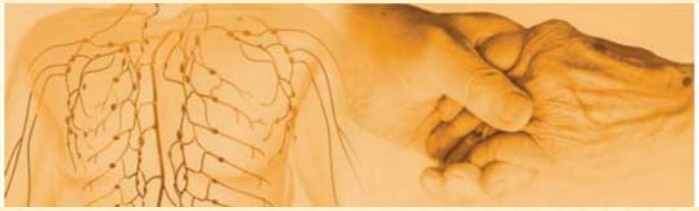
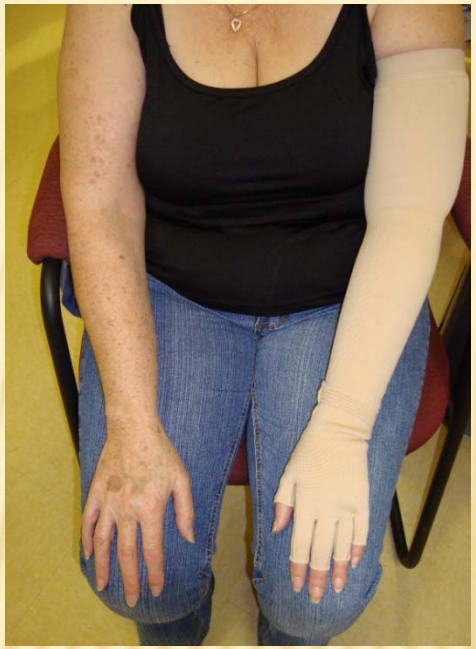
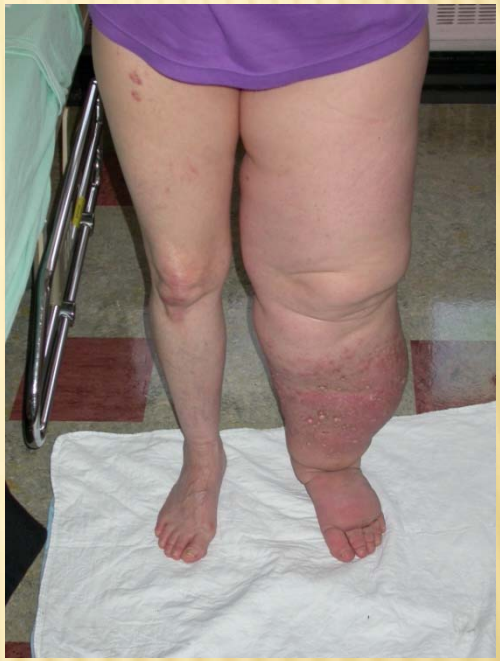
CANADIAN LYMPHEDEMA FRAMEWORK



PARTENARIAT CANADIEN DU LYMPHOEDÈME

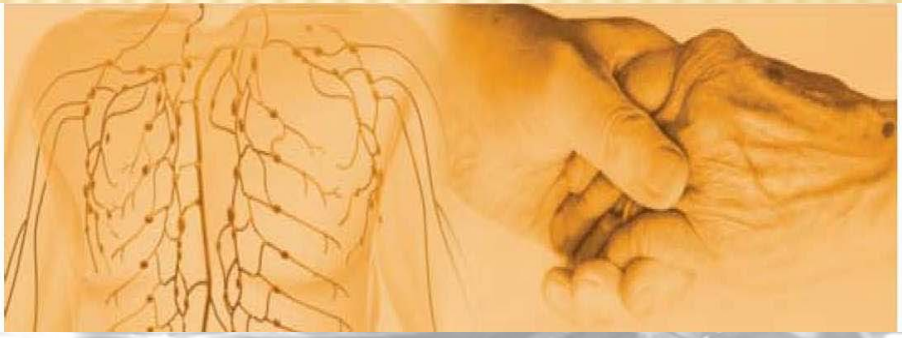




The Canadian Lymphedema Framework: Improving Lymphedema education, research and management

Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada

CANADIAN LYMPHEDEMA FRAMEWORK

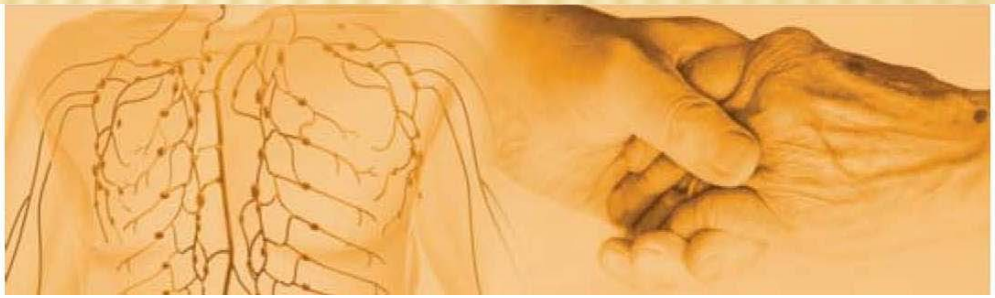


PARTENARIAT CANADIEN DU LYMPHOEDÈME

CONTENT

- The lymphedema problem in Canada and worldwide: where are we at?
- Activities of the Canadian Lymphedema Framework
- Standards of care
- Educational and Research priorities
- Models of lymphedema care for the future

CANADIAN LYMPHEDEMA FRAMEWORK



PARTENARIAT CANADIEN DU LYMPHOEDÈME

THE LYMPHEDEMA PROBLEM.....

Lack of awareness, lack of research, insufficient education, nonexistent or inadequate clinical programmes...

CELLULITIS RATES

- Reoccurrence rate at 26% per year for persons with arm lymphedema with at least one episode of erysipelas (Vignes).
- A study in France to assesses risk factors for hospital admission for cellulitis gave the highest odds ratio for lymphedema=71.2X (Dupuy)

OBESITY

- Obesity: BMI 30-39.0
- Morbid Obesity: BMI 40 or higher

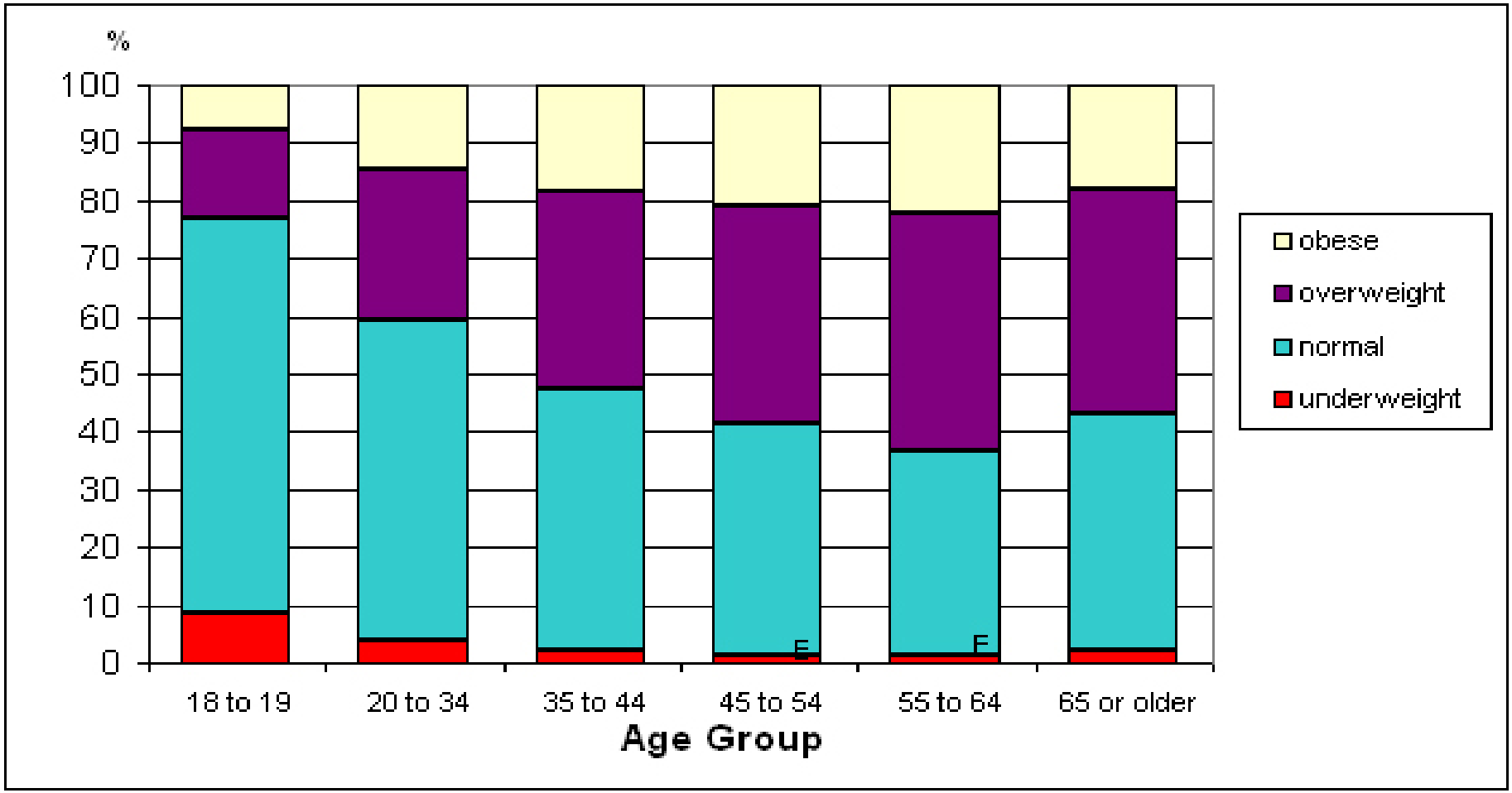
OBESITY RATES

- Obesity is the fastest growing chronic condition in North America
- Almost one-third of intensive care unit patients are obese

OBESITY AND LYMPHEDEMA

- Under-recognized link between obesity and lymphedema
- Bariatric treatments
- Unrecognized value of conservative treatments for lymphedema related to obesity, in favour of surgical debulking
- Public health issue

THE OBESITY PROBLEM IN CANADA

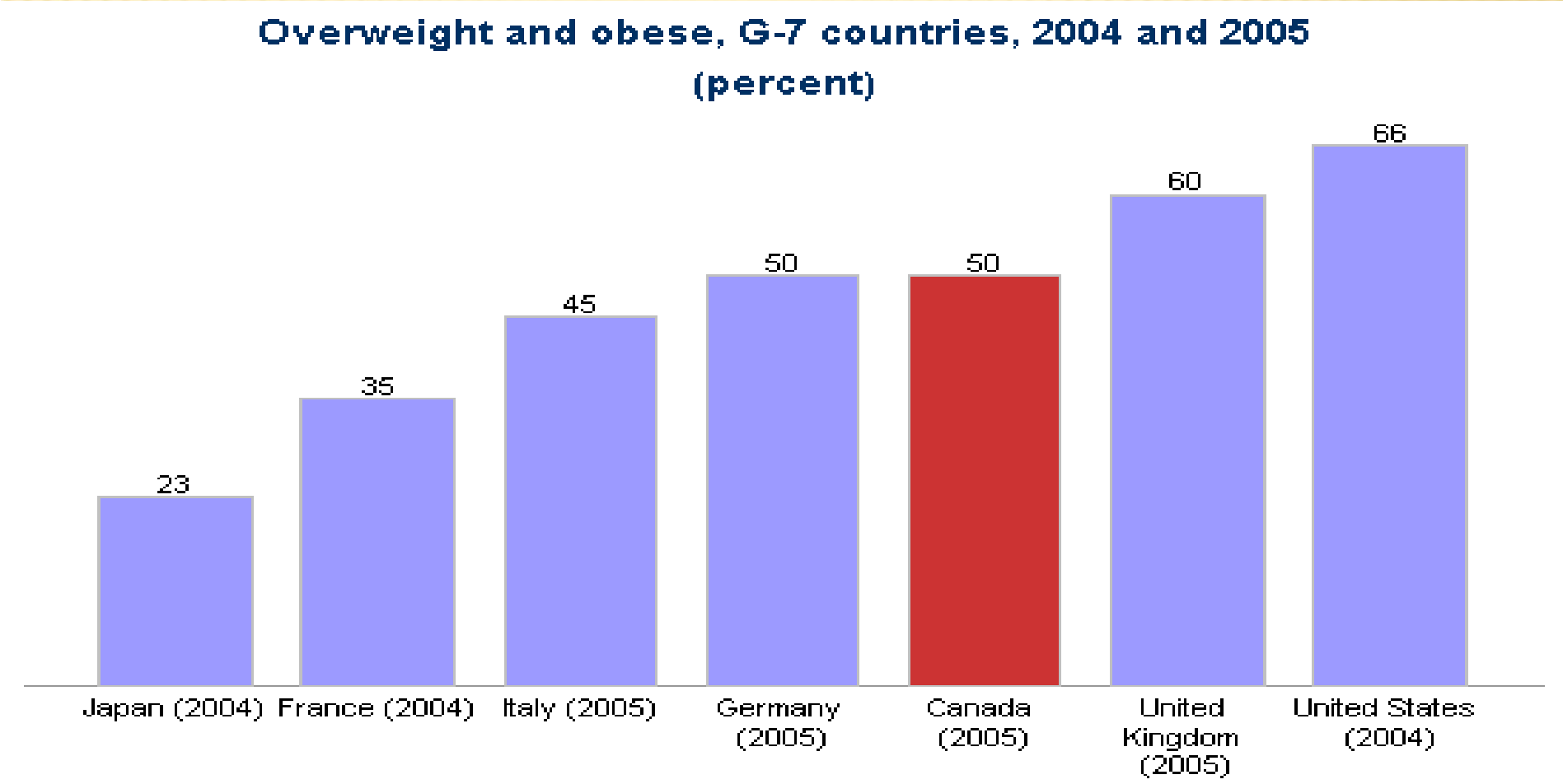


Percentage who were underweight, normal weight, overweight and obese (self-reported), by age group, household population 18 or older, Canada Public Health survey, 2010

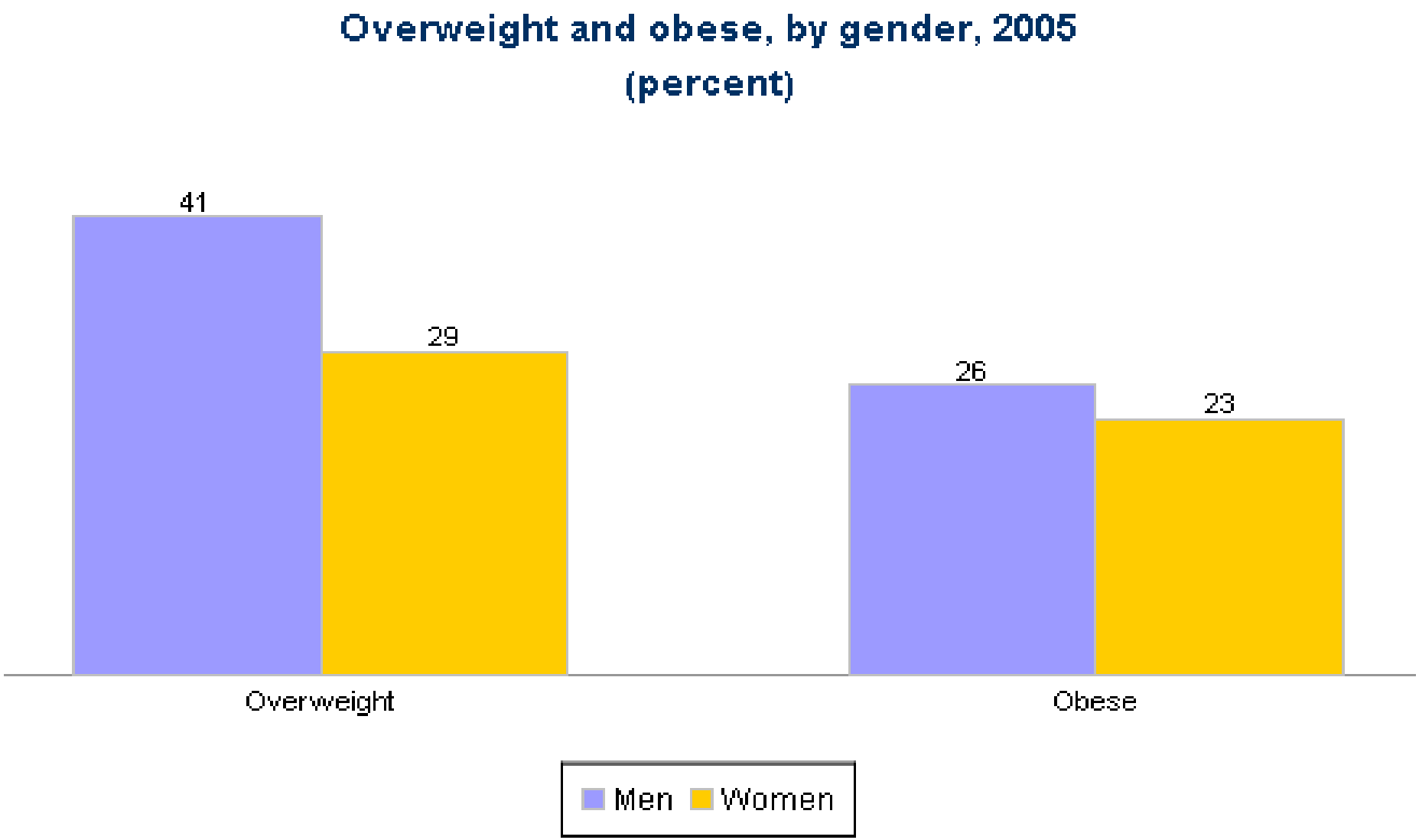
On the basis of measured height and weight from multiple sources during 2007-2009,

more than one in four adults in Canada are obese.

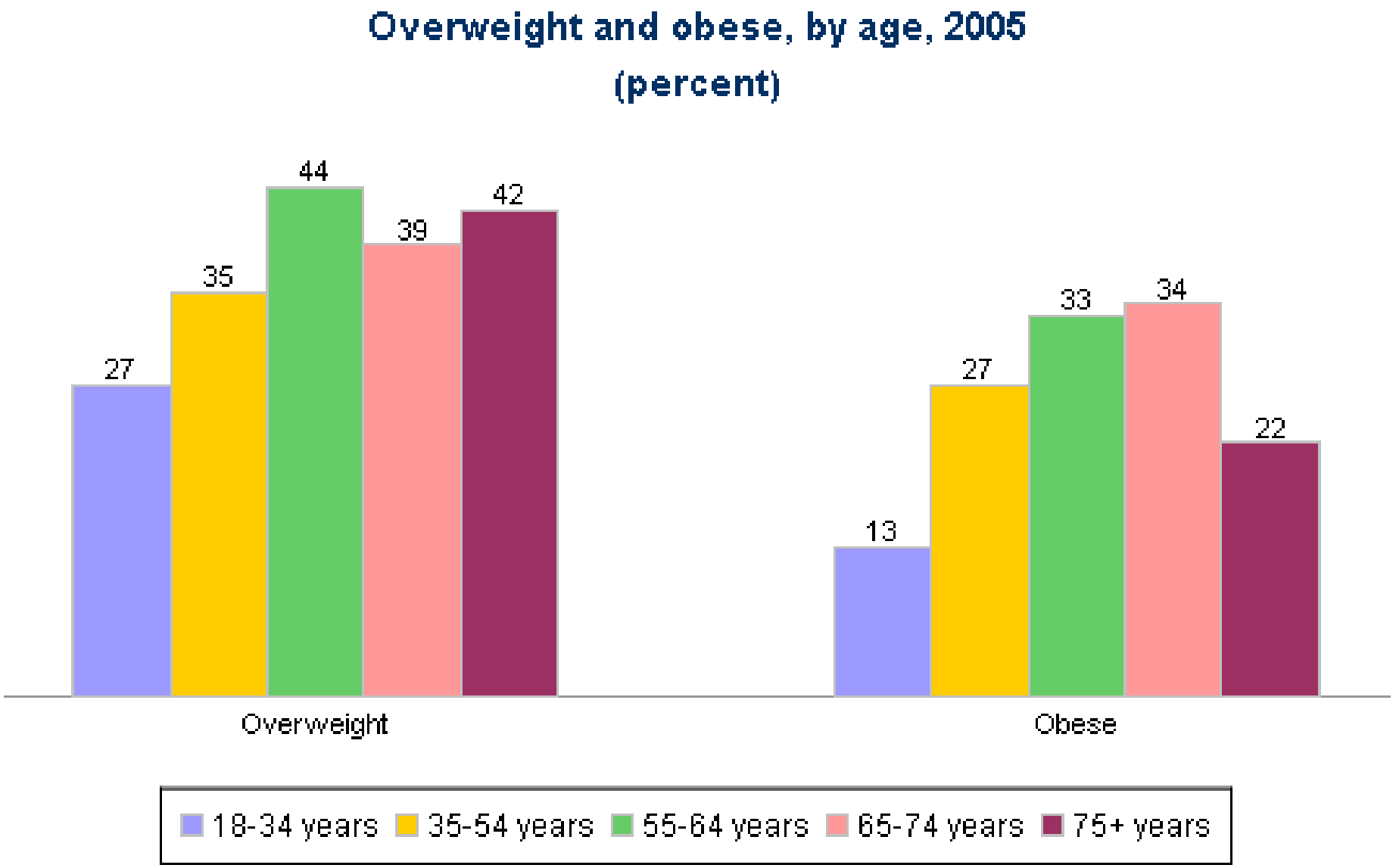
% OF POPULATION OVER 20% OF IDEAL BODY WEIGHT



FOR CANADA....


Overweight and obese, by gender, 2005
(percent)
41
29
26
23
Overweight
Obese
Men
Women

FOR CANADA…

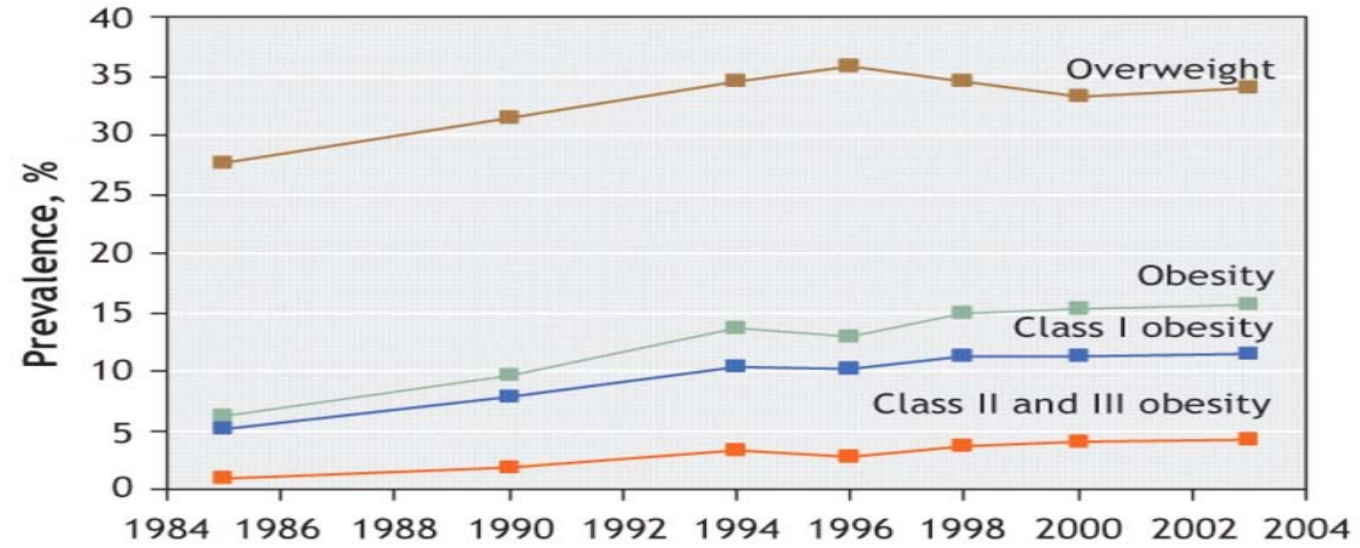

Overweight and obese, by age, 2005
(percent)
27
35
44
39
42
13
27
33
34
22
Overweight
Obese
18-34 years
35-54 years
55-64 years
65-74 years
75+ years

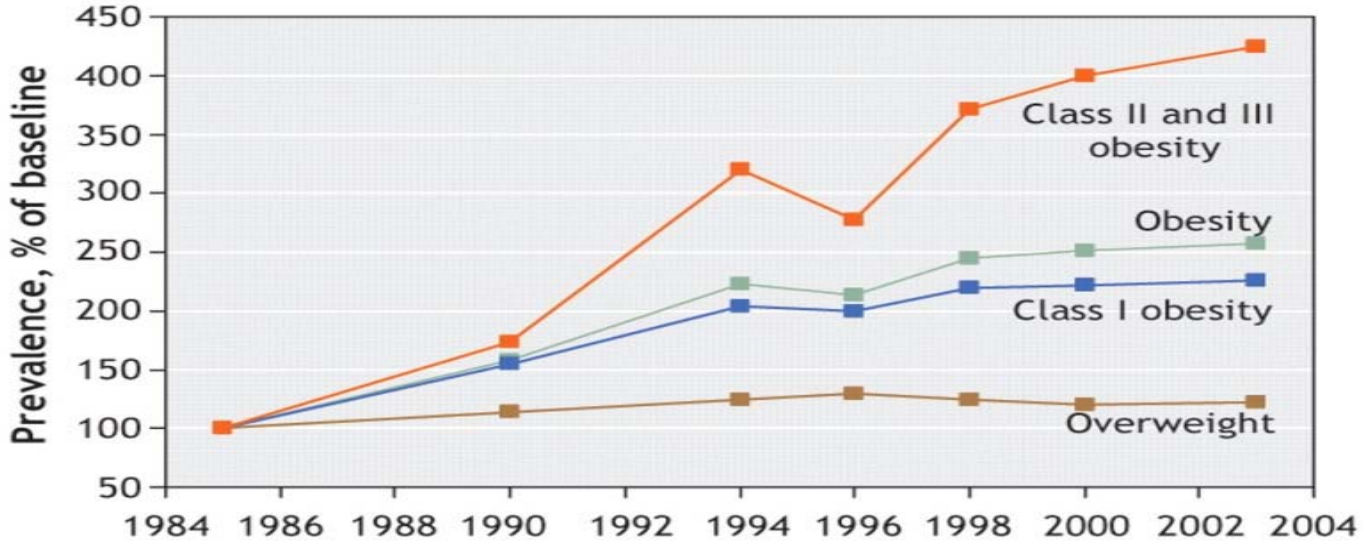
OBESITY IN CANADA 1978-2005

(PREVALENCE- MEASURED VALUES)

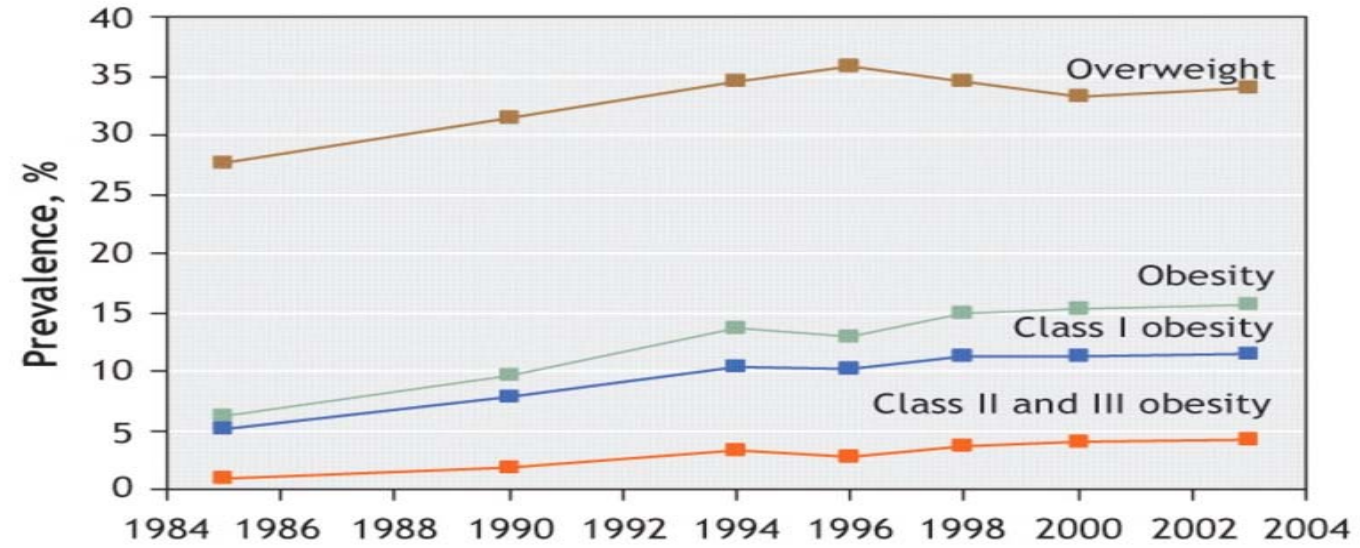
Canada, 1978-2005 (18 or older)	1978	2004	2005
Total overweight and obese (BMI □ 25)	49	59	59
Overweight (not obese) (BMI = 25 to 29.99)	35	36	35
Obese (BMI □ 30)	14	23	24
Obese Class I (BMI = 30 to 34.9)	10,5	15	17
Obese Class II (BMI = 35 to 39.9)	2,3	5,1	4,8
Obese Class III (severe) (BMI ≥ 40)<	0,9	2,7	2,1

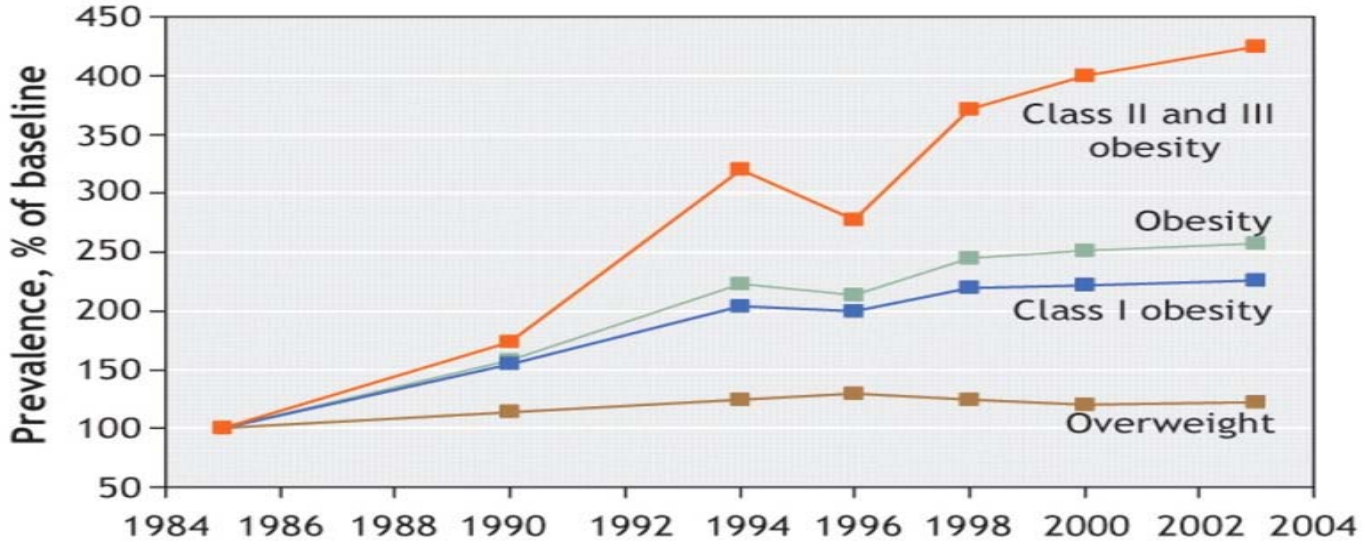
OBESITY RATES IN CANADA





OBESITY RATES IN CANADA



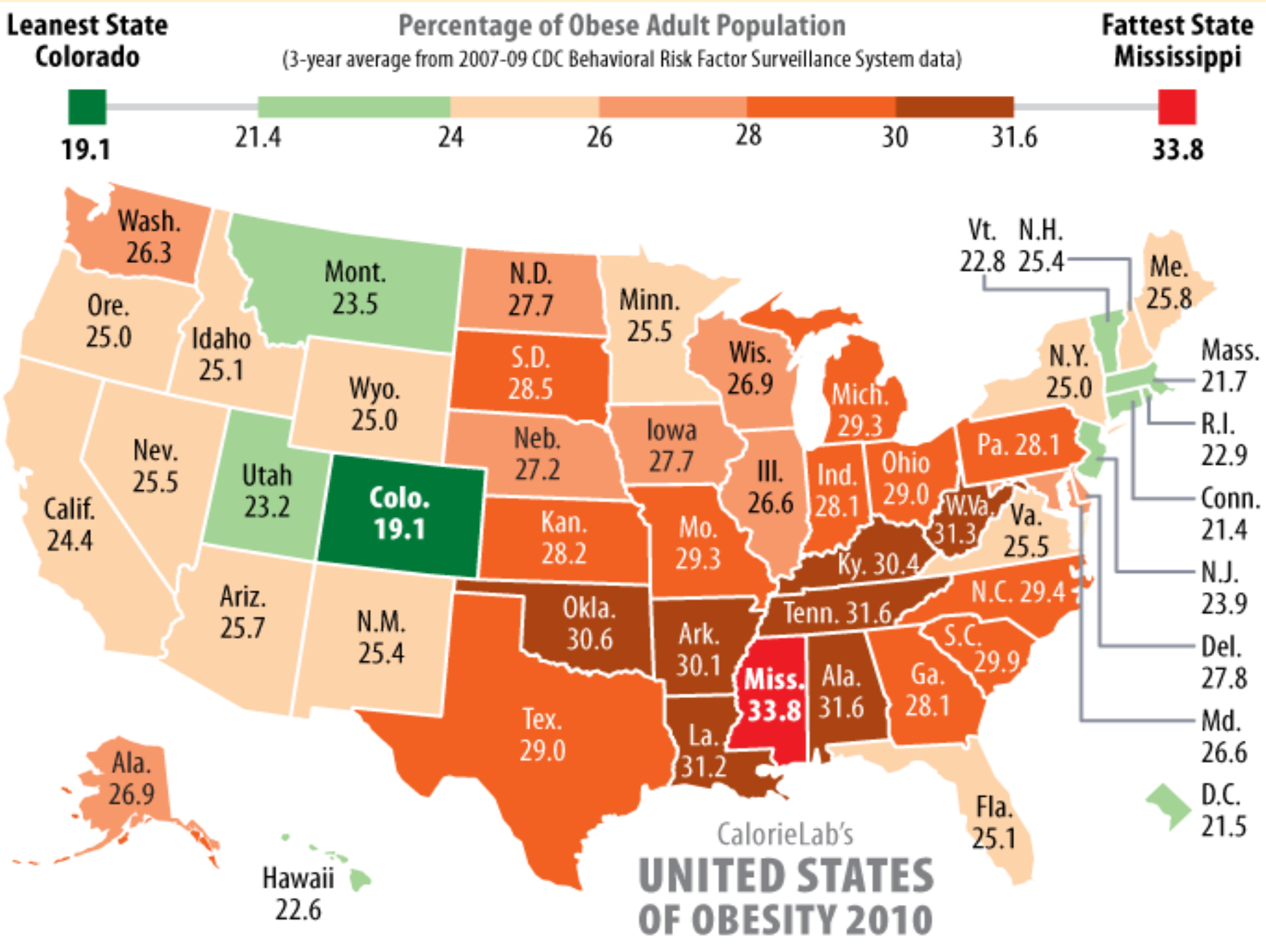


Obesity trends among U.S. Adults between 1985 and 2010

During the past 20 years, there has been a dramatic increase in obesity in the United States.

In 2010, no state had a prevalence of obesity less than 20%.

12 states had a prevalence of 30% or more.

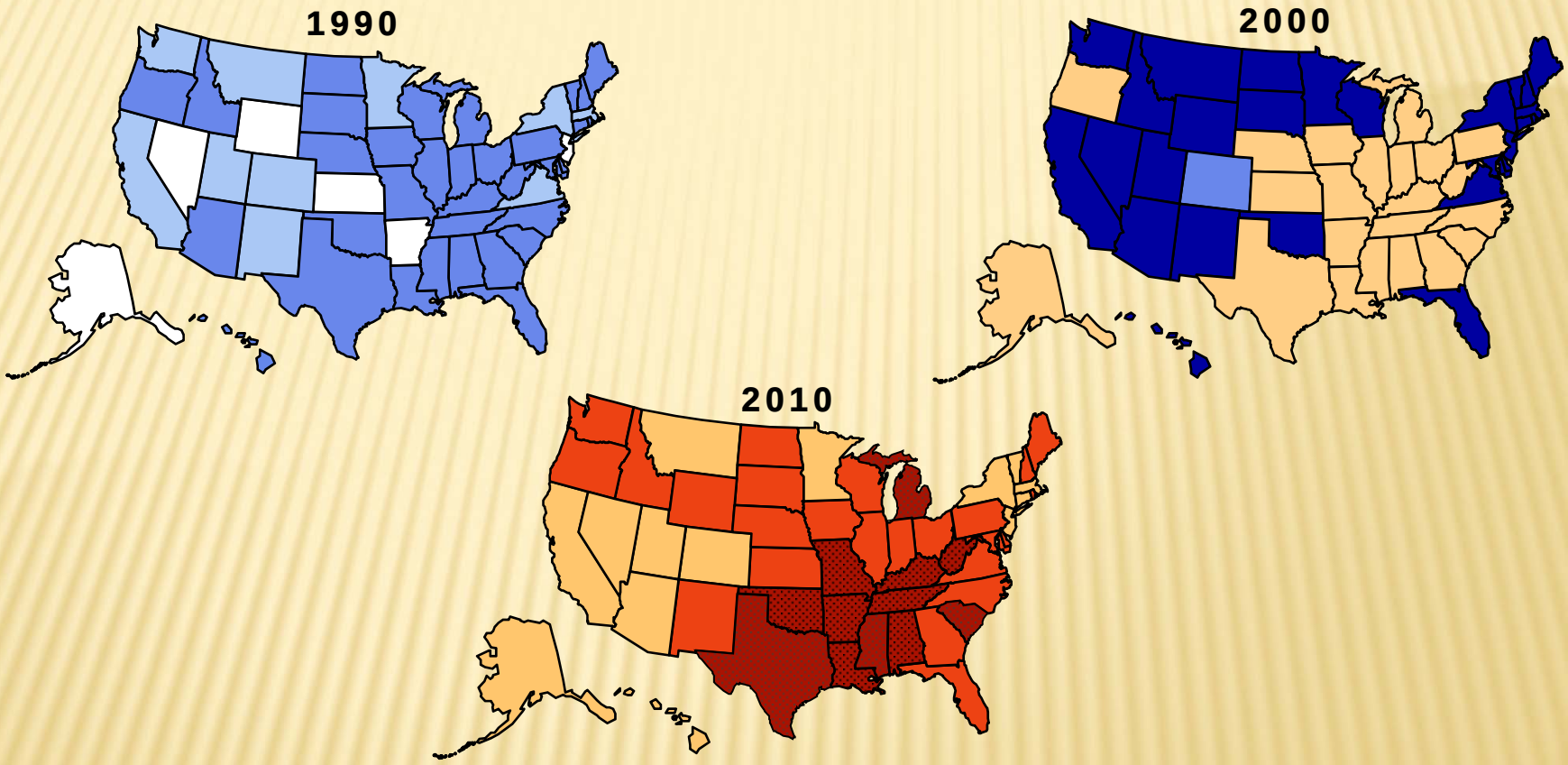

Leanest State
Colorado
Percentage of Obese Adult Population
(3-year average from 2007-09 CDC Behavioral Risk Factor Surveillance System data)
Fattest State
Mississippi
19.1
21.4
24
26
28
30
31.6
33.8
Wash. 26.3
Ore. 25.0
Idaho 25.1
Mont. 23.5
Wyo. 25.0
Nev. 25.5
Calif. 24.4
Utah 23.2
Colo. 19.1
Ariz. 25.7
N.M. 25.4
N.D. 27.7
S.D. 28.5
Neb. 27.2
Kan. 28.2
Okla. 30.6
Tex. 29.0
Minn. 25.5
Iowa 27.7
Mo. 29.3
Ark. 30.1
La. 31.2
Wis. 26.9
Ill. 26.6
Mich. 29.3
Ind. 28.1
Ohio 29.0
W.Va. 31.3
Ky. 30.4
Tenn. 31.6
Miss. 33.8
Ala. 31.6
Ga. 28.1
Fla. 25.1
S.C. 29.9
N.C. 29.4
Va. 25.5
Pa. 28.1
N.Y. 25.0
Vt. 22.8
N.H. 25.4
Me. 25.8
Mass. 21.7
R.I. 22.9
Conn. 21.4
N.J. 23.9
Del. 27.8
Md. 26.6
D.C. 21.5
Ala. 26.9
Hawaii 22.6
CalorieLab's
UNITED STATES
OF OBESITY 2010

In 1990, 10 states had a prevalence of obesity less than 10% and no state had prevalence equal to or greater than 15%.

Obesity Trends* Among U.S. Adults

BRFSS, 1990, 2000, 2010

(*BMI ≥30, or about 30 lbs. overweight for 5'4" person)



BACK IN CANADA…

The Canadian Physical Activity Levels Among Youth (CAN PLAY) study estimated that during the 2007-2009 period, 88% of children and youth aged 5 to 19 did not meet the guidelines of Canada's Physical Activity Guide.[5]

.

In the 2007/08 CCHS survey,
only half (51%) of Canadians aged 12 and over were active or moderately active

RECOGNIZED STRONG ASSOCIATIONS WITH OBESITY ESPECIALLY WITH INCREASED VISCERAL FAT

- Diabetes
- Cardiovascular disease
- Hypertension
- Cerebrovascular accident (stroke)
- Pulmonary dysfunction
- Gallbladder disorders
- Multiple organic dysfunction syndrome (MODS)
- Cancer and cancer recurrence (breast)
- Arthritis, gout

OBESITY-RELATED LYMPHEDEMA

A crude estimate of approximately 15000 patients attending a US clinic showed almost 75% of morbidly obese patients have chronic oedema of the legs (Todd, 2009)

OBESITY-RELATED LYMPHEDEMA

…. and the lymphedema is mostly unrecognized and untreated

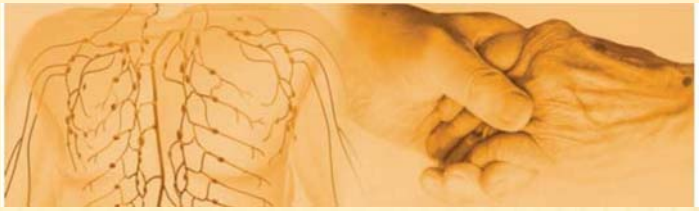
COMPLICATIONS OF OBESITY-RELATED LYMPHEDEMA

- Cellulitis
- Life-threatening septicemia
- Chronic wounds that do not heal
- Immobility
- Disability and job loss

OBESITY AND LYMPHEDEMA

Little research has been done to study the link between obesity and lymphedema, and the impact of lymphedema on skin integrity and wound healing

CANADIAN LYMPHEDEMA FRAMEWORK



PARTENARIAT CANADIEN DU LYMPHOEDÈME

Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada

Improving lymphedema care: the power of international collaboration

INTERNATIONAL LYMPHEDEMA FRAMEWORK

Prof Christine Moffatt
University of Glasgow

Eight standards of practice for people with lymphedema:

a framework for the ILF and its partner organisations to work towards.

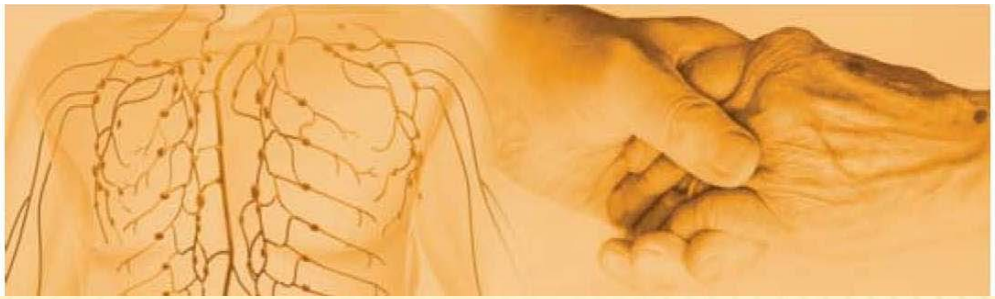
STANDARDS OF PRACTICE FOR LYMPHEDEMA

- **Standard 1:** Awareness and knowledge of lymphedema within the community
- **Standard 2:** Identification of people at risk of or with lymphedema
- **Standard 3:** Empowerment of people at risk of or with lymphedema
- **Standard 4:** Provision of lymphedema services that deliver high quality clinical care that is subject to continuous improvement

- **Standard 5:** Access to appropriately trained health care professionals
- **Standard 6:** Provision of high quality clinical care for people with cellulitis
- **Standard 7:** Provision of optimal, individualised programmes of care
- **Standard 8:** Provision of multi-disciplinary health and social care

- American Lymphedema Framework Project
  - Dr Jane Armer, University of Missouri
  - Founded in 2008
- Canadian Lymphedema Framework
  - Dr Anna Towers, Dr. David Keast
  - Founded in 2009

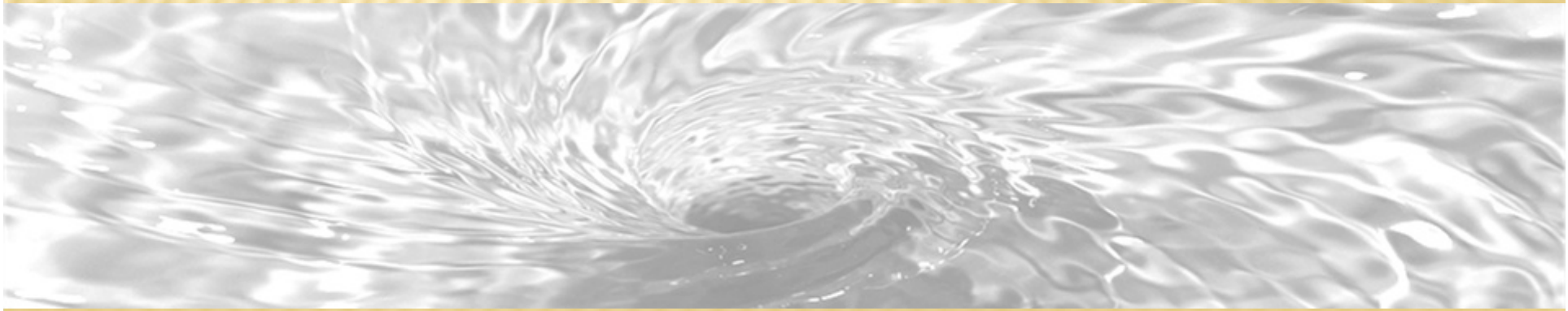
CANADIAN LYMPHEDEMA FRAMEWORK



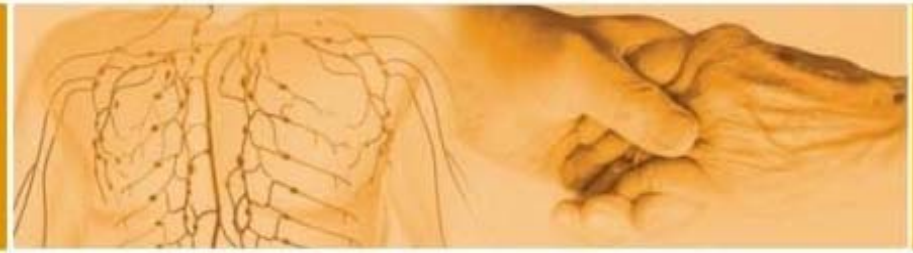
PARTENARIAT CANADIEN DU LYMPHOEDÈME

Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada

CLF: WORKING TOGETHER TO IMPROVE LYMPHEDEMA MANAGEMENT IN CANADA AND BEYOND



CANADIAN LYMPHEDEMA FRAMEWORK



PARTENARIAT CANADIEN DU LYMPHOEDÈMA

Executive Committee Members

Dr. Anna Towers: Co-Chair
Dr. David Keast: Co-Chair
Anna Kennedy, Rachel Pritzker and Christine Moffatt

Administrative support:

Jill Allen, Pamela Hodgson

A registered charity, the CLF is an academic and patient stakeholder collaboration - part of an international initiative that aims to promote research, best practices and lymphedema clinical development, worldwide.

Theme of stakeholder meeting Nov 2009:
What can we do to improve the management of lymphovenous disorders in Canada?

STAKEHOLDER MEETING PARTICIPANTS

110 lymphedema stakeholders attended

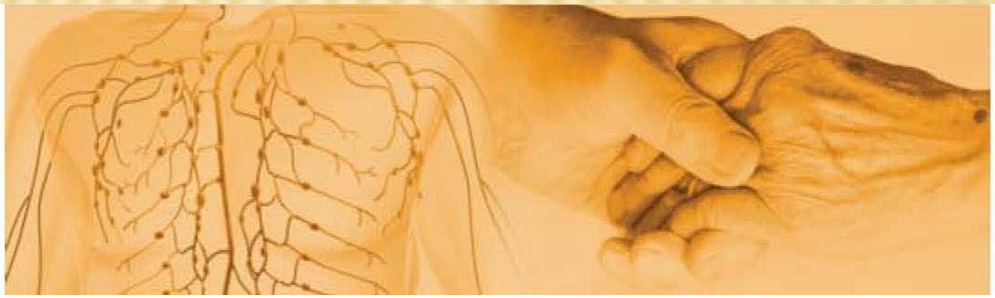
with almost equal participation from

therapists	physicians
patients	nurses
industry representatives	funders
government representatives	


EXIT


EXIT

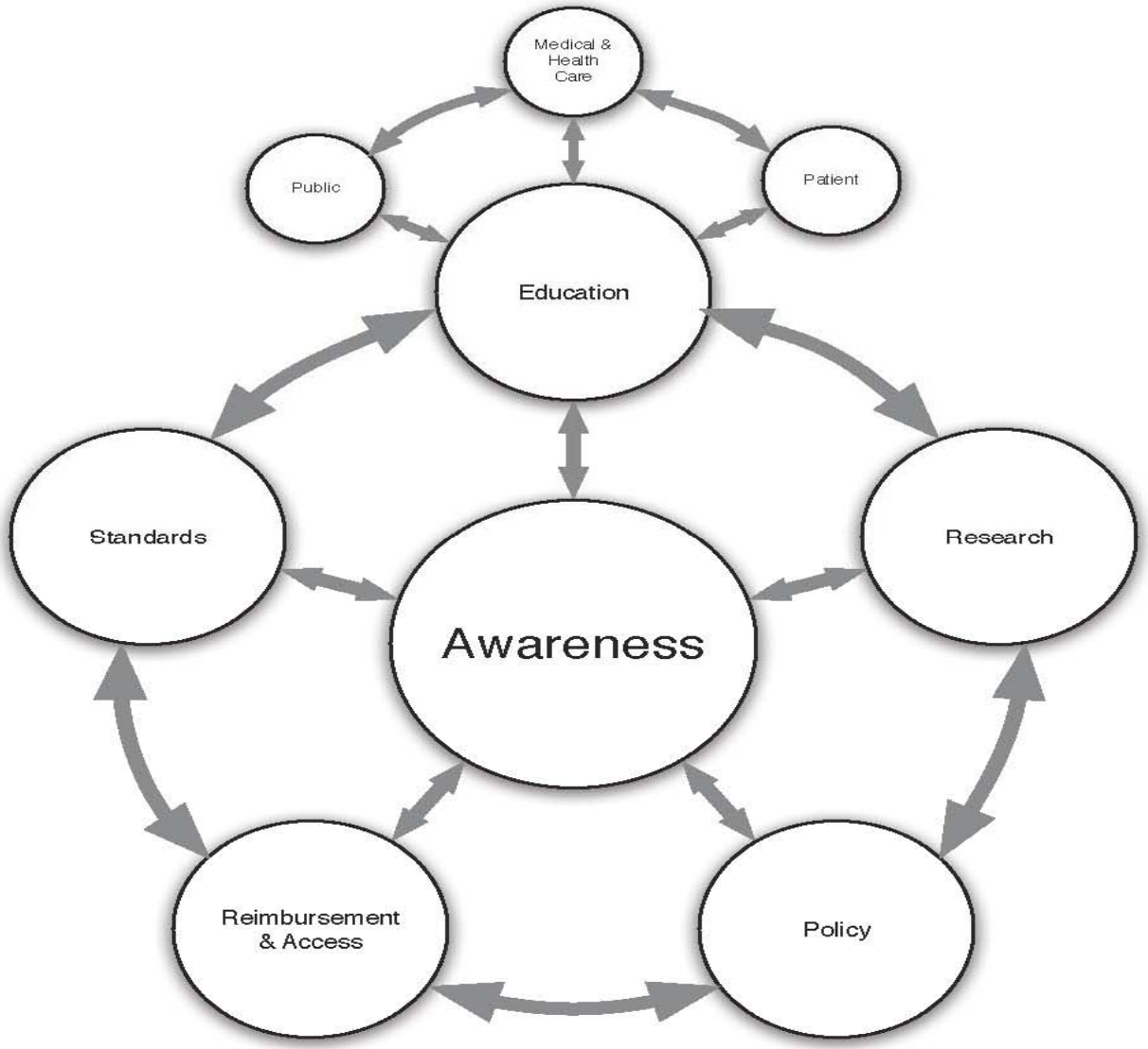
“A vicious circle of lacks.”



KEY DEVELOPMENT AREAS IDENTIFIED

- Research
- Advocacy
- Reimbursement and policy issues
- Education
- Standards of care

THE LYMPHEDEMA WEB OF AWARENESS



WORKING GROUPS

1. Education
2. Research
3. Partnership building and fundraising

RESEARCH

- Prevalence of lymphedema :“We need to survey the landscape”
- Resource list for existing Canadian research
- Encourage clinical trials on the effectiveness of lymphedema therapy
- Risk reduction and prevention

Improving education for lymphedema therapists, and all health care practitioners

MULTI-DISCIPLINARY EDUCATIONAL INITIATIVES

- Lymphedema therapists
- Physicians
- Physiotherapists
- Nurses
- Occupational therapists
- Massage therapists

EDUCATION

Curriculum Development:

Undergraduate

Postgraduate

Continuing education

Education Working Group

Nadine Maraj-Niri, Martina Reddick (Co-Chairs)

Linda (Koby) Blanchfield, Michael Eid, Adriana Golob, Robert Harris, Pamela Hodgson, Michelle Horst, Pamela Hilliard, Leslie Hutchings, Jan McFarland, Edith Mulhall, John Mulligan, Casi Shay, Dorit Tidhar, Anna Towers, Janice Yurick

Educational activities

Training standards

- Collated curriculum Information from the major (private) lymphedema schools in Canada

Consistency in presentations to health professionals

- Organised a resource library of 355 slides

Under-graduate health sciences curricula

- Survey/questionnaire distributed to 100 university and college programs across Canada

Research

- Collected information on lymphedema studies in Canada and developed a comprehensive list of Canadian researchers working in the field

- Created an extended Research Advisory Network to assist development of funded research projects

- Planning a prevalence study, CIHR

Research Working Group

Bev Lanning, Roanne Thomas-MacLean (Co-Chairs)

Sylvia Crowhurst, Pamela Hodgson, Miles Johnston, Winkle Kwan, Margie McNeely, Cathy McPherson, Deborah Ruskin, John Semple, Andrea Tilley, Anna Towers

Partnership Development and Fundraising

Bonnie Baker (Chair)
Kim Avanthay, David Keast, Anna Kennedy, Claire Ann Deighton-Lamy, Rachel Pritzker, Linda Venus

The CLF is modelled on, and has a partnership agreement with, the International Lymphoedema Framework, and through it links with other national frameworks.

CLF STRUCTURE

ADVISORY BOARD MEMBERS

Roanne Thomas MacLean Saskatoon, Saskatchewan	Researcher specializing in the impact of psycho-social issues of lymphedema in breast cancer patients
Robert Harris Victoria, British Columbia	Director of Vodder School International – teaching certification classes to therapists
Jan McFarland Cookstown, Ontario	Co-Director of Toronto Lymphocare. Provides treatment for patients as well as teaches classes to therapists
Kim Avanthay Lac du Bonnet, Manitoba	Lymphedema advocate and mother of a young son with lymphedema
Martina Reddick St. John's, Newfoundland	Lymphedema nurse practitioner, Cancer Care Program at East Health Region
Cathy McPherson Toronto, Ontario	Patient with primary lymphedema and Website manager/administrator of www.Lymphovenous–Canada.org
Linda Venus Winnipeg, Manitoba	Lymphedema patient Senior Director at Canada Cancer Society, Manitoba Division
Janice Yurick Edmonton, Alberta	Physiotherapist with the lymphedema program at Cross Cancer Institute in Edmonton
Casi Shay Montreal, Canada	Physiotherapist, McGill Lymphedema Program

Other CLF Projects and Activities

- Co-hosted the 3rd ILF Conference
- Contributing to Canadian lymphedema education
  - Peer-reviewed journals and other
  - publications
  - Invited presentations
- Contributing to global health education
  - Ugandan hospital site visits

KEY MILESTONES TO DATE

- February 5-6, 2009: CLF Founders meeting
- November 6, 2009: National Stakeholder Meeting, Toronto
- February 2010: Palliative Care Best Practices
- June 2010: national charitable status approval
- March – June: 2010 Therapist survey
- June 16-18 2011 – hosted ILF Conference, Toronto
- PATHWAYS magazine- April 2012

INTERNATIONAL LYMPHOEDEMA FRAMEWORK

3rd INTERNATIONAL CONFERENCE

In collaboration with the

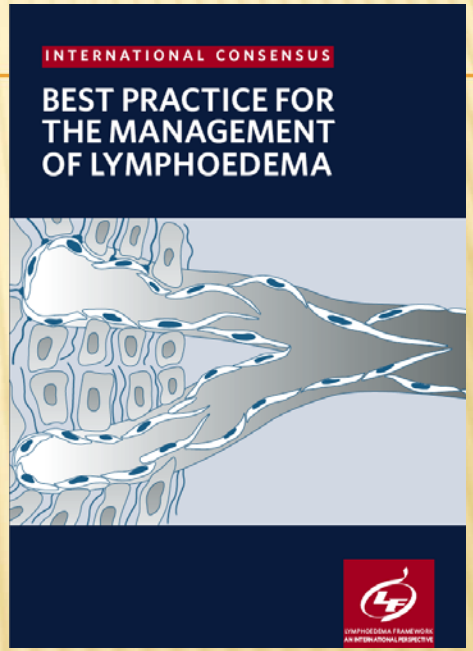
CANADIAN LYMPHEDEMA FRAMEWORK

TORONTO JUNE 16-18, 2011

www.lympho.org/3rd-ilf-conference.php

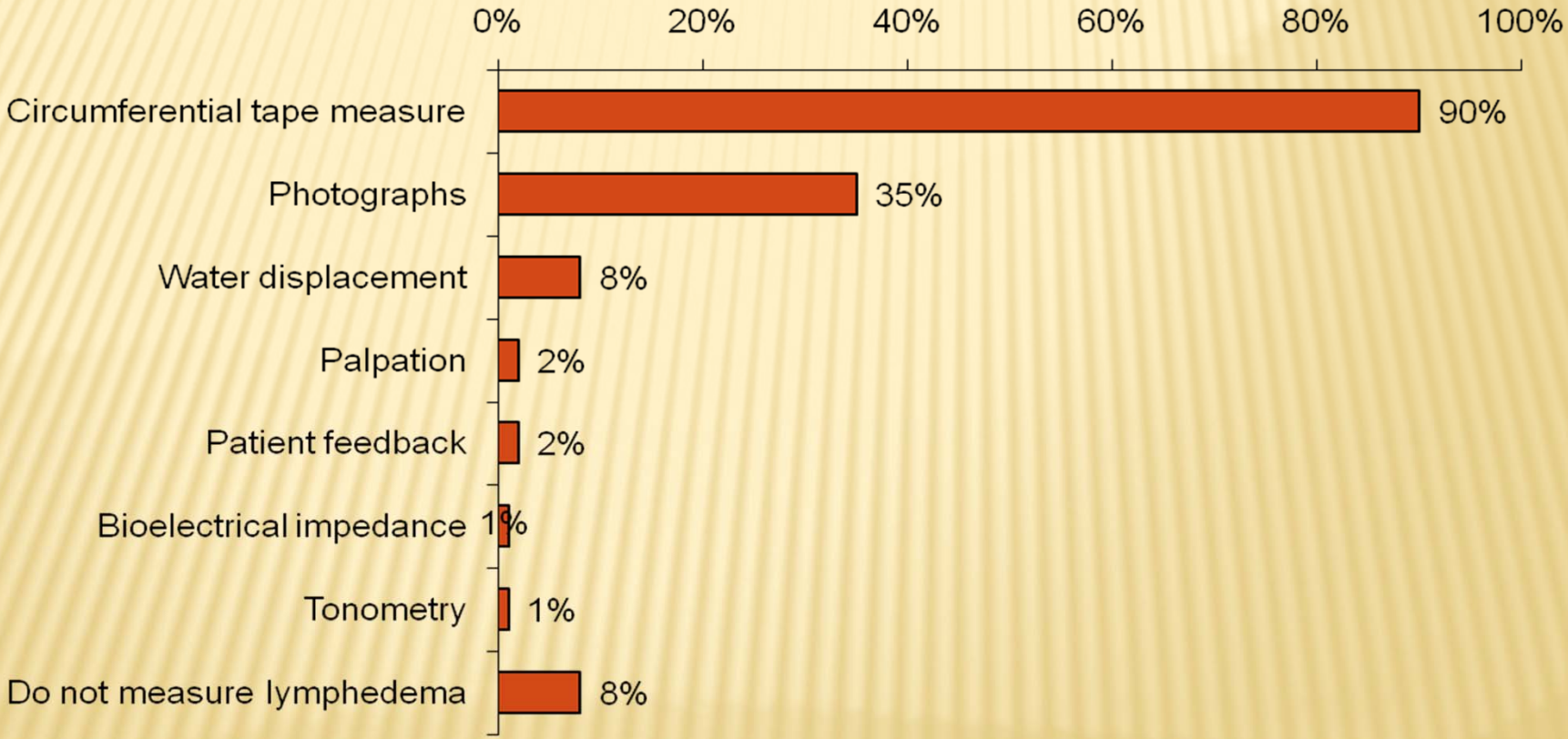
IMPLEMENTING BEST PRACTICE FOR THE MANAGEMENT OF LYMPHEDEMA

Update of Best Practice Guidelines Based on systematic reviews



CLF survey 2010

MEASUREMENT METHODS USED TO ASSESS LYMPHEDEMA



Source: Q20

Base: All respondents (N=239)

HOW DO WE PROMOTE THE USE OF BEST PRACTICE?

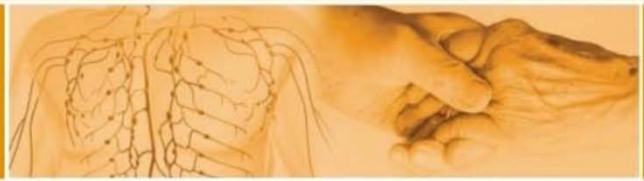
- Advocate for Best Practice being a core for basic and continuing education for lymphedema and other health care professionals
- Advocate to have lymphedema indicators as part of accreditation standards for departments and institutions (e.g. cancer centres, wound clinics)

Assessing the Lymphedema Landscape

Phase 1- Online Survey

LYMPHEDEMA LANDSCAPE

CANADIAN LYMPHEDEMA FRAMEWORK



PARTENARIAT CANADIEN DU LYMPHOEDÈMA

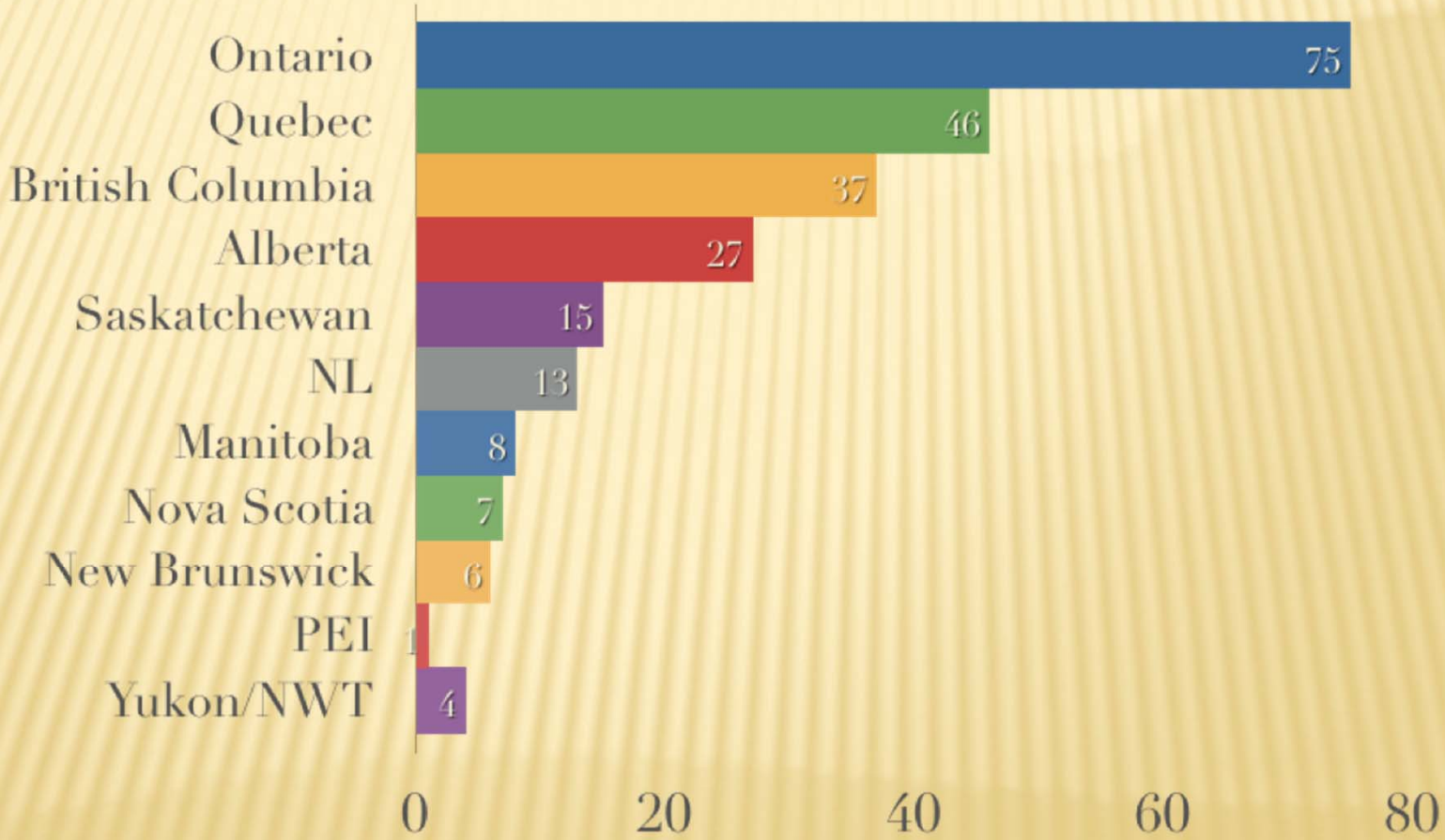
Canadian Survey - 2010

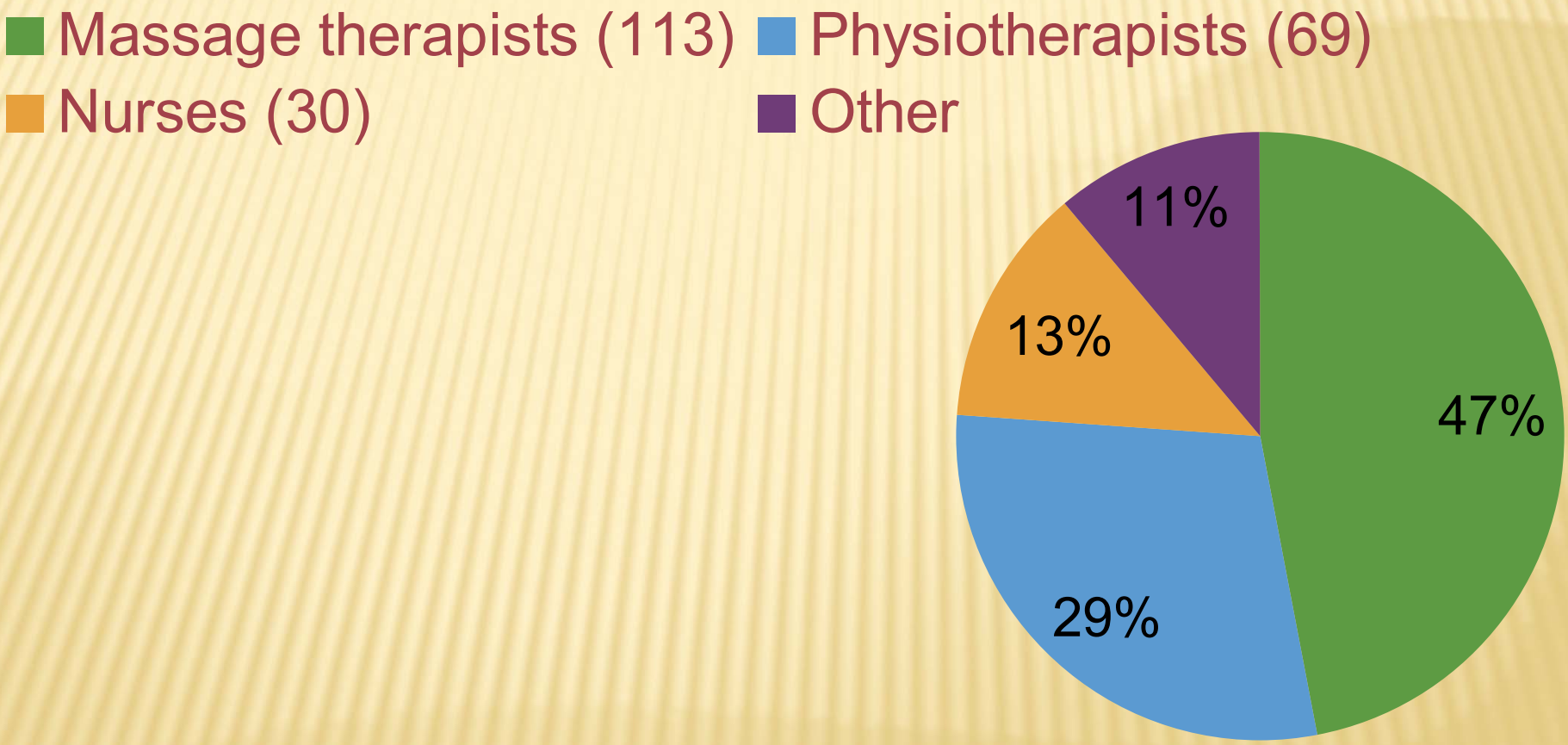
A collaborative project with 3M

PURPOSE - TO DOCUMENT

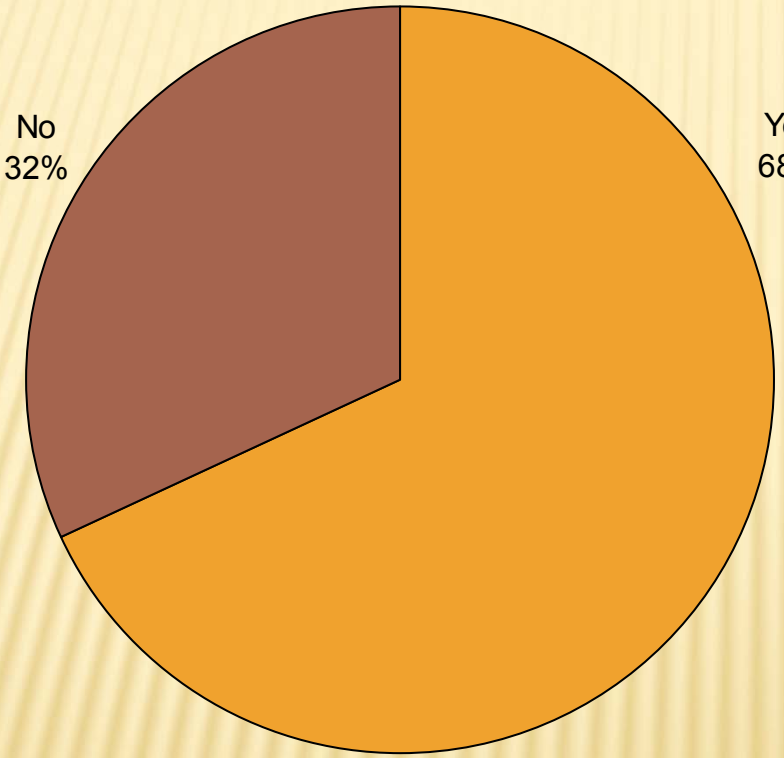
- level of lymphedema training and certification of health professionals who assess/treat patients with lymphedema
- types of lymphedema seen
- the profile of care settings
- treatments and services provided

TOTAL RESPONSE: 239




Massage therapists (113)
Physiotherapists (69)
Nurses (30)
Other
11%
13%
47%
29%

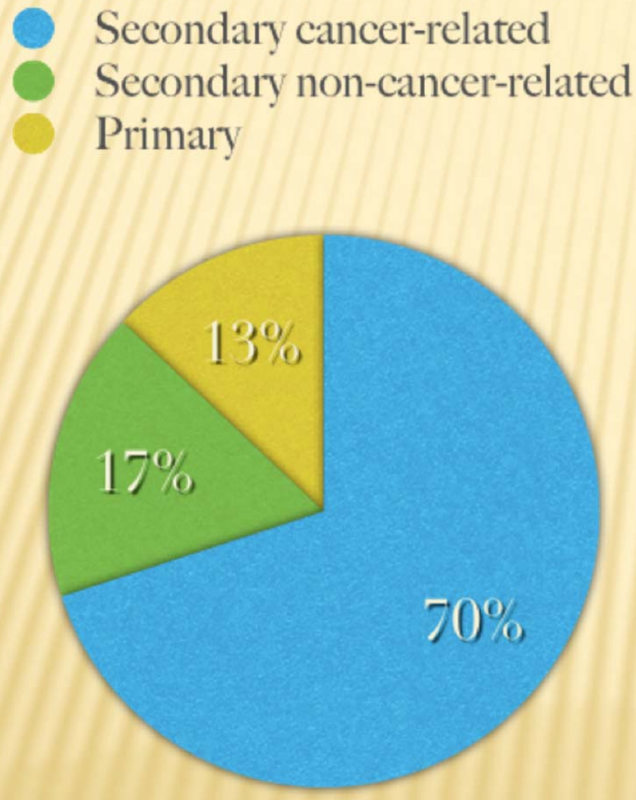
WHETHER HAVE TRAINING IN CDT FROM A QUALIFIED SCHOOL

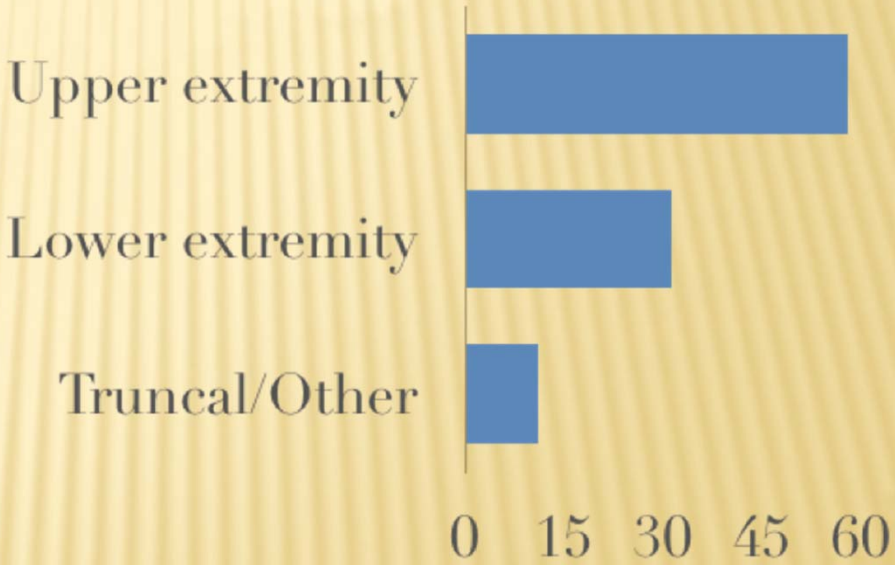


RMT	87%
Physio	67%
RN/NP/RPN	47%

Source: Q12/13
Base: All respondents (N=239)

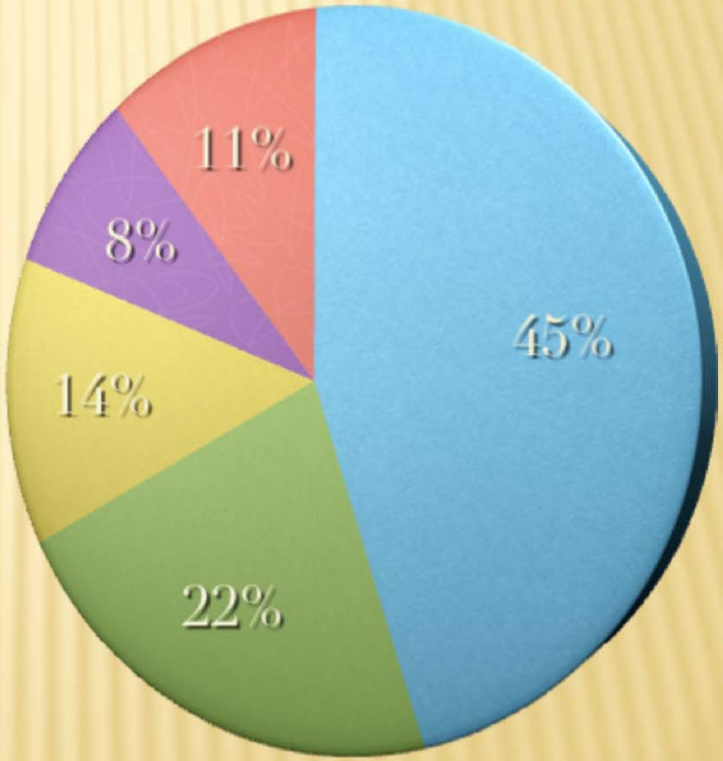
TYPES OF LYMPHEDEMA SEEN





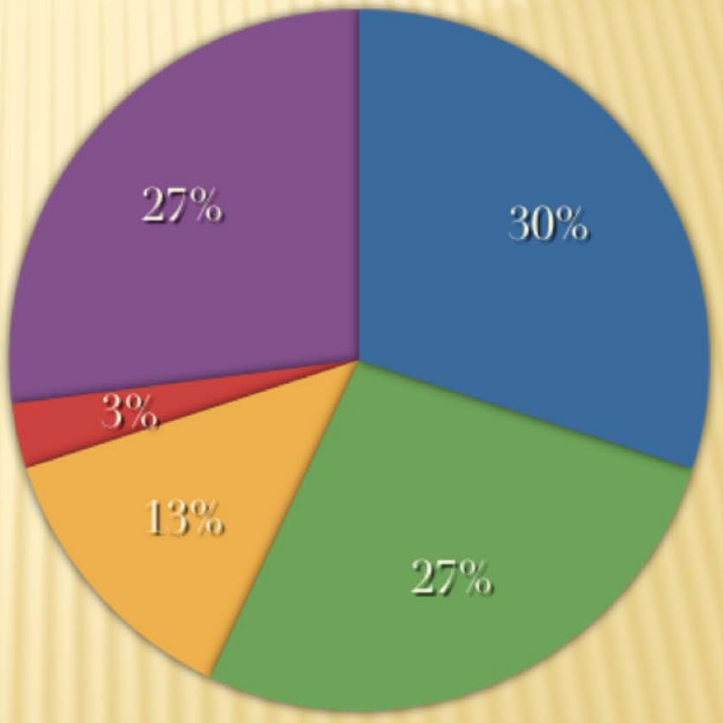
PRACTICE SETTING

- Private practice
- Hospital
- Home care
- Palliative/longterm care
- Other

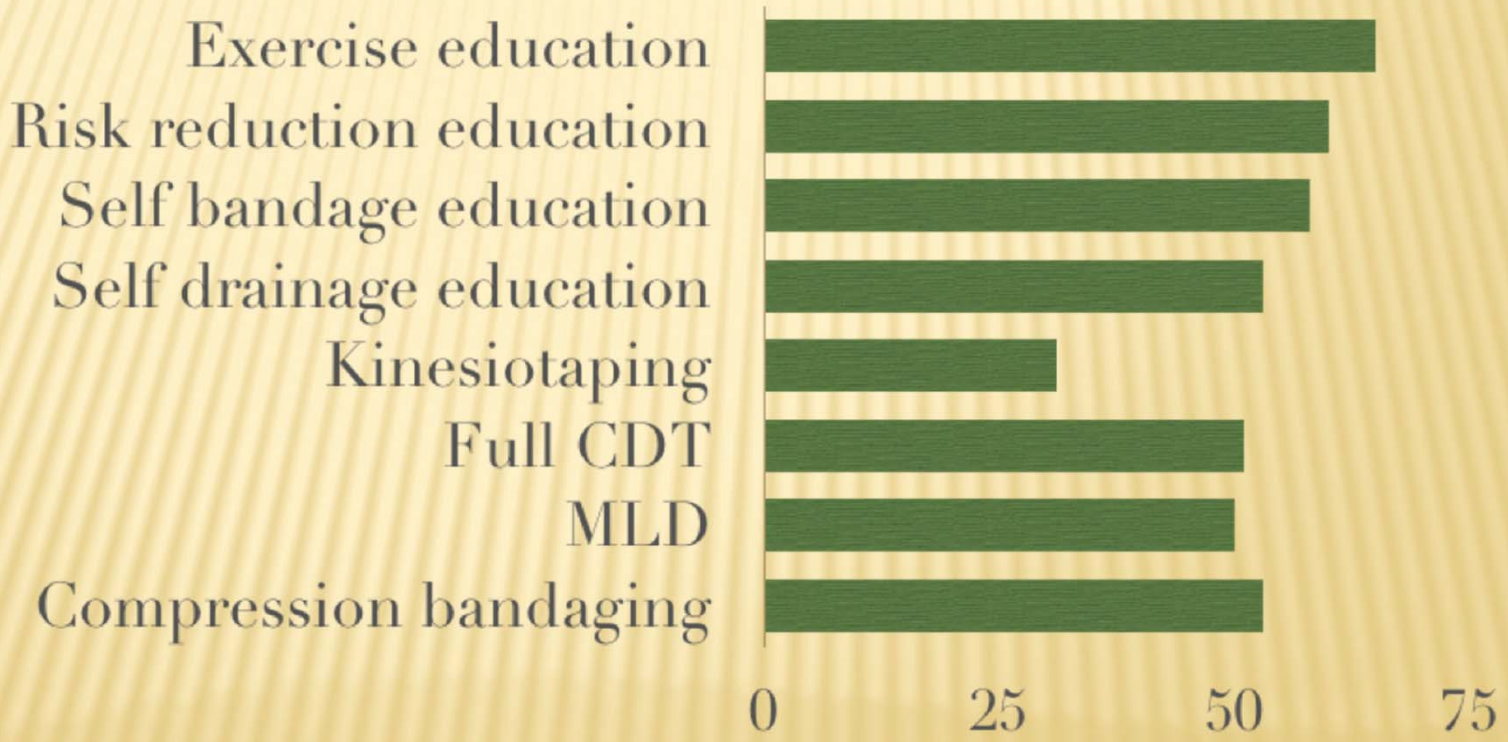


INTENSIVE PHASE
FREQUENCY OF PATIENT VISITS

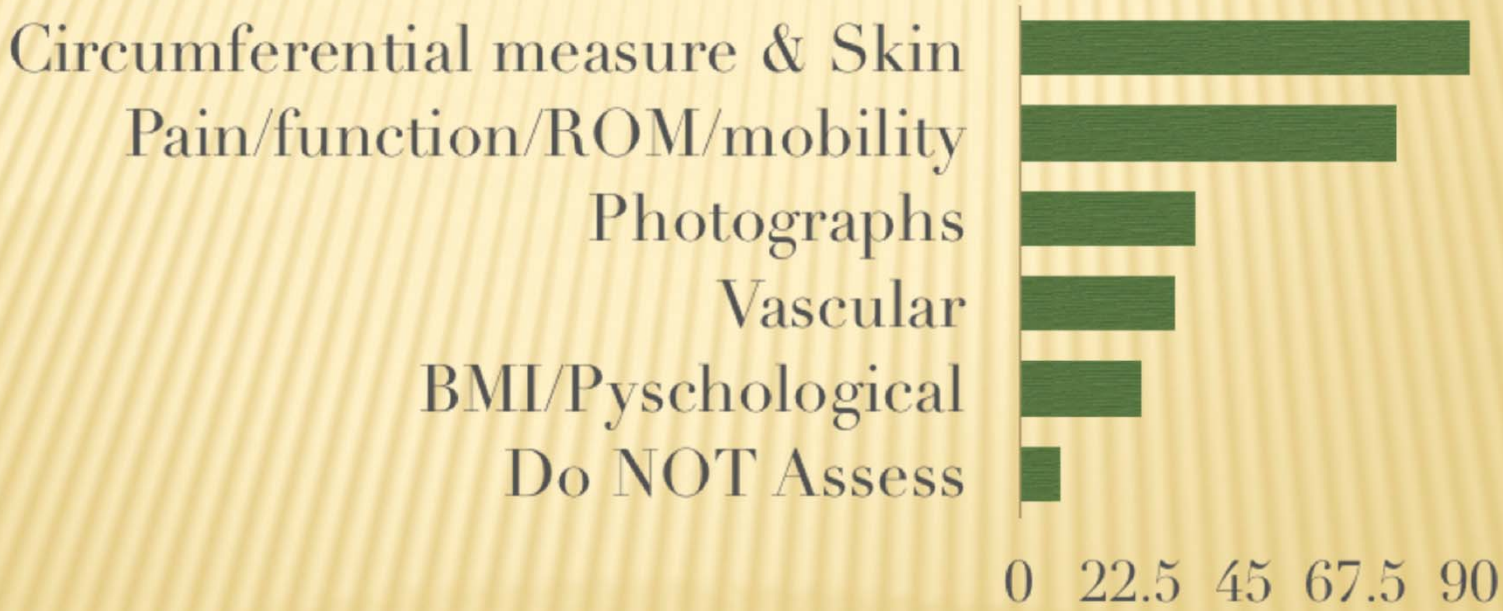
- 4-5 x/wk
- 2-3 x/wk
- 1 x/wk
- every 2 wks
- Less than every 2 wks



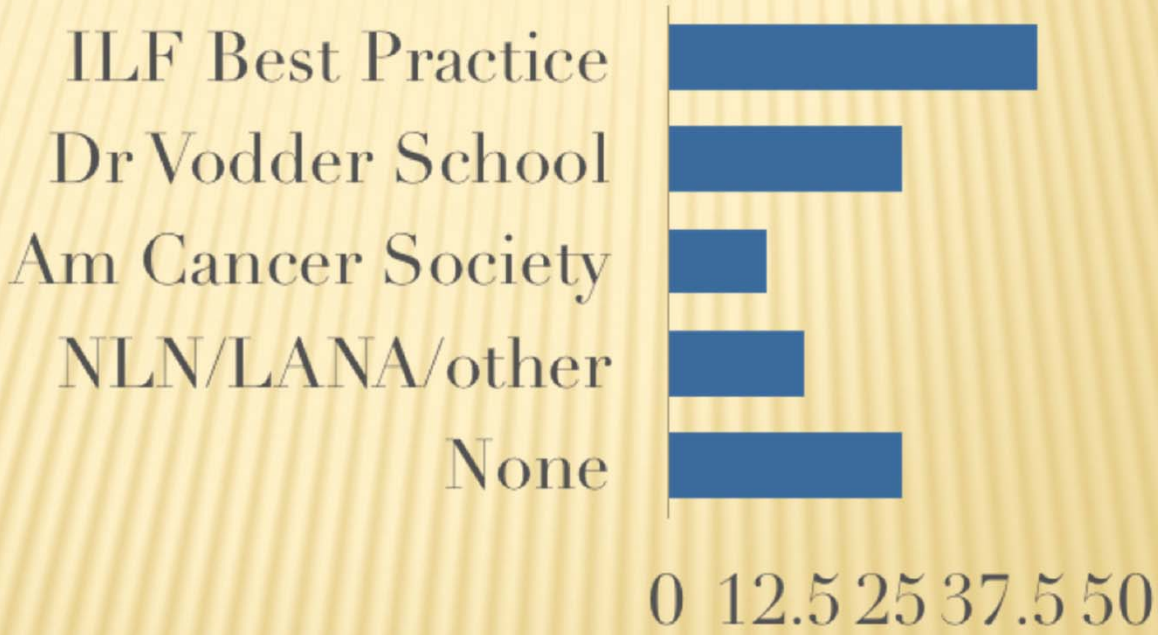
COMPONENTS OF CARE



MEASUREMENT TOOLS



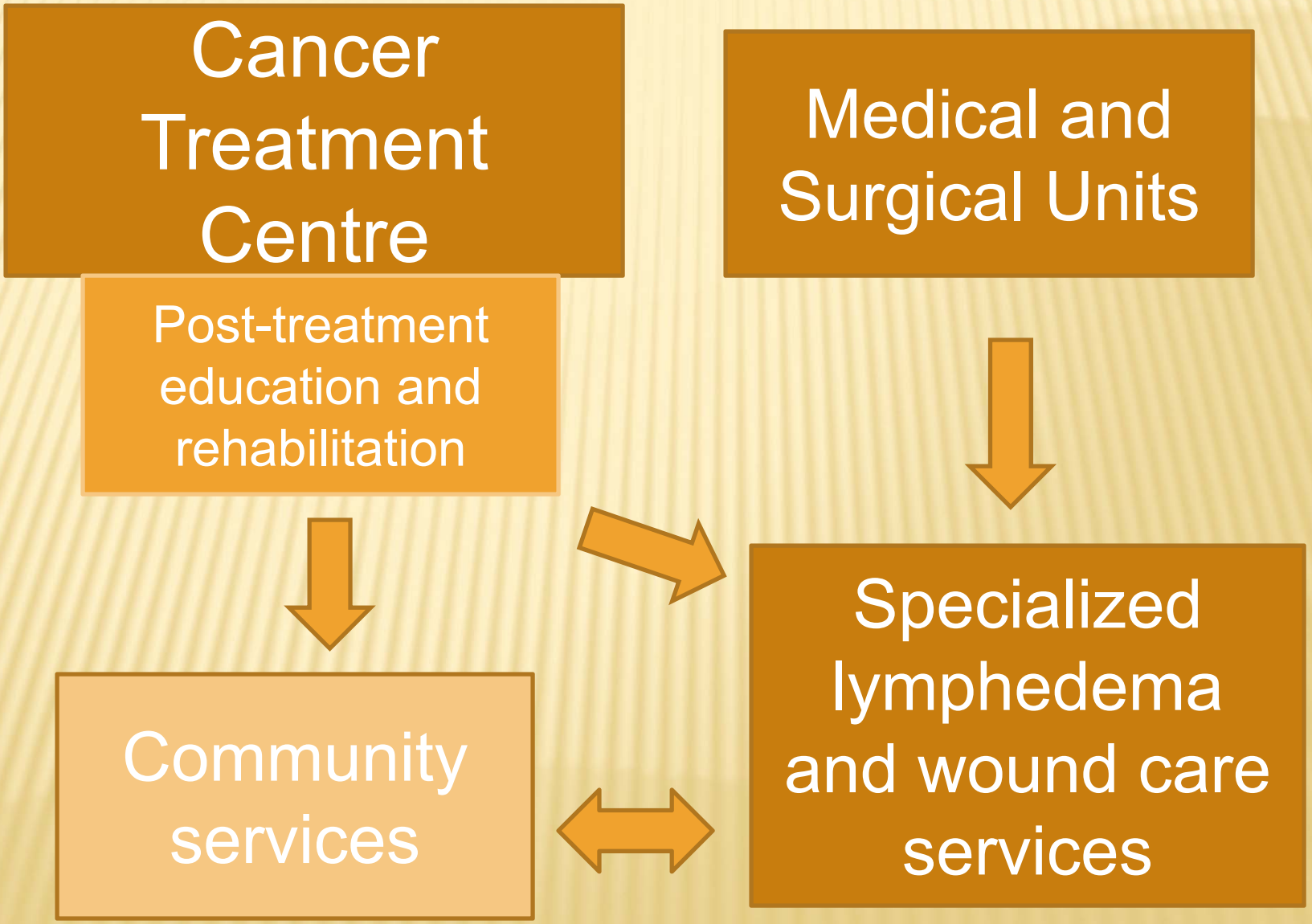
CLINICAL GUIDELINES FOLLOWED



KEY LEARNINGS

- Post-graduate training needed among health professionals managing lymphedema
- Use of clinical guidelines and assessment tools need fuller integration into lymphedema care

INTERDISCIPLINARY MODELS OF CARE



THE CHRONIC CARE MODEL

REF Best Practices for Lymphedema
version 2, 2012

The chronic care model is a pragmatic approach based on the following assumptions:

- That the patient is the center of the care process
- That all professionals integrate into the model and cooperate closely together
- That the patient has an active role (care manager) rather than being a passive ‘care consumer’. Aspects such as self management and self efficacy are very important
- That healthcare workers do not merely focus on symptom control (for example, reduction of swelling), but act as ‘coaches’ with ‘hands-off’ approach

The chronic care model is based on the following assumptions (2):

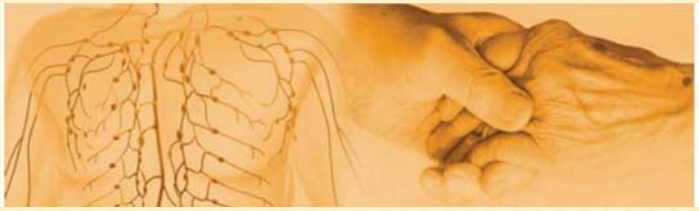
- That the model and integrated approach is based on guidelines, evidence based medicine and best practice documents, to which all health professionals are committed
- That standardized and validated measuring methods and questionnaires will be used to monitor the effects of treatment programs
- That effective, digital electronic patients files and mutual communication between healthcare workers and patients will be ensured

- **The role of self-management**
- The CCM allows self-management as a core component. Self-management is the ability of a individual to cope with symptoms, treatment, physical and social consequences and lifestyle changes related to a life living with a chronic disease[15]. To achieve this goal, four domains are offered (box 1):

SELF MANAGEMENT DOMAINS (REF BDP 2- 2012)

- Activities focused on health improvement and build up of physical resistance
- Coping with healthcare providers and compliance to treatment

CANADIAN LYMPHEDEMA FRAMEWORK

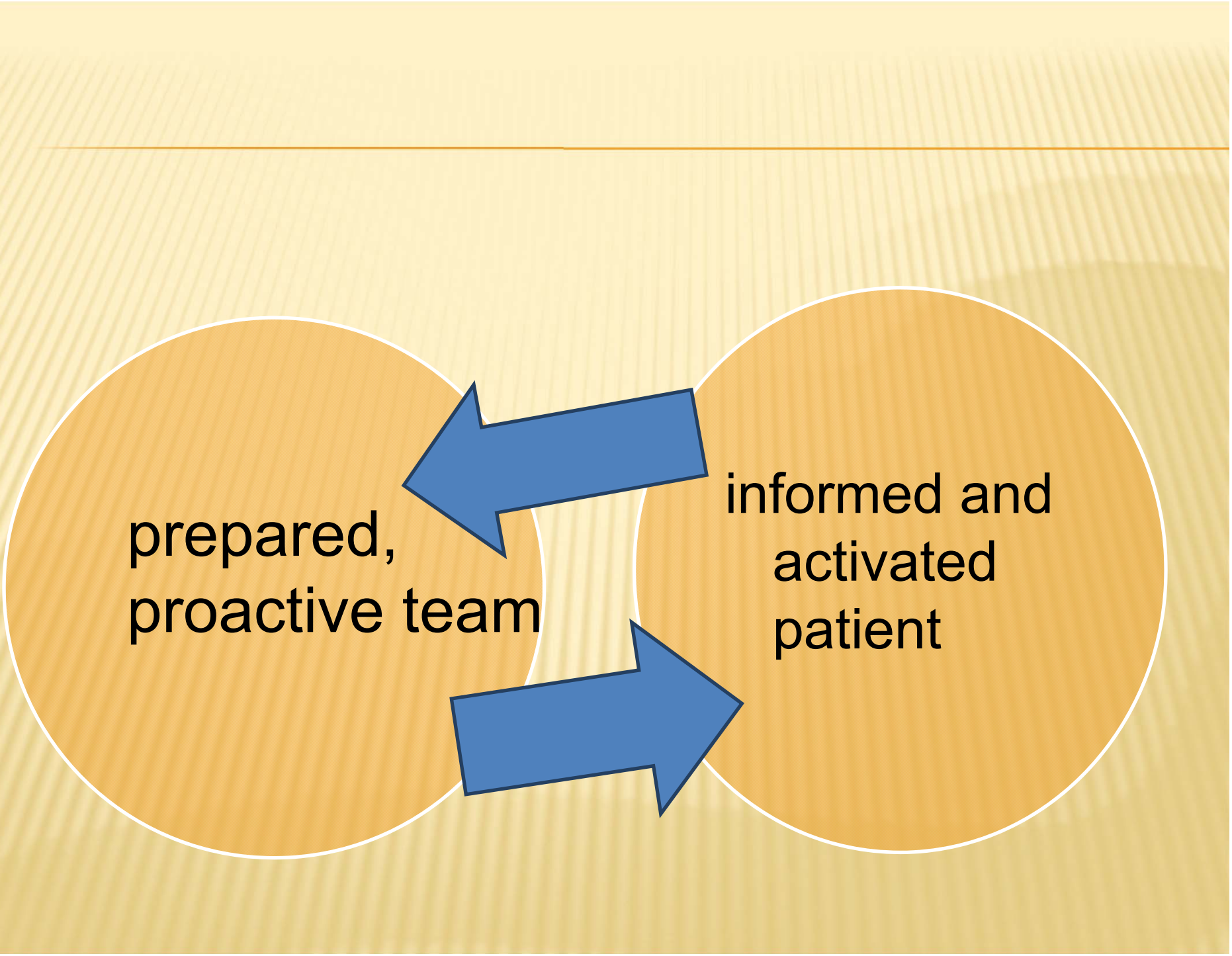


PARTENARIAT CANADIEN DU LYMPHOEDÈME

Comprehensive effective treatment for lymphedema and related disorders will be accessible to all persons across Canada

"THERE IS MUCH THAN CAN AND SHOULD BE DONE."

DR JUDITH CASLEY-SMITH


prepared,
proactive team
informed and
activated
patient