



Which effects of gynaecological radiotherapy matter most to patients? Think-aloud interviews with ranking exercise within the GRACE project

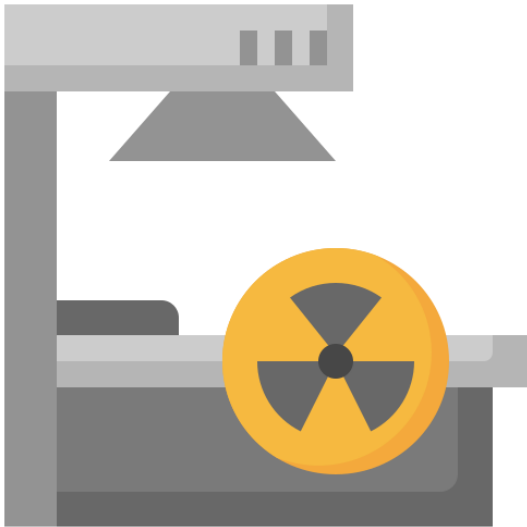
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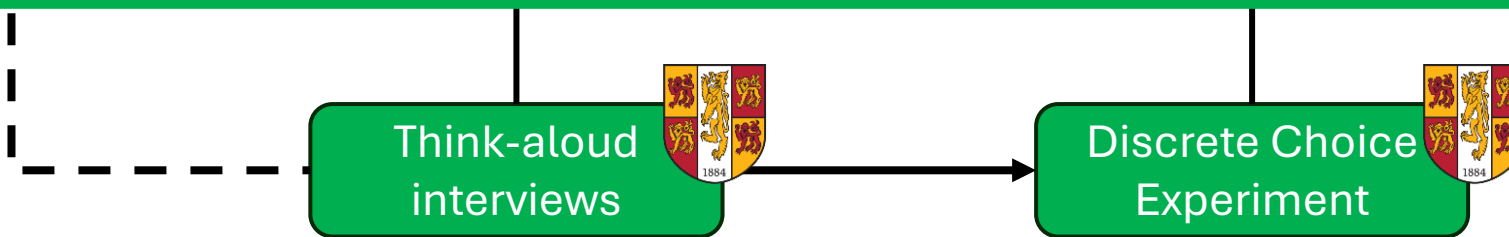
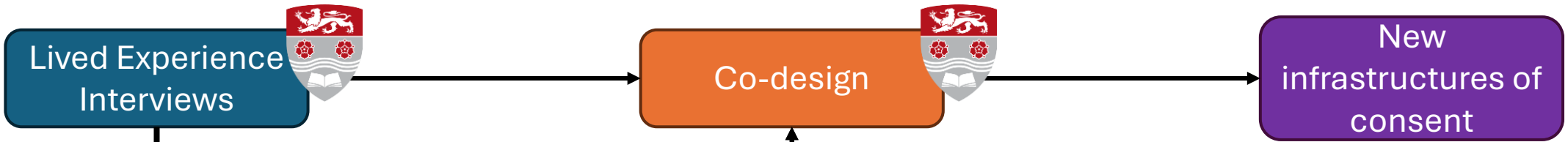
Gynae Radiotherapy Consent Enhancement (GRACE)

How could health services better **support people to make decisions to consent for gynae-radiotherapy** to improve psychosocial wellbeing and quality of life?

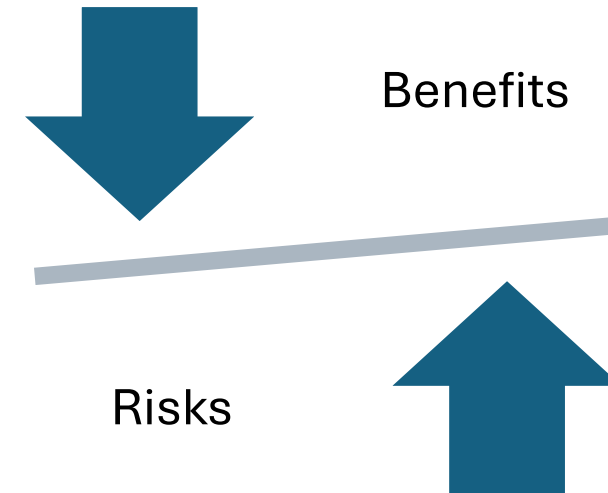


Creating **patient-centred infrastructures** to enhance informed consent and improve patient experience of radiotherapy for gynaecological cancers





Making **decisions by weighing** benefits and risks



Benefit-risk **preferences**

Method: 22 patient think-aloud interviews

22 adults offered **curative/adjuvant gynaecological radiotherapy**, identified via five NHS treatment sites, interviewed online or by phone



Shown the **short-term (≤ 24)** and **late (≤ 23) effects** from the RCR consent forms relevant to their own radiotherapy pathway



"if consenting today, which would concern you most?", select **four short-term** and **six late**



Asked to **rank the ten** chosen effects



Assigned **weighted score** per effect, combining average ranked position with how often the effect was presented (10 = most important, 1 = least)



The list and wording of risks was drawn from **Royal College of Radiologists** consent forms for EBRT, VBT, and CBT.

Late effects of external beam radiotherapy and brachytherapy

May happen many months or years after radiotherapy and may be permanent. Many of these late side effects, taken in combination, are often referred to as pelvic radiation disease.

Existing research shows that these are the **late side effects** of gynaecological radiotherapy. Imagine you were consenting to radiotherapy today. Knowing what you know now, could you please choose **6 late effects that would concern you the most**? Choose by ticking the box ☐ next to the 6 side effects that would concern you the most.

Expected (50%-100%)

Common (10%-50%)

Less common

- ☐ Vaginal narrowing, shortening or dryness – this may impact vaginal intercourse, and the comfort and quality of a vaginal examination. You may be advised to use vaginal dilators after treatment which may reduce this risk.
- ☐ Bowel frequency (opening your bowels more often than normal) and urgency (a sudden urge to open your bowels)
- ☐ Urinary frequency (passing urine more often than normal) and urgency (a sudden urge to pass urine)
- ☐ Urinary incontinence – including urine leaking when coughing or straining
- ☐ Asymptomatic pelvic bone fractures particularly when post-menopausal
- ☐ Looser stools compared to normal
- ☐ Radiotherapy to the lower pelvis/vulva
 - Hair loss in treatment area
 - Lymphoedema – (fluid build-up) in your legs or pubic area
 - Skin thickening or discoloration lighter or darker for any skin tone, or visible blood vessels
 - Skin thinning
- ☐ Cystitis/pain when you urinate

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[Less than 10%]

Rare (Less than 1%)

- ☐ Reduced bladder capacity
- ☐ Faecal discharge/soiling
- ☐ Rectal pain/discomfort – which may worsen on opening your bowels. This may also affect your sex life if you receive anal sex.
- ☐ Bowel/bladder damage which may require surgery – due to stricture (narrowing), fistula (abnormal connection between two parts of your body) and may require stoma formation.
- ☐ Bleeding from your bladder or bowel or vagina
- ☐ Duodenal ulceration
- ☐ Symptomatic pelvic bone fractures particularly when post-menopausal
- ☐ Kidney impairment
- ☐ Malabsorption – problems with nutrient absorption
- ☐ Hair loss in treatment area
- ☐ Lymphoedema – (fluid build-up) in your legs or pubic area
- ☐ Ureteric strictures – narrowing of tubes running from kidneys and bladder
- ☐ A different cancer in the treatment area
- ☐ Skin thickening or discoloration lighter, darker or visible blood vessels
- ☐ Radiation induced nerve damage in the lower back area

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PLEASE DO NOT COMPLETE BEFORE THE INTERVIEW

 **GRACE**
GYNAECOLOGICAL RADIO THERAPY CONSENT ENHANCEMENT

Answer sheet for the ranking exercise

You have chosen 4 short-term side effects and 6 late effects of radiotherapy.

Please rank all 10 effects from most to least important to you by writing them into the boxes below.

1. (most important)	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10. (least important)	

Thank you for completing the ranking exercise! Please send this answer sheet and the booklet back to researchers at Lancaster University using the enclosed Stamped Addressed Envelope.

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Treatment-specific versions of the ranking exercise

The interview also covered **measures of benefit** (5-year survival, local control rate) and four **example choice tasks**.

Demographic summary

- 22 **participants**
- **White** (includes British, Irish, Northern Irish, Gypsy, Irish Traveller, Roma or any other White background)
- 96% **heterosexual** or straight
- 64% **over 65** y.o.
- 73% **retired**
- 82% **married** or in domestic partnership
- 64% **Christian**
- 82% **no neurodiversity**
- 50% have a **physical health condition(s)** or other **long-standing illness**
- 41% have income **between £20,000 and £40,000**

Clinical summary

- By **cancer type**:
 - 50% - Endometrial,
 - 27% - Cervical
 - 14% - Vulval
 - 9% - Vaginal cancer
- By **stage**:
 - 55% - Stage I,
 - 23% - Stage III
 - 9% - Stage II
 - 5% - Stage IV
- By **RT type**:
 - 55% - External Beam RT (EBRT)
 - 23% - Vaginal Vault Brachytherapy (VBT)
 - 14% - EBRT + Cervical Brachytherapy
 - 9% - EBRT + VBT
- 73% had **surgery**
- 77% had **RT in the last 5 years**

Results of the ranking exercise for all patients across all types of gynae-radiotherapy > 2.0 weighted score	Short-term side effect (S)	Late effect (L)	SCORE	RCR FREQUENCY
Bowel/bladder damage which may require surgery (L)			4.9	Less common (1% — 10%)
Bowel frequency and urgency (L)			4.8	Common (10% — 50%)
Bowel frequency and urgency (S)			4.3	Expected (50% — 100%)
Urinary incontinence (L)			3.8	Less common – Common (1% — 50%)
A different cancer in the treatment area (L)			3.5	Rare (0% — 1%)
Lymphoedema (L)			2.4	Less common (1% — 10%)
Bleeding from the bladder or bowel or vagina (L)			2.2	Less common (1% — 10%)
Bleeding from the vagina after using vaginal dilators or vaginal sexual intercourse (L)			2.1	Expected (50% — 100%)
Symptomatic pelvic bone fractures particularly when post-menopausal (L)			2.1	Less common (1% — 10%)
Radiotherapy to the lower pelvic/vulva: Skin soreness, itching, colour change and breakdown, irritation when passing urine and opening bowels, rectal pain/discomfort, vaginal itching or discharge (S)			2.1	Expected (50% — 100%)
Vaginal narrowing, shortening or dryness (L)			2.1	Expected – Definite (50% — 100%)
Urinary frequency and urgency (L)			2.1	Common (10% — 50%)

Findings

- **Late effects were chosen more frequently and ranked higher** than short-term side effects.
- **Bowel-related risks** were the most important, both as short-term and late effects, likely due to high impact on quality of life.
- Additionally, risks to the **skin, bladder, vagina, bones, and the lymphatic system** were concerning to patients.
- As a measure of benefit, **5-year survival was better understood** than local control rate. Neither was discussed with patients explicitly.
- Patients were **able to trade** between the benefits and risks.

Conclusion and discussion

- The early findings suggest **changes to bowel/bladder function and skin damage** are particularly important for patients.
- The interview data will be combined with the **GRACE lived experience data**, input from the **patient and public involvement group** and a **panel of experts** to inform a large-scale discrete choice experiment (DCE) to quantify benefit-risk trade-offs in gynae-cancer decision-making.

Thank you

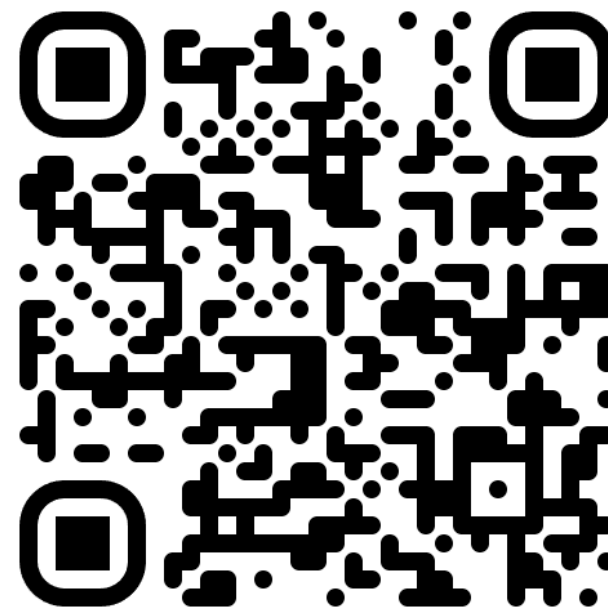


If you would like to learn more about GRACE and take part in our survey – **please scan the QR code**

Happy to take questions

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<https://wp.lancs.ac.uk/grace/get-involved/>