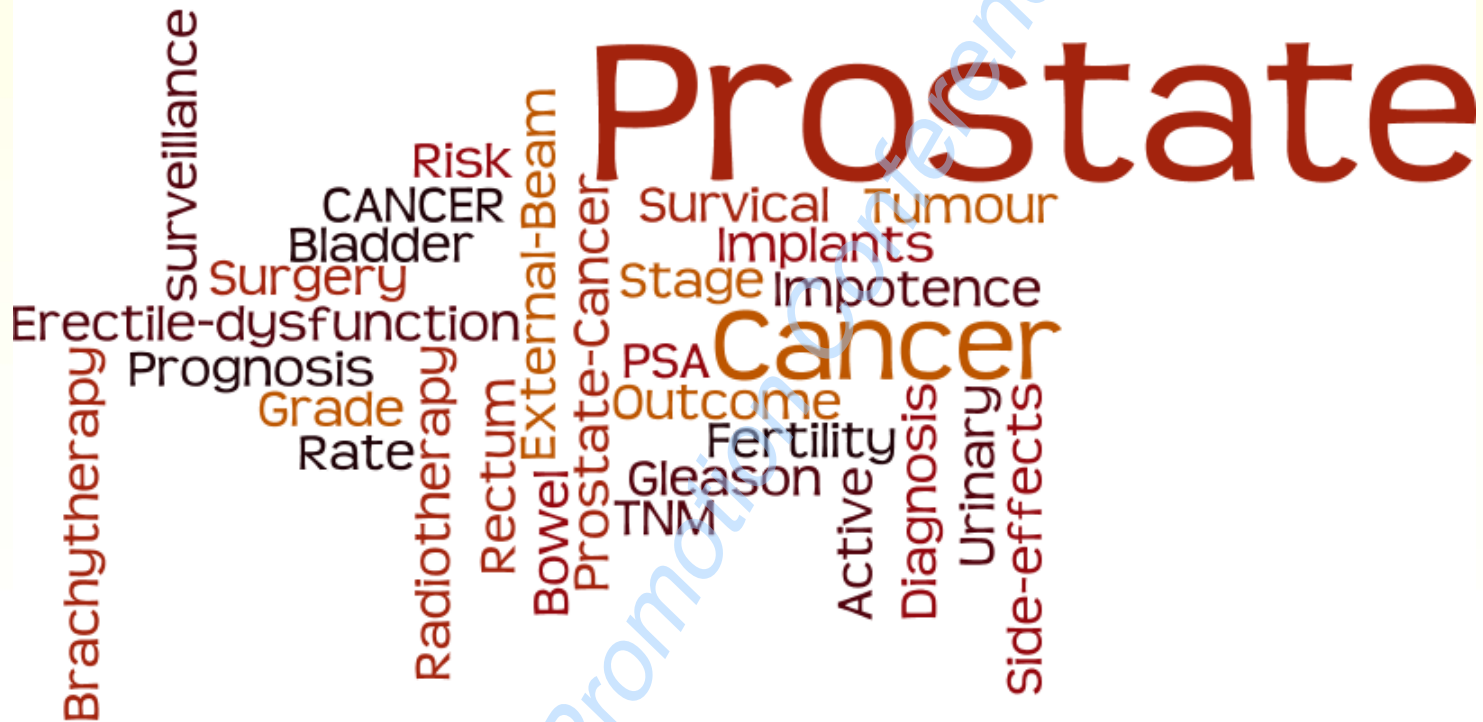
Study Aims

1. Evaluate the impact health literacy level has on cancer knowledge

2. Ascertain if patients involved in decision-making are knowledgeable about their options

Methodology

M E T H O D S

Phase 1 — Nominal Group Technique *
Previous Pr Ca Patients/Cancer survivors

To ascertain the information required to make a decision about treatment

Phase 2 — Survey
Newly Diagnosed Pr Ca patients

Phase 3 — Semi Structured interviews
Random selection from phase 2 sample

*Delbecq, A. L., Van de Ven, A. H., & Gustafson, D. H. (1975)

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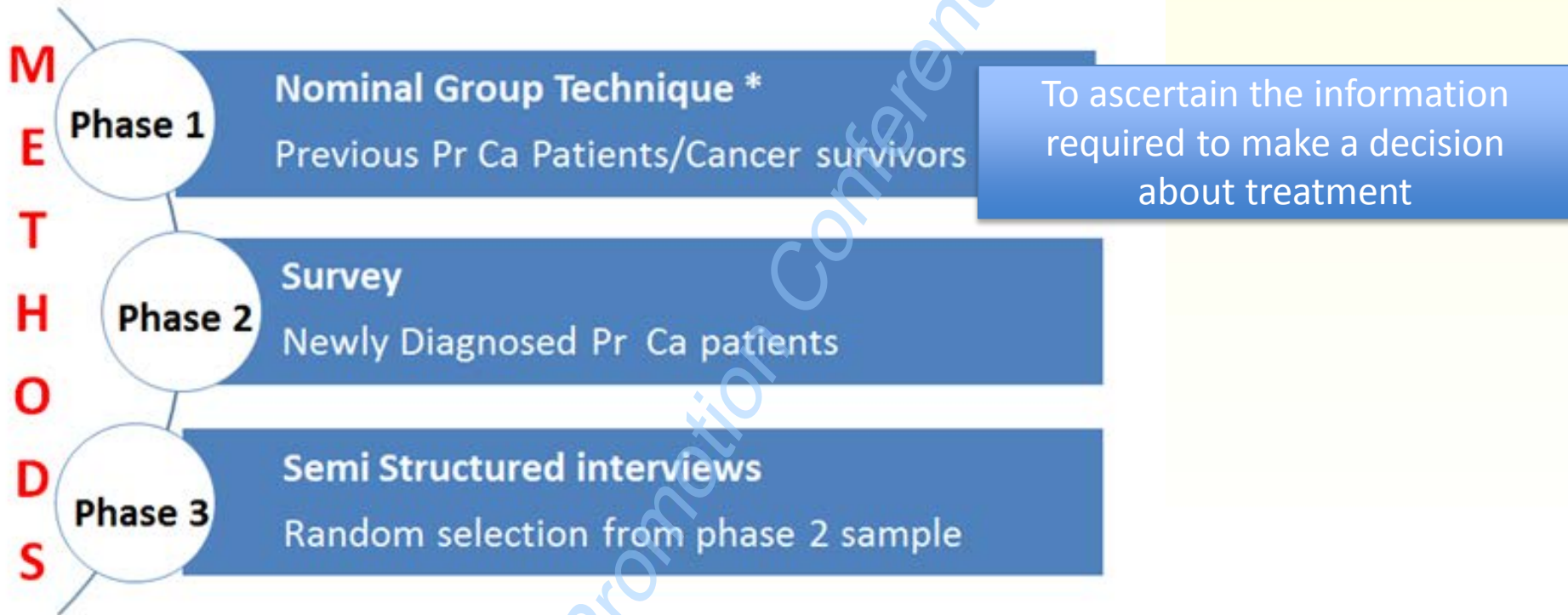
Phase 1-Nominal Group Technique (NGT)

Structure of Nominal Group Technique	
Step 1: **Introduction**	Welcome, purpose and procedure. Consent and Demographics
Step 2: **Generating Ideas**	Question given to participants. Participants -silently write down any ideas that come to mind.
Step 3: **Sharing Ideas**	Share the ideas Round robin style feedback session No debate A written record is made of all the ideas generated
Step 4: **Group Discussion**	Participants can ask for clarity on any of the ideas generated.
Step 5: **Voting and Ranking**	Prioritising of ideas generated from the original question. The meeting concludes after reaching a specific outcome e.g. The top ten ideas from the discussion.

Delbecq, A. L., Van de Ven, A. H., & Gustafson, D. H. (1975)

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Phase 1- NGT

"Based on your experience,

what do you think men diagnosed with prostate cancer should know before deciding on their treatment?"

N=7

Age range: 60-75 yrs

Recruitment: Previous Prostate Cancer Pts, Irish Cancer Society

Treatment included: (alone or combination)

Surgery, Hormone Therapy,

Radiotherapy: photons, brachytherapy, protons.

Phase 1-NGT Results

"pull down the shutters"

"How to weed out the information"
"health warning"

Words like "active surveillance and watchful wait"???

Item	Step 3 "sharing of ideas" step 4 "discussion round"
1	Pros and cons of each treatment
2	Urgency of condition->decision (timeframe to make a decision)
3	Best practice on current treatments available (consultants to advise)
4	Involve wife/family
5	Side effects (short-term)
6	How to research +evaluate treatment available (worldwide)
7	Supports
8	Explanation of own condition
9	Life expectancy (before/after treatment)
10	Cancer society/talk to Peers
11	How to deal with situation after Diagnosis
12	Costs and availability
13	Long term effects/afterwards
14	Treatment sequence +consequences
15	Non-medical language
16	Duration of treatments
17	Possible pathways at initial diagnosis
18	Alternative options/2nd opinion
19	When to know when to change treatment path
20	Quality of information -> open, honest

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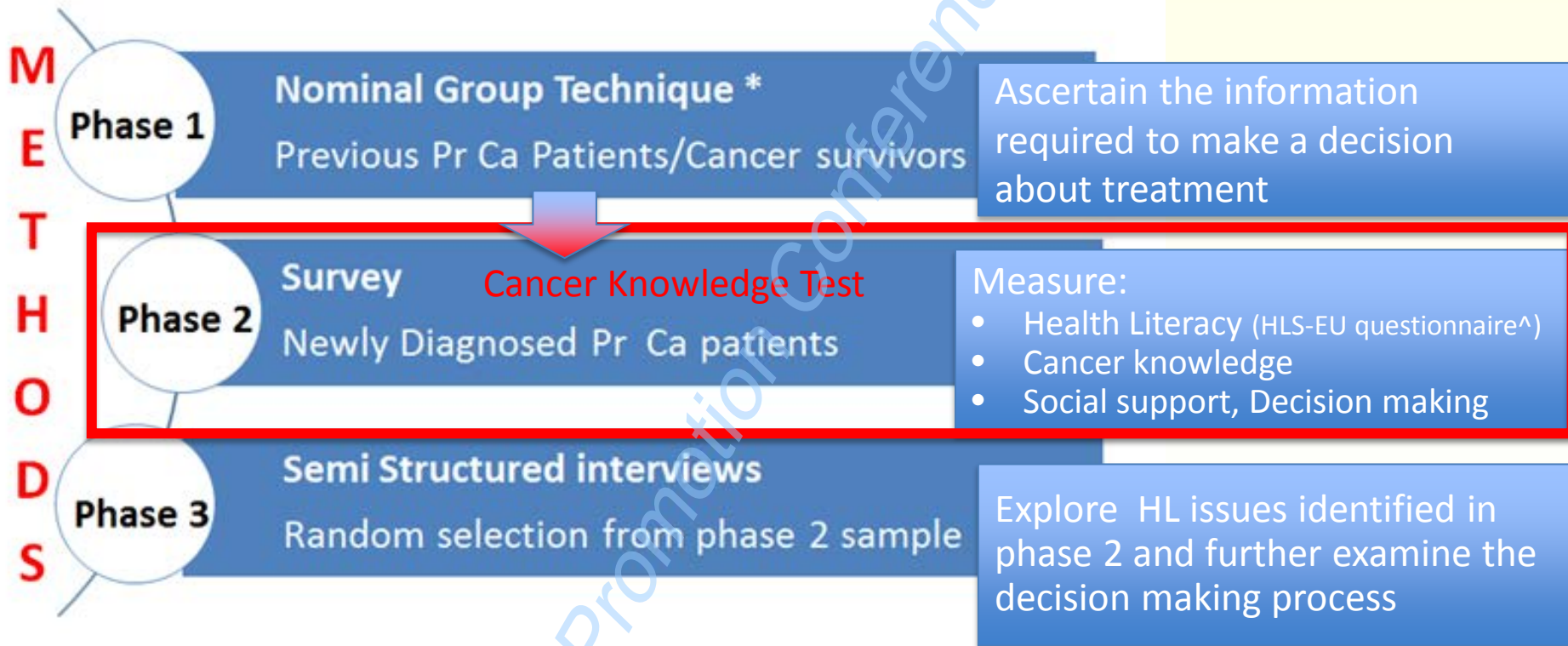Applied Radiation Therapy
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Phase 1-NGT Results

Cancer is slow growing…? "weeks/months"

"everyone's cancer and circumstances are different"

Item	Step 3 "sharing of ideas" step 4 "discussion round"	Step 5 Voting and ranking		
		Vote	Total	Rank
1	Pros and cons of each treatment	6. 3. 7. 4.	20	3rd
2	Urgency of condition->decision (timeframe to make a decision)	5. 7. 5. 3. 7.	27	1st
3	Best practice on current treatments available (consultants to advise)	7. 5.	12	5th
4	Involve wife/family	3. 2. 4. 1.	10	8th
5	Side effects (short-term)	3. 6.	9	9th
6	How to research +evaluate treatment available (worldwide)	7.	7	
7	Supports	2. 2. 2. 6.	12	5th
8	Explanation of own condition	6.6.5.5.	22	2nd
9	Life expectancy (before/after treatment)	3.	3	
10	Cancer society/talk to Peers	2.3.	5	
11	How to deal with situation after Diagnosis	5.4.	9	9th
12	Costs and availability	5.4.	9	9th
13	Long term effects/afterwards	3.2.	5	
14	Treatment sequence +consequences	1.	1	
15	Non-medical language	1.1.7	9	9th
16	Duration of treatments	1.4.1.	6	
17	Possible pathways at initial diagnosis	4.6.7.	17	4th
18	Alternative options/2nd opinion	2.	2	
19	When to know when to change treatment path		--	
20	Quality of information -> open, honest	4.6.1.	11	7th

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Next Step

		Nominal Group Technique *	Ascertain the information required to make a decision about treatment
M E T H O D S	**Phase 1**	Previous Pr Ca Patients/Cancer survivors	
	Phase 2	Survey — Cancer Knowledge Test — Newly Diagnosed Pr Ca patients	Measure: • Health Literacy (HLS-EU questionnaire^) • Cancer knowledge • Social support, Decision making
	Phase 3	Semi Structured interviews — Random selection from phase 2 sample	Explore HL issues identified in phase 2 and further examine the decision making process

*Delbecq, A. L., Van de Ven, A. H., & Gustafson, D. H. (1975)
^http://www.healthliteracy.ie/academics/eu-health-literacy-survey

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