

**The difficulties in making it all reality:
Who's role is it anyway?**



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Questions

In your Unit:

What is the

- 1. i. geographical distribution of patients and hospitals**
ii. the number and function of the MDT
iii. the configuration of clinics
- 2. How is patient information delivered?**

Questions

In your Unit:

What is the

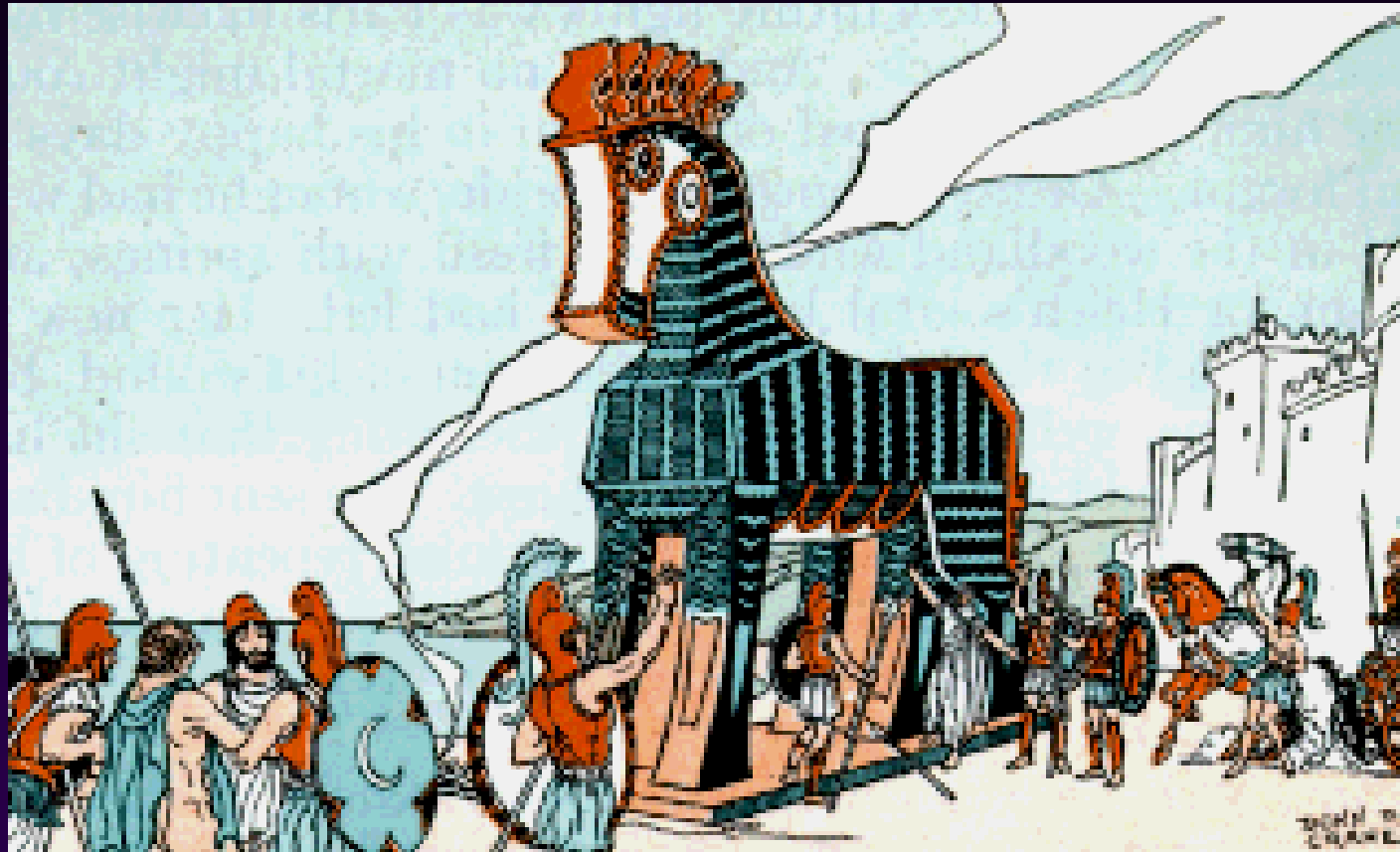
- 3. How are the needs of patient and carers identified?**
- 4. What resources do you have available?**
- 5. How do you define and monitor success in the patient cancer journey?**

H&N Cancer - the patients perspective

'Patients' score

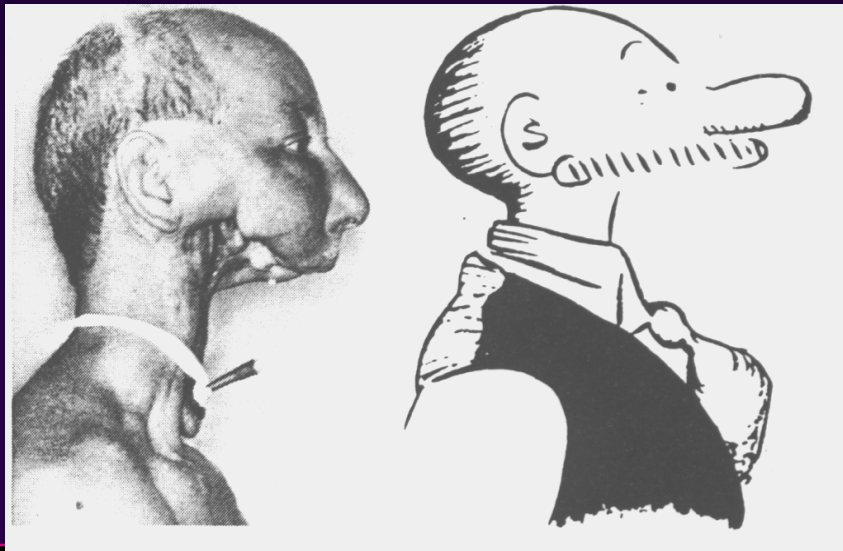


Head and neck cancer - QOL



QOL has been like a Trojan Horse in H&N cancer care

Head and neck cancer - improved outcomes



Things are better than they have ever been – still unmet expectations

Head and neck cancer - improved outcomes



Things are better than they have ever been – still unmet expectations

QOL data for the MDT-

- **In research and in clinical practice**

2000 to 2005 Questionnaires, H&N cancer, QOL

Predicators

Function

Questionnaire development

RCT

Reviews

QOL data for the MDT-

- In research and in clinical practice

2000 to 2005 Questionnaires, H&N cancer, QOL

Predicators	64
Function	46
Questionnaire development	38
RCT	11
Reviews	10
	169

Are we speaking the same language ?



Specific questionnaires – precision and responsiveness

QOL data for the MDT-

- **In research and in clinical practice**

Saliva as an important issue

Objective and subjective data

IMRT

The reality

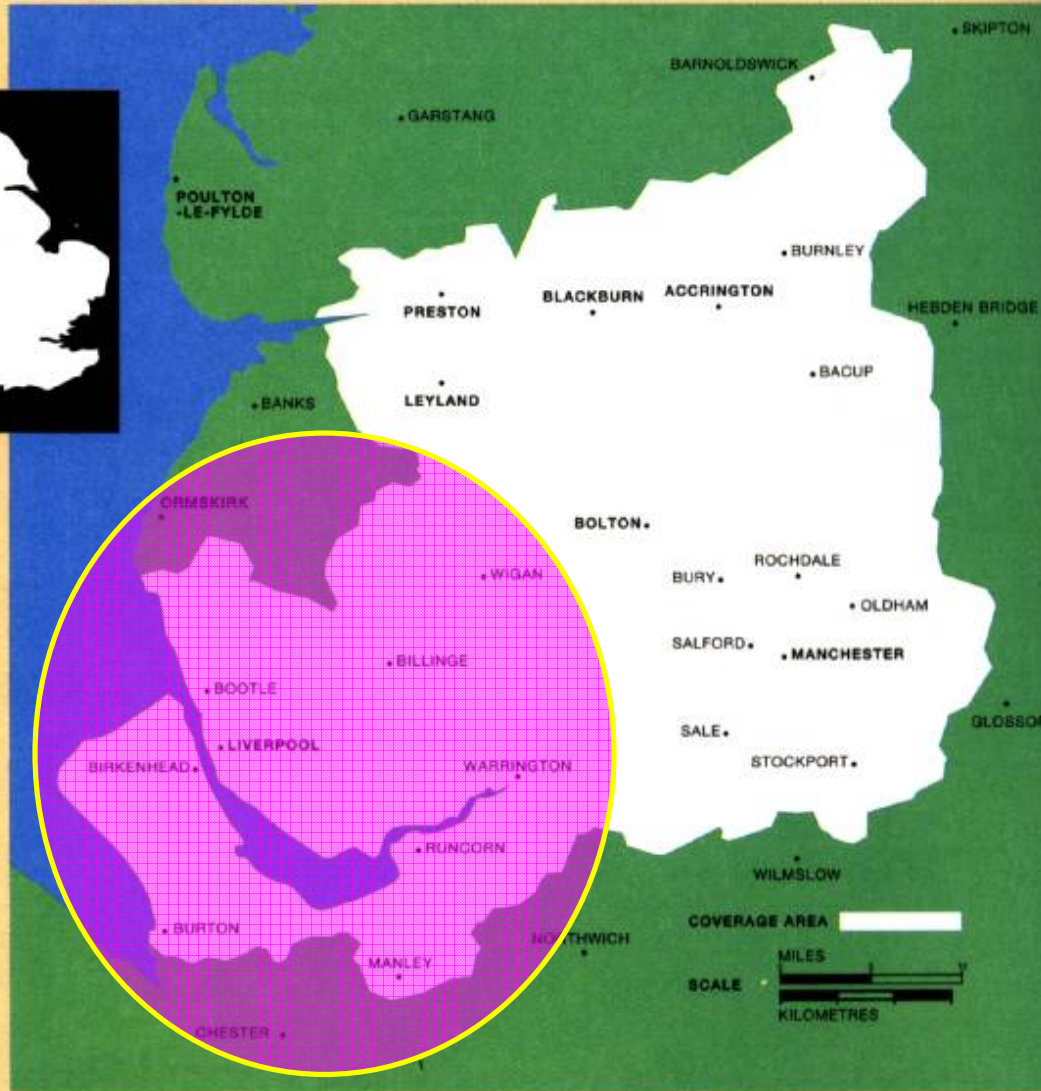
- ① Configuration of head and neck services**
- ② Patient characteristics**
- ③ The multidisciplinary team**
- ④ The process / implementation**
- ⑤ The evidence base**
- ⑥ The future**

Configuration of head and neck services

- **Regional service**
- **Improving outcomes guidance**
- **Hub and spoke**

Mersey Region

UHA
Clatterbridge
Peripheral clinics
Liverpool Dental
Chester



Configuration of Head & Neck Services Mersey (pop. 2.4 million)

Regional Head and Neck Service



Operating

Twenty + operating sessions/week

Eight surgeons- teams of two

Sub-speciality interests

Head and Neck Fellow



Configuration of head and neck services



Oncology

Three Clinical Oncologists



Configuration of head and neck services

Clinics / MDTs

Multidisciplinary Team Meeting Wednesday am UHA

90 minutes

?once a week / once a month at the Royal

Joint clinics at Arrowe Park, Royal Liverpool, UHA,
Whiston

Clinical Nurse Specialist – two plus others

Configuration of head and neck services

- **Funding issues**
 - **Limited funds**
 - **Tariff**
 - **Multiple specialities**
 - **PCTs**
 - **Cancer network**

The reality

- ① Configuration of head and neck services
- ② Patient characteristics
- ③ The multidisciplinary team
- ④ The process / implementation
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- ⑥ The future

Patient characteristics

- **Head and neck cancer**
- **Deprivation**
- **Alcohol and smoking**
- **Maleness**
- **Patient and carers needs**
- **Small numbers**

Patient characteristics

Head & Neck cancer

'Is in your face'

**It affects many different
functions**



Patient characteristics

Head & Neck cancer

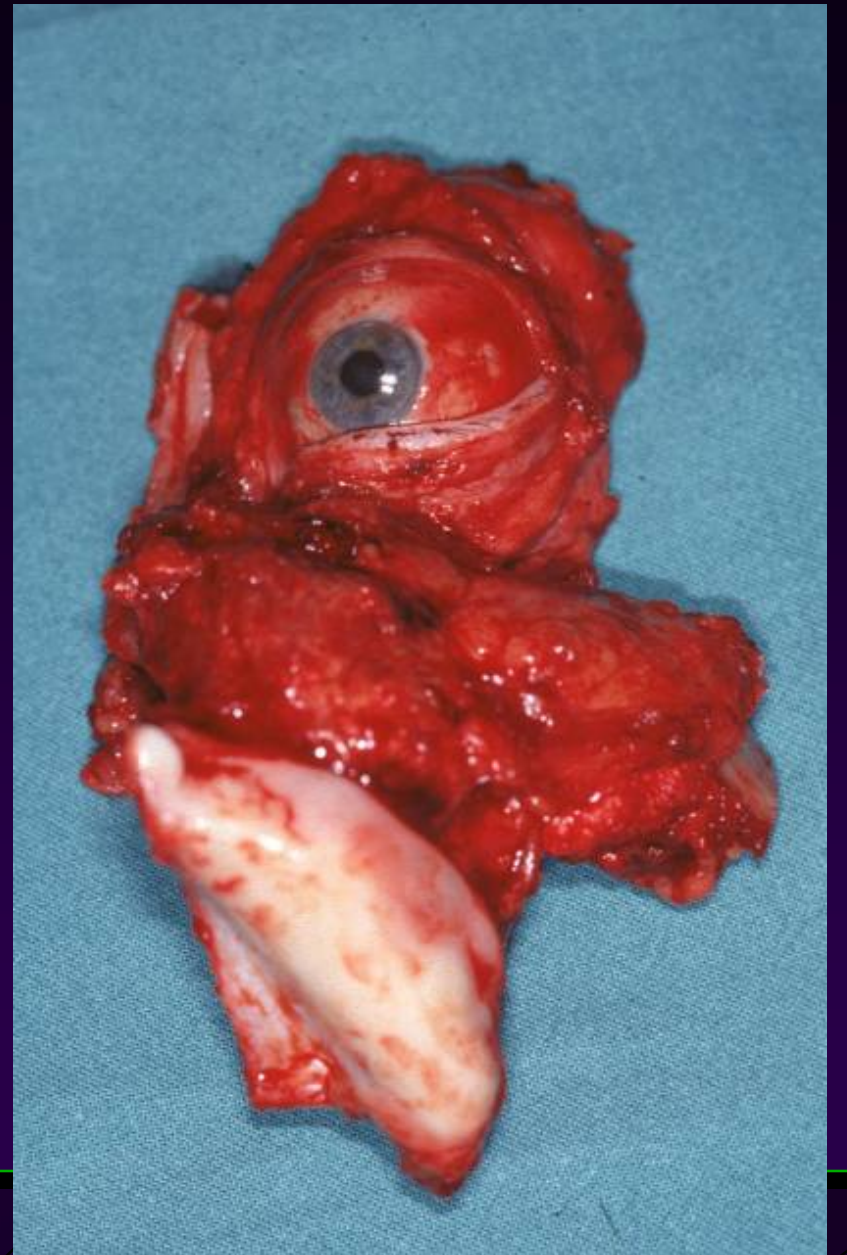
**Cancer - more than just
cure and survival**



Radiotherapy



Surgery



Patient characteristics

Patients with H&N cancer can have

- **Poor self esteem**
- **Not wish to be a trouble**
- **Feel guilty / responsible for their cancer**
- **Other patients in need of your time**
- **Be from deprived background**

Patient characteristics

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- **Deprivation**
- **Alcohol and smoking**
- **Maleness**
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- **Small numbers**

The reality

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The multidisciplinary team

Large team dynamics

Preconceived ideas

Identification of clear roles

Communication

The multidisciplinary team - geographical



The multidisciplinary team - geographical

Family / Carer



The multidisciplinary team - geographical

Family / Carer



Local support

GP, GDP, District Nurse

CNS, MacMillan,

Community services

Support group

The multidisciplinary team - geographical

The Cancer Unit

Referring team

Family / Carer



Local support

GP, GDP, District Nurse

CNS, MacMillan,

Community services

Support group

The multidisciplinary team - geographical

The Cancer Centre

Clinical Nurse Specialist
Clinical psychologist
Chaplain
Dentist
Dietician / Nutritionalist
Emotional support therapist
Hygienist
Nursing staff
Occupational therapist
Oncologists
Oral Rehabilitation team
Other
Palliative Medicine Team
Physiotherapy
Psychiatrist (liaison)
Speech and Language Therapist
Social worker
Surgeons

The Cancer Unit

Referring team

Family / Carer



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The multidisciplinary team - geographical

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Family / Carer



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Centralised units – not marginalised patient
Functional network - carepathway

The reality

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The process / implementation

Which patients

Delivery

Training

The process / implementation

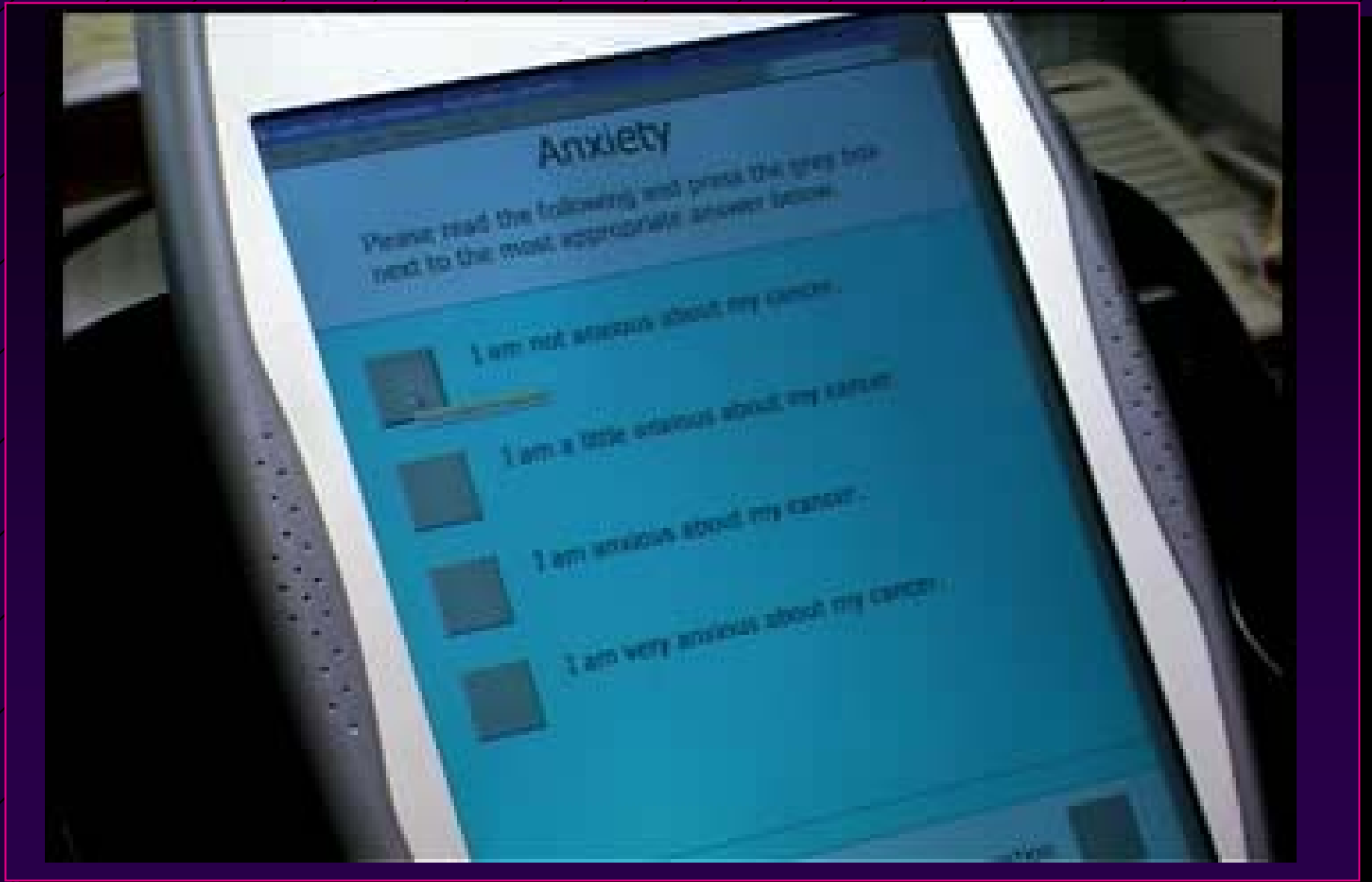
Which patients

All patients

When -at which time points

Those at need -screening / triage

Touchscreen



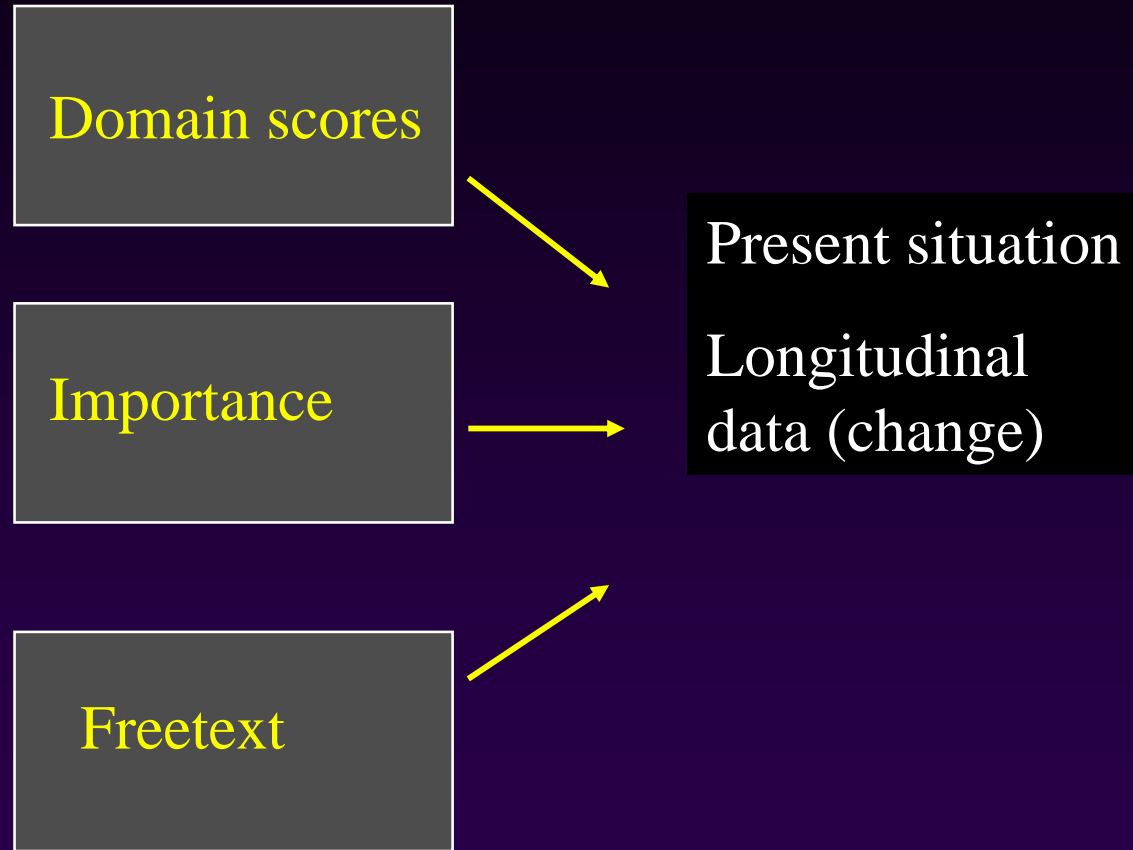
HRQOL in clinical practice

Domain scores

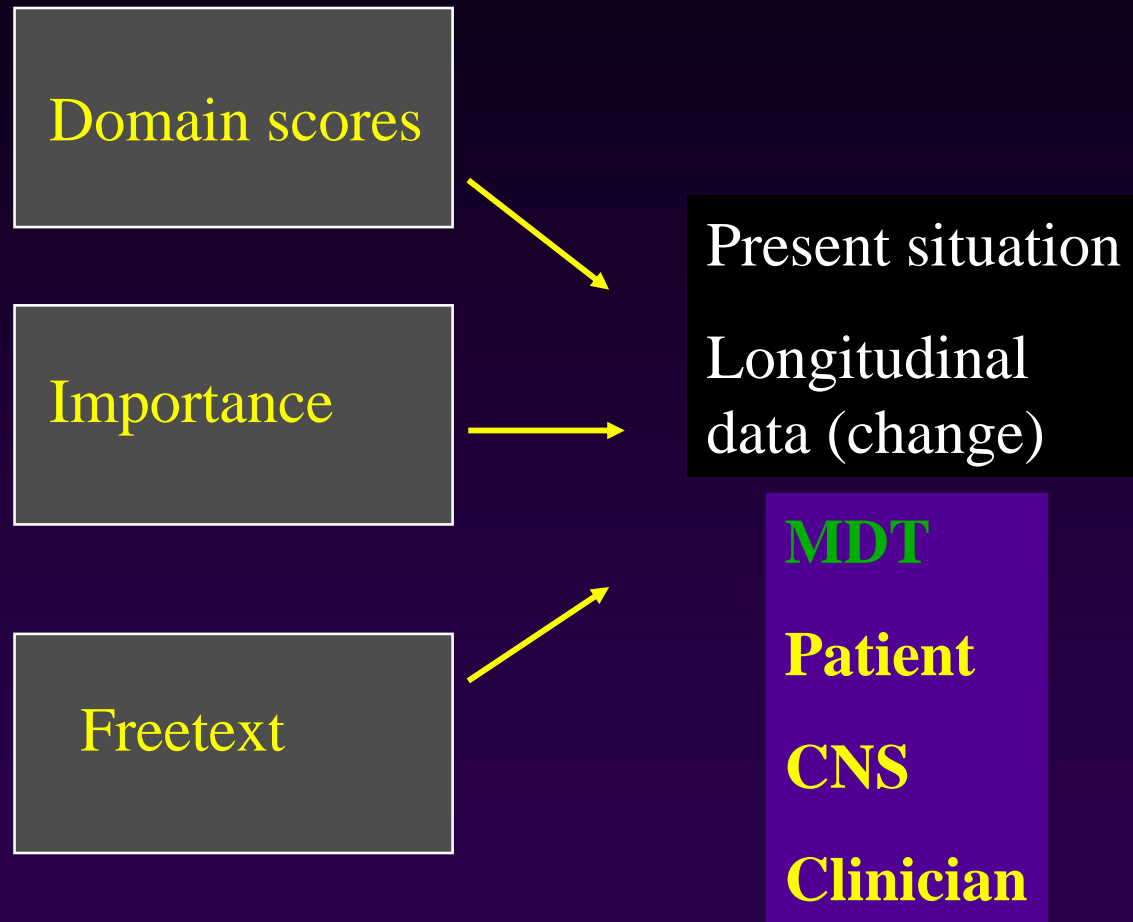
Importance

Freetext

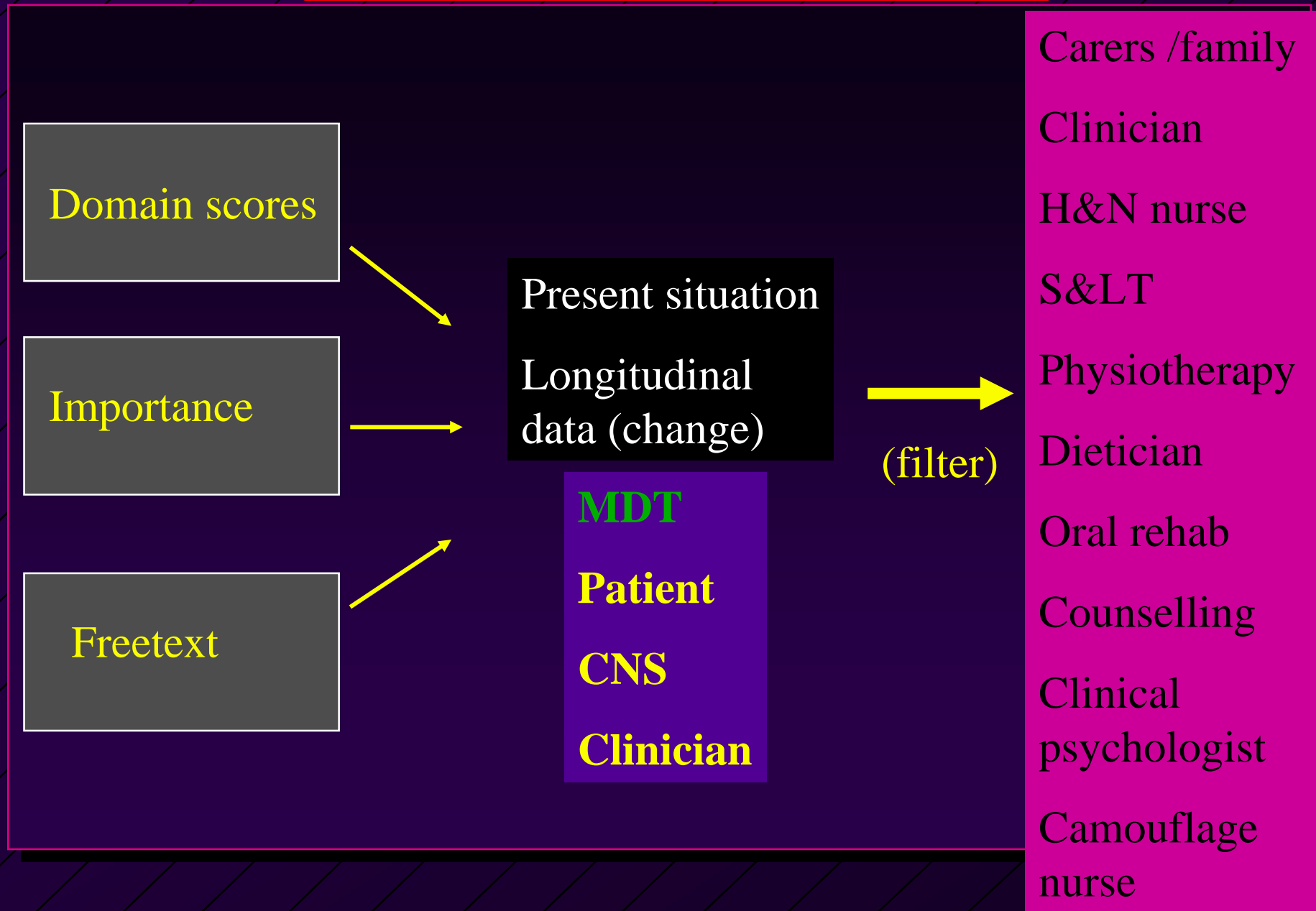
HRQOL in clinical practice



HRQOL in clinical practice



HRQOL in clinical practice



The process / implementation

Delivery

Which intervention

Where – hub /spoke /community

By whom

How frequently

For how long

What outcome/ evaluation of success

The process / implementation

Training

Training the individual, patient, carer

Training the team

Team support - burnout

Team evaluation

Line management / reinforcement

The reality

- ① Configuration of head and neck services
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The evidence base

QOL in clinical practice or intervention – in its infancy



Psycho-educational
Psychosocial
Self help manuals

The reality

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The future

- **Understanding the patient life history**
- **QOL in routine clinical practice**
- **QOL in research**

The future

➤ Understanding the patient life history



**Nearly half of patients
present with T4 disease**

The future

➤ **QOL in routine clinical practice**

IT support -touch screen

Electronic patient record

Individual Patient Assessment tool

Clinical meaning

How to optimise information / perception of risk

Streamline and improve effectiveness of clinic

Targeting unmet needs

Recognise key issues / times – e.g. end of life

Evaluation of training / support

How to use HRQOL information ?

447 consecutive patients undergoing surgery for previously untreated oral and oropharyngeal squamous cell carcinoma from Jan 1995 to Dec 2002

Over 2500 questionnaires

How to use HRQOL information ?

HRQOL outcomes in oral and oropharyngeal SCC

Key factors

Site

Size

Surgery

Adjuvant Radiotherapy

How to use HRQOL information ?

Oral Cavity SCC < 4cm + free flap

Long-term

Speech

How to use HRQOL information ?

Oral Cavity SCC < 4cm + free flap

Long-term

Speech

	PATIENTS in DATABASE	My speech is the same as always	I have difficulty saying some words but I can be understood over the phone	Only my family and friends can understand me	I cannot be understood	MEAN SCORE	Speech was an important issue
DXT	55	33%	48%	19%	0%	70	27%
NO DXT	82	28%	69%	2%	2%	78	45%



Treatment

How to use HRQOL information ?

Oral Cavity SCC < 4cm + free flap

Long-term

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Incidence and survival

How to use HRQOL information ?

Oral Cavity SCC < 4cm + free flap

Long-term

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% best


% worst

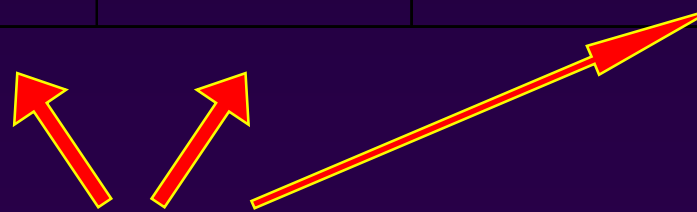
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Average - key difference

How to use HRQOL information ?

Oral Cavity SCC < 4cm + free flap

Long-term

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Importance

The future

➤ QOL in research

Understanding the questionnaire

Evaluating new questionnaire – Psychosocial

Understanding other issues: e.g personality

Data from existing RCTs

Pilot data / feasibility studies

Complementary research at regional level

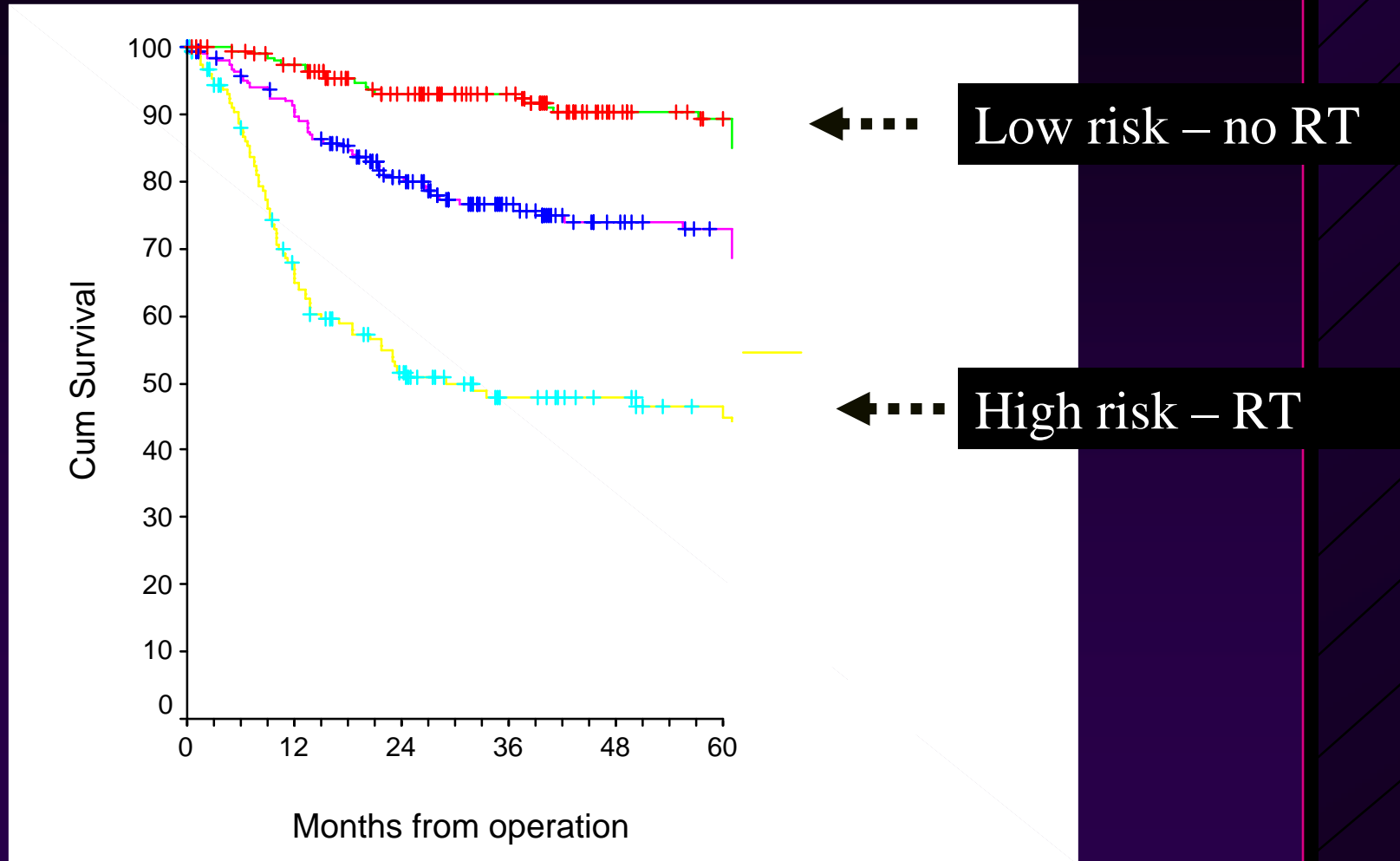
Collaboration – national / international

Venerable group – agreed key study

Translational research

Survival – QOL trade off

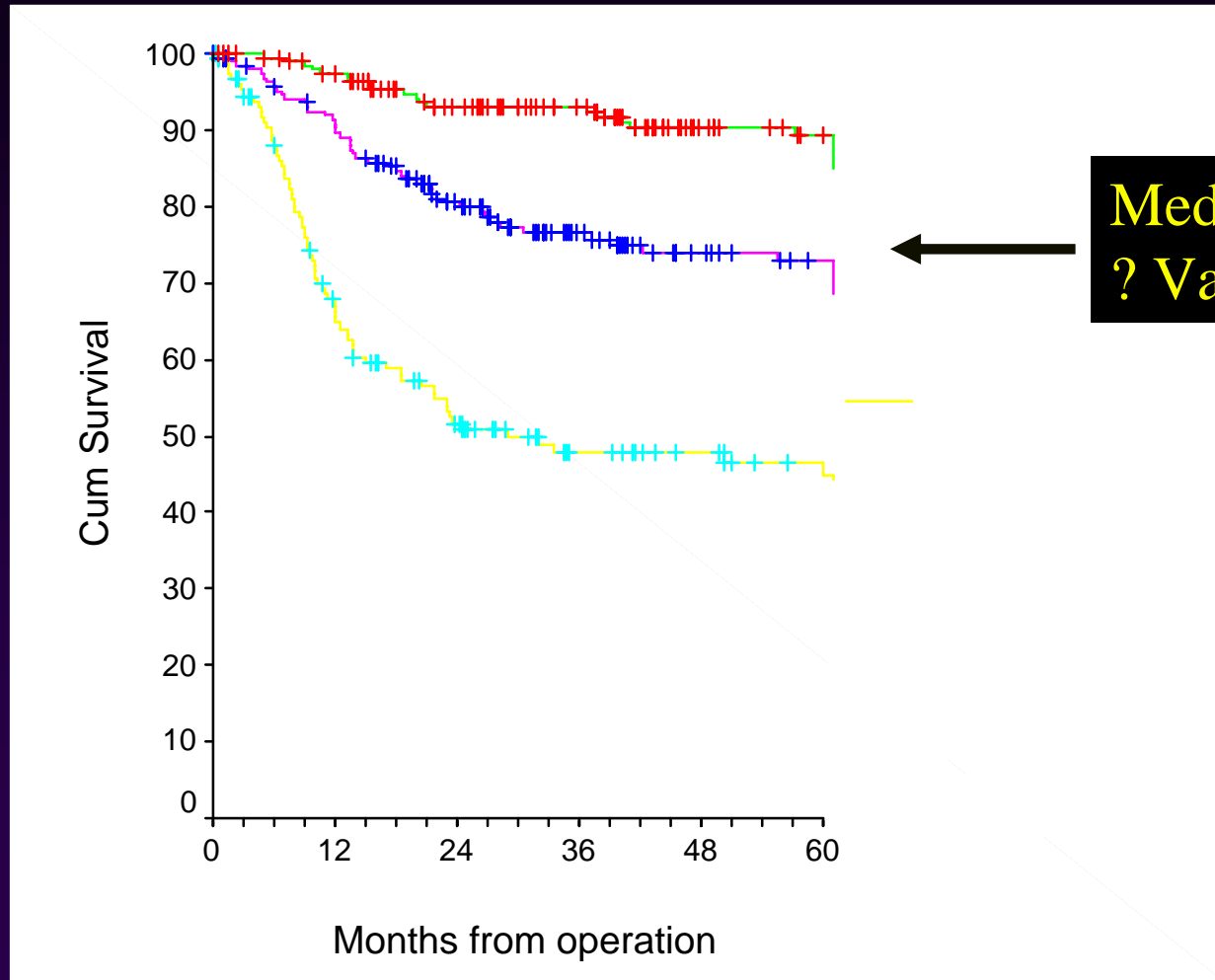
Survival and adjuvant radiotherapy



Liverpool – Oral and oropharyngeal SCC 1992-2002 n:559

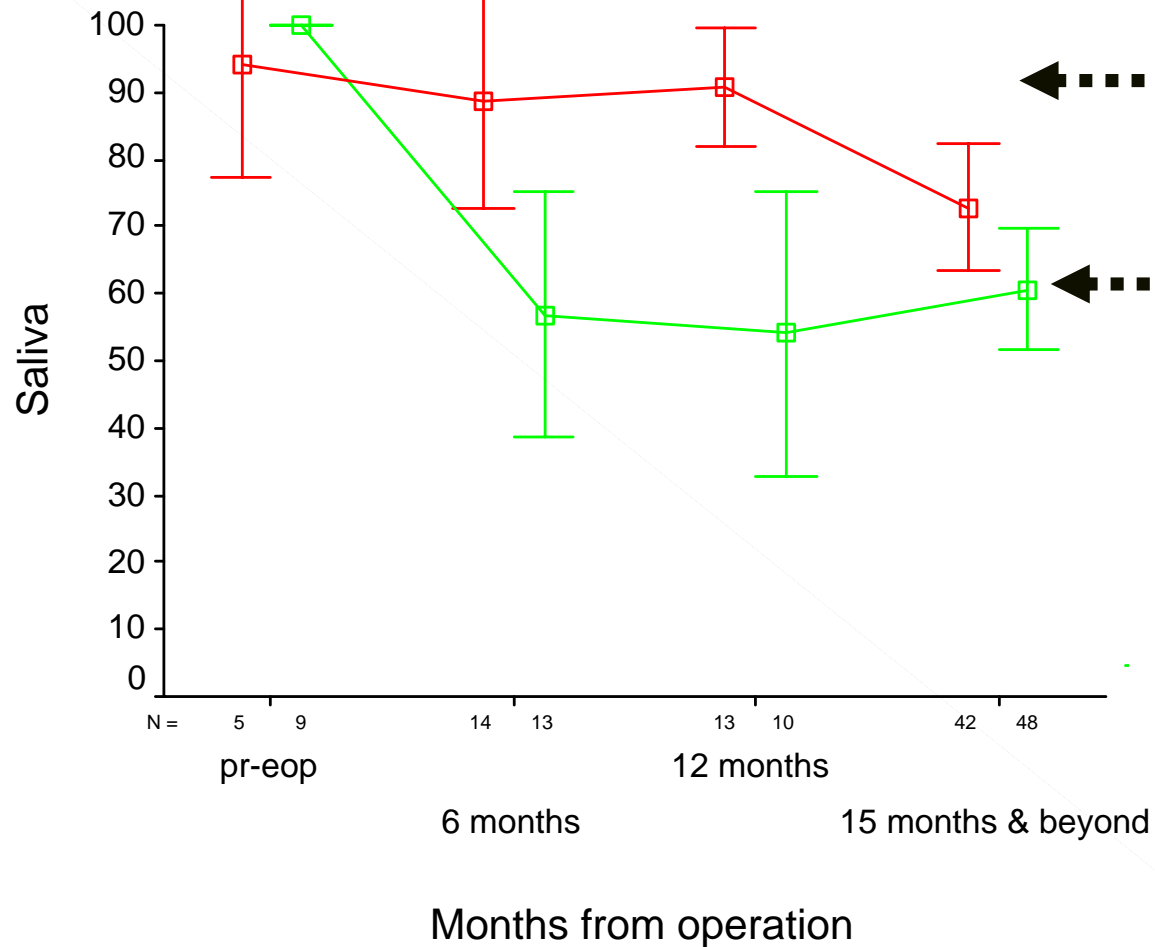
Survival – QOL trade off

Survival and adjuvant radiotherapy



Medium risk group
? Value of RT

Survival – QOL trade off – Saliva dysfunction



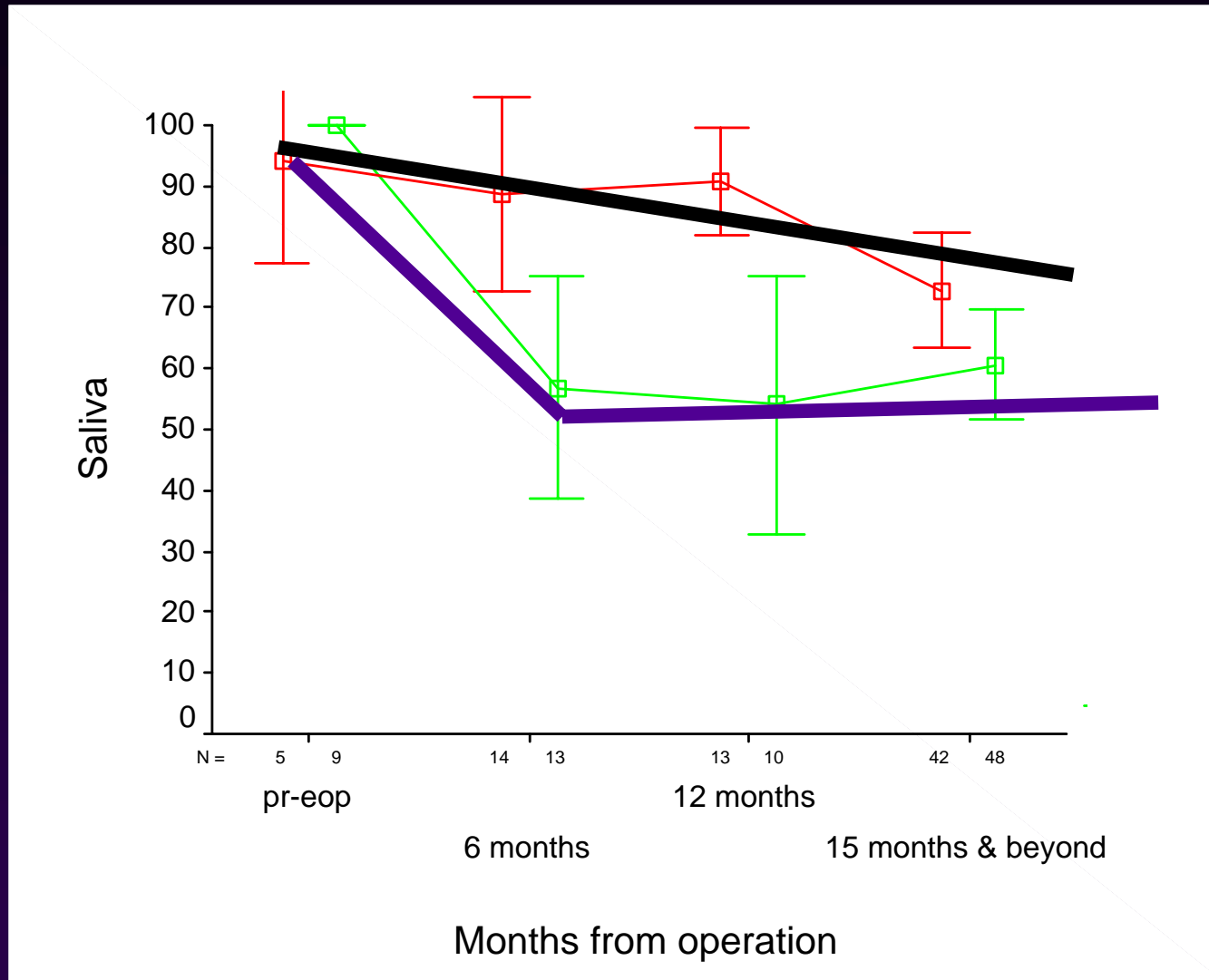
Medium risk group

No RT

RT

Liverpool – Oral and oropharyngeal SCC 1992-2002 n:559

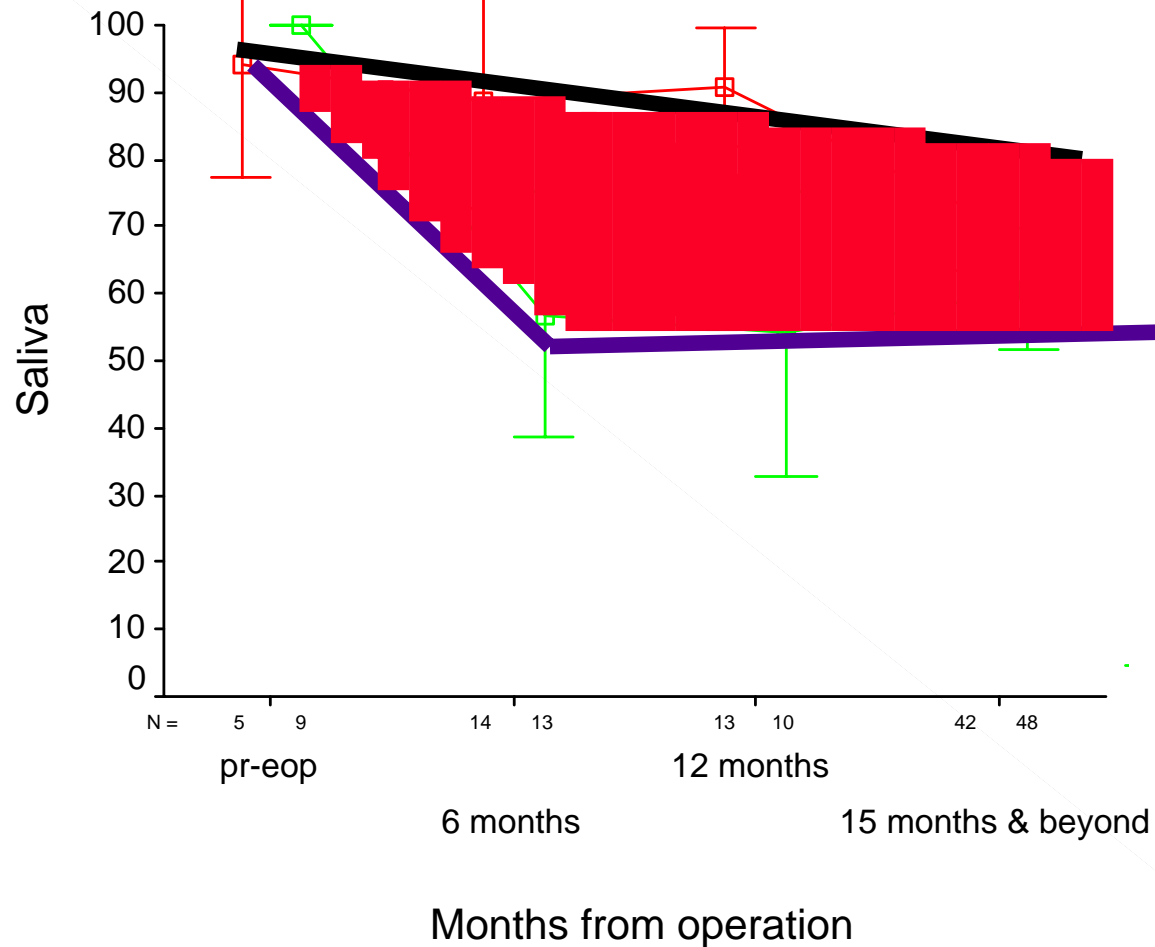
Survival – QOL trade off – Saliva dysfunction



Adjuvant RT
and
HRQOL

Liverpool – Oral and oropharyngeal SCC 1992-2002 n:559

Survival – QOL trade off – Saliva dysfunction



Life-long
difference

Liverpool – Oral and oropharyngeal SCC 1992-2002 n:559

Outcome



The future



**We still have a lot to do
That's up to all of us !**

Reflection from the 5th QOL Workshop



Thank you