The difficulties in making it all reality:
Who’s role is it anyway?
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?
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?
‘Patients’ score
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
- In research and in clinical practice

### 2000 to 2005 Questionnaires, H&N cancer, QOL

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
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<tbody>
<tr>
<td>Predicators</td>
<td>64</td>
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<tr>
<td>Function</td>
<td>46</td>
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<tr>
<td>Questionnaire development</td>
<td>38</td>
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<tr>
<td>RCT</td>
<td>11</td>
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<tr>
<td>Reviews</td>
<td>10</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>169</strong></td>
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</tbody>
</table>
Are we speaking the same language?

Specific questionnaires – precision and responsiveness
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
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
5. The evidence base
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
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

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

1. Configuration of head and neck services
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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

Local support
- GP, GDP, District Nurse
- CNS, MacMillan,
- Community services
- Support group

The Cancer Unit
- Referring team
The multidisciplinary team - geographical

**The Cancer Centre**
- Clinical Nurse Specialist
- Clinical psychologist
- Chaplain
- Dentist
- Dietician / Nutritionalist
- Emotional support therapist
- Hygenist
- Nursing staff
- Occupational therapist
- Oncologists
- Oral Rehabilitation team
- Other
- Palliative Medicine Team
- Physiotherapy
- Psychiatrist (liaison)

**The Cancer Unit**
- Referring team

**Family / Carer**

**Local support**
- GP, GDP, District Nurse
- CNS, MacMillan,
- Community services
- Support group

Centralised units – not marginalised patient
Functional network - carepathway
The reality

1. Configuration of head and neck services
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The process / implementation

Which patients

Delivery

Training
Which patients

All patients
When - at which time points
Those at need - screening / triage
Touchscreen

Anxiety

Please read the following and press the grey box next to the most appropriate answer below.

1. I am not anxious about my cancer.
2. I am a little anxious about my cancer.
3. I am anxious about my cancer.
4. I am very anxious about my cancer.
HRQOL in clinical practice

- Domain scores
- Importance
- Freetext
HRQOL in clinical practice

Domain scores

Importance

Freetext

Present situation

Longitudinal data (change)
HRQOL in clinical practice

Domain scores
Importance
Freetext

Present situation
Longitudinal data (change)

MDT
Patient
CNS
Clinician
HRQOL in clinical practice

Domain scores
Importance
Freetext

Present situation
Longitudinal data (change)

MDT
Patient
CNS
Clinician

Carers /family
Clinician
H&N nurse
S&LT
Physiotherapy
Dietician
Oral rehab
Counselling
Clinical psychologist
Camouflage nurse

(filter)
Delivery

Which intervention
Where – hub /spoke /community
By whom
How frequently
For how long
What outcome/ evaluation of success
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
2. Patient characteristics
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6. The future
The evidence base

QOL in clinical practice or intervention
– in its infancy

Psycho-educational
Psychosocial
Self help manuals
The reality

1. Configuration of head and neck services
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The future

- Understanding the patient life history
- QOL in routine clinical practice
- QOL in research
Nearly half of patients present with T4 disease.

The future

Understanding the patient life history

Nearly half of patients present with T4 disease.
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 oro-pharyngeal squamous cell carcinoma from Jan 1995 to Dec 2002

Over 2500 questionnaires
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
**Oral Cavity SCC < 4cm + free flap**

**Long-term Speech**

<table>
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<tr>
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**Treatment**
### How to use HRQOL information?

**Oral Cavity SCC < 4cm + free flap**

**Long-term Speech**

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**Incidence and survival**
How to use HRQOL information?

**Oral Cavity SCC < 4cm + free flap**

**Long-term Speech**

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How to use HRQOL information?
How to use HRQOL information?

**Oral Cavity SCC < 4cm + free flap**

**Long-term**

**Speech**

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**Average - key difference**
How to use HRQOL information?

Oral Cavity SCC < 4cm + free flap

Long-term

Speech

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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 and adjuvant radiotherapy


Low risk – no RT

High risk – RT

Survival – QOL trade off
Survival and adjuvant radiotherapy

Survival – QOL trade off – Saliva dysfunction


Adjuvant RT and HRQOL
Survival – QOL trade off – Saliva dysfunction

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