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Signed:

Dated: 8th January 2014
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1.0 Introduction

My Churchill fellowship focused on the management of head and neck lymphoedema. Lymphoedema is a condition in which an impairment of the lymphatic system results in swelling of an area within the body. Lymphoedema that affects the head and neck region most commonly occurs after head and neck cancer treatment. Research into clinical practice for this condition is relatively limited when compared with other types of lymphoedema.

This fellowship enabled me to develop a comprehensive understanding of international approaches to head and neck lymphoedema research, assessment, treatment and service delivery. I attended conferences, centres of excellence in clinical practice and met with researchers in the field of lymphoedema through travel to Italy, the United Kingdom and the United States.

This report provides a summary of observations and learnings from my Churchill Fellowship. The observations and comments included in this report reflect the topic at the focus of my trip; they are not intended as a comprehensive report on each service.

2.0 Acknowledgements

I acknowledge with gratitude the many people who freely gave up their time to meet with me and to allow me to visit their services. Key contacts were incredibly generous with both their time and knowledge. Their generosity, enthusiasm, openness, sharing of knowledge, engaging in discussion, and providing opportunities for clinical observation and learning was greatly appreciated. I would like to express particular thanks to Dr Kristiania Gordon, Dr Peter Mortimer, Dr Vaughan Keeley, Dr Harvey Mayrovitz, Dr Hiroo Suami and Mr Brad Smith for their generosity in accommodating extended visits.

Thank you also to the patients who allowed me to observe their treatments to see the practical implementation of lymphoedema techniques.

Thank you to the generous support provided by the Occupational Therapy Department at the Princess Alexandra Hospital, particularly to Mary Whitehead for her encouragement and to Ruth Cox for her practical support. Thanks also to my colleagues Jodie Nixon and Megan Trevethan who provided support while I was travelling and covered the clinical impact of my absence.

Finally, I am grateful for the opportunity provided by the Churchill Memorial Trust and the Dorothea Lee and Irene Sandars Churchill fellowship. This has been a wonderful once-in-a-lifetime experience.
3.0 Executive summary

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My Churchill Fellowship project examined international approaches to head and neck lymphoedema assessment, treatment, research and service delivery. My itinerary targeted a variety of activities designed to maximise my exposure to these aspects of head and neck lymphoedema management.

Through the completion of my Fellowship:

- I developed an understanding of the latest research in the field of Lymphology through attendance at the International Society of Lymphology Congress and the British Lymphology Society Conference and had the opportunity to present findings from my own research at these conferences.
- I obtained an understanding of advanced diagnostics and genetics investigations for primary lymphoedema and complex atypical lymphoedematous conditions through clinic attendances with Professor Peter Mortimer and Dr Kristiana Gordon at St George’s Hospital, London and Dr Vaughan Keeley at Derby Hospital.
- I observed a wide variety of head and neck lymphoedema assessment and treatment approaches at Guys Hospital and University College Hospitals, London, Memorial Sloan Kettering Cancer Centre, New York and in particular, the specialist approach developed by Mr Brad Smith, MD Anderson Cancer Centre, Houston.
- I had the opportunity to learn about the historical development of anatomical research of the lymphatic system through my meetings with Dr Hiroo Suami, MD Anderson Cancer Centre, Houston; and about research into lymphoedema assessments through my meetings with Dr Harvey Mayrovitz, Nova South Eastern University, Fort Lauderdale.

Through meeting with international colleagues, I have confidence that lymphoedema practice in Australia is broadly consistent with international practice principles. There are many resource constraints affecting lymphoedema practice in Australia and this issue was consistent at all sites visited. Each of the health systems visited experienced challenges with resourcing of staff and consumables to meet the high patient demand. The types of assessment and treatment and the models of care used at each clinic varied. Some commonalities were identified with the need for balance between therapist- and patient-directed treatment approaches. At initial presentation and during exacerbations, a therapist-directed intensive treatment approach appeared beneficial to stabilise the condition. A patient self management approach was often employed once the condition had stabilised. However, ongoing therapist support was required throughout the self management phase to ensure best outcomes.

As a lymphoedema therapist, service manager, researcher and educator I will utilise the knowledge and experiences gained through this Churchill Fellowship to inform my own direct clinical practice, to guide delivery of lymphoedema service in my workplace and to shape future research endeavours. I intend to disseminate the findings of my trip via published manuscripts, delivery of workshops, and dissemination of this fellowship report to key stakeholders.
# 4.0 People and organisations visited

<table>
<thead>
<tr>
<th>Location</th>
<th>Date</th>
<th>Institution</th>
<th>Key Contacts</th>
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<tbody>
<tr>
<td>Rome, Italy</td>
<td>15-20 September</td>
<td>International Society of Lymphology (ISL) Congress</td>
<td></td>
</tr>
<tr>
<td>London, UK</td>
<td>23 September</td>
<td>University College Hospital (UCH)</td>
<td>Ms Jennifer Gilbert, Ms Carla Zanichelli</td>
</tr>
<tr>
<td></td>
<td>24 September</td>
<td>Guys Hospital (GH)</td>
<td>Ms Eunice Jeffs</td>
</tr>
<tr>
<td></td>
<td>25-27 September</td>
<td>St George's Hospital (SGH)</td>
<td>Professor Peter Mortimer, Dr Kristiana Gordon, Ms Fiona Kent</td>
</tr>
<tr>
<td>Derby, UK</td>
<td>30 September</td>
<td>Royal Derby Hospital (RDH)</td>
<td>Dr Vaughan Keeley, Ms Katie Riches</td>
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<td></td>
<td>1 October</td>
<td>Nottingham Hospital (NH)</td>
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<td>2 October</td>
<td>Mansfield Hospital (MH)</td>
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<td></td>
<td>3-4 October</td>
<td>Royal Derby Hospital (RDH)</td>
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<td>Birmingham, UK</td>
<td>6-8 October</td>
<td>British Lymphology Society (BLS) Conference</td>
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<tr>
<td>Doylestown, Pennsylvania, USA</td>
<td>10-12 October</td>
<td>Klose Training Conference (KTC)</td>
<td>Mr Guenter Klose</td>
</tr>
<tr>
<td>New York, New York, USA</td>
<td>22 October</td>
<td>Memorial Sloan-Kettering (MSK) Cancer Center</td>
<td>Ms Jeannette Zucker</td>
</tr>
<tr>
<td>Fort Lauderdale, Florida, USA</td>
<td>24 October</td>
<td>Nova South Eastern University (NSEU)</td>
<td>Dr Harvey Mayrovitz</td>
</tr>
<tr>
<td>Houston, Texas, USA</td>
<td>28-30 October</td>
<td>MD Anderson Cancer Centre (MDACC), Head and Neck Surgical Unit</td>
<td>Mr Brad Smith, Dr Hiroo Suami</td>
</tr>
<tr>
<td></td>
<td>31 October - 1 November</td>
<td>MD Anderson Cancer Centre (MDACC) Rehabilitation Unit</td>
<td>Ms Susan Lilly</td>
</tr>
</tbody>
</table>
5.0 Background to lymphoedema

5.1 What is lymphoedema
Lymphoedema is a condition characterised by the development of swelling in any part of the body. Lymphoedema develops as a result of damage or malformation to either the structure of the lymphatic system or from impairment in the functioning of the lymphatic system.

Lymphoedema can be classified as a primary or secondary condition. Primary lymphoedema is caused by a congenital impairment of the lymphatic system and is a rare condition. Secondary lymphoedema is more frequent and most commonly develops as a result of acquired damage to the lymphatic system by treatment for cancer.

5.2 Head and neck lymphoedema
Head and neck lymphoedema (HNL) is a swelling condition that occurs in the head and/or neck region. Secondary HNL is the most frequent presentation of this condition and most commonly develops as a result of acquired damage to the lymphatic system by treatment for head and neck cancer. Surgery and radiotherapy are the two primary modalities used to treat head and neck cancer and both can precipitate the development of HNL.

There is an emerging change in the presentation of head and neck cancer that is also affecting HNL. Head and neck cancer was historically mediated by prolonged exposure to alcohol and tobacco; it presented at an older age (60-80); and, had a relatively low cure rate. More recently there are increasing cases of virally-mediated head and neck cancer associated with the human papilloma virus (HPV) rather than alcohol and tobacco. This HPV-positive cancer has a shorter delay between exposure to the virus and onset of cancer and as a consequence it commonly presents at a younger age (40-60 years). HPV-positive head and neck cancer is associated with relatively higher cure rates compared with the traditional HPV-negative type.

With the emergence of HPV-positive head and neck cancer, the impact of HNL has also changed. People present with the condition at a younger age and due to improved survival rates, they live with its impact for longer than they would have done previously. Those who develop HNL may feel a greater impact from the morbidity of the condition and may be more active in seeking treatment. Such an increase in service demand for HNL treatment was seen during my Fellowship visit to Guys Hospital, London, where the HNL caseload has increased from 1% four years ago to 20% currently.

HNL has been less well understood than other forms of lymphoedema. Increasing awareness of the condition and its management is necessary to meet the needs of increasing numbers of people seeking treatment.
6.0 Assessment of head and neck lymphoedema

There are a wide range of assessments used to measure HNL in both published research and in the clinical practices I observed. Whilst much research has been conducted into assessments for limb lymphoedema, the complexities of the head and neck region make assessment of this area far more challenging. A recent literature review found that there are no specific tests available to diagnose lymphoedema of the head and neck\(^2\). Depending on the assessment used, the area examined, and the type of treatment delivered, the diagnosis of lymphoedema can vary substantially.

All clinics visited on my fellowship routinely conducted some form of structured HNL assessment at the initial and discharge appointments. Follow up assessment frequency varied. Those centres with a stronger focus on HNL conducted routine reassessment at most review appointments (GH, MDACC).

Assessment of head and neck lymphoedema can involve examination of either internal or external structures. Depending on the assessment used, reported rates of HNL can vary.

6.1 Assessment of internal oedema

Internal oedema cannot be physically palpated and is invisible without instrumentation (e.g. endoscope). Internal lymphoedema assessment was not routinely conducted at most sites. Due to the additional equipment and expertise required, internal assessment is more common as a research tool. The use of the Patterson Scale\(^3\) to assess internal HNL was reported at the ISL congress. This is a method used to subjectively assess observations of oedema made during endoscopy. Each structure is examined and subjectively rated for the degree of oedema present. The only intra-oral internal oedema observed in clinical practice was at the MDACC where a light source and visual examination were used to gauge the level of oedema present.

MDACC also conducted informal swallowing assessment/screening to determine any association between swallowing dysfunction and HNL. Questions included:

- Is the swelling worse in the morning?
- Does it change throughout the day?
- Is your swallowing worse/better when your swelling is worse/better?

6.2 Assessment of external lymphoedema

External HNL is visible swelling in the soft tissues of the head or neck regions\(^4\). The most common locations for external HNL are the neck or submental region\(^4, 5\).

Assessments I observed being used to measure external HNL varied between sites. Those sites without a specific interest in HNL used more generalised assessments such as a generalised grading or description. Those sites with a specific focus on HNL (GH, MDACC) used more formal assessments. External HNL was examined using both objective and subjective assessments.
6.2.1 Objective HNL Assessments

Objective assessments are used to record the presence and quality of a condition. Objective assessment of HNL has proved challenging for a number of reasons: the head and neck region is not a uniform shape; it surrounds many different anatomical structures that can alter measurements; and, it has no contralateral area for comparison. As HNL is associated with these challenges and is less common than other lymphoedema presentations, there has been little research into its objective assessment.

The objective assessments observed during my fellowship included:

**Palpation**
Palpation was used to assess for pitting/ thickening/ fibrosis of the epidermis and dermis (using stemmer sign) at all sites. Palpation was reported to be the most beneficial objective assessment available for HNL and in the UK, palpation appeared to be the dominant assessment used by medical professionals for all types of lymphoedema (e.g. RDH, SGH).

**Visual inspection**
Visual inspection and description was used to report on:
- Changes in the architecture of the skin and tissues
- Location of oedema
- Posture
- Skin condition
- Oral mucosa and airway

**Rating scales**
Rating scales were used in an attempt to systematise the descriptions obtained from palpation and visual inspection. Rating scales combine qualitative and quantitative observations. No one consistent scale rating scale was being used to evaluate HNL, instead the use of a variety of scales was observed. Examples included the Head and neck lymphoedema grading scale, Guys Hospital, London, the MD Anderson Cancer Centre HNL rating scale and the International Society of Lymphology/ Foldi Scale.

**Tape measurements**
Surface tape measurements between facial landmarks were also used to evaluate HNL. Tape measurements do not represent a volumetric measurement but they can be used to monitor progress over time. Dr Harvey Mayrovitz recommended the use of Gulick II tape measure (Allegro Medical Supplies, Mesz AZ, USA) which has a force gauge to improve consistency of tape measurements. The measurement system proposed by Smith and Lewin at MDACC evaluates both facial and neck lymphoedema. The left and right sides of the face cannot be compared for lymphoedema-related differences due to asymmetry; however, the composite score can be compared over time. A two percent change in either the face or neck composite score has been found to equate to a clinically significant change (MDACC). Measurements were taken at each appointment and recorded in a database for future comparison.
Images
Digital photographs were inconsistently taken at most clinics. The most common time point for photography was at the start of treatment (particularly in more severe cases) and at the point of discharge. Enuice Jeffs (GH) suggested a method of improving consistency between photographs where a fixed tape measure was held between the subject's nose and the photograph. This improved consistency of the horizontal and vertical position of the camera compared with the face. MDACC use the 3dMD system (3dMD.com) to take a 3D image of the head and neck area. The picture was converted into a volume and the image could also be superimposed on previous images for comparison. This equipment was expensive and was prone to reliability challenges with alignment of the subject.

6.2.2 Objective assessment of associated issues:
In addition to direct assessment of swelling, there are a range of symptoms associated with HNL that were also assessed at some clinics.

Range of motion
Range of motion of the jaw, neck and shoulders was commonly assessed as movement can be limited by the presence of HNL. The following assessment methods were observed:

- Visual estimate: This was the most commonly observed method
- Goniometer assessment
- Cervical Range of Motion Device (CROM): The CROM records precise neck range using a positioning device and magnets (Heidi Miranda-Walsh, KTC).
- Jaw opening distance: Trismus (impaired mouth opening) is a common symptom after head and neck cancer treatment. Measurement between the incisors was conducted to show the degree of trismus present.

Posture
Postural changes are common following treatment for cancer of the head and neck. Assessment of postural changes associated with HNL was observed to be descriptive in nature.

Function
The impact of HNL on face and neck function was measured using the following scales:

- Facial disability index which examines impact on physical and social functioning10 (MSK).
- Performance Status Scale for Head & Neck Cancer Patients (PSS-HN) which examines normalcy of diet, understandability of speech, eating in public and feeding tube requirements11 (MDACC).
- Jaw opening distance (MSK, MDACC).

Swallowing assessment
Two sites used swallowing assessments. A simplified descriptive assessment was used at GH. MDACC used formal speech pathology swallowing assessment with different textured foods. In addition to this, quick screening questions were suggested to assess whether lymphoedema impacted on swallowing:

- Is the swelling worse in the morning?
- Does it change throughout the day?
If the pattern of swallowing impairment mimicked the lymphoedema pattern, a link was considered likely.

**Observations of current practice:**
Objective assessments used to measure external HNL varied between sites. Palpation and visual inspection were the most consistently observed assessments followed by the use of HNL rating scales. Objective assessment commonly occurred at initial assessment and discharge. Evaluation at other treatment points was much less consistent. Clinics without a specific interest in HNL used more generalised assessments such as observation whereas clinics with a specific focus on HNL used more specific measurements such as tape measurements or standardized photography.

### 6.2.3 Potential future objective assessments for HNL

The following assessments were not in routine clinical use but were identified as research and/or future clinical tools during my visits. Dr Harvey Mayrovitz provided valuable input into potential future objective assessments and their applicability to HNL.

**Tissue Dielectric Constant**
The MoistureMeterD (MMD) (Delfin Technologies Ltd) has been proposed as an assessment tool for HNL through its measurement of the tissue dielectric constant. I have been trialling the MMD in a current research project and I aimed to gain a more detailed understanding of its operation and use for future research.

I did not find any services using the MMD in clinical practice. During my Fellowship, I met with two key contacts to discuss the workings of the MMD: Dr Harvey Mayrovitz, Nova South Eastern University, Fort Lauderdale; and, Mr Tipani Lahtinen the developer of the MMD and Chairman of the board for Delfin Technologies.

The MMD (pictured) generates an ultra high-frequency electromagnetic (EM) wave in its control unit. A probe is placed in contact with the skin and the EM wave is transmitted to the area of tissue beneath the probe. A portion of the EM energy is absorbed by tissue water and the remainder is reflected back into the probe. The amount of signal reflected represents the tissue dielectric constant (TDC). The TDC measurement is sensitive to both free and bound water contained within the volume that is measured. TDC is used as a measure of local tissue water. The more lymphoedema present, the more tissue water present, and the higher the TDC reading.
Dr Harvey Mayrovitz recommended considering the following factors when using TDC readings in future research:

- **Positioning:** A change in the position of a body will have a small but observable effect on TDC. TDC increases when a limb is dependent or constricted and decreases when a limb is elevated. The impact on TDC value is only small (range -3% to +3.5%)\(^{14}\). Dr Mayrovitz advised that positioning is likely to have only a minimal impact on clinical readings but should be considered for research purposes. Subjects should ideally rest supine for 10-15 minutes prior to MMD administration. The more caudally located the body part, the greater the rest time required.

- **Number of measurements:** Previous research has taken an average of three readings from each measurement point examined with the MMD rather than using a single reading. Dr Mayrovitz has examined the extent to which single and averaged measurements yielded similar TDC values and shown that the 95% confidence interval for differences between single and averaged TDC values was less than ±1 TDC unit\(^{15}\). These differences are small and as such Dr Mayrovitz advises that for most clinical evaluations or time limited situations, suitable assessment can be made with a single measurement; however, where small differences are relevant, an average of three measurements is preferred.

- **Location of measurement:** Different body tissues have different TDC values. When assessing forehead, cheek and forearm TDC values, all are reported to have significantly different values\(^{13}\) without any significant differences found between dominant and non-dominant sides. An unavoidable limitation of treatment outcome studies is that the tissue will change and move as volume decreases. Thus the tissue type measured may not be identical between measurements. Dr Mayrovitz advised that every effort should be made to maximise consistency of the measurement location.

- **Sex:** Male TDC values have been reported to be higher than female TDC values\(^{13}\). This may be because skin thickness differs between males and females with males having thicker skin than females which could result in more low-water content. Subcutaneous fat may be included in the TDC measurement volume for women thus reducing the TDC value\(^{16}\). Also there may be underlying differences in tissue water content between females and males.

- **Age:** A pattern of TDC value change with age is not completely clear. Early research suggests a possible trend towards increasing TDC value with increasing age\(^{16}\). Age may be a factor to consider when comparing absolute values of TDC.

- **Weight:** A trend towards increasing TDC value with decreasing BMI has been identified\(^{16}\). Weight should be considered when comparing absolute values between subjects.

- **Probe depth:** The MMD has four probes, each of which has a different tissue penetration depth (0.5mm, 1.5mm, 2.5mm, 5mm). The MoistureMeterD Compact is a smaller version of the MMD with a stated penetration depth of 2.5mm. Skin components differ among anatomical sites and at different tissue depths\(^{13}\). In general terms, the 0.5mm probe measures the epidermis and upper dermis; the 1.5mm probe measures the epidermis and most or all of the dermis; the 2.5mm probe also measures some subcutaneous fat. Each layer of tissue has different water content. Thus, as a consequence of the depth of recording, each probe will obtain a different TDC value\(^ {17}\). However, the direction and even the presence of the depth to water content relationship, is variable with different tissue types\(^ {13}\).
**Tissue indentation resistance**
Tissue indentation resistance (TIR) is a measurement (in grams) of the force required to indent tissue to a specified depth. Dr Mayrovitz has developed the Tissupress device to measure TIR. This portable handheld device acts like a “calibrated thumb to provide a uniform indentation force” to the target tissue\(^4\). The time taken for the tissue to recover from the indentation is used as an index of the tissue change. There are advantages of this approach over existing measures (e.g. Tonometers). For example, the device doesn't need to be completely vertical and the device doesn't need to be supported by the tissues during measurement\(^4\). Dr Mayrovitz advised that the force applicator used with this device is small and may be appropriate for use with HNL where comparable devices such as a Tonometer may be too large.

**Indurometer**
Mr Vanderstelt (Flinders University) presented a paper at the ISL congress, "**Indurometer vs Tonometer: which is best?**" The Indurometer measures the compression of the tissue by a plunger to 200g. The device differs from the previously used Tonometer in that it does not need to be applied in a vertical plane, thus increasing its suitability for use with HNL. The Indurometer is still in development and prototype devices appear to have a large plunger that may not be suitable in head and neck locations at this time.

**Bioimpedance Spectroscopy**
Water has relatively higher electrical conductivity when compared with most other substances. As such, tissues with increased amounts of water (e.g. lymphoedematous areas) will have a reduced electrical resistance. Bioimpedance uses the difference in electrical resistance associated with changes in tissue water to measure lymphoedema. While bioimpedance has widespread use in some areas for limb lymphoedema, its use in midline lymphoedema assessment has not been reported.

**6.2.4 Subjective Assessments**
Subjective assessments describe the perception of a symptom to the person it is affecting. Clinical observation indicates that there can be a substantial discrepancy in the objective and subjective evaluation of HNL with a bi-directional relationship possible. In other words, one person may be highly distressed by a small volume of HNL whilst another may have a very low level of distress about a large volume of HNL. At the sites visited, HNL was subjectively measured using the following tools:

**Distress:**
The distress thermometer was used to measure overall distress about swelling on a scale from 0-100 (UCH).

**Symptom Burden:**
A high frequency, severity and distress of symptoms has been reported in people who have undergone head and neck cancer treatment\(^18\). Symptom indexes are designed to record the number and/or intensity of symptoms present and can be used to monitor progress. During my Fellowship the following symptom indexes were observed in use:
• A modified symptom index to record a range of head and neck symptoms (UCH)
• MD Anderson Symptom Inventory (MDASI-HN)\textsuperscript{19, 20}
• Lymphoedema Symptom Intensity and Distress Survey: A paper by Jie Deng (USA) was presented at the International Society of Lymphology congress, "Comparison of symptom burden among head and neck cancer patients with and without secondary lymphoedema". This paper introduced the Lymphoedema Symptom Intensity and Distress Survey. This is a 64 item scale inventory assessing the impact of symptoms associated with head and neck cancer. Respondents are asked to rate the presence/absence of a symptom; and, the severity and bother of that symptom on a scale of 1-10 (from slight to severe). This scale is not available for distribution at present.

Quality of life tools:
No quality of life tools were observed in clinical use, however, several were identified through attendance at the ISL congress and BLS conference and discussions at site visits. These tools commonly assess domains of communication, speech, appearance, swallowing, eating, and oral symptoms:

• Quality of Life Instrument for Head and Neck Cancer (QLQ-H&N)\textsuperscript{21}
• Functional Assessment of Cancer Therapy (FACT H&N)\textsuperscript{22}
• University of Michigan H&N QOL Questionnaire (HNQOL)\textsuperscript{23}
• H&N Cancer Inventory (HNCI)\textsuperscript{24}
• EORTC QLQ-H&N35\textsuperscript{25}
• University of Washington Quality of Life Revised (UW-QOL-R)\textsuperscript{26}

No scale listed above contains specific reference to lymphoedema however an update of the EORTC scale was presented by Dr Pinto at the ISL congress that did contain reference to HNL. This scale is due to be available in the coming months and would be useful for consideration in the measurement of quality of life in HNL. In clinical practice these scales can be burdensome without having additional impact on clinical decision-making. As such they may be more relevant as research tools.
7.0 Head and neck lymphoedema treatment

7.1 Treatment modalities

HNL is not a simple condition with a uniform presentation and thus a limited modality approach may not be successful with all cases. Intensity and duration of treatment modality application was observed to be highly variable. In practice a wide variety of techniques were employed as outlined below:

Exercise/ Movement

Isolated and composite neck and facial exercises were prescribed in most clinical settings to increase range of motion and to compensate for a reduction in natural muscle movements following cancer treatment. To enhance this effect, exercises were also performed in conjunction with compression.

Eunice Jeffs (GH) developed a unique program of "manual lymphatic drainage by exercise". Neck and shoulder exercises were performed against the gentle resistance of small styrofoam balls contained in an orthopaedic collar (Hereford collar, Medi) applied firmly or held in place. Examples of movements included a shoulder shrug as axillary stimulation and neck rotation as cervical stimulation. Because the aim of this exercise program was to increase lymph flow, movements were not held at end range but instead used gentle and continuous motion.

Manual lymphatic drainage (MLD)

MLD is a form of massage where gentle rhythmic stretching of the skin is used to stimulate the lymph capillaries and vessel contractibility. MLD aims to facilitate lymph movement away from areas of congestion towards healthy, functioning lymphatics. Use of MLD was observed to vary significantly between centres with some using it as their primary treatment modality (MSK) and others having less frequent usage (MDACC).

MLD drainage pathways varied between centres and between individual practitioners. As observed with Dr Hiroo Suami, recent anatomical findings have shown that the superficial lymphatic drainage of the head and neck is "virtually unpredictable". Different lymphatic network patterns have been observed between subjects and even between different facial sides of the same subject with vessels from one area of tissue draining to different lymph node groups. Vessels crossing the midline and crossing scars have also been observed. These findings may indicate support for different, more individualised MLD pathways in future.

The following observations of MLD were made during my Churchill Fellowship:

- Intra-oral MLD: MLD was performed inside the mouth if required using the patient’s own tongue or a gloved finger which had been lubricated with water or flavoured tea (Heidi Miranda-Walsh, KTC).
- External MLD: The most common pathways observed involved clearing fluid from the torso and draining excess fluid to the axillary lymph nodes unless the supra clavicular fossa was unaffected (MDACC; Heidi Miranda-Walsh, KTC). Deep breathing was...
included at the start of the MLD routine to assist in circulating fluid through the whole system (MDACC).

- **Scars**: MLD at surgical scar sites was variable with approaches ranging from: directing fluid around the scar, seeing it as a barrier to lymph flow (RDH); to performing MLD across thin scars but diverting around thicker scars (MDACC); to performing MLD directly through the scar to target the closest unaffected lymph node group (Heidi Miranda-Walsh, KTC; MSK).

- **Position for MLD**: A seated or semi-reclined position was used to engage the support of gravity to assist drainage (Heidi Miranda-Walsh, KTC; MDACC).

- **Self MLD**: While all centres instructed patients in self/carer MLD, it was commonly acknowledged that therapist MLD achieved a better result in a shorter period of time. Due to resource limitations from insurance restrictions in the USA (MSK, MDACC) and staffing limitations in the UK (SG), treatment of mild swelling with a self management approach was seen as a reasonable compromise. Self MLD technique was taught using stationary circles not effleurage (MSK, MDACC). Maximum possible training (GH, UCH MDACC) with support of handouts, photos, or self-video was recommended (MDACC) to facilitate independence. Technique modifications were suggested to accommodate physical impairments with self-MLD. For example, one-handed self MLD, the use of a paint roller (UCH), alternative hand positions (fist, knuckles, dorsum of the hand) (MDACC), or abbreviated programs where the SCF was used as the drainage pathway rather than the axilla.

- **Precautions for MLD**: Age/Carotid artery stenosis: Age is commonly cited as a "relative contraindication" for MLD to the cervical lymph nodes in those over 60 years of age due to concerns regarding movement of atherosclerotic plaques. As the external carotid artery supplies blood to the face and the internal carotid supplies the brain, some consider it unlikely that a light technique such as MLD would apply sufficient pressure to affect the internal carotid and have a negative outcome. I was interested to see how different clinics approached practice in this area. Therapists were observed to:
  - Monitor for signs of vasovagal response and if symptoms did occur, to modify the MLD pattern to avoid the lateral neck (MSK).
  - Stimulate cervical lymph nodes one side at a time if adverse symptoms or contraindications were present, otherwise simulate bilateral cervical nodes (Heidi Miranda-Walsh, KTC).
  - Use medical history to determine any known carotid artery stenosis, previous carotid stent or any other intervention to the carotid (MDACC). At MDACC stenosis <50% was not considered an MLD contraindication. Stenosis >50% required clearance from the relevant doctor prior to MLD.
  - Use symptom-based questions (e.g. do you get dizzy when you wash your neck/shave?). Positive responses were considered to be an indicator of potential vasovagal response (MDACC).

**Elastic taping**

Elastic tape has an elastic core wrapped in cotton thread and woven into fabric tape with adhesive applied to one side in a designated pattern. Elastic tape was used to assist removal of oedema from congested areas such as the head and neck. Elastic tape was used straight off the paper with all stretch removed from the tape and only the stretch to the skin engaged (Joyce Bosman, BLS conference) or applied with light stretch to the tape (MSK).
Joyce Bosman, reported at the BLS conference that "reactions" to elastic tape were usually explained by an irritation to rough removal of the tape. Recommendations for removal were to apply oil, Cavilon or Serilium, to dissolve the glue; stretch the skin gently; and, peel the tape off close to the skin. Water does not dissolve the glue on the tape.

The use of elastic tape was employed by most clinics, however, some used it infrequently (MDACC), whereas others used taping as one of their primary treatment modalities (MSK). Elastic tape was applied in a number of application patterns (see table 1). Written and verbal documentation was completed to self monitor for symptoms of syncope including light-headedness, nausea, dizziness and skin reaction (MSK). If any symptoms developed, the tape was removed and the person was instructed to contact their local doctor. Photos of the application were provided to the patient (UCH) to self apply.

Table 1: Elastic tape applications

<table>
<thead>
<tr>
<th>Application Pattern</th>
<th>Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple thin &quot;I&quot; shaped pieces - meandering waves applied in parallel (JB)</td>
<td></td>
</tr>
<tr>
<td>Single thick &quot;I&quot; shaped pieces (MSK)</td>
<td></td>
</tr>
<tr>
<td>Square section used for the submental region (UCH)</td>
<td></td>
</tr>
<tr>
<td>Inverted &quot;Y&quot; to SCF (UCH)</td>
<td></td>
</tr>
<tr>
<td>&quot;X&quot; multiple small crosses overlapping to lift a scar (UCH) (the point of crossing has increased effect)</td>
<td></td>
</tr>
<tr>
<td>&quot;Web&quot; over areas of fibrosis to break down (UCH)</td>
<td></td>
</tr>
</tbody>
</table>

Compression

Compression of the head and neck is recommended to be applied with low pressure\(^\text{31}\) to avoid constriction and potential increase in facial oedema\(^\text{6}\). All clinics employed the use of compression for HNL management. However, the specifics of the applications varied.

- **Bandaging:** Short stretch bandages were used to apply neck/ submental compression, secured with Velcro attachment\(^\text{32}\) or cohesive bandages\(^\text{33}\) (UCH). The overlapping join was placed under the chin if the patient couldn’t reach the top of their head. Bandages were relatively low in cost, used materials available to most clinics, were easily assembled and could be adjusted to respond to changes in oedema. However, they were also cumbersome and did not provide coverage of the face.

- **Garments:**
  - Custom face masks were used to cover extensive areas of swelling, particularly anterior cheek swelling; or, to support irregular anatomy. Alterations were often required to obtain a well-fitting neck section and/or to sit as close to the stoma as possible without occluding it.
  - Off-the-shelf compression was used for oedema confined to the neck region.
• Inserts: A variety of inserts were used underneath or within compression.
  o "Grey foam" collar: Grey foam is half inch wide high-density, open cell foam cut to size to contour to the neck to flatten the tissue. Foam was held in place with a strap (MSK) or a compression garment (MDACC). The edges were bevelled and vents cut into the top side to facilitate contouring.
  o Chip bag: Pieces of open cell foam in a bag made from cotton liner were used to fill tissue defects. Caution was advised as chip bags can roll when placed under compression and can change position.
  o Schneider pack (MDACC): Small Komprex chips between two layers of medical tape were used to soften the tissue.
  o JoViPitPak (www.jovipak.com): These are low profile packs with hard cherry pits in channels that can be used inside light compression. They applied strong pressure and were only used for a short time period (e.g. 3-5mins).
  o Silicone mould: These were used to soften and flatten scars and oedema
  o Lymph pads. Eunice Jeffs (GH), used large nap lymph pads held against the area of fibrosis and moved in a circular motion to achieve a “fibrosis reduction” massage which was performed prior to exercise or other self-MLD.

Recommended cautions with the use of HNL compression at MDACC included:
• compression was not used during radiotherapy due to its potential to retain heat,
• compression was not used over tumour sites as it had potential to increase oedema,
• light pressure was used and if any facial swelling occurred the compression was further loosened,
• observation to ensure there were no indentations from the edge of the garment on removal.

Particular improvement in HNL was observed with the compression regimen employed by Brad Smith at MDACC. A Schneider pack was applied under compression for 30mins prior to MLD to soften tissue. MLD or self MLD was then conducted. Following MLD, flat pack grey foam compression was applied under compression garment for a minimum of four hours or longer. The use of compression overnight was encouraged.

Skin care
Skin care of the head and neck was encouraged to maintain skin integrity and prevent infection\textsuperscript{34}. Cellulitis is a known complication of lymphoedema and while rates in the head and neck region appear lower than that of the limbs, there is no data available to confirm. Both Dr Vaughan Keeley and Mr Brad Smith anecdotally reported incidences of head and neck cellulitis at their clinics.

Positioning/ elevation
Sitting, standing and sleeping postures can contribute to oedema progression. Elevation was recommended through gentle inclination of the head and upper body when sleeping with the neck in a neutral position. Devices used included foam wedges, pillows, and a travel neck cushion (Heidi Miranda-Walsh, KTC).
Techniques to reduce scar/tissue tension/tightening
Myofascial release (MFR) was observed being used with two particular techniques:
- Slow and sustained stretch of soft tissues to release adherent or restricted tissue caused by surgical or radiotherapy. This was used to facilitate easier movement of lymph fluid through unrestricted tissue. Self-MFR was taught and performed daily until tissues were released (MSK).
- Trigger point release was also used to reduce muscle tension and increase lymph flow (Heidi Miranda-Walsh, KTC, MDACC). Common trigger point locations were trapezius, sternocleidomastoid, masseter and temporalis muscles.

Surgical treatment of HNL
Two clinics reported the use of surgical approaches in the management of HNL. In a single palliative case, Dr Vaughan Keely (DH) had used a subcutaneous drain implanted into the face to relieve severe end-stage lymphoedema. Success was reported as limited in this case.

At MDACC lympho-venous anastomosis was performed in four patients following failure with conservative therapy. Functional and dilating lymph vessels were identified using pre and intra-operative fluorescent lymphography and a lymph vessel was anastomosed with a vein. The lymph vessel subsequently drained into the venous system rather than the obstructed lymphatic system. This surgery was not routine or widely available.

Observations of current practice:
MLD and compression were observed to be the most frequently used modalities. Particular benefit was seen with the use of compression and inserts. In general only one or two additional modalities were used by most therapists.

7.2 Treatment intensity
Perhaps the greatest variation in practice observed, was in the design of the HNL treatment program used at each clinic. The models used fell into three broad categories:

1. Therapist directed treatment followed by self care
This approach involved the trained therapist delivering treatments directly to the patient. Therapist-directed treatment required multiple visits to a clinic to receive treatment. The patient performed self-management on the intervening days between therapy appointments. This approach was commonly preferred for moderate-severe HNL due to the improved outcomes observed. Appointments were scheduled as follows:
   - MLD twice weekly for variable duration (RDH).
   - 45min of MLD daily for 2-3 weeks (UCH)
   - 2x/wk for 8 weeks (MSK)
2. **Self care**
Self-care only was preferred for people with mild to moderate HNL\textsuperscript{6, 35}. Insurance limitations, staffing restrictions, and travel distances all contributed to the decision to select a self-management treatment program. With self-care programs, treatment modifications were required such as simplification of MLD and the use of compression garments rather than compression bandaging. The advantage of this self management approach was fewer clinic visits and reduced therapy resource expenditure for the clinic. The disadvantage of this approach was that self-management may not be as effective as treatment performed by a clinician\textsuperscript{36}. Follow up reviews appeared crucial to the success of the self-management approach. At review appointments the self management techniques were revised and corrected, new problems were addressed and the treatment program was modified to target further clinical improvement.

3. **Self management followed by therapist directed treatment**
This approach involved an initial appointment for education in self management with a follow up review to ensure techniques had been understood. Further follow up was provided for review only. This approach involved a structure such as:
- First appointment for education and self-management;
- Second appointment delayed 2-6 weeks to review the results of self-management and commence therapist-directed treatment if required (GH).
8.0 Models of Care

Lymphoedema service operation was reviewed for comparison with Australian service provision. Models of care use to approach assessment and treatment of lymphoedema were examined.

8.1 Assessment models of care

1. Multidisciplinary assessment
   This model employed a joint assessment by a medical doctor and a therapist (RDH, SGH) with two different medics:
   - Lead consultant clinic: Complex cases were reviewed by a lead consultant. This included cases such as unknown cause or primary lymphoedema.
   - Junior/less experienced medical consultant clinic: Non-complex cases with an identifiable diagnosis such as cancer-related lymphoedema were seen in these clinics.

2. Supported therapy-only assessment
   This model saw the lead lymphoedema therapist in a clinic performing the initial assessment for non-complex cases (SGH, NH, MH). The caseload was tailored to the skill of the individual practitioner. This model was employed where a medical doctor was working within the service and was available for review/support as required. The supported therapy-only assessment was used to reduce the resource demand on the medical doctor.

3. Therapy-only assessment
   Some clinics did not have a medical doctor (e.g. GH, UCH, MSK) so all initial assessments were performed by the lead lymphoedema therapist (nurse, OT, PT etc). Two assumptions operated: the doctor referring the patient had screened for any significant contraindications to lymphoedema treatment; and, the referrer was accessible and willing to perform any additional investigations requested. Challenges were observed in meeting these two assumptions.

8.2 Treatment models of care

I observed a variety of lymphoedema treatment models of care. These can be broadly described by the relationship between the patient and clinician and the scope of the role performed by the clinician as described in the table below.
In cases of split scope lymphoedema treatment, a treatment prescription was provided by the lymphoedema clinician and the assistant performed MLD, bandaging, taping, exercises and/or skin care as directed. The lymphoedema clinician performed all education, evaluation, compression garment prescription. The assistant had completed a full lymphoedema training certification but did not have a university degree. The assistant often had additional qualifications (e.g. massage therapy). In one clinic (SGH), assistants were employed for a maximum of three days per week in recognition of the high manual handling demands of this role.

Another part scope role was observed with garment prescription. The lymphoedema clinician determined the type of compression garment required and provided a request for this garment to an administrative officer. The administration officer then completed garment quotes, ordering and purchase order processes, with chosen garments then posted directly to the patient by the manufacturer. Any garment issues were taken up with the administrative officer.

Treatment was primarily delivered using face-to-face appointments due to the need for visual evaluation and hands-on treatments. As an alternative, St George’s Hospital, London used a "virtual clinic" conducted via phone. This structure was used for select patients who were stable with their management over more than one review. The aim of these appointments was to verbally discuss progress, identify any new issues that had arisen since the last face-to-face review and reorder garments if they continued to be appropriate for ongoing use. This approach could potentially be expanded further to include other technologies.
9.0 Consumer engagement

I became aware of two highly successful examples of consumer engagement during my Fellowship.

- The Lymphoedema Support Network (LSN) (www.lymphoedema.org) in the United Kingdom is a consumer driven organisation that engages professionals to develop lymphoedema education resources. Examples of LSN resources include:
  o Resources for patients: Numerous LSN fact sheets about aspects of lymphoedema were stocked in all the clinics I visited in the United Kingdom to distribute to patients during treatment appointments.
  o Resources for professionals: An online learning module had been developed by key leaders in the field and is accessible through BMJ. This module aimed to increase awareness of lymphoedema amongst medical professionals.

- The Lymph Science Advocacy Program (LSAP) in the USA was highlighted by Ms Saskia Thiadens at the ISL congress. This initiative started in 2000 and provides education for people with lymphoedema through attendance at the National Lymphoedema Network (NLN) conference. Applicants self nominate or are nominated by a clinician and must provide letters of recommendation. Successful applicants receive:
  o Three preparatory webinars regarding the state of lymphoedema research and history, conference abstract reviews, tips for advocacy and preparation for conference.
  o Attendance at the NLN conference including mentorship and discussion groups with expert lymphologists is provided to review the lectures from the day before and plan for the day ahead. Following the conference, participant reviews are published on the NLN website and newsletter, including plans for how participants will bring their new knowledge back to their local area.

This initiative aims to provide education in the basic science of lymphoedema and related disorders and to engage and motivate people with lymphoedema and/or caregivers to action. The program has thirty-six "graduates" to date.
10.0 Reflections, conclusions and recommendations

My Churchill Fellowship provided me with an opportunity to observe international best practice in lymphoedema research, assessment, treatment and service delivery. I visited two different health care systems and was exposed to diverse approaches to clinical care, assessment, treatment and service delivery.

I concluded that each model of care had evolved to best function within its specific health care environment. Due to differences between the health systems I observed and the system in which I operate, some service delivery structures are not suitable for translation. For all lymphoedema services, the importance of therapist-delivered lymphoedema care remains essential. However, this must be combined with a self management approach to balance best treatment outcomes with the realities of resource limitations.

The use of routine structured assessment was beneficial for monitoring progress of head and neck lymphoedema and related symptoms. I plan to employ this approach and commence use of a standardised assessment battery in my clinical practice. The treatment techniques observed were not dissimilar to those used in Australia however extensions to standard practice of these techniques resulted in greater effectiveness. I plan to incorporate components of different treatment modalities as an extension to my current practice. Due to the limited evidence for each of these treatments in the head and neck caseload, treatment modalities will be tailored to individual patients.

I had the opportunity to reflect on existing research I am conducting and to refine my next research project. Alternative assessments and treatment models will be included in the next phase of my head and neck lymphoedema research. I have developed linkages with international researchers which I plan to continue collaboration.

My position as the Team Leader of a cancer-related lymphoedema service at a tertiary teaching hospital involves clinical practice, teaching and research roles. I have an active training role in my professional Occupational Therapy Association and the Australasian Lymphology Association. Through these roles, I will utilise and share the knowledge I have gained during the fellowship in the following ways:

- To disseminate information at a local level I will conduct multidisciplinary team inservices at my workplace and update local practice guidelines to consolidate introduction of new information and improve sustainability of the changes.
- To disseminate information at a national level I will incorporate knowledge and resources from my fellowship into my oedema management training program with Occupational Therapy Australia.
- To disseminate information internationally I will author a manuscript outlining my findings for submission to the Journal of Lymphoedema; include findings from my fellowship in an authored paper by my research team; and, present my key observations at the Australasian Lymphology Association Conference.

I aim to continue to liaise with key Fellowship contacts to engage them in future educational opportunities within Australia.
11.0 References