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# Modelling the development of an Online Learning Resource by Health Care Professionals.

(Vol. 2 of 2)

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Thesis submitted in fulfilment of the requirements for Degree of Doctor  
of Philosophy in Health Science

School of Medicine  
College of Medical, Veterinary and Life Sciences

University of Glasgow

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## Appendix 1: Job titles and roles.

Table A-0-1 Job titles and description proposed 2007

Title	Skills for Health Career Framework (CF) level	Examples of key components	Educational level
Lymphoedema Practitioner	5	Plans care for those with uncomplicated or stable lymphoedema.  Acts as resource for colleagues.	State registered practitioner.  Degree level education and clinical training in assessment and management of uncomplicated lymphoedema
Lymphoedema Specialist Practitioner	6	Manages all types of lymphoedema with a degree of autonomy.  Supports and guides practitioners at CF level 4 and 5	State registered practitioner.  Degree level education and clinical training as above plus certificate in complex management including Manual Lymphatic Drainage and multilayer bandaging.
Lymphoedema Advanced Practitioner	7	Experienced clinical professional empowered to make high level clinical decisions, high level of skills and theoretical knowledge.  Manages and leads service developments and retains educational role. Supports practitioners at levels 5 and 6.	As above plus holds or working towards masters degree.
Lymphoedema Consultant	8	High level strategic role, clinical expert, education and teaching role.	As above plus master's degree, possibly working towards doctorate.

Adapted from: Sneddon, M. C. (2007) Roles in lymphoedema. In Template for Management: developing a lymphoedema service, MEP Ltd, London.

## Appendix 2: Ethical approval Phase 1

Ms Rhian Davies  
Nursing and Health Care School  
University of Glasgow  
57-61 Oakfield Ave  
Glasgow  
G12 8LL

17<sup>th</sup> January 2011

Dear Ms Davies

Medical Faculty Ethics Committee

***Project Title: Health Professionals' Education Needs Scotland: Lymphoedema***  
***Project No.: FM02710***

The Faculty Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study now that the requested revisions have been incorporated. They are happy therefore to approve the project, subject to the following conditions:

- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- If the study does not start within three years of the date of this letter, the project should be resubmitted.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Dr David Shaw  
Faculty Ethics Officer

**Dr D Shaw**  
Lecturer in Ethics and Ethics Officer

School of Medicine, University of Glasgow, 378 Sauchiehall Street,  
Glasgow, G2 3JZ

Tel: 0141 211 9755  
E-mail: [david.shaw@glasgow.ac.uk](mailto:david.shaw@glasgow.ac.uk)

## Appendix 3: Questionnaire to Generalist HCP

### Education Needs Scotland: Chronic Oedema/Lymphoedema

#### What is this?

This survey is part of a University of Glasgow project supported by NHS Education Scotland(NES)and Macmillan Cancer Support.

Many health care professionals come across patients with swollen limbs, face or genitalia swelling or weeping legs in the course of their work. This survey aims to explore what education and training health care professionals in Scotland need regarding the recognition, prevention and management of lymphoedema or chronic oedema. The knowledge gained from this project will allow organisations to provide relevant education for health care professionals. It is recognised that as patients' expectations of you as health care professionals increase and funding decreases it is ever more important that you have the information you need, when you need it and in the format you prefer. Completion of the questionnaire is taken as consent for the researchers to use the data in this study.

The questionnaire will take less than 10 minutes to complete. Questions marked with an asterisk\* are particularly important to the study so require an answer. All answers are anonymous; no e-mail or IP address are stored or harvested by the host. You have the option of voluntarily supplying your e-mail address at the end of the survey if you wish to take part in a one-off follow up focus group.

Thank you for helping us.  
Rhian Davies  
University of Glasgow

You can move back and forth between the pages by clicking on the "next" and "previous" buttons. Use the scroll bar at the side to scroll down to the buttons. On the last page click "done" to submit your answers; if you leave the survey before doing this your responses will not be saved/sent.

#### Your role

##### \* 1. What is your job title/role?

(If you have more than one job please indicate your main one)

- |  |  |
|--|--|
| <input type="radio"/> Breast Care Nurse                | <input type="radio"/> Occupational Therapist |
| <input type="radio"/> Community/District Nurse         | <input type="radio"/> Physiotherapist        |
| <input type="radio"/> General Practitioner             | <input type="radio"/> Podiatrist             |
| <input type="radio"/> Health Care Assistant/Technician | <input type="radio"/> Practice Nurse         |
| <input type="radio"/> Hospital based doctor            | <input type="radio"/> Radiographer           |
| <input type="radio"/> Hospital based nurse             |  |
| <input type="radio"/> Other (please specify)           |  |

##### \* 2. At what banding are you employed in your main role?

- |                         |                         |  |
|-------------------------|-------------------------|--|
| <input type="radio"/> 8 | <input type="radio"/> 5 | <input type="radio"/> 2                |
| <input type="radio"/> 7 | <input type="radio"/> 4 | <input type="radio"/> N/A or GP scales |
| <input type="radio"/> 6 | <input type="radio"/> 3 |  |

## Education Needs Scotland: Chronic Oedema/Lymphoedema

**3. Is your work based in:**  
(please indicate all that apply)

☐ General Practice

☐ Hospice

☐ In-patient unit(s)

☐ Out-patient unit(s)

☐ Patients homes

☐ Residential/Care homes

Other (please specify)

**\* 4. In which area do you work?**

(If more than one please indicate main one)

☐ Ayrshire & Arran

☐ Borders

☐ Dumfries & Galloway

☐ Fife

☐ Forth Valley

☐ Grampian

☐ Greater Glasgow & Clyde

☐ Highland

☐ Lanarkshire

☐ Lothian

☐ Orkney

☐ Shetland

☐ Tayside

☐ Western Isles

**5. What do you feel is your role regarding lymphoedema?**

(Please indicate all that apply)

☐ Prevention advice to those at risk of lymphoedema

☐ Identification of possible lymphoedema

☐ Diagnosing lymphoedema

☐ Provision of lymphoedema management advice

☐ Pharmaceutical management

☐ Prescription of compression garments

☐ Application of bandages or other forms of compression

☐ Referral to other service/professional

☐ Not my role

☐ other (please specify)

## Current knowledge



## Education Needs Scotland: Chronic Oedema/Lymphoedema

**6. Please indicate the most appropriate responses:**

**(You can indicate more than one box in a row e.g "Disagree" and "Education/information would help".)**

	Agree	Disagree	Education/information would help	Not my role
I am confident in distinguishing lymphoedema from other causes of swelling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of diagnostic tests that might be requested to confirm a diagnosis of lymphoedema	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If a lymphoedema patient presented with infection (cellulitis) I know where to find the latest consensus guidelines on management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know which type of emollient would be prescribed to prevent skin problems typical of lymphoedema	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to refer a patient to the nearest specialist lymphoedema service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to access SIGN guidelines for liposuction for lymphoedema	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware that there is a difference between compression garments for lymphoedema and support hosiery for vascular problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am aware of the clinical reasons for prescribing class 2 or 3 compression garments rather than class 1 for some patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Any comments on the above?

## Keeping up to date about lymphoedema

**\* 7. Have you had any education/training on lymphoedema diagnosis and management in the last 5 years?**

☐ Yes

☐ No

## Education Needs Scotland: Chronic Oedema/Lymphoedema

### 8. Who provided this education/training?

(You can indicate more than one if applicable)

- ☐ A local lymphoedema service
- ☐ A national/regional conference
- ☐ A manufacturer/supplier
- ☐ Self-study with journals/literature
- ☐ Self-study with on-line material
- ☐ A Higher Education Institution

Other (please specify)

## Tell us your needs, if any....

### 9. To what extent do you perceive your education needs regarding lymphoedema are already met:

	Not at all	Partially	Mostly	Completely
Degree to which these needs are met:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any comments:

### \* 10. Do you feel you would benefit from access to further education on lymphoedema recognition and/or management?

- ☐ Yes it would be of benefit to me
- ☐ No. It would be of no benefit to me

## Education Needs Scotland: Chronic Oedema/Lymphoedema

**11. In which of the following would education enhance your role? (Indicate the 3 most important)**

- ☐ Advising on skin care to reduce risk of cellulitis in mild/moderate lymphoedema
- ☐ Applying multi-layer bandaging for lymphoedema
- ☐ Assessment of patients with chronic oedema/lymphoedema
- ☐ Awareness of current lymphoedema management techniques
- ☐ Differential diagnosis of lymphoedema
- ☐ Exercise prescription for lymphoedema patients
- ☐ Head & neck oedema – supporting self management
- ☐ Identification of patients at risk of lymphoedema
- ☐ Lymphoedema management in acute oncology
- ☐ Management of oedema in advanced disease
- ☐ Measuring & fitting compression garments
- ☐ Prescribing and advising on intermittent pneumatic compression pumps for lymphoedema
- ☐ Applying supportive bandaging for lymphoedema in advanced disease
- ☐ Teaching self massage - Simple Lymphatic Drainage
- ☐ Wound care/leg ulcer care with lymphoedema patients

Other (please specify)

## Delivery method of information and education

**\* 12. What would be the best way to address these needs?  
(Indicate those that you feel would be most useful)**

- ☐ Training provided by the local lymphoedema practitioner
- ☐ Courses provided by universities or colleges
- ☐ Courses provided in health care setting
- ☐ Group training provided by industry
- ☐ On line training packages
- ☐ Other (please specify)

## Almost finished..

**13. Any other comments?**

**Education Needs Scotland: Chronic Oedema/Lymphoedema****A final request..**

In order to expand on the knowledge gained, from this survey we intend arranging a focus group of representatives of each participating profession. This will be held at the University of Glasgow on Thursday 12th or 19th May at 2pm until 3pm. If you are willing to give an hour of your time to attend this focus group you can enter your e-mail address below or to separate your responses from your e-mail address please contact with your preferred date or that you could attend either date [Emma.Fisher@glasgow.ac.uk](mailto:Emma.Fisher@glasgow.ac.uk) Reasonable travel expenses will be paid.

**14. I am willing to be contacted about attending a focus group my e mail address and preferred date is:**

Thank you for participating in this project. We would like to reassure you once again that unless you have given your e mail address above, which will be used for the purposes of the focus group only, all answers are completely anonymous and no e mails or IP addresses have been given to the survey host or any other persons. If you would like further information about the project you can e mail the project lead Rhian Davies at [Rhian.Davies@glasgow.ac.uk](mailto:Rhian.Davies@glasgow.ac.uk) or call 0141 330 2972.

## Appendix 4: Questionnaire for Specialists

### Education Needs Scotland: Lymphoedema

#### What is this?

This survey is part of a University of Glasgow project supported by NHS Education(NES) and Macmillan Cancer Support.

The aim of the survey is to establish the education needs of health care professionals in Scotland working with lymphoedema patients and their preferred learning method.

#### Why now?

With increasing fiscal constraints and high patient expectations it is ever more important that you have the education you need, when you need it and in the format you prefer. As someone who has undertaken specific training in lymphoedema you also need the generalist health care professionals around you to have the knowledge and information they need to support you in that role.

The questionnaire firstly asks you about your own continuing professional needs and secondly asks for your perception of the education needs of generalist health care professionals. A separate questionnaire is concurrently being issued to GPs, District Nurses and Allied Health Professionals to survey their perception of their needs.

In order to give you opportunity to fully express your views on this subject the survey is expected to take about 20 minutes but we would welcome as much information as possible. You can complete the survey any time over the next 10 days. All answers are anonymous; no e-mail or IP addresses will be passed on the survey host or any other persons. The researchers will only have your e-mail if, at the end of this survey, you supply it yourself in order to be contacted to be part of a one-off follow up focus group.

The knowledge gained from this project will inform the development of lymphoedema education. In so doing it is anticipated that it will improve the care and support of patients with lymphoedema. Completion of the questionnaire is taken as consent for researchers to use the data.

Thank you for participating,  
Rhian Davies  
University of Glasgow

You can move back & forth between pages by clicking on the "next" and "previous" buttons. Use the scroll bar at the side to scroll down to the buttons. On the last page click "done" to submit your answers, your answers will not be saved or submitted until you have done this.

#### Your role

##### \* 1. Which of these best describes your job title/role?

- |   |   |
|---|---|
| <input type="radio"/> Lymphoedema Key-worker            | <input type="radio"/> Oncology/Palliative Care Nurse                  |
| <input type="radio"/> Lymphoedema Practitioner          | <input type="radio"/> Oncology/Palliative Care Occupational Therapist |
| <input type="radio"/> Lymphoedema Specialist            | <input type="radio"/> Oncology/Palliative Care Physiotherapist        |
| <input type="radio"/> Lymphoedema Advanced Practitioner | <input type="radio"/> Radiographer                                    |
| <input type="radio"/> Breast Care Nurse                 | <input type="radio"/> Doctor/Surgeon                                  |
| <input type="radio"/> Community/District Nurse          |   |
| <input type="radio"/> Other (please specify)            |   |

## Education Needs Scotland: Lymphoedema

2. How many years experience do you have of working with lymphoedema patients beyond the role expected of a generalist?

- ☐ Less than 1 year
 ☐ 4-9 years  
☐ 1-3 years
 ☐ Over 10 years

3. How much of your work time is taken up with your lymphoedema role over an average month:

- ☐ 80-100%
 ☐ 40-59%
 ☐ less than 20%  
☐ 60-79%
 ☐ 20-39%

4. Is this protected time for lymphoedema?

- ☐ Yes  
☐ Partially protected  
☐ No

5. Is your work based in:  
(indicate all that apply)

- ☐ Out-patient unit(s)
 ☐ Patients homes  
☐ In-patient unit(s)
 ☐ Residential Care  
☐ Hospice
 ☐ General Practice  
☐ Other (please specify)

6. Are you part of a team?

- ☐ No, sole practitioner/alone working  
☐ Yes, part of a team but I'm the only person with lymphoedema remit  
☐ Yes, part of a team, some/all of whom have a lymphoedema remit

Other (please specify)

## Education Needs Scotland: Lymphoedema

### \* 7. How would you describe your geographical area of work?

- ☐ Large urban city/town of >125,000 people
- ☐ Urban town of 10,000 -125,000
- ☐ Small town of 3,000 -9,999
- ☐ Rural settlements < 3,000 but within 30 mins of a town of >10,000
- ☐ Remote rural (over 30 mins drive to a town of over 10,000)

## Your education in Lymphoedema Management

### \* 8. Please select the best description of your lymphoedema training/education (indicate the main source for each level of training)

	Initial training/management of uncomplicated lymphoedema	Advanced training/management of complex lymphoedema
Accredited course through a higher education institution (HEI)	<input type="checkbox"/>	<input type="checkbox"/>
Accredited course through another establishment	<input type="checkbox"/>	<input type="checkbox"/>
Unaccredited CPD courses at an HEI	<input type="checkbox"/>	<input type="checkbox"/>
Unaccredited CPD course through another establishment	<input type="checkbox"/>	<input type="checkbox"/>
Experiential learning in your job	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="text"/>	

### \* 9. What was the main teaching method used (indicate the closest description for each level):

	Initial training/management of uncomplicated lymphoedema	Advanced training/management of complex lymphoedema
Entirely face to face classroom/workshop teaching	<input type="checkbox"/>	<input type="checkbox"/>
Mixture of face to face classroom/workshop and some distance learning	<input type="checkbox"/>	<input type="checkbox"/>
Entirely distance learning	<input type="checkbox"/>	<input type="checkbox"/>
Workplace learning with an expert/mentor	<input type="checkbox"/>	<input type="checkbox"/>
Workplace learning self-directed	<input type="checkbox"/>	<input type="checkbox"/>
Not applicable	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="text"/>	

## Identifying your continuing education needs

## Education Needs Scotland: Lymphoedema

**\* 10. How do you identify your lymphoedema education needs?**  
(indicate all that apply)

- ☐ Professional Development meeting with manager
- ☐ Critical Incident/ difficult case review
- ☐ Personal reflection
- ☐ Personal interest/curiosity
- ☐ Peer pressure
- ☐ Service benchmarking
- ☐ Other (please specify)

\_\_\_\_\_

**\* 11. To what extent do you perceive your educational needs are met:**

My education needs are met: Completely Mostly Partially Not at all

☐ ☐ ☐ ☐

## Accessing Continual Professional Education (CPD)

**\* 12. Have you participated in lymphoedema education within the last 2 years for your own professional development?**

- ☐ Yes
- ☐ No

**13. What factors have been most significant in enabling/motivating your recent lymphoedema education?**

	A significant enabler/motivator	A moderate enabler/motivator	Not an enabler/motivator	Not available	Not applicable
Adequate study leave	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Funding for course fees	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Funding of travel expenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support of manager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Need of qualifications for role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other personal reasons	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Any additional comment:

\_\_\_\_\_



## Education Needs Scotland: Lymphoedema

14. What was the source of funding for the last lymphoedema course you attended?

	Employer	Grant/Scholarship	External source/charity	Self-funded	Other	Not applicable
Course Fee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. What percentage(%) of the course time was given as study leave? (enter a number between 0 and 100)

## What are your current lymphoedema education needs?

16. Choosing ONLY UP TO 3 subjects, which do you feel will be a priority need for updating/further education for yourself over the next 2-3 years?

- ☐ Application of Kinesiotaping for lymphoedema
- ☐ Application of Manual Lymphatic Drainage techniques
- ☐ Assessment & differential diagnosis of complex patients Diagnostic tools in lymphoedema
- ☐ Exercise prescription
- ☐ Latest innovations in lymphoedema management
- ☐ Lymphoedema management in acute oncology
- ☐ Lymphoedema service management & development
- ☐ Management of lymphoedema related dermatology issues ( Advanced Skin care)
- ☐ Management of oedema in advanced disease
- ☐ Measuring & fitting for alternative forms of compression
- ☐ Measuring & fitting of made to measure compression garments
- ☐ Research skills for lymphoedema studies
- ☐ Supporting self-management
- ☐ Supporting patients undergoing liposuction for lymphoedema
- ☐ Teaching Simple Lymphatic Drainage massage to patients/carers
- ☐ Teaching skills & methods of supporting other health care professionals
- ☐ The safe use of Laser with lymphoedema patients
- ☐ The management of genital oedema
- ☐ The management of Head & neck oedema
- ☐ Use of intermittent pneumatic compression pumps for lymphoedema management
- ☐ Wound and ulcer care in lymphoedema patients

Other (please specify)

## Education Needs Scotland: Lymphoedema

### Technology in lymphoedema education

**\* 17. Do you think that greater use of technology would enhance lymphoedema education?**

☐ Yes

☐ No

☐ Unsure

**18. Please state whether the following technology would encourage or discourage you from taking a lymphoedema related course?**

	Encourage	Mildly encourage	No effect	Mildly discourage	Discourage
Self-assessment tests on line with suggested reading	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Web-based guided reading with submitted work to accrediting organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Case scenarios and problem solving on line	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Live on-line support from tutor at set times	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
On-line discussion groups with other course students	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Downloadable Podcasts of lectures/expert talks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DVD film sequences of expert master-classes/techniques	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CD/DVD of modular learning with self assessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CD/DVD of modular learning with submission of work to accrediting organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telehealth master-classes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any other technology we should consider? (please specify)

### Meeting your future needs

**19. How do you perceive your lymphoedema educational needs should be met in the longer term?**

(Please write in the box below).

### The education needs of generalist health care professionals

In the following questions we ask your opinion of the educational needs of the generalist health care professionals (HCPs); professionals who only occasionally come in to contact with lymphoedema patients or patients at risk of

**Education Needs Scotland: Lymphoedema**

lymphoedema.

Due to the rapid and sometimes significant changes that have happened in health care in recent years we ask you base your replies on the last 12 months only. It may be useful to reflect on any delays in referral to your service, the type of information you receive with referrals, the queries or problems of HCPs on transfer of patient care from your service and your teaching and support experiences.

**\* 20. In your opinion do generalist Health Care Professionals have an unmet education need regarding lymphoedema, based on your experiences over the last 12 months?**

- ☐ Yes
- ☐ No
- ☐ Unsure

**What lymphoedema education do other health care professionals need?**

Only a few more questions to go....



## Education Needs Scotland: Lymphoedema

Other (please specify or explain further if necessary)

### Delivering education to other health care professionals

**\* 22. What would be an appropriate means of delivering education to other health care professionals? (indicate all that apply)**

- ☐ Training provided by the local lymphoedema practitioner
- ☐ Courses provided by universities or colleges
- ☐ Courses provided in health care setting
- ☐ Group training provided by industry
- ☐ On line training packages
- ☐ Other (please specify)

**23. If you provide education to other health care professionals what additional education resources would help you?**

(Please answer in the box below, it will grow as you write).

### Anything else you would like to say?

**24. Any other comments?**

(Please write in the box below)

### A final request..

In order to expand on the knowledge gained from this survey we intend arranging a one-off focus group of representatives from each participating profession. This will be held at the University of Glasgow on Thursday 12th or 19th May at 2pm until 3pm. If you are willing to attend this focus group you can supply your e-mail below and preferred date or to ensure your responses are completely separate from your e-mail address you can contact us directly at [Emma.Fisher@glasgow.ac.uk](mailto:Emma.Fisher@glasgow.ac.uk) Reasonable travel expenses will be paid.

**25. If you are willing to be contacted to attend a one-off focus group please supply your e mail address here with preferred date or e mail us directly as above:**

## Education Needs Scotland: Lymphoedema

Thank you for participating in this project. If you would like further information about the project you can e-mail the project lead Rhian Davies at [Rhian.Davies@glasgow.ac.uk](mailto:Rhian.Davies@glasgow.ac.uk) or call 0141 330 2972. Press the "done" button to submit your answers, thank you.

## Appendix 5: Template for Focus Group interviews

Opener	<p>Welcome, ensure forms signed, explanation of process including recording of session and continued anonymity of transcription. Expense forms. Confirm finish time.</p> <p>Definition for the purposes of today: “Lymphoedema will include non-specific <u>chronic oedema</u> that has been present for more than 3 months”.</p> <p>As introductions can you tell us your First name (or other if distinctive), Profession and briefly the type of lymphoedema/chronic oedema patient you might see in your role?</p> <p>Are they cancer and non-cancer-related?</p>
Introductory	On the whole how are patients with lymphoedema identified in your work?
Transition	What leads you to conclude they have lymphoedema?
Patient care theme	<p>What do you find most rewarding about dealing with lymphoedema patients?</p> <p>What kinds of things frustrate or make dealing with lymphoedema patients difficult?</p> <ul style="list-style-type: none"> <li>▪ Mobility/place of care issues</li> <li>▪ Lack of services</li> <li>▪ Role for technology, suggestion of type</li> </ul> <p>What support systems exist to help you care for your patient?</p> <p>To what extent does this meet your needs? How could it be better?</p> <p>Is there a role for teleconferencing (telehealth) in supporting your role with this group of patients? What would this add to care? Are you currently using it?</p> <p>How prepared do you feel to care for lymphoedema patients?</p> <ul style="list-style-type: none"> <li>▪ To deal with sustained/long term care</li> <li>▪ Expectation of being able to make a difference</li> <li>▪ Patient expectations of outcome realistic</li> </ul>
Education theme	<p>Thinking about your background to caring for Lymphoedema patients. Was lymphoedema included in your pre-registration training?</p> <p>Is there a right time to introduce it?</p> <p>Have you had any specific training in lymphoedema?</p> <ul style="list-style-type: none"> <li>▪ If industry what type? Valuable? Sufficient?</li> </ul>

	<ul style="list-style-type: none"> <li>▪ undergraduate/post graduate -</li> </ul> <p>How might you best be further supported in learning?</p> <p>For your profession/location where does lymphoedema information need to be for access 'as and when' needed?</p> <ul style="list-style-type: none"> <li>▪ In existing systems</li> <li>▪ Leaflets, posters, booklets</li> <li>▪ On-line, intranet, other national websites - which ones? (E.g. GP intranet portal, Macmillan Learnzone, BLS, LNS)</li> </ul> <p>What do you see as the role of Universities/colleges?</p> <p>A high percentage of respondents wanted education provided by the local lymphoedema practitioner but they are limited in number. What would your suggestions be to make this feasible for your profession?</p> <ul style="list-style-type: none"> <li>▪ Content - priorities</li> <li>▪ Practical/theory balance - what would make you feel competent at assessment and diagnosis or practical skills</li> <li>▪ Location - free up time to attend or L practitioner to attend</li> <li>▪ Supporting learning with technology - what's practical/works</li> </ul> <p>Many respondents wanted greater awareness of latest management techniques in lymphoedema....meaning what?</p> <ul style="list-style-type: none"> <li>▪ what goes on in a specialist clinic (to support patient)</li> <li>▪ the latest thing that can be implemented in <u>your</u> workplace</li> <li>▪ the latest research and technology (interest)</li> </ul> <p>Early identification of patients with lymphoedema tends to lead to better outcomes in preventing symptoms and long term effects. How would you suggest that recognition of those 'at risk' of lymphoedema heightened?</p> <ul style="list-style-type: none"> <li>▪ Location specific issues?</li> <li>▪ Pathways/protocols</li> <li>▪ Conflict of opinion in areas where risk is played down</li> </ul>
Ending question	<p>The aim of the study is investigation of the education needs of health care professionals in Scotland regarding lymphoedema and how these might best be met. Have we left anything out?</p> <p>What have been the key messages from this meeting would you say?</p>

## APPENDIX 6: Example post-focus group debriefing and initial analysis

### **Note-takers' immediate impression - summary of education needs:**

The main thing that came across strongly that there was a feeling of inequality/disparity of access to services for patients and that this in turn affected the learning needs of the health care professional.

There was a need for education but due to generalists only seeing a few/occasionally they get de-skilled even if given the opportunity to learn.

Resources for services, education & research is a major issue and that inappropriate care (hospitalisation) was wasting resources.

A suggestion that it was the budget holders that needed the education!

A need for greater communication and networking to use the specialist knowledge that does exist.

Recognition of the need, by having SIGN guidelines is important which would require more resources for research.

That the solution to the need is multimodal involving specialist clinics, Universities, generalists, industry & greater use of technology .

### **Moderator and note takers' debriefing.** (taken from Krueger 1997 book 6)

- ☐ What were the most important themes or ideas discussed?
- ☐ How did these differ from what was expected?
- ☐ Were there any unexpected or unanticipated findings?
- ☐ What points need to be included in the report?
- ☐ What quotes should be remembered and possibly included in the report?
- ☐ Should we do anything different in the next focus group?

Group was strong on need for research and need for SIGN guidelines to maximise impact on patient care and QOL and highlight lymphoedema in its own right.

Clear differences of available services for cancer & non-cancer related lymphoedema.



Exposure of generalists to lymphoedema is occasional – not frequent enough to be upskilled/maintain skills.

Need more than just access to knowledge, need practical skills and access to mentors.

Comfortable sourcing information from internet.

Need to educate others than registered HCPs too, like carers and HCSW.

There is a hierarchy of knowledge/skills required depending on role and access to specialist support.

Frustrations at patients not taking responsibility e.g. morbidly obese, returning mobility and leaky legs.

Need risk assessment and prevention message to patients and carers.

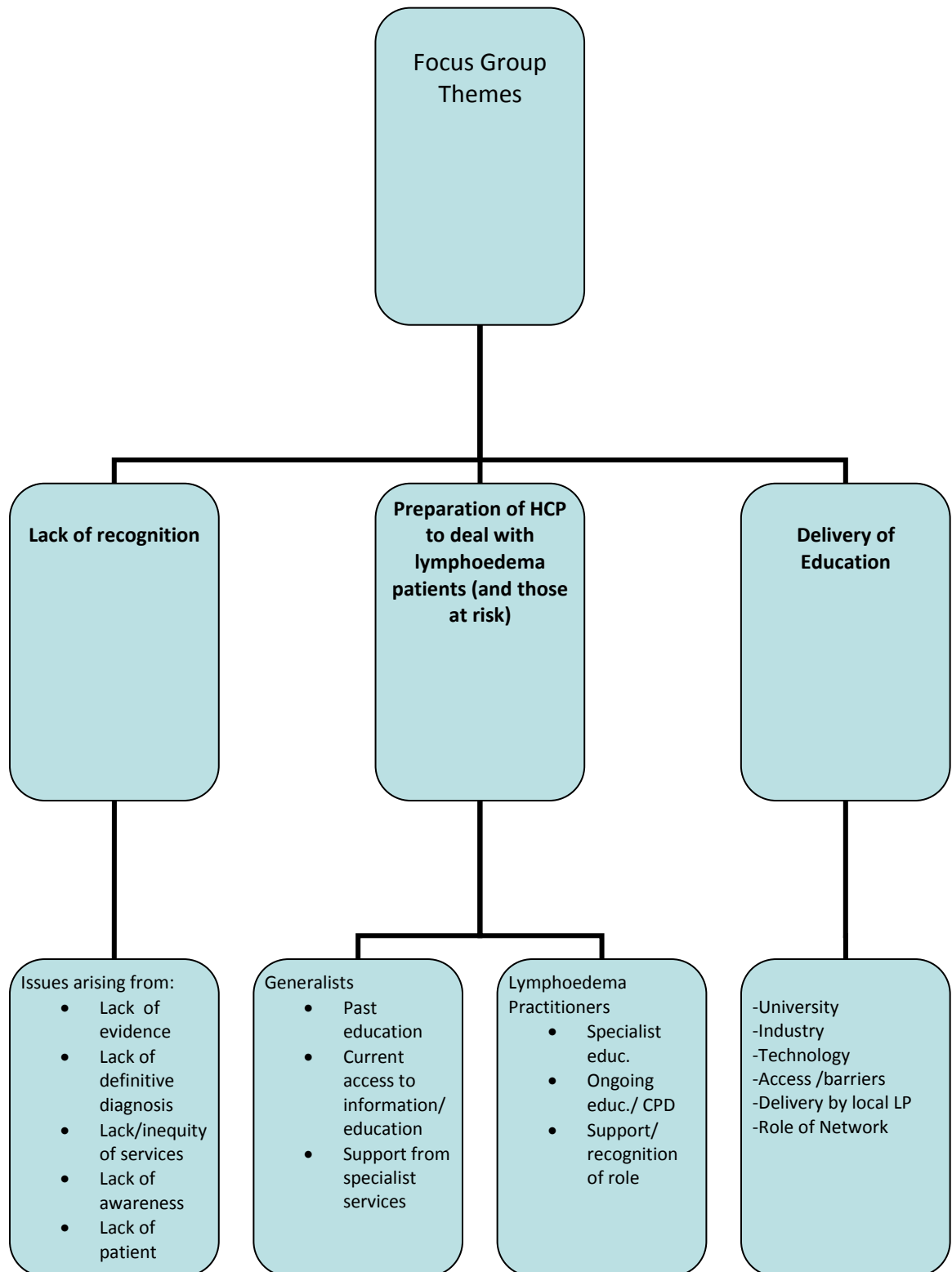
Need a systematic assessment tool for generalists to identify it or those at risk.

Research into cost of stay in hospital for lymphoedema under-treatment/mismanagement.

Policy makers need to understand implications of disparity in services.

Facilitator AON and researcher RD 19.5.11: 15.30hrs

## APPENDIX 7: Initial framework analysis themes Phase 1



## **Appendix 8: Recommendations from Phase 1**

As reported in Davies (2012)

- A. Lymphoedema specialists should continue to be supported by their managers in maintaining their specialist skills and knowledge by attending relevant HEI and CPD courses.
- B. Succession planning should be incorporated into job plans to ensure continuity of service.
- C. An expert group should be reconvened to produce a robust evidence-based clinical guideline for the care and management of patients with lymphoedema aiming for acceptance as a SIGN guideline
- D. Recognition of lymphoedema and its contemporary management should be included in all pre-registration/undergraduate HCP education
- E. Continuing education for all generalist HCPs should include the topics of current management in lymphoedema, skin care to prevent cellulitis, identifying those at risk and information on accessing specialist services.
- F. Further research is recommended to identify educational needs in relation to lymphoedema of practice nurses, social care providers and unpaid carers.
- G. Specialist Lymphoedema Education and CPD should continue to be available through HEI and accessible to qualified health care professionals working with this patient group.
- H. A national network of lymphoedema specialists should be created based around a core website for communication and sharing of resources.
- I. The specialists' role in supporting, acting as resource and educating at a local level should be explicit in job descriptions and job plans allowing time to implement structured training plans.

- J. HCPs should have dedicated time to attend in-service training provided by local lymphoedema practitioners based on local need.
- K. Generalist HCPs should have access to information on current best practice of lymphoedema through NHS and GP intranet systems including a link to national cellulitis guidelines, information about the referral criteria of specialist services and patient sources of support and information.
- L. Awareness should be raised of the online resource on Chronic Oedema/Lymphoedema (differential diagnosis and current management) through BMJ learning <http://learning.bmj.com/learning/module-intro/lymphoedema-.html?moduleId=10029385>.
- M. Consideration should be given to the creating systems for local generalist HCP to have virtual consultations with a lymphoedema specialist,
- N. Scottish Health Boards should use the opportunity to work with the Macmillan Lymphoedema Project Manager to review the current model of service provision with a view to providing access to high quality care to patients regardless of underlying cause.
- O. Community Health Care Partnerships should consider providing access to a lymphoedema specialist as a source of advice for all community-based generalist HCPs.

## Appendix 9: Ethical approval and Clinical Governance Phase 2

27<sup>th</sup> February 2013

Rhian Davies  
Nursing and Health Care  
University of Glasgow  
59/406 Oakfield Ave  
Glasgow G12 8LL

Dear Rhian Davies

### **MVLS College Ethics Committee**

***Project Title:*** Developing a model for producing an educational resource for health care professionals: an exploration of the processes involved.

***Project No:*** 200120009

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- If the study does not start within three years of the date of this letter, the project should be resubmitted.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely



Professor William Martin  
College Ethics Officer

**Appendix 9 (continued) R&D opinion (by e-mails)**

From: Dr Erica Packard, [mailto: ] Academic Research Co-ordinator, NHS Greater Glasgow and Clyde, Research and Development Central Office, The Tennent Institute, 1st Floor, Western Infirmary General, 38 Church Street, Glasgow, G11 6NT. Tel: 0141 232 9448

Sent: 07 March 2013 09:13

Dear Rhian,

Based on review of the GU ethics form provided this study appears to be service development rather than research. You do not require R&D review/approval.

best wishes

Erica

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From: Dr Judith Godden [mailto: ] Manager/Scientific Officer, West of Scotland Research Ethics Service, Tennent Institute, Western Infirmary, Glasgow G11 6NT. Tel: 0141 211 2126

Sent: 07 March 2013 11:48

To: Rhian Davies

Subject: RE: advice re ethics level required

Dear Rhian

Thank you for sending me your study for comment. The study does not require to be reviewed by an NHS research ethics committee as it does not fall under our remit as described in GAfREC 2011. You should check independently with the R&D Department for one of the Health Boards to see if they require a level of management approval. If R&D approval is required then they will help you with a central approval through NRS.

Kind regards

Judith

## Appendix 9(continued) Clinical Governance Registration

Health Board	Clinical Governance Registration Contact	Reg form requested	Reg form or e-mail back from them	Reg form completed (where supplied) and requested supporting docs sent	Date confirmation rec'd that project registered
Glasgow	<i>contact details removed</i>	✓	✓	✓	16.04.13
Forth Valley	<i>contact details removed</i>	✓	✓	✓	24.04.13
Ayrshire	<i>contact details removed</i>	✓	✓	✓	26.04.13
Borders	<i>contact details removed</i>	✓	✓	✓	24.04.13
Dumfries	<i>contact details removed</i>	✓	✓	✓	15.04.13
Fife	<i>contact details removed</i>	✓	✓	✓	16.04.13
Grampian	<i>contact details removed</i>	✓	✓	✓	24.05.13
Highland	<i>contact details removed</i>	Repeat request sent 06.05.13	E mail sent 18.06.15 for copy of original registration.		Registration re-confirmed 22.06.15
Lothian	<i>contact details removed</i>	✓	✓	✓	15.04.13
Lanarkshire	<i>contact details removed</i>	✓	✓	✓	06.05.13
Orkney	<i>contact details removed</i>	✓	✓	✓	15.04.13
Shetland	<i>contact details removed</i>	✓		(no participants)	-
Tayside	<i>contact details removed</i>	✓		✓	19.04.13
Western Isles	<i>contact details removed</i>	✓		✓	15.04.13

## Appendix 10: Table of Phase 2 outset literature

Reference	Aim	Method	Funding	Outcome	Relevance
Street et al 2007	Improve existing web-based information resource in palliative care (in Australia) for health professionals and carers	Action-research inspired study. Survey of needs (n=166). Content developed by working parties of academic and research nursing, clinical and management staff. Cycles of feedback from end-users and experts. Resource actually built by external IT experts.	Government funded (Victoria, Australia).  Overall cost of the project in 2007 declared  A\$ 184,872	New website produced. Study compared results of pre- to post-development online evaluation - evaluated well for content 82% c.f. 65%; but process time consuming and costly. It needed extra funding to ensure	Study provides useful insight into a) some of the difficulties of iterative study designs in terms of knowing what data are going to be of significance later in the study; b) the costs in terms of volunteer time and administrative time due to the vast amount of data produced; c) that web-design issues that can remain even with the combination of expert IT



Reference	Aim	Method	Funding	Outcome	Relevance
				sustainability.	and user input.
Gresty et al 2007	To explore the development of an online resource to support genetics health education.	Action research. Survey of need (demand) for resource to nurses and mid-wives (n=93). Website content developed by research team (unclear but seem to be academics rather than clinicians) but clinicians encouraged to be contribute. Evaluated in practice by student nurses and open access with electronic feedback.	Teaching Fellowship Funding, amount not declared.	Early stage evaluation stage of an online learning resource only reported. However high usage recorded electronically in 2006.	The iterative cycles of work expected in action research appear to be predominantly in relation to evaluation against literature and initial survey. The participative input of practicing clinicians to the website content is unclear. This study links website design to pedagogic theory for e-learning often missing in learning website design literature.
Archambault	Scoping	Protocol for scoping	a Canadian Institutes	Findings	Awareness of this large

Reference	Aim	Method	Funding	Outcome	Relevance
et al 2012 (N.B. the final report was taken into account mid-study when published in 2013)	review of the evidence of the impact of collaborative writing applications as Knowledge Translation (KT) tools in the health care sector and factors that affect their use.	review. Map literature, compare features, describe evidence of effect, inventory the facilitators and barriers to use, produce action plan and research agenda.	for Health Research Knowledge Synthesis Grant (FRN 116632); a Fonds de recherche du Québec–Santé career scientist award (24856); a Fonds de Recherche du Québec–Santé, Establishment of young researchers–Juniors 1 Grant (24856); and a research grant from the Centre de santé et services sociaux Alphonse-Desjardins (CHAU de Lévis).	published Oct 2013 ( <i>7 months after the start of Phase 2 of this study</i> ). <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3929050/?report=printable">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3929050/?report=printable</a>	review at the start of Phase 2 confirmed the lack of collated evidence around collaborative online resource development in health care and, when the final report was published (at the end of our 2 <sup>nd</sup> cycle) it informed our ongoing work from SLPN3.
Byington	To describe	This is not a research	No funding.	Recommends	The particular format of

Reference	Aim	Method	Funding	Outcome	Relevance
2011	the set up of an online CoP using blogs.	study but a practical guide based on a review of the literature pertaining to the use of blogs for support and learning within CoP.		blogs to increase collaboration to support and increase teacher learning. A hybrid CoP (virtual and face-to-face) requiring core elements of leadership, topic relevance and supportive organizational environments.	the OLR was to be discussed at the start of Phase 2 (e.g. standard website, blog, wiki) so this paper informed that discussion. In addition, it gave an indication of some of the elements which may emerge as components of the model of the process of OLR development.
Welsh and Houston 2010	To develop and evaluate a nursing portal in one	Team included nurses, clinical and technical staff (IT dept.). 4 stages: design and layout,	Claim no specific direct ( <i>additional</i> ) costs as team members participated within	43% response rate (n=496), mean score for usefulness and	Despite the involvement of nurses in the development team this paper was an example of

Reference	Aim	Method	Funding	Outcome	Relevance
	USA medical centre.	content development, technical development, staff education. Purpose of portal - general communication, clinical resource information, patient information. Actual technical built done by IT technologists, no mention of development cycles, waterfall approach. Build period 2004-2006. Technology Acceptance Model used to evaluate usefulness of portal through 2007 with online survey. Essentially a	existing working hours. In addition, staff required training to use the portal.	ease of use were both 4.65 on a scale of 1 - 7 where 7 = strongly agree. Number of hits and number of different users were also counted. Mainly used to access patient information.	a top down, single organisation approach. Portal not exclusively a learning resource, but a communication tool. Costs claimed to be nil yet there were multiple examples of additional work e.g. the informatics nurses providing additional training, therefore opportunity costs are implied. Helped distinguish different purpose.

Reference	Aim	Method	Funding	Outcome	Relevance
		product evaluation.			
Ruiz et al 2007	To develop an e-learning package to enhance geriatric education (USA)	An evaluation framework was described as being in development on the basis of a lack of evidence for one particular evaluation method. Peer review, expert opinion and evaluation theory being the basis.	Voluntary consortium with many voluntary meetings and collaborations but financial disclosure record the support of Stein Gerontological Institute and the State of Florida Agency for Health Care Administration (Florida's Teaching Nursing Home Program).	Website and digital repositories created to support geriatricians teaching other HCP and for HCP to access directly due to lack of specialist geriatricians.	This consortium project was in response to an increasing demand for education on geriatrics as a specialist subject of concern to generalist HCP. A lack of suitably experienced/qualified specialists making the provision of e-learning a useful alternative to previous education delivery. As such this represented a (largely) voluntary collaborative development of OLR but effectiveness had yet to

Reference	Aim	Method	Funding	Outcome	Relevance
					be evaluated.
Behl et al 2012	Evaluation of the creation of a Learning Community to develop a resource on Telehealth in Hard of Hearing services (USA)	1 year evaluation. Qualitative and quantitative data through 2 surveys of participants (administrators and clinicians n=19).	Unclear. Launched by The National Center for Hearing Assessment and Management at Utah State University. Each (6) participating areas committed to financial resources to sustain/expand program for 1 year, a practitioner and a technical support person)	A free online Practical Guide with multiple tools. Learning reported as regarding state policies, evaluation methods and tele-practice. Evaluation of Learning Community as process.	Learning communities are an alternative to CoPs or networks, but products such as resources are not always produced as in this Behl et al study. Points to take are the significant time and effort for busy clinicians, the issues around sustainability, the financial investment and technical support and the crucial role of the facilitator and sharing responsibility for leadership and feedback to the larger group.

Reference	Aim	Method	Funding	Outcome	Relevance
					Quasi-experimental design with qualitative data considered appropriate.
Seddon and Postlethwaite 2007	Creation of a model of reflection for collaborative construction of knowledge	Participatory action research. In steps, group agreement of research question, create prototype model from literature review, feedback on trials of prototype, review on an intermediate tool, and review of final version. Data drawn from observation of online dialogues focused online discussion and face-to-	Unclear. Authors' organisations UK National College for School Leadership (NCSL) and University of Exeter.	A model of reflection and facilitation of reflection to create knowledge within an online community is developed and tested. The model was developed with heads of schools and as such the users would be	The process of constructing a model from a theoretical basis and refining it through cyclical online review was informative, as was the means of gaining data in this environment. The model itself is of the cognitive process of knowledge construction rather than the overall process of OLR construction. It could be

Reference	Aim	Method	Funding	Outcome	Relevance
		face interviews.		expected to have a high level of understanding and ability in making explicit some of the answers required in the model.	used within our process as a tool for critical reflection on content but as an additional learning requirement. Reflective logs more familiar to our participants may be useful however.
Jakubik M 2008	Create a model of knowledge creation in a CoP	Action research, participative inquiry. Value mapping	Unclear, but study held with 2 large business organisations.	KM could learn from looking at the human interaction side of knowledge creation rather than being dominated by non-human process focus of	Consideration of how knowledge is considered in KM (e.g. Nonaka) rather than traditional learning theories and the concept of knowledge as commodity/asset in relation to contemporary asset based management in health care.



Reference	Aim	Method	Funding	Outcome	Relevance
				IS literature	
Younger 2010	Collate evidence of the online information seeking behaviours of doctors and nurses.	Review of evidence 1995-2009 in PubMed, CINAHL, Embase (Ovid), LISA, LISTA. Search terms given and findings charted.	Not specified.	Doctors and nurses preferred to ask colleagues first. Their searching behaviours are not significantly different but idealised academic model of searching less likely in community and geographically remote settings.	<p>The preference for easy access, quick information from colleagues or public search engines reflective of discussion in Phase 1 focus group.</p> <p>The preference of asking a colleague may be historic or reflect lack of ease of access to the internet.</p> <p>Different terms used for information seeking useful.</p>
Perzeski 2012	Information	Survey of alumni of Ohio	None reported.	Responses n=143	Quick search engine

Reference	Aim	Method	Funding	Outcome	Relevance
	seeking behaviour of Podiatric Physicians (USA)	College of Podiatric Medicine		Sample size not achieved.	search may have replaced asking a colleague in real world clinical settings.
Harland and Drew 2013	To discover UK Physiotherapists use online resources for CPD	Online survey through recognised channels for registered physiotherapists in UK conducted using SurveyMonkey in 2011.	Not declared.	93% (n=774) completion rate. Distribution broadly representative. Most commonly used source was Google (567/774, 73%). Most commonly searching for evidence based guidelines.	Notwithstanding reservation about some of the assumptions made in the conclusion of this study there are some useful inferences that can be made. Despite the availability of focussed medial search data bases, physiotherapists are predominantly accessing more public sources such as through Google. OLR

Reference	Aim	Method	Funding	Outcome	Relevance
				(685/774, 89%). Being unsure of robustness significantly frustrating (298/744, 39%). Less than half had heard of NHEvidence (47%) and fewer still had used it (35%).	which can raise awareness of the relevancy of their skills and increase their knowledge therefore needs to be easily found through Google and similar tools.
Farrimond et al 2006	Development and evaluation of a computer assisted learning CAL	Developed in academic context (medical school in Manchester, UK). Action research by 5 teachers (clinical educators) and 13	Curriculum Innovation Fund, University of Manchester.	A CAL package was developed which was positively evaluated for usability but non-	The process of learning resource development using clinical-educators and students through the iterative method of action research produced

Reference	Aim	Method	Funding	Outcome	Relevance
	package for medical students for dermatology	students. Cycles included defining requirements from literature and student survey, creation of prototype by storyboarding then electronic draft, sent out for expert review, then further development and evaluation for usability, likability and perceived value as an instructional tool. Think aloud techniques and timed cases used as well as end of task questionnaire and researcher observer questioning.		stakeholder experts remained sceptical as to the learning of practical skill achieved through this medium. Further evaluation was ongoing and further research into the learning achieved was recommended.	a resource with good fidelity to the requirements identified. The lack of engagement of non-stakeholders in the finished product could threaten the sustainability or increased use in practice, however further positive evaluation may address this. The use of talk out loud for OLR evaluation is worthy of consideration.

Reference	Aim	Method	Funding	Outcome	Relevance
Carroll et al 2009	To add to CPD evidence regarding online learning of HCP	A systematic review of qualitative data from studies reporting health professionals' experience of e-learning in HEA-based stand-alone CPD courses. Ranging from 1992. Process and criteria for inclusion and exclusion clear. 19 papers finally included.	Commissioned by the UK Higher Education Academy (HEA).	Concludes a number of recommendations for on-line courses to include assessment, discussion forums and interactive content.	The tutor:student interaction not relevant, assessment may be in later phases but use of film/media to increase interest and applicability to users' work important. Experience is better if social. Forum for peer discussion (not so much for doctors) and allowing for 'lurking' (passive learning). Search-ability important (search box).

# Appendix 11: Example OLR analytics

Figure A11-0-1 Example of analytics of OLR

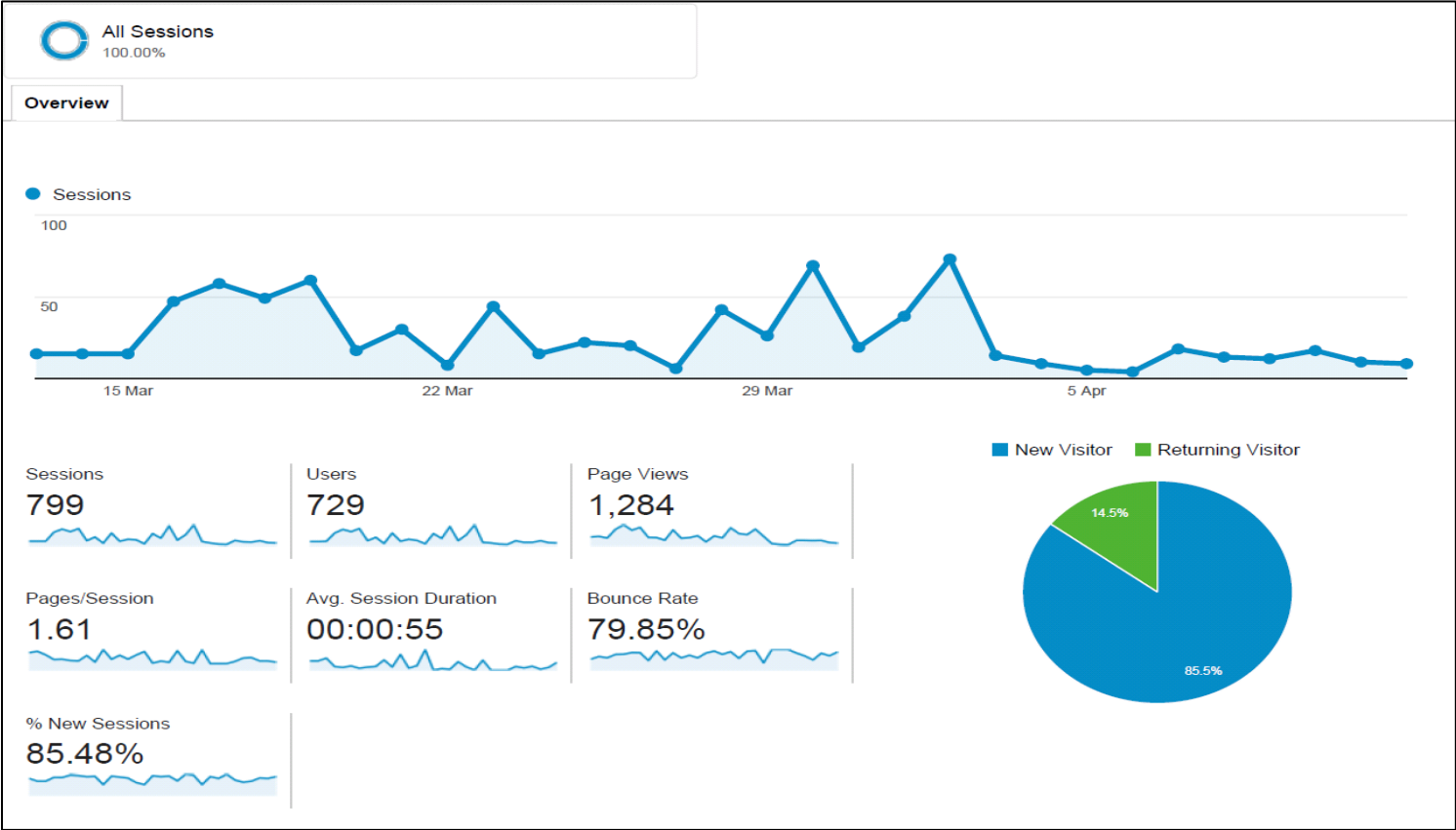
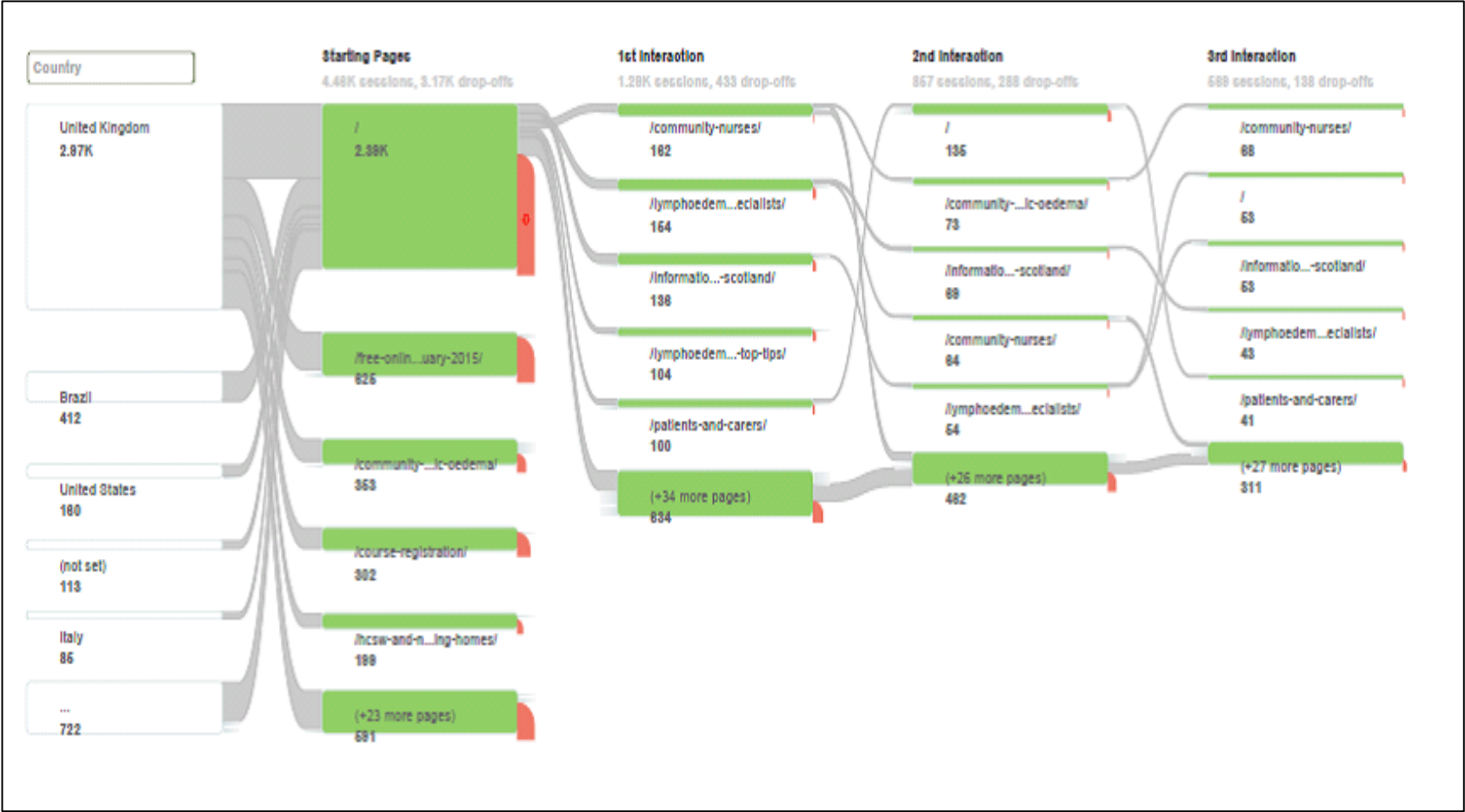


Figure A11-0-2 Example of visitor flow to OLR



## Appendix 12: Subgroup Participant Information

**Study:** Developing a model for producing an educational resource for health care professionals: an exploration of the processes involved.

**Researcher:** Rhian Davies tel: XXXXX e-mail: XXXXXXXXXXXXX

You are being invited to take part in the above research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

### What is the purpose of the research?

The aim of this phase of the study is to explore whether existing expertise and infrastructures can be utilised to develop a model for producing an education resource to meet the identified education need. The researcher seeks to work in partnership with SLPN to evaluate the feasibility of developing and implementing an on-line resource designed to meet identified education needs of both generalist health care professionals and lymphoedema specialist practitioners.

### Why have I been chosen?

Members of the SLPN are invited to work with the researcher in subgroups to develop a section of a resource to meet the identified education needs.

### Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you are still free to withdraw at any time without giving a reason and without consequence.

### What will happen to me if I take part?

You will form part of a small subgroup of 2-4 members depending upon area of interest. Each subgroup will be given a summary of the self-identified and specialist identified education needs of one group of health care professionals e.g. community nurses or GPs. Facilitated by the researcher the subgroup will then negotiate its intended way of working, e.g. planned on-line working, sharing of documents, teleconferences and/or number of meetings and goals with timelines. You are asked to document/log the decisions of the subgroup about how you intend to work as a subgroup and later log any changes to the plan and any decisions made in developing the resource. You will be asked to consent to the researcher using these notes/logs for analysis of the processes involved in developing the resource. This work will continue from March 2013 to September 2014 with the researcher facilitating each subgroup as required and providing technical



support. The time commitment is expected to be the equivalent of 1 hour per month over a maximum of 18 months. You will also be invited towards the end of this period to be interviewed regarding your experience of participating in the subgroup, which would be expected to up to 30 minutes. The interview would be arranged by mutual convenience, face-to-face or by telephone.

When a section of resource is ready for pilot testing you will be asked, as part of the subgroup, to identify 2 or 3 HCP and a lymphoedema specialist (who hasn't been involved in developing that section) who may be willing to test the section and give feedback through a brief interview with the researcher. As a subgroup member you will ask these 'end-users' if their details can be passed on to the researcher, who will then contact the potential end user to give them the End-user Participant Information Sheet to consider for a minimum of 48 hours before re-contacted them to see if they are willing to participate.

If there is disagreement between end-users commenting on a particular section of the resource and/or between those involved in developing the resource, the researcher will feedback summaries of the feedback which will be depersonalised by coding and their initial analysis to all relevant participants with an invitation to verify content and further comment. In the event of continued discordance on any aspect of the resource, the results will be feedback to the SLPN group for resolution.

All data will be depersonalised by coding before sharing and all original transcripts/recordings will be held securely as per University of Glasgow data security policy.

### **What are the possible benefits of taking part?**

In addition to the benefits identified in the SLPN Participant Information Leaflet of promoting the work of the SLPN and your education role as a lymphoedema specialist it is anticipated that subgroup participants will gain knowledge and skills from the process of design and development of on-line education resources which would be transferable to other aspects work. Ultimately the development of a resource to meet the identified education need is hoped to improve the patient experience of healthcare in relation to their lymphoedema.

### **Disadvantages of taking part in this study**

The anticipated disadvantage is the time required, however this could to be considered part of the lymphoedema specialists' educational role and will be annexed to regular SLPN meetings as much as possible to minimise disruption. It is acknowledged that the

process will likely have its frustrations but with good communication processes and the facilitation of the researcher this should be minimised.

**Will my taking part in this study be kept confidential?**

All data will be depersonalised beyond the research team by coding of data and your information will be treated with the strictest of confidence at all times. Your responses will be numbered for identification, e.g. subject 4. All information will be stored securely at the University. On completion of the research it is anticipated that the findings will be published but individuals will not be identified within the publication.

**What will happen to the results of the research study?**

The study will be used in fulfilment of a PhD in Health Care at the University of Glasgow. The study findings will be shared with the SLPN and may inform the development of education resources for health care professionals in other specialities. It is hoped that the study would also be published in scientific journals and presented at scientific meetings. Individuals will not be identified in any report or publication.

**Who is organising and funding the research?**

The research is being organised by post-graduate PhD student - Rhian Davies who is supervised by XXXXXXXX and XXXXXXXX of XXXXXXXXXXXX. The previous phase of this research was funded as part of a larger project by NHS Education for Scotland and Macmillan Cancer Support and supported by the Nursing and Health Care School, University of Glasgow. An executive summary is available on the NES website (<http://tinyurl.com/NESLymphoedemaReport>). This second phase is currently not externally funded.

**Who has reviewed the study?**

This study has been reviewed and approved by the College of Medicine, Veterinary and Life Sciences Research Ethics Committee.

**Contact for further information**

Rhian Davies e-mail XXXXXXXXXXXXXXXX

or phone XXXXXXXX.

or by post: XXXXXXXXXXXX

XXXXXXXXXX (supervisor) e-mail XXXXXXXXXXXXXXXXXXXX

XXXXXXXXXX (supervisor) e-mail XXXXXXXXXXXXXXXXXXXX

**Thank you for taking the time to read this information and for considering this request for help with the study**

## Appendix 13: Non-subgroup Participant Information

**Study:** Developing a model for producing an educational resource for health care professionals: an exploration of the processes involved

**Researcher:** Rhian Davies tel: xxxxxxxx e-mail:xxxxxxxxxxxxxx

You are being invited to take part in the above research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

### What is the purpose of the study?

The aim of the second Phase of the current research programme is to investigate whether existing expertise and infrastructures could be utilised to develop a model for producing an education resource to meet identified HCP education need and whether, by using feasibility and process evaluation research tools, the factors that facilitate or hinder development of such a model might be identified, therein creating new knowledge to further inform research theory. The researcher seeks to work in partnership with SLPN to evaluate the feasibility of developing and implementing an on-line resource designed to meet identified education needs of both generalist health care professionals (HCP) and lymphoedema specialist practitioners.

During 2011 members of SLPN participated in a survey and follow up focus groups investigating the education needs of HCP regarding lymphoedema. The results have been previously presented to the SLPN group but some salient points are highlighted below. An executive summary is available on the NES website (<http://tinyurl.com/NESLymphoedemaReport>).

Lymphoedema Specialists identified education needs which were about supporting continued professional development after attendance at formal specialist courses and in maintaining peer support through national networking. These were of particular concern given current austerity measures on study leave and travel to meetings. In addition, specialists identified a need for a repository of teaching resources. Regarding the needs of generalist HCP, the specialists identified education needs which the generalists did not self-identify; specialists expressed frustration regarding access to generalists for education and also that arranged education events were often poorly attended. Generalist HCP self-identified education needs which were profession and context specific. They also expressed frustration at limitations to access to lymphoedema specialists in many areas. The first preference of generalists on how their education

needs should be met was for teaching from the local lymphoedema specialist but the scarcity of specialists was acknowledged; as was the higher priority of target driven health care. However 44% identified on-line learning as a means of meeting their education need.

**Why have I been chosen?**

You have been chosen for this study because you are a member of SLPN.

**Do I have to take part?**

It is up to you to decide whether to take part. If you do decide to take part, you are still free to withdraw at any time without giving a reason.

**What will happen to me if I take part?**

There are various levels of involvement possible:

- i) Consent is sought for any comments and suggestions you make when the education resource is discussed as part of SLPN business, either during meetings or in subsequent e-mail communications, to be documented. The information will only be used after you have been given the opportunity to comment on the veracity (truthfulness) of the content and any preliminary analysis. All such data will be depersonalised to those beyond the researcher by coding the data.
- ii) Consent is also sought from you to participate in an interview with the researcher during the development period, about your views on the process of development and planning the implementation of the on-line resource. This could be a face-to-face or telephone interview and would be expected to last no longer than 30 minutes. This would be arranged by mutual convenience. You will have opportunity to comment on the veracity of the interview notes and any preliminary analysis. Only the researcher and supervisors will have access to the interview transcripts/recordings.
- iii) You can also take part in a working subgroup to develop a particular part of the resource; further details are included in the Subgroup Participant Information leaflet and requires an additional Subgroup participant consent form.

**What are the possible benefits of taking part?**

Participation in this study has the potential to raise the profile of SLPN as an expert group in Scotland and wider health care environment and meet the needs identified by lymphoedema specialists/practitioners in the earlier phase of this study regarding their own education needs and those of generalist HCP. Involvement could facilitate your specialist role as educator and allow your views and experience to be considered in the creation of this resource. It is anticipated that most participants will also gain some knowledge and experience from the process of design and development of on-line education resources which would be transferable to other aspects work.

Ultimately the development of a resource to meet the identified education need is hoped to improve the patient experience of healthcare in relation to their lymphoedema.

### **Disadvantages of taking part in this study**

The anticipated disadvantage is the time required, however this could to be considered part of the lymphoedema specialists' educational role and will be annexed to regular SLPN meetings as much as possible to minimise disruption. It is acknowledged that the process will likely have its frustrations but with good communication processes and the facilitation of the researcher this should be minimised.

### **Will my taking part in this study be kept confidential?**

Data will be depersonalised by coding of the data and your information will be treated with the strictest of confidence at all times. Your responses will be numbered for identification, e.g. subject 4. All information will be stored securely at the University. On completion of the research members of SLPN will be given a report of the study and it is anticipated that the findings will be published however individuals will not be identified within the publication.

### **What will happen to the results of the research study?**

The study will be used in fulfilment of a PhD (Nursing and Health Care) at the University of Glasgow. The study findings will be shared with the SLPN and may inform the development of education resources for health care professionals in other specialities. It is hoped that the study would also be published in scientific journals and presented at scientific meetings. Individuals will not be identified in any report or publication.

### **Who is organising and funding the research?**

The research is being organised by post-graduate PhD student Rhian Davies, who is supervised by xxxxxxxxxxxx and xxxxxxxxxxxx of xxxxxxxxxxxx. The previous phase of this research was funded as part of a larger project by NHS Education for Scotland and Macmillan Cancer Support and supported by the Nursing and Health Care School, University of Glasgow. This second phase is currently not externally funded.

### **Who has reviewed the study?**

This study has been reviewed and approved by the College of Medicine, Veterinary and Life Sciences Research Ethics Committee.

### **Contact for further information**

Rhian Davies e-mail xxxxxxxxxx or phone xxxxxxxx or by post: (supervisor) e-mail xxxxxxxxxxxxxxxxxxxxxxxxxxxxxx (supervisor) e-mail xxxxxxxxxxxxxxxxxxxxxx

**Thank you for taking the time to read this information and for considering this request for help with the study**

## Appendix 14: End-user Participant Information

**Study:** Developing a model for producing an educational resource for health care professionals: an exploration of the processes involved

**Researcher:** Rhian Davies tel: XXXXXXXXXX e-mail: XXXXXXXXXX

You are being invited to take part in the above research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

### What is the purpose of the study?

The aim of this phase of the study is to explore whether existing expertise and infrastructures can be utilised to develop a model for producing an education resource to meet identified education need in health care professionals regarding lymphoedema. The researcher is working in partnership with the Scottish Lymphoedema Practitioners Network (SLPN) to evaluate the feasibility of developing and implementing an on-line resource designed to meet the needs identified by generalist health care professionals (HCP) and lymphoedema specialist practitioners regarding lymphoedema in a previous phase of this study. The first part of this study found that preferences for meeting the need included on-line resources. An executive summary is available on the NES website (<http://tinyurl.com/NESLymphoedemaReport>).

### Why have I been chosen?

For each round of testing we are aiming to recruit 2 - 3 people from each of the following professions: General Practitioners (GPs), Physiotherapists, Community/District Nurses and Podiatrists and a lymphoedema specialist. The subgroup developing one of the sections of this resource has identified that you may be interested in participating.

### Do I have to take part?

It is up to you to decide whether to take part. You will be contacted by the researcher, Rhian Davies, over 48 hours after receiving this information to establish your willingness to participate. If you do decide to take part, you are still free to withdraw at any time without giving a reason and without consequence.

**What will happen to me if I take part?**

Firstly you will be asked to sign a letter of consent to participate. You will then be asked to review a section of information/education resource on a website and provide feedback. You will be given a link to a section of website developed for your particular profession to access within an agreed time frame. While thinking of a patient presenting to you with probable or confirmed lymphoedema you are asked to navigate the resource and consider its appropriateness, usefulness and ease of use. Different people will explore more or less of the given website pages and links but the process is not expected to take more than 20 minutes in total. The researcher will have agreed a time and date for the feedback interview which can be face-to-face or by telephone and is expected to take 15-30 minutes to discuss the appropriateness, usefulness and ease of use of the resource and any suggestions you may have for facilitating its use by other health care professionals. You will also be asked if you would like to participate in future cycles of testing but you would be under no obligation to do so. All interview data will be depersonalised by coding of the data and held securely by the research team.

**What are the possible benefits of taking part?**

Participants may benefit from the opportunity to take part in this pilot test by developing a greater understanding of lymphoedema and to some extent the development of on-line resources. However the ultimate beneficiaries of the study should be the patients suffering from lymphoedema as the health care professionals helping them to manage their condition will have greater access to the information and education identified as needs in the previous phase of the study.

**Disadvantages of taking part in this study**

We ask you to freely volunteer your time as we are not able to pay participants, however we anticipate that this will be offset by the learning you may gain regarding lymphoedema and this development process.

**Will my taking part in this study be kept confidential?**

Data will depersonalised by coding of the data and your information will be treated with the strictest of confidence at all times. Your responses will be numbered for identification, e.g. subject 4. All information will be stored securely at the University. On completion of the research it is anticipated that the findings will be published but individuals will not be identified within the publication.

**What will happen to the results of the research study?**

The study will be used in fulfilment of a PhD (Nursing and Health Care) at the University of Glasgow. The study findings will be shared with the SLPN and may inform the development of education resources for health care professionals in other specialities. It is hoped that the study would also be published in scientific journals and presented at scientific meetings. Individuals will not be identified in any report or publication.

**Who is organising and funding the research?**

The research is being organised by post-graduate PhD student - Rhian Davies who is supervised by XXXXXXXXXX and XXXXXXXXXX of XXXXXXXXXX. The previous phase of this research was funded as part of a larger project by NHS Education for Scotland and Macmillan Cancer Support and supported by the Nursing and Health Care School, University of Glasgow. This second phase is currently not externally funded.

**Who has reviewed the study?**

This study has been reviewed and approved by the College of Medicine, Veterinary and Life Sciences Research Ethics Committee.

**Contact for further information**

Rhian Davies e-mail XXXXXXXXXXXXXXXX  
or phone XXXXXXXXXX.  
or by post: XXXXXXXXXX  
XXXXXXXX (supervisor) e-mail XXXXXXXXXXXXXXXX  
XXXXXXXX (supervisor) e-mail XXXXXXXXXXXXXXXX

**Thank you for taking the time to read this information and for considering this request for help with the study.**



## Appendix 15: Subgroup feedback to SLPN

Date: \_\_\_\_\_ 5<sup>th</sup> March 2014 \_\_\_\_\_

Subgroup: \_\_\_\_\_ Lymphoedema\_Specialist pages \_\_\_\_\_

<b>What the plans for the last quarter had been:</b>	
<i>This would be a summary of your initial meeting log e.g. how many actual/virtual meetings were planned, how was communication planned, what actions were decided upon, any roles people took or tasks assigned, whether specific dates for completion had been set or SMART goals?</i>	
<b>Communication by group e-mail between 4 members</b> <b>Specialist website has now been established within the Knowledge Network</b> <b>3 members now have editing rights</b> <b>2 members completed over the phone training on how to edit website</b> <b>Arranged a date to meet up and start to construct website</b>	
<b>What was actually done (progress and changes to plan):</b>	
<b>3 members met up to start constructing the website</b> <b>Discussed how website should operate</b> <b>Developed 5 main categories</b> <b>Up loaded useful resources</b>	
<b>If there were changes to the plans – why, what drove those changes?</b>	
<b>Not really a change, but since the ethos of this project is development of the website by the users, it was decided to focus more on other practitioners sending in particles, ideas, PPPs, case studies,, etc rather than the 4 group members finding and uploading them all</b>	
<b>What are the plans for the next quarter?</b>	
<b>To continue developing the website</b> <b>Obtain feedback from website users via the SLPN</b> <b>Adapt as required</b> <b>Encourage users to send in resources</b>	
<b>Issues for discussion with rest of SLPN group</b>	<b>Decisions taken after discussion with SLPN</b>
<b>Thoughts on website</b> <b>Clarity of headings</b> <b>Ease of use</b> <b>Thoughts on idea of discussion forums</b>	<b>Need to discuss how and who we are allowing access too</b> <b>Investigate if there is anyway a short “application” form can be forwarded to someone requesting access</b>

Please continue overleaf/next page if you need to.

Please bring with you to the SLPN meeting and send an electronic copy to Rhian, thank you.

## Appendix 16: Subgroup interview templates

### Semi-structured interview template for subgroup member v1.0

First cycle of interviews (under 30 minutes, to be recorded and transcribed).

Date:

Participant ID:

	Field notes	coding
<b>Introduction</b> and reminder of purpose, confidentiality, right to withdraw, member checking process.		
<b>Overall impression</b> of the current process e.g. what is your sense of what's going on?		
<b>Engagement/involvement</b> What influenced your decision to be involved in a subgroup/that subgroup? What keeps you <b>motivated</b> to keep going? Quality and quantity of <b>communication</b>		
<b>Usefulness /Relevance/value</b> of the project? To who mostly? In what way? <b>Usefulness</b> to you? Of resource, of having been involved? <b>Do you think SLPN will gain</b> from having been involved in this?		
<b>Time</b>		
<b>Any concerns about it?</b> These can be content, workload, sustainability, barriers to success, quality anything...		
<b>Roles</b> and how they developed <b>Researcher role</b>		
<b>Suggestions</b> for improvement to process		
Anything else to add		
Thanks and what happens next		

**Semi-structured interview template for subgroup member. v2.0**

Second cycle of interviews (under 30 minutes, to be recorded and transcribed).

Date:

Participant ID:

	Field notes	coding
<b>Introduction</b> and reminder of purpose, confidentiality, right to withdraw, member checking process.		
<b>Impression</b> of the current <b>process</b> of website(s) development? How do you feel it's worked? What are the key factors that hinder? Key facilitators? <b>Suggestions</b> for improvement to process		
<b>Time</b> would you normally have time for teaching/education? How does the time spent on this compare?		
Open question relevant to this person?		
Tell me a bit about <b>your experience</b> of being in a subgroup to develop this OLR (Enjoyed/hard/frustrated?)		
<b>Engagement/involvement</b> What influenced your decision to be involved in a subgroup/that particular subgroup? What keeps you going on it?		
Do you feel you are <b>learning</b> during the process? What sort of things? Do you think <b>others</b> are learning? Like?		
Is working together on this changing the way the <b>group functions</b> in any way?		
How do you think of the SLPN, as a <b>network</b> of professionals or as a <b>community of practice</b> or something else?		
Would you say you feel a sense of belonging?		
What do <b>you</b> want/need out of the SLPN? Can the OLR support that in any way?		
Anything else to add		
Thanks and what happens next		

## Appendix 17: Non-subgroup interview templates

### Semi-structured interview template for SLPN member non-subgroup members, v1.0

First cycle of interviews (under 30 minutes, to be recorded and transcribed).

Date:

Participant ID:

	Field notes	coding
<b>Introduction</b> and reminder of purpose, confidentiality, right to withdraw, member checking process.		
<b>Overall impression</b> of the current process, awareness. e.g. what is your sense of what's going on? What do you make of it?		
<b>Relevance/value</b> of the project? Appropriate use of time for those in subgroups? And using a part of the SLPN meeting? <b>Usefulness</b> to you? Will you use it? In what way? Which part of it? (repository, discussion forum) <b>Do you think SLPN will gain</b> from having been involved in this?		
<b>Engagement/involvement</b> e.g. did you choose to be involved in the larger outer group rather than the working subgroups or did that happen by default because of timing/attendance at meetings etc? can you remember the reason for your choice? Would you want to be involved in a subgroup working on web-pages in future?		
<b>Any concerns about it?</b> These can be content, workload, sustainability, barriers to success, quality anything...		
Quality and quantity of <b>communication</b>		
<b>Researcher role</b> impression of		
<b>Suggestions</b> for improvement to process		
Anything else to add		
Thanks and what happens next		

**Semi-structured interview template for SLPN member non-subgroup members.****v2.0**

Second cycle of interviews (under 30 minutes, to be recorded and transcribed).

Date:

Participant ID:

	Field notes	coding
<b>Introduction</b> and reminder of purpose, confidentiality, right to withdraw, member checking process.		
<b>Overall impression</b> of the current process, awareness. e.g. what is your sense of what's going on? What do you make of it?		
<b>Relevance/value</b> of the project? Appropriate use of time for those in sub-groups? And using a part of the SLPN meeting? <b>Usefulness</b> to you? Will you use it? In what way? Which part of it? (repository, discussion forum) <b>Do you think SLPN will gain</b> from having been involved in this?		
<b>Any concerns about it?</b> These can be content, workload, sustainability, barriers to success, quality anything...		
Quality and quantity of <b>communication</b>		
<b>Researcher role</b> impression of?		
<b>Suggestions</b> for improvement to process		
<b>Engagement/involvement</b> e.g. did you choose to be involved in the larger outer group rather than the working sub-groups or did that happen by default because of timing/attendance at meetings etc? can you remember the reason for your choice? Would you want to be involved in a subgroup working on web-pages in future?		
Anything else to add		
Thanks and what happens next		

## Appendix 18: End-user interview template

**Semi-structured interview template for End-user.**

First cycle 15-30 mins, telephone or face-to-face, notes taken during interview.

Date:

Participant:

	Field note	coding
<b>Introduction</b> reminder of purpose, confidentiality, right to withdraw, right to comment on interview notes.		
<b>First impression</b> any problems with access etc. Ease of use/layout/navigation Suggestions on navigation/layout		
<b>Content</b> appropriateness, usefulness Suggestions on content		
<b>Other comments/suggestions</b>		
Would you be happy to be involved in giving feedback in future cycles?		

## Appendix 19: Programme Manual

	Function criteria (to include planning, conducting, reporting and evaluating)	Data from	Significant influencing factors	Variances to plan	Alternative method (added to end of list in left column for cyclic process)
1	Decisions about the overall purpose ( <b>definition</b> ), look and functionality of the website to be made by whole SLPN group	Meeting minutes, subgroup logs, interviews.			<i>Input here “No change from plan” or “Stop see new process e.g. number 15)</i>
2	Each subgroup of 2-3 SLPN members will have an initial <b>training</b> session with the researcher on web-page planning and building				
3	Individual pages will be <b>planned and created</b> by subgroups of 2-3 SLPN members				
4	Individual pages will be <b>developed</b> collaboratively by subgroups members using face-to-face or virtual meetings				
5	Subgroups will have the <b>support</b> of the researcher to provide or source <b>technical</b> help ( <i>fortnightly?</i> )				

	Function criteria (to include planning, conducting, reporting and evaluating)	Data from	Significant influencing factors	Variances to plan	Alternative method (added to end of list in left column for cyclic process)
6	Subgroups will have the support of the researcher to provide <b>learning theory support</b> ( <i>monthly?</i> )				
7	Subgroup members will keep a <b>log</b> of their activity on website development to include time and nature of activity, problems encountered and how solved				
8	Subgroups will provide a <b>report</b> on progress to the larger SLPN group at each quarterly meeting				
9	Whole SLPN group will provide <b>support</b> and dispute resolution for subgroups on web-page development				
10	Subgroups will identify appropriate end-users to test ( <b>evaluate</b> ) the developed web page				



	Function criteria (to include planning, conducting, reporting and evaluating)	Data from	Significant influencing factors	Variances to plan	Alternative method (added to end of list in left column for cyclic process)
11	Researcher will provide a summary of end-user <b>evaluation</b> to the subgroup for each iteration				
12	Disputes/disagreements on web-page content/function within the subgroup or from end-users are resolved by further opportunity to comment by subgroup and end-users OR are taken forward to larger SLPN group for resolution				
13	Subgroup will use end-user evaluation to further develop the web page( <b>cycle of iterations</b> )				
14	A number of iterations will be followed for each web page				

## Appendix 20: Extract of display of data relating to one theme Phase 2

### Display v1.0 of data from SLPN3 (transcript of meeting 5<sup>th</sup> November 2013)

RR=role of researcher, MO=motivating factors, TM= Time factors,  
SG = small group working factors, SK= skills & knowledge.

Coding	Description /Memo	SLPN3/ first line/speaker	Quote	other codes
RR	Facilitating but also controlling	6/P7	People who are in the subgroups do you want me to just to quickly show where the website is at a whole or do you want to show your things as you talk about them	Roles coded under Process in the other.
RR	Researcher role – keeping to process	14/P7	do you want to carry on saying anything else that's on your [ <i>subgroup feedback</i> ] sheet?	Process
RR	Summarising/Clarifying point - facilitating	71/P7	So you're still seeing it as a place that is a repository for teachers in a way, for all your teaching things yes? And then as a 'this is our safe space as specialists to share our concerns or practice or whatever'. Is that the two main ways you're still thinking of it as?	
RR	Facilitating contribution from other in the room	93/P7	so has anyone got any ideas you know on how we can get the rest of SLP engaged in saying what they want on there?	Barriers
RR	Educator; advisor?	127/P7	but if we create something that's genuinely new and its our creation... there is something called a Creative Commons license that you can do that doesn't cost anything but is like a copyright except that you can say how people can use it	

## Appendix 21: Site Map example



## Appendix 22: Completed subgroup feedback

Website subgroup feedback to SLPN

Date: \_\_\_\_\_ 5<sup>th</sup> January 2014 \_\_\_\_\_

Subgroup: \_\_\_\_\_ Specialist subgroup \_\_\_\_\_

<b>What the plans for the last quarter had been:</b>	
<p><i>This would be a summary of your initial meeting log e.g. how many actual/virtual meetings were planned, how was communication planned, what actions were decided upon, any roles people took or tasks assigned, whether specific dates for completion had been set or SMART goals?</i></p> <p>Communication by group e-mail between 4 members          Specialist website has now been established within the Knowledge Network          3 members now have editing rights          2 members completed over the phone training on how to edit website          Arranged a date to meet up and start to construct website</p>	
<b>What was actually done (progress and changes to plan):</b>	
<p>3 members met up to start constructing the website          Discussed how website should operate          Developed 5 main categories          Up loaded useful resources</p>	
<b>If there were changes to the plans – why, what drove those changes?</b>	
<p>Not really a change, but since the ethos of this project is development of the website by the users, it was decided to focus more on other practitioners sending in particles, ideas, PPPs, case studies,, etc rather than the 4 group members finding and uploading them all</p>	
<b>What are the plans for the next quarter?</b>	
<p>To continue developing the website          Obtain feedback from website users via the SLPN          Adapt as required          Encourage users to send in resources</p>	
<b>Issues for discussion with rest of SLPN group</b>	<b>Decisions taken after discussion with SLPN</b>
<p>Thoughts on website          Clarity of headings          Ease of use          Thoughts on idea of discussion forums</p>	<p>Suggestions taken back to subgroup.          Encourage all SLPN members to contribute through circulation of minutes.</p>

Please continue overleaf/next page if you need to.

Please bring with you to the SLPN meeting and send an electronic copy to Rhian, thank you.

## Appendix 23: End-user feedback

First cycle 15-30 mins, telephone or face-to-face, notes taken during interview.

Date: 19.02.2014

Participant: P21

		coding
Introduction reminder of purpose, confidentiality, right to withdraw, right to comment on interview notes.	Accepted	
First impression any problems with access etc. Ease of use/layout/navigation Suggestions on navigation/layout	Easy to navigate and straight forward. The links are good for more information if you want it. More visual information would be good, photos for people who can't work the film e.g. toe bandaging, different types of oedema, cellulitis. Film works, that would be really helpful and reassuring for a nurse in someone's house who needs a reminder of how to do it.	
Content appropriateness, usefulness Suggestions on content	The pages I'd be most interested in have not been completed yet. So far though content does seem appropriate for the different levels of experience on this in the community. The referral pathway was useful to know when to refer, but the names at the bottom need updating or making generic. Lymphorrhoea pathway useful too even if only rarely used.	
Other comments/suggestions	Make sure it's really accessible out there, maybe speak to Prof Nurse Adviser xxxxxxxxx about how that could be linked to her work or her equivalents elsewhere? The DNs in xxxxx are all going to get hand held Microsoft tablets soon so make sure its all compatible with that.	
Would you be happy to be involved in giving feedback in future cycles?	Yes	

## Appendix 24: Kotter's 8 steps in this study

Steps	Actions	Audience	Desired effect(s)
<b>Establish a sense of urgency</b>	<ul style="list-style-type: none"> <li>Point out relevance of OLR at SLPN meetings and other appropriate meetings</li> </ul>	SLPN members, Macmillan Lymphoedema Scotland Project Steering Group, SMASAC, potential funders.	<p>SLPN to minute group decision to action development of OLR</p> <p>External organisations and groups to include/acknowledge the OLR as part of wider plans and not produce their own.</p>
<b>Creating a guiding coalition</b>	<ul style="list-style-type: none"> <li>Informal discussions and e-mails as well as more formal discussions with key influencers within SLPN</li> <li>Seek formal and informal sources of IT support e.g. Knowledge Network, University sources, within SLPN, colleagues/friends.</li> <li>Use academic supervisors as guides for process of action research and unpinning academic theory of on-line learning and librarians as experts in information seeking theories.</li> </ul>	<p>Key influencers of SLPN. IT experts/experienced contacts.</p> <p>Librarian and academic supervisors.</p>	<p>To have a core group of champions to help drive through the development</p> <p>To have identified various sources of training and support for the researcher and thereby indirectly the group</p>
<b>Developing a change vision</b>	<ul style="list-style-type: none"> <li>Facilitate but give time for SLPN to develop a vision of how they might use technology to address their needs</li> <li>Facilitate refinement into characteristics of a vision (Kotter)</li> </ul>	SLPN members	That SLPN will have developed ideas from the researcher into a vision of their own about the finished product (OLR)

<b>Communicate the change vision</b>	<ul style="list-style-type: none"> <li>• Use opportunities with SLPN meetings and others (e.g. with Macmillan) to communicate vision</li> <li>• Use e mails and meeting minutes to communicate vision with SLPN members not present.</li> </ul>	SLPN members, Macmillan Lymphoedema Scotland Project Steering Group, SMASAC, potential funders	That all groups currently driving service changes in lymphoedema in Scotland understand the vision and incorporate it in their plans.
<b>Empowering broad based action</b>	<ul style="list-style-type: none"> <li>• Give opportunity for all to be involved in different ways</li> <li>• Provide adequate training and support</li> <li>• Cover several different professional areas/context of work to make it relevant</li> </ul>	SLPN members, sample of end-users	<p>That all members of SLPN feel involved as much as they want to be in the process.</p> <p>That participating end-users feel their input is valued</p> <p>That the OLR addresses the need identified in more that one profession and context</p>
<b>Generate quick wins</b>	<ul style="list-style-type: none"> <li>• Identify subject/target end user group (profession) and SLPN members who are most likely to produce a successful start to their subgroup OLR pages</li> <li>• Identify and remove as many barriers as possible especially in the early days</li> <li>• Ensure adequate training and sources of support for researcher to cascade knowledge and skills through group.</li> </ul>	<p>One or two subgroups and target end-users.</p> <p>Researcher and informal technical support.</p>	<p>At least one-group develops a clear vision of what they need to do, how and quickly create a prototype resource page from one of the identified professions.</p> <p>That all those involved can see a prototype section of the OLR and how it might work</p>

<b>Consolidating gains and producing more change (keeping going)</b>	<ul style="list-style-type: none"> <li>• Ensure reporting process is in place within group and external to the group, to provide regular positive feedback and quick address of problems/barriers/ challenges</li> <li>• Ensure system has clear route of feedback from end-users both during the first development stages and in the longer term from the website</li> <li>• Explore potential development awards or similar recognition that might reward the group for their efforts</li> <li>• Include group in publication plans/conferences</li> </ul>	<p>SLPN members, their employers and managers, potential awarding bodies.</p> <p>Wider academic and professional bodies.</p>	<p>SLPN group is engaged and enthusiastic about the OLR</p> <p>That end-users use the OLR and communicate some feedback about its relevance and usefulness even beyond this project.</p> <p>Recognition of the action research work from an external body to continue to inspire the group.</p>
<b>Anchoring the new approach (incorporating into the routine and structure)</b>	<ul style="list-style-type: none"> <li>• A routine of checking content and web-links longer term is established as part of the group process.</li> <li>• OLR content and further development has a regular place on the agenda of SLPN quarterly meetings.</li> <li>• Seek acknowledgement of this task as part of the educational element of their specialist role</li> </ul>	<p>SLPN members.</p> <p>Employers/managers.</p>	<p>Continued development, evaluation and keeping the OLR contemporary is established as an ongoing continuous role of the SLPN group, possible with recognised partners.</p> <p>That employers/managers recognise the development and upkeep of OLR as part of the specialist role.</p>
Adapted from Kotter JP (1996) <u>Leading Change</u> Boston MA: Harvard Business Review Press.			



