

Promoting symptom appraisal and presentation in primary care



World Cancer Congress
Kuala Lumpur, Malaysia
1–4 Oct 2018

Strengthen
Inspire
Deliver



Track 2- Advances in screening and early detection

Disclosure of interest: None declared

Overview

- **Prof Jon Emery, University of Melbourne, Australia**

‘Using lessons from the UK to develop and implement public health and primary care interventions to promote timely presentation with possible cancer symptoms in low and middle income countries.’

- **Dr Amos Mwaka, Makerere University, Uganda**

‘Social, cultural and clinical issues which may delay timely presentation with breast or cervical cancer symptoms in rural Uganda.’

- **Prof Jennifer Moodley, University of Cape Town, SA**

‘Adapting the Cancer Awareness Measure (CAM) and the Awareness and Beliefs about Cancer (ABC) tools for African populations.’

- **Dr Corrine Ellsworth-Beaumont, Worldwide Breast Cancer, USA**

‘A Visual Education Approach for Early Detection: Know Your Lemons’

- **Dr Nur Aishah Mohd Taib, KL, Malaysia**

‘Mitigating breast cancer late presentation in Malaysia: A community psycho-educational approach’

- **Panel Discussion time**

Lessons from the UK to inform interventions to promote timely presentation with possible cancer symptoms

Prof Jon Emery
University of Melbourne
On behalf of
Dr Fiona Walter



World Cancer Congress
Kuala Lumpur, Malaysia
1–4 Oct 2018

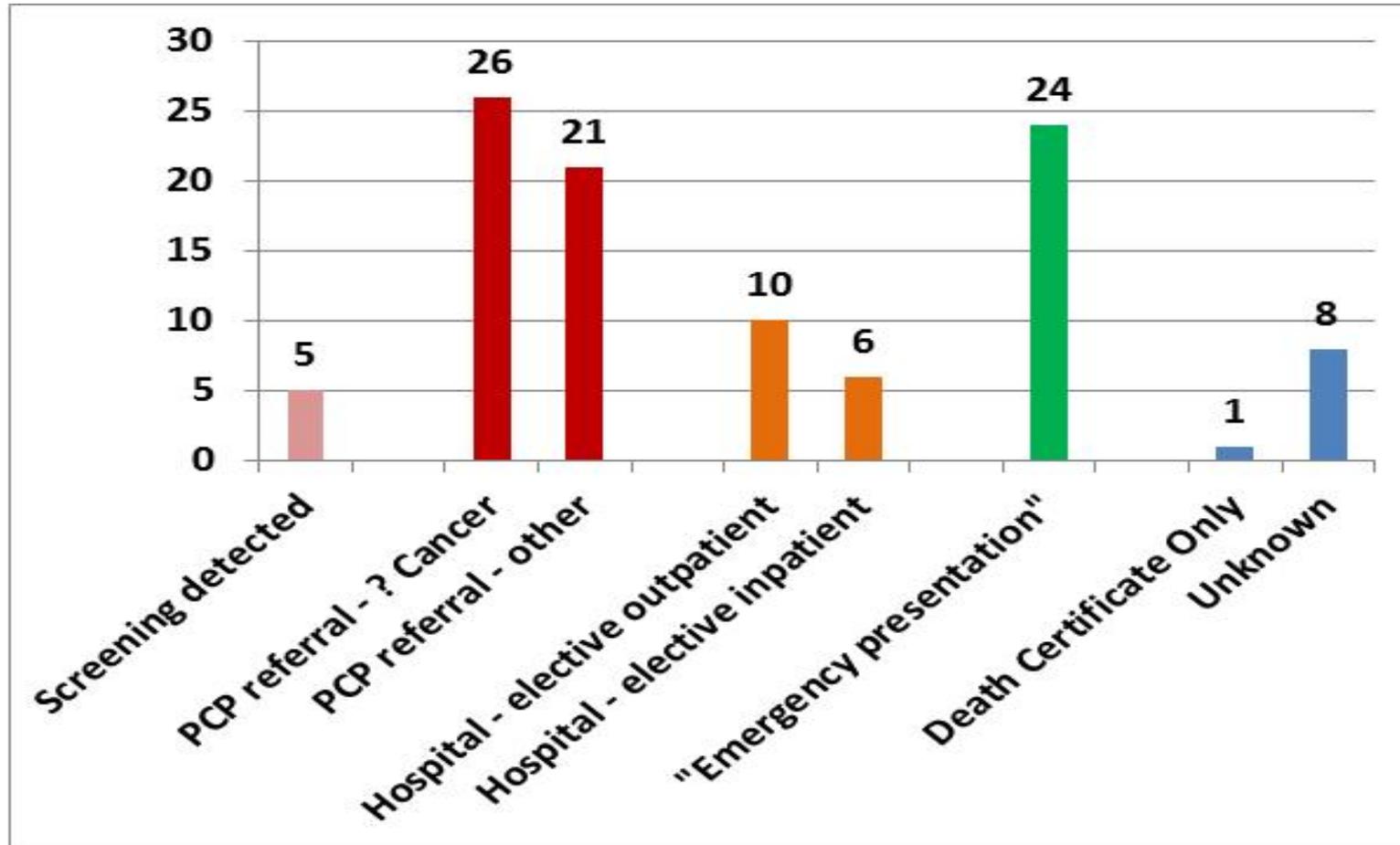
Strengthen
Inspire
Deliver



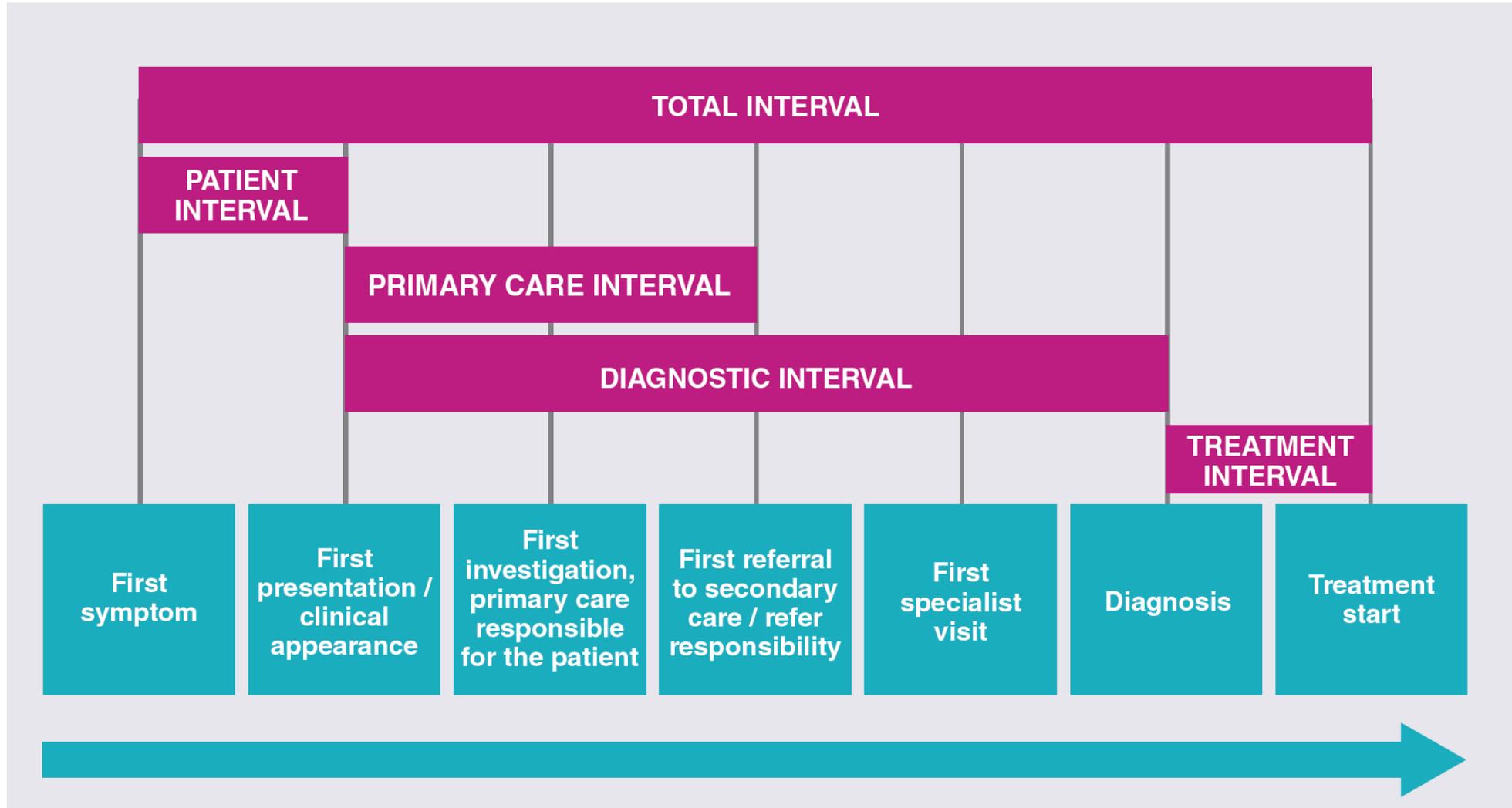
Track 2- Advances in screening and early detection

Disclosure of interest: None declared

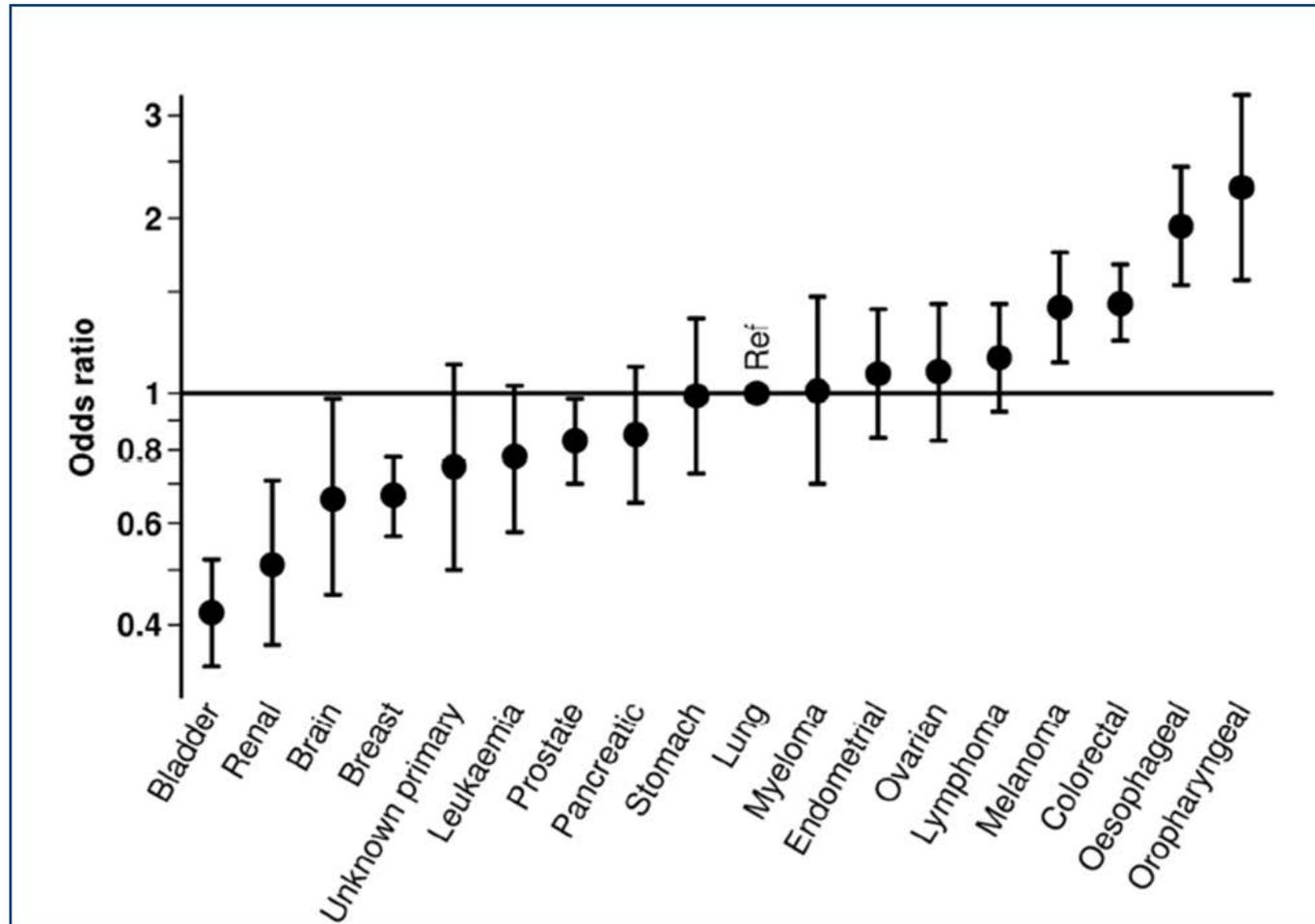
Most cancer patients are diagnosed after symptom onset



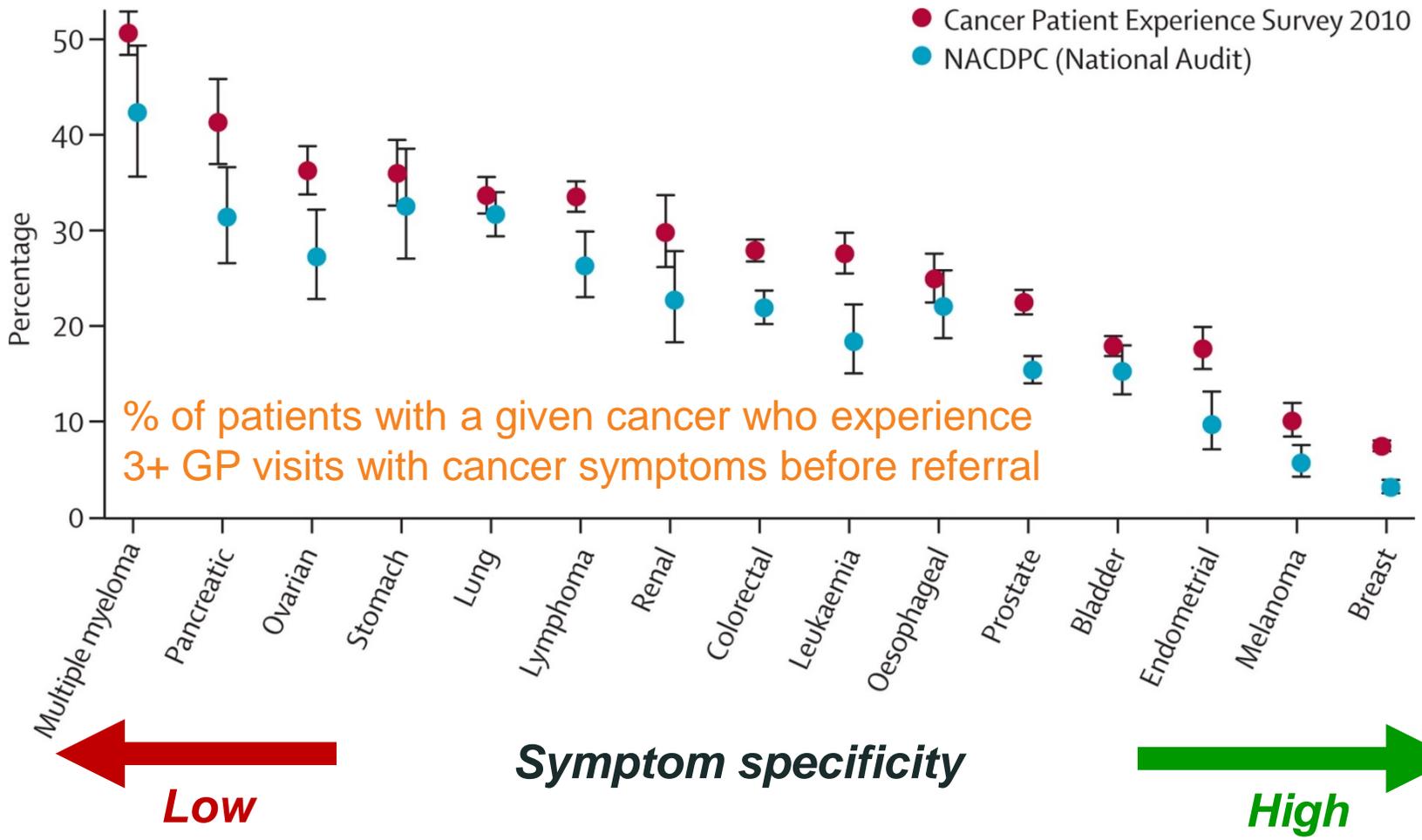
The patient interval



Variations in promptness of presentation between cancers....

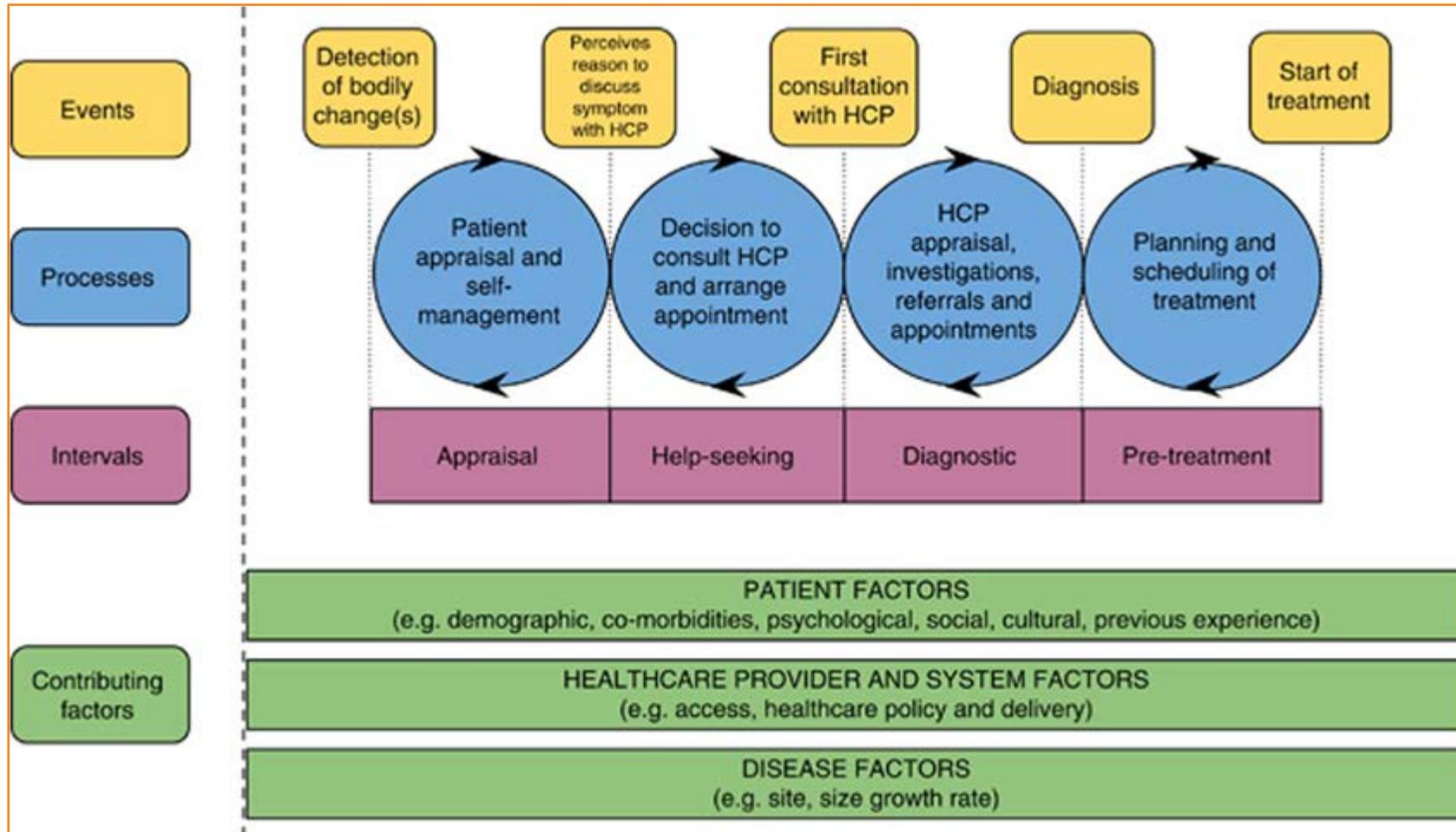


The 'symptom signature' may explain some differences



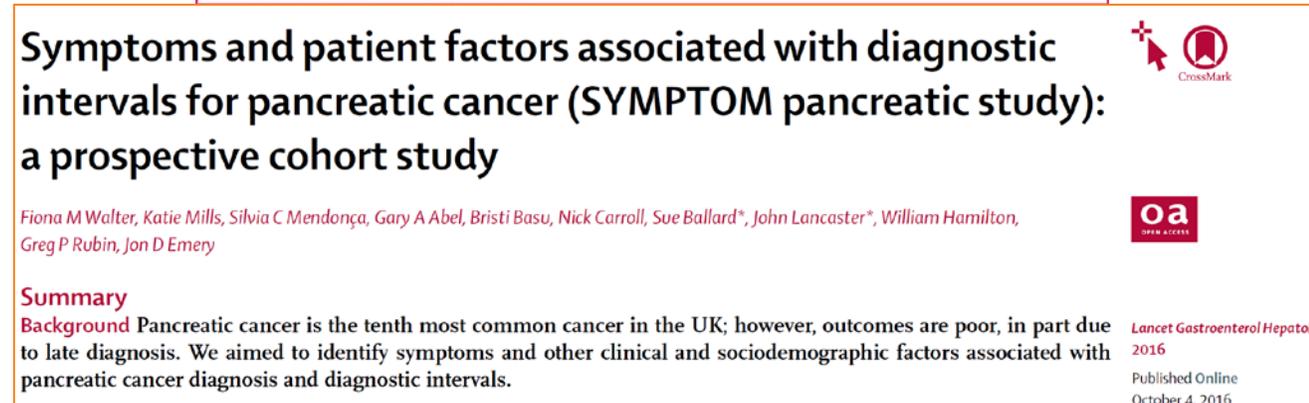
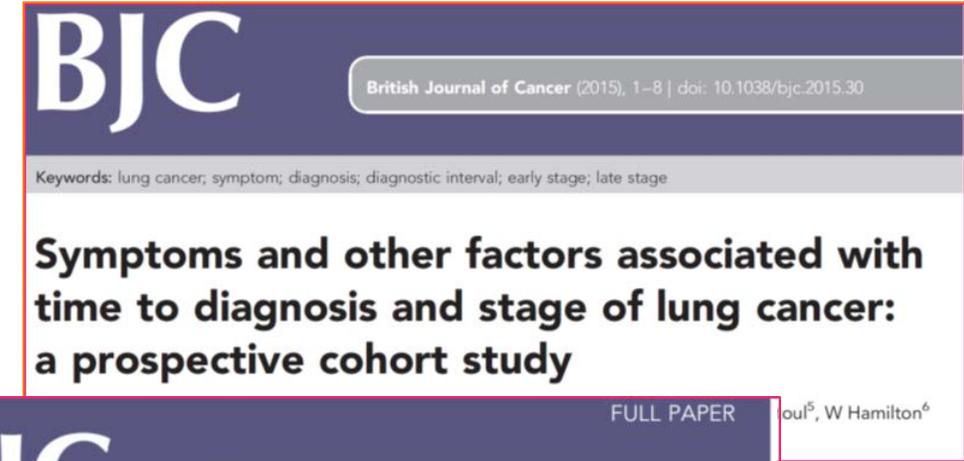
Lyratzopoulos *et al*, Lancet Oncology, 2012
Mendonca *et al*, BJGP, 2016

The Model of Pathways to Treatment

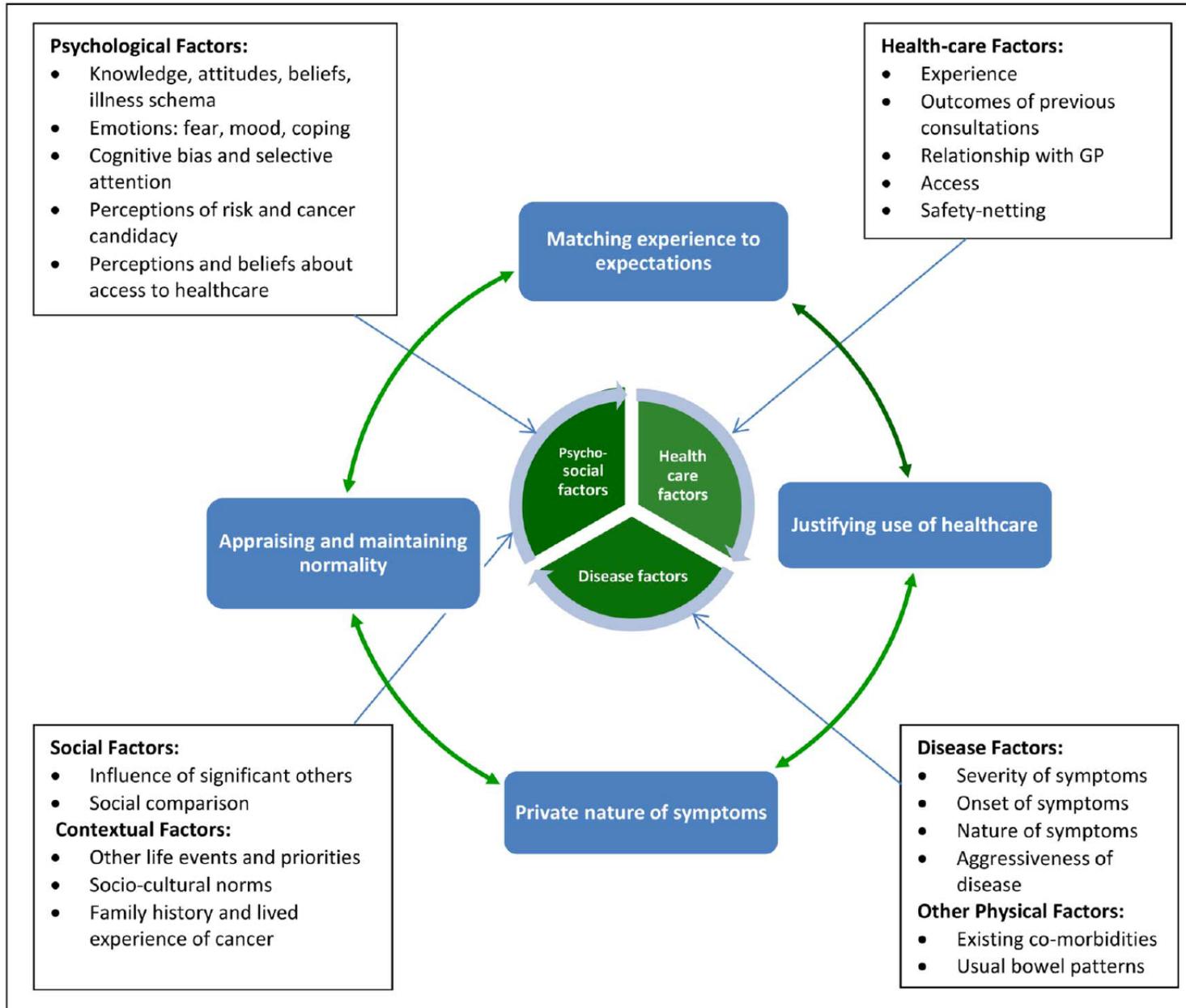


The Symptom studies

- Multiple first symptoms were common
- Symptoms evolved over time
- ‘trigger symptom/s prompted presentation’
- Anxiety, depression and co-morbidities associated with longer patient and diagnostic intervals



Factors affecting symptom appraisal and help-seeking among people with colorectal cancer symptoms



Be Clear on Cancer



Dr Ian Watson

If you've been coughing for 3 weeks, it might not be 'only a cough', so tell your doctor.

Everyone gets a cough now and again, but if you've had one for over three weeks you should see your doctor. Coughing could be a sign of lung cancer. Of course, in the vast majority of cases it won't be serious. But if there is something wrong, finding it early means it's more likely to be treatable, so tell your doctor.



nhs.uk/kingcancer



Knowing the signs of cancer could save your life.



Be Clear on Cancer.

Learn more about our recent TV campaigns

 <p>Breast cancer in over 70s</p>	 <p>Oesophagogastric cancer</p>	 <p>Ovarian cancer</p>
--	---	---

Learn more about our other campaigns

 <p>Bladder and kidney cancer</p>	 <p>Bowel cancer</p>	 <p>Lung cancer</p>
---	---	---

GP's advice

If you spot any signs of cancer, go to your doctor to get it checked out. You're not wasting anyone's time, and if it isn't serious, your mind will be put at rest. But if it is cancer, early diagnosis can make all the difference. The sooner cancer is detected, the better the chances of successful treatment.

Breast cancer

One in three women who get breast cancer are aged 70 and over.

[Learn more about Breast cancer](#)

Oesophagogastric cancer

Heartburn most days for three weeks or more? Tell your doctor.

[Learn more about Oesophagogastric cancer](#)



Dr Anurag Sachdev

If you notice blood in your pee, even if it's 'just the once', tell your doctor.



Be Clear on Cancer

‘The national bowel and lung campaigns reached their target audience and have also influenced younger and more affluent groups. Differences in impact within the target audience were also seen.’

FULL PAPER

BJC

British Journal of Cancer (2015) 112, S14–S21 | doi: 10.1038/bjc.2015.31

Keywords: lung cancer; bowel cancer; colorectal cancer; awareness; GP attendance; health campaign; inequalities; men

The impact of national cancer awareness campaigns for bowel and lung cancer symptoms on sociodemographic inequalities in immediate key symptom awareness and GP attendances

J Moffat^{*,1}, A Bentley¹, L Ironmonger¹, A Boughey¹, G Radford² and S Duffy³

¹Cancer Research UK, Angel Building, 407 St John Street, London EC1V 4AD, UK; ²Anglia and Essex Centre Director, Public Health England, Eastbrook, Shaftesbury Road, Cambridge CB2 8DF, UK and ³National Health Service England, Quarry House, Quarry Hill, Leeds LS2 7UE, UK

Overview

- **Dr Fiona Walter, University of Cambridge, UK**

‘Using lessons from the UK to develop and implement public health and primary care interventions to promote timely presentation with possible cancer symptoms in low and middle income countries.’

- **Dr Amos Mwaka, Makerere University, Uganda**

‘Social, cultural and clinical issues which may delay timely presentation with breast or cervical cancer symptoms in rural Uganda.’

- **Prof Jennifer Moodley, University of Cape Town, SA**

‘Adapting the Cancer Awareness Measure (CAM) and the Awareness and Beliefs about Cancer (ABC) tools for African populations.’

- **Dr Corrine Ellsworth-Beaumont, Worldwide Breast Cancer, USA**

‘A Visual Education Approach for Early Detection: Know Your Lemons’

- **Dr Nur Aishah Mohd Taib, KL, Malaysia**

‘Mitigating breast cancer late presentation in Malaysia: A community psycho-educational approach’

- **Panel Discussion time**

Social, cultural and clinical issues which may delay timely presentation with Breast or cervical cancer symptoms in rural Uganda

Community, Patients' and Healthcare professionals' perspectives from northern Uganda

3rd October 2018

Amos Deogratus Mwaka (MBChB, M.MED., Ph.D.)



World Cancer Congress
Kuala Lumpur, Malaysia
1–4 Oct 2018

Strengthen
Inspire
Deliver



Track 2 - Advances in screening and early detection

Disclosure of interest: None declared

Background (1): Culture

- Culture - an integrating framework, a lens through which people view the world.
- Culture is reflected in specific behaviours and activities of individuals.
- Understanding culture can inform design of effective targeted interventions to promote prompt health seeking and increase access to treatments.

(Kagawa, 2016, Carpenter, 2007, Fox 2005, Richer 2000).

Background (2): Measures of Culture

- Characteristics often measured as reflecting aspects of culture:
 - Religious beliefs,
 - Health seeking behaviours,
 - Language,
 - Spiritual practices,
 - Social structure and dynamics,
 - Dietary and food preparation practices,
 - Rituals, and
 - Trust in health practitioners/ care organisations/ researchers.

(Kagawa 2016, 2010)

What have we done?

- Undertaken three set of studies:
 - Two in northern Uganda (2) and
 - One in Central Uganda (1) – Kampala.

Motivation and main study question

- Majority (>80%) of cancer patients in low- and middle-income countries (LMICs) are diagnosed in advanced stages, experience high disease burden and benefit less from cancer specific treatments.
 - Why diagnoses in advanced stages?
- Most cancer patients in the LMICs often visit Traditional Health Practitioners (THPs) for management of their symptoms/cancers.
 - What reasons prompt visit to THPs?
 - Can THPs be allies in the early detection of symptomatic cancers?
 - Are THPs barriers to early detection?

Purpose of the three set of studies

- Inform interventions to:
 - Increase awareness,
 - Promote uptake of risk reduction behaviours,
 - Promote prompt symptoms recognition and help-seeking, for early detection, and
 - Promote choice of appropriate treatments of cancers;

In order to improve survival from cancers.

Method (1): Study 1

- Aim: To assess perceptions, beliefs and awareness about cervical cancer, the help-seeking processes and barriers to health seeking in Gulu district northern Uganda.
- Design: Cross sectional
- Participants and approaches to data collection: 3 sub studies:-
 - 1st group: Community members - Men and women, not directly affected with cervical cancer.
 - 24 FGDs: 12 women, 12 men.
 - Survey: 448 men and women.

Method (2): Study 1

- 2nd group: Patients with cervical cancer.
 - In-depth interviews with 18 women with cervical cancer to establish help-seeking pathways and symptoms attributions.
 - Survey – 149 women with cervical cancer to establish factors associated with stage at diagnosis.

Method (3): Study 1

- 3rd group: Doctors and midwives in gynecology departments of two referral hospitals – a private-not-for-profit hospital and a public hospital.
 - 15 key informant interviews to describe perceived barriers to cervical screening and health seeking for cervical cancer symptoms.

Method (5): Study 2

- Aim: To examine perceptions of medical students and their lecturers in Makerere University School of Medicine, and THPs in Kampala regarding training in traditional medicine in the medical schools in Uganda.
- Design: Cross section
- Participants and approaches of data collection:
 - In-depth interviews with 8 Faculty, and 5 THPs.
 - 7 FGDs (4 for males/3 for females) with medical students.
 - Survey with 327 medical students.

Method (4): Study 3

- Aim: To examine cancer awareness and perceptions about treatments that work as well as perceptions regarding integration of biomedicine with traditional health practices among traditional health practitioners (THPs) in northern Uganda.
- Design: Cross section
- Participants and approaches to data collection:
 - 28 In-depth interviews with THPs.
 - Survey with 424 THPs in 8 districts.

Key findings (1): Study 1

- Community members referred to cervical cancer as “blood disease”, were aware of most of the risk factors and symptoms, and perceived the disease as chronic, and non-curable except when diagnosed early (92%; N = 448).
- Several perceived risk factors including that lubricants on condoms and long term use of hormonal contraceptives (63%; N=448) cause cervical cancer.
- Use of complementary and traditional medicines (CTM) for cancer treatments is promoted by perceived/experienced barriers to biomedical care and community beliefs in the effectiveness of traditional medicines.

Key findings (2): Study 1

- Most women with cervical cancer:
 - Did not perceive themselves to be at risk,
 - Initially attributed their symptoms to normal bodily changes or other more common illnesses e.g. sexually transmitted diseases (STDs),
 - Were diagnosed at advanced stages (66%).
- Help seeking decisions and timing were often influenced by lay consultations with husbands, relatives and friends.

Key findings (3): Study 1

- Prompt help-seeking was frequently triggered by:
 - Perception of symptoms as life threatening;
 - Symptom burden sufficient to interfere with patients' work; and
 - Persistence of symptoms in spite of home-based treatments.
- Women who reported financial difficulty for health seeking were more likely to be diagnosed with advanced stage cervical cancer (aOR=5.5: 95%CI, 1.58 – 20.64)

Key findings (4): Study 1

- Healthcare professionals (HCPs) in northern Uganda reported several challenges facing cervical cancer control and care that influence their decisions and management goals and practices for women with symptoms of cervical cancer.

Key findings (5): Study 2

- The majority of participants recommended the inclusion of CTM principles into medical school curricula.
- The main reasons advanced were:
 - patients are already using these medicines - doctors need to understand;
 - doctors would be more accommodating to use and not rebuke patients;
 - promote patient safety;
 - foster therapeutic alliance and adherence to therapy;
 - uphold patients' right to self-determination;
 - lead to discovery of new drugs from traditional medicines;

Key findings (6): Study 2

- Operational and ethical challenges included:
 - Inadequate number of faculty to teach the subject,
 - Congested curricula,
 - Increased costs in research to produce evidence-base data,
 - Obstruction by pharmaceutical companies,
 - Inaccessibility to and depletion of medicinal plants,
 - Potential conflicts due to diversity in culture and values.
 - Risk of loss of patent and income following disclosure of THP practices

Key findings (7): Study 3

- Traditional health practitioners (THPs) in rural Uganda were found to be very willing to work with biomedical trained healthcare professionals (HCPs). They however believe that HCPs are not willing to work with them and often criticized them.
- THPs were concerned with disclosing their medicinal products and formula unless government puts in place regulations to protect their trade.
- THPs were concerned with extremely high rate of depletion of medicinal plants – “destruction” of natural forests for timber and charcoal.

Conclusions and recommendations (1)

- Interventions to promote prompt symptoms recognitions, health seeking and treatment preference could be hankered around culture and sociocultural practices of the communities.
- Health promotion interventions and biomedical services for cancer need to be culturally sensitive and carefully done to promote local practices that encourage good and healthy behaviours.

Conclusions and recommendations (2)

- THPs could be allies rather than adversaries in promoting health seeking for symptomatic cancers.
- Including CTM principles and practices into medical school curricula of the LMICs could improve knowledge of HCPs regarding CTM and enhance integration process.
- Integration and alliance could lead to improved treatment outcomes.

Acknowledgements

Mentors and Institutions:

1. Prof. Martin Roland, Dr. G. Lyratzopoulos, and Dr. Fiona M. Walter, University of Cambridge
2. Prof. Martin Roland, Dr. G. Lyratzopoulos, and Dr. Fiona M. Walter, University of Cambridge
3. Prof. Henry Wabinga, and Prof. Christopher G. Orach, Makerere University
4. Colleagues in Makerere University
5. Prof. Jennifer Moodley, University of Cape Town

Funding:

1. Training Health Professionals into Vocational Excellence in East Africa
2. Wellcome Trust
3. Alborada Fund
4. Newton Fund: GSK, MRC UK/SAMRC

Thank you for your attention

I appreciate your contributions to the debate

mgratius@gmail.com

Adapting the Cancer Awareness Measure (CAM) and Awareness and Beliefs about Cancer (ABC) tools for African populations

J Moodley, FM Walter, AD Mwaka, S Scott, D Constant, JN Githaiga, T Stewart, A Payne, L Cairncross, N Somdyala



World Cancer Congress
Kuala Lumpur, Malaysia
1–4 Oct 2018

Strengthen
Inspire
Deliver



Track 2: Advances in screening and early detection

Disclosure of interest: None declared

African Breast and Cervical Cancer Symptom Awareness (ABCCSA) tool: first version

Item Generation

- Review BCAM, CCAM, ABC tools
- Literature review of studies in Africa
 - List of items for first version of ABCCSA tool
 - sociodemographic,
 - symptom and risk factor awareness,
 - misconceptions,
 - age-related risk,
 - help-seeking behavior,
 - confidence skills,
 - barriers to care
 - Pictures of breast cancer symptoms on dark-skinned women

African Breast and Cervical Cancer Symptom Awareness (ABCSCSA) tool: first version

Refinement of first version

- Cognitive think aloud interviews, Uganda (n = 10) and South Africa (n= 10)
- Cancer experts in SSA (n = 25) scored each item on clarity and relevance

Changes

- Items deleted e.g. age-related risk factors, religion
- Added explanations for less well understood terms e.g. menopause, HRT
- Questions with Likert type response options were not well understood and were scored poorly by experts and were revised e.g. “How confident are you that you would notice a change in your breast?” Response Options - very confident/ fairly confident/slightly confident/not confident at all to. Changed Q “Are you confident that you would notice a change in your breast - Responses options Yes/No/Not sure
- Rephrased questions for clarity

ABCSEA: Psychometric testing

Refined ABCSEA tool completed by:

- Community participants (Uganda n = 67, SA n = 72)
- Non medical UCT staff (n= 23) completed questionnaire twice, 2 weeks apart
- Cancer experts SSA (n = 21), online
- Generated risk factor and symptom knowledge scores for breast and cervical cancer

Validity measures

- Construct validity - compared knowledge scores of cancer experts and community participants, t-test
- Internal reliability - Cronbachs alpha > 0.7 good
- Test- retest reliability - compared knowledge scores of non-medical staff, intra-class correlation

ABCSCSA: Psychometric testing results

Construct validity

	Breast Cancer				Cervical Cancer			
		Community	Experts	p-value		Community	Experts	p-value
	Max. Score	Mean	Mean		Max. Score	Mean	Mean	
Known risk factors	13	5.2	11.1	<0.001	10	6.7	8.3	0.005
Risk misconceptions	7	2.5	6.1	<0.001	1	0.8	0.9	0.390
Symptoms	15	12.7	13.9	0.020	11	7.6	8.9	0.001
Risk factors, misconceptions and symptoms	35	20.6	31.1	<0.001	22	15.4	18.4	<0.001

ABCCSA: Psychometric testing results

Internal reliability

	Breast Cancer		Cervical cancer	
	N	Cronbach's Alpha	N	Cronbach's Alpha
Known risk factors	166	0.7817	154	0.6022
Risk misconceptions	166	0.7281	154	N/A*
Symptoms	180	0.7858	179	0.7994
Risk factors, misconceptions and symptoms	166	0.7932	154	0.7980

* 1 misconception item

- Cervical cancer risk factors with low item to total correlation:
HPV, not going for regular screening, using family planning pills > 5 years
All retained on grounds of content validity

ABC CSA: Psychometric testing

- Test-retest reliability high for risk factors, symptoms and misconception items for both breast and cervical cancer, all $p < 0.001$

Post-psychometric testing adjustments to tool

- Responses to open questions on symptoms and risk factors identified additional misconceptions and these were added to the final tool
- Reduced questions barriers to seeking care (7 questions removed)

ABC CSA: Development of local language versions

- Translation into isiXhosa and Acholi, back translation
- Cognitive think-aloud interviews with local language speaking community participants (Uganda n = 10, SA n = 10)
- Cancer experts in Uganda (4) and SA (4) scored each question on equivalence of meaning
- Changes in phrasing to more commonly used language

Final ABCCSA

Domain	Breast Cancer Questions (50)	Cervical Cancer Questions (41)
Introductory	2	2
Risk factors	1 open	1 open
	13 prompted risk factors	11 prompted risk factors
	6 prompted misconceptions	4 prompted misconceptions
Symptom awareness	1 open	1 open
	15 prompted symptoms awareness	11 prompted symptom awareness
	3 images of symptoms	No images
	1 prompted misconception	1 prompted misconception
Confidence in detecting symptom	4	3
Help-Seeking behavior	7	7
Socio-demographics		12
Barriers to seeking care for breast and cervical cancer		12

ABCCSA currently being used in community-based surveys in Uganda and SA

Acknowledgements

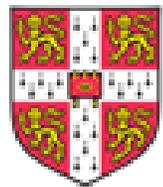
- Participants, primary health care clinic managers, UCT management
- Funders: CANSA; the University of Cape Town, and; the South African Medical Research Council with funds received from the South African National Department of Health, GlaxoSmithKline R&D, and the UK Medical Research Council and with funds from the UK Government's Newton fund.
- The Outcome Registry Intervention and Operation Network (ORION) team at Cambridge University, who developed and host the electronic surveys on their platform.



**African Breast and
Cervical Cancer
Symptom
Awareness
(ABCCSA)
Questionnaire**



Please select language:



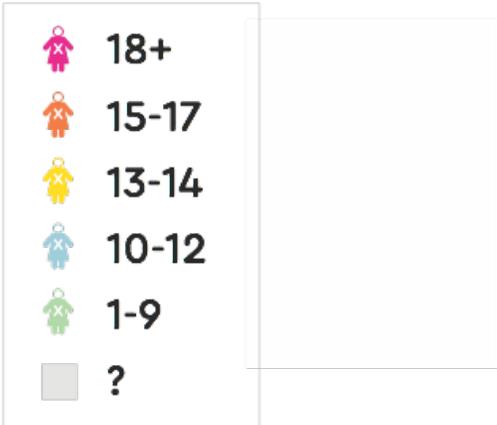
**UNIVERSITY OF
CAMBRIDGE**



A Visual Education Approach for Early Detection: Know Your Lemons®

Breast cancer mortality map

Out of 100,000 people, how many die from breast cancer?



Map by Corinne Elsworth Beaumont, PhD (Worldwidebreastcancer.org) and Kathleen Ragon, PhD. Rates are all age standardized to the world standard population, through data from: (1) United States Cancer Statistics: 1999-2012 Mortality, WONDER Online Database, United States Department of Health and Human Services, Centers for Disease Control and Prevention; 2015. Accessed at <http://wonder.cdc.gov/CancerMort-v2012.html> (2) Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin DM, Forman D, Bray F. GLOBOCAN 2012 v1.0, Cancer incidence and mortality worldwide: IARC CancerBase No. 11. [Internet]. Lyon, France: International Agency for Research on Cancer; 2015. <http://globocan.iarc.fr/Pages/Maps.aspx>. Mercator projection drawing by Geardie Batsonko [CC BY-SA 3.0 (<http://creativecommons.org/licenses/by-sa/3.0/>), via Wikimedia Commons].

worldwide
breast cancer

How is breast cancer found?

Patients.

Engaged Patients.

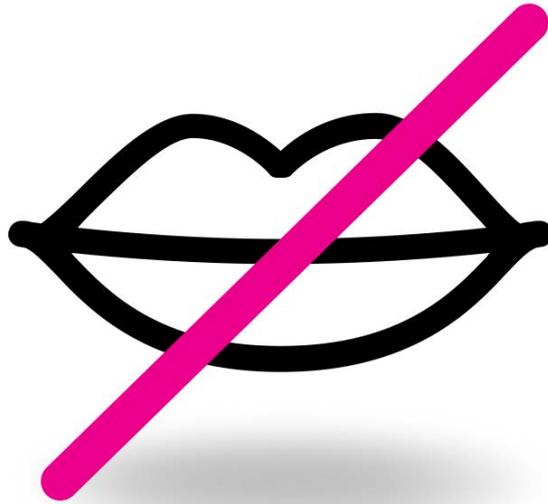
Engaged Patients:

Health Literate —> Willingness to Participate

Engaged Patients:

Information —> Health Literate —> Willingness to Participate

**Great, let's just tell everyone
what they need to know!**



“I don’t want to talk about cancer.”

Okay, then we will **show** them!



“Looking at breasts is taboo.”



worldwide
breast cancer

Okay, no pictures. They can **read instead!**



“I cannot read this.”

Learning about symptoms through words: (how it's usually done)

Check for:

- Obvious lumps or thickening, puckering or dimpling of the skin
- A change in size or contour, or position of the nipple
- Veins which are more prominent than usual
- Inflammation or rash on the breast
- Blood or discharge from the nipple
- New sensation – particularly if only in one breast

How this communicates to someone who is illiterate:

Ofoar ter:

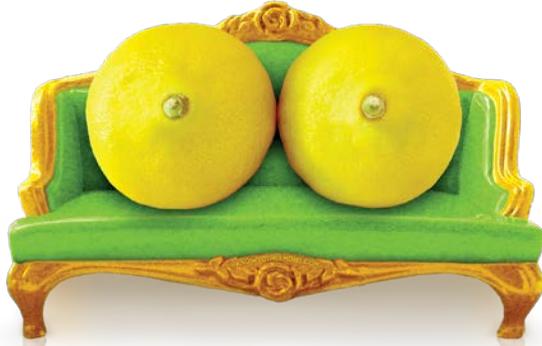
- Cdnouis tengn xo fhlmtonlmp, jooforlwj er pinjfimp ct ftz zfiv
- A nachg ni zsie ar toncoru, ro nitpision ot lhe uiggte
- Yoixz sticf ouc ncru gomipensf htoc nznof
- Ictlonmetiau uo socr eu hfe freozf
- Rieap ec pizofenjo tien fho middlo
- Hov domesofiam – jenfioleritj ti emlp ni aen hroezf

How this communicates to someone who is not concerned about breast cancer:

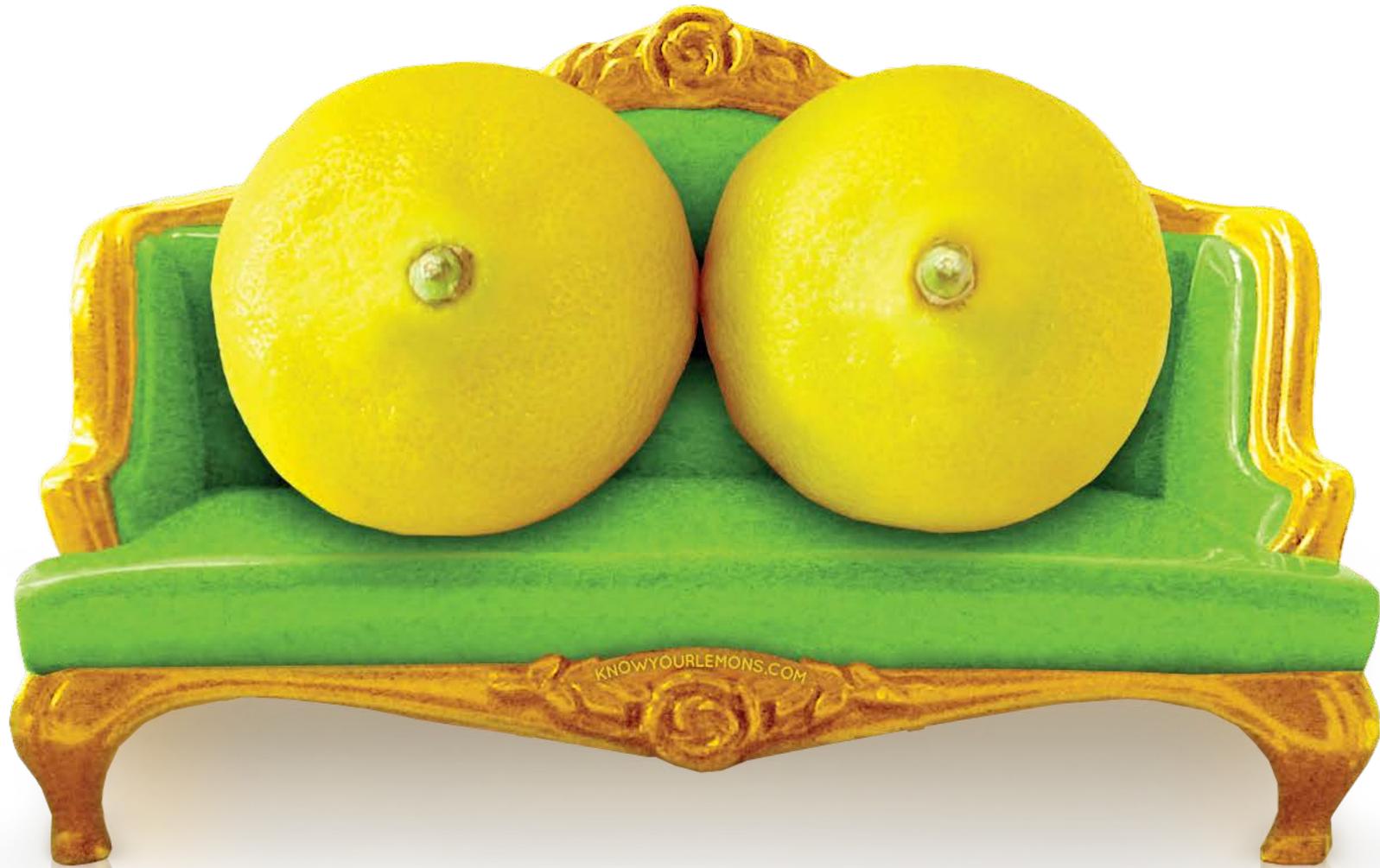
Check for:

- Something about a breast lump
- And something else I should know
- And another thing I'm not sure how to picture
- Looks like there's a lot here
- I'll read this later on when I have time
- Okay I'm good, on to something else now





Let's change the picture of breast cancer.



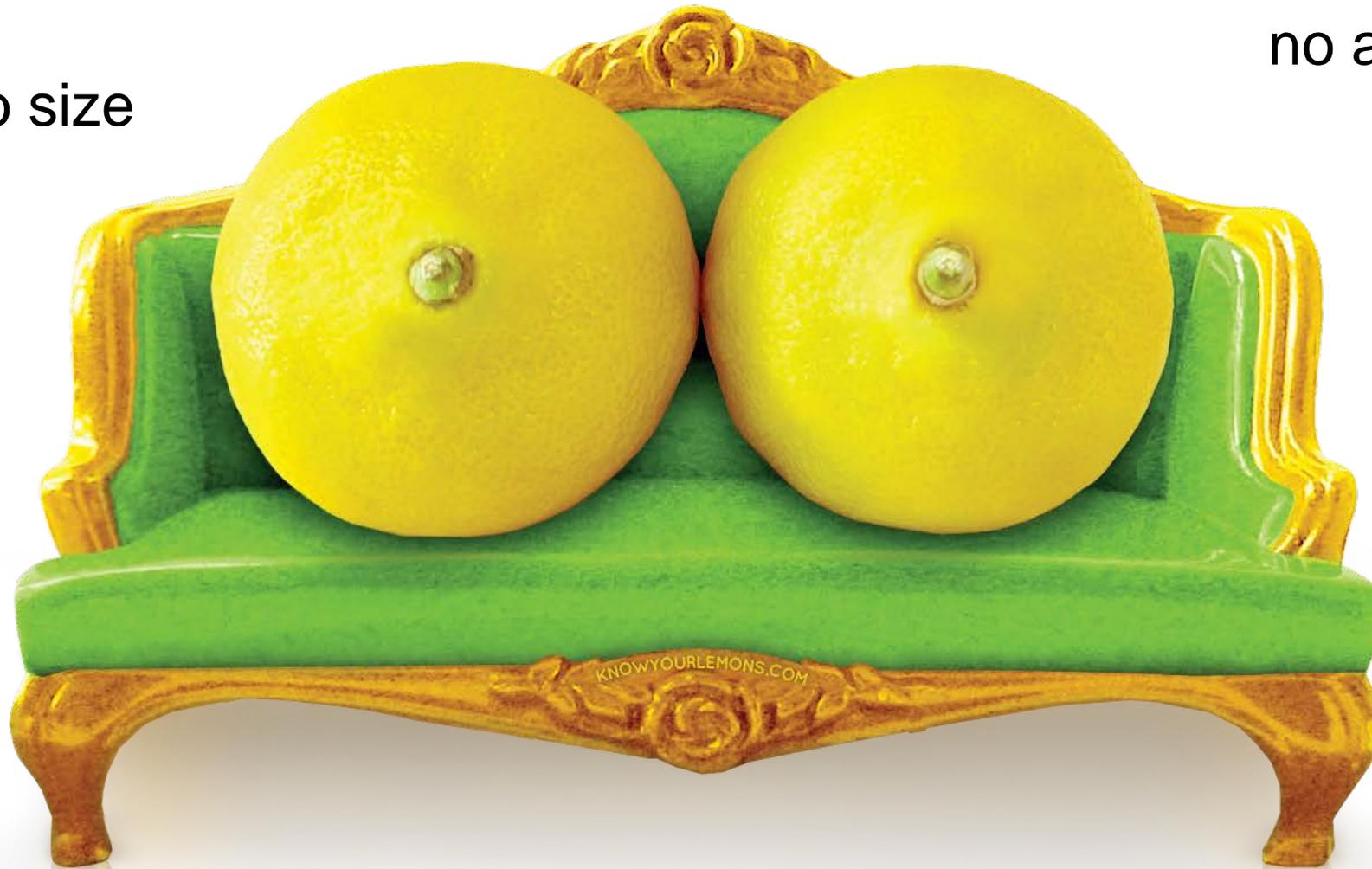
KNOWYOURLEMONS.COM

no size

no age

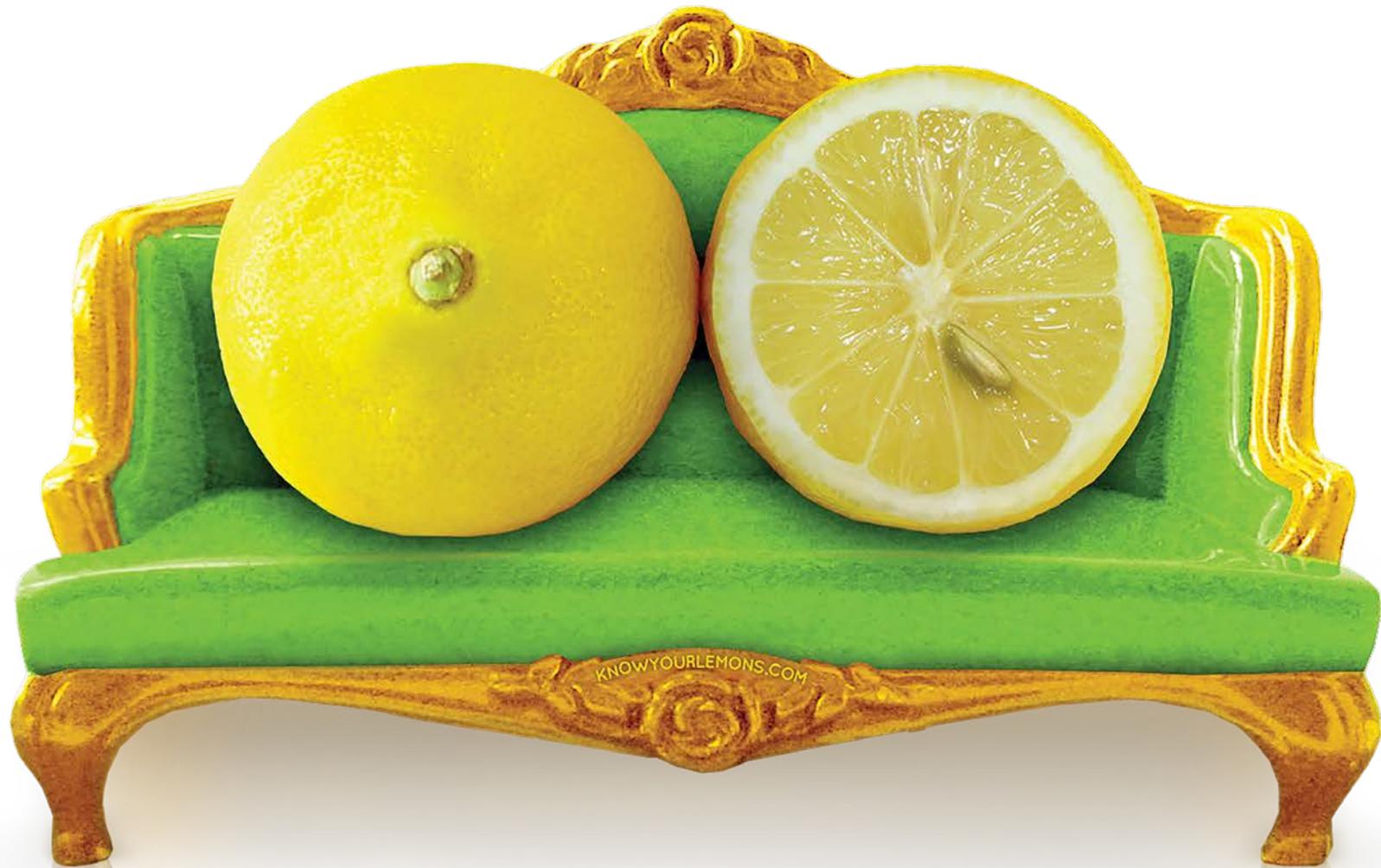
no gender

no race

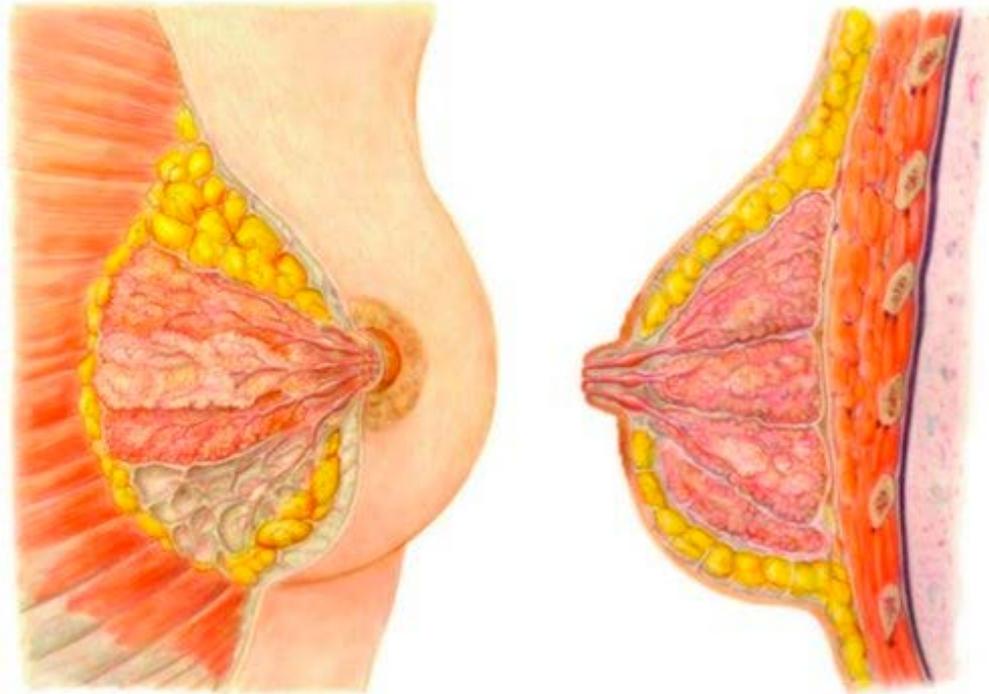
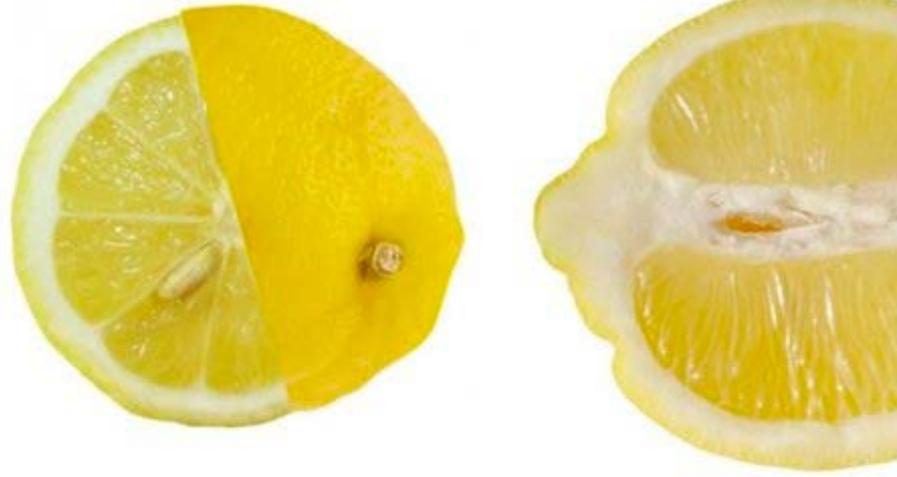


KNOWYOURLEMONS.COM

no body, no taboo



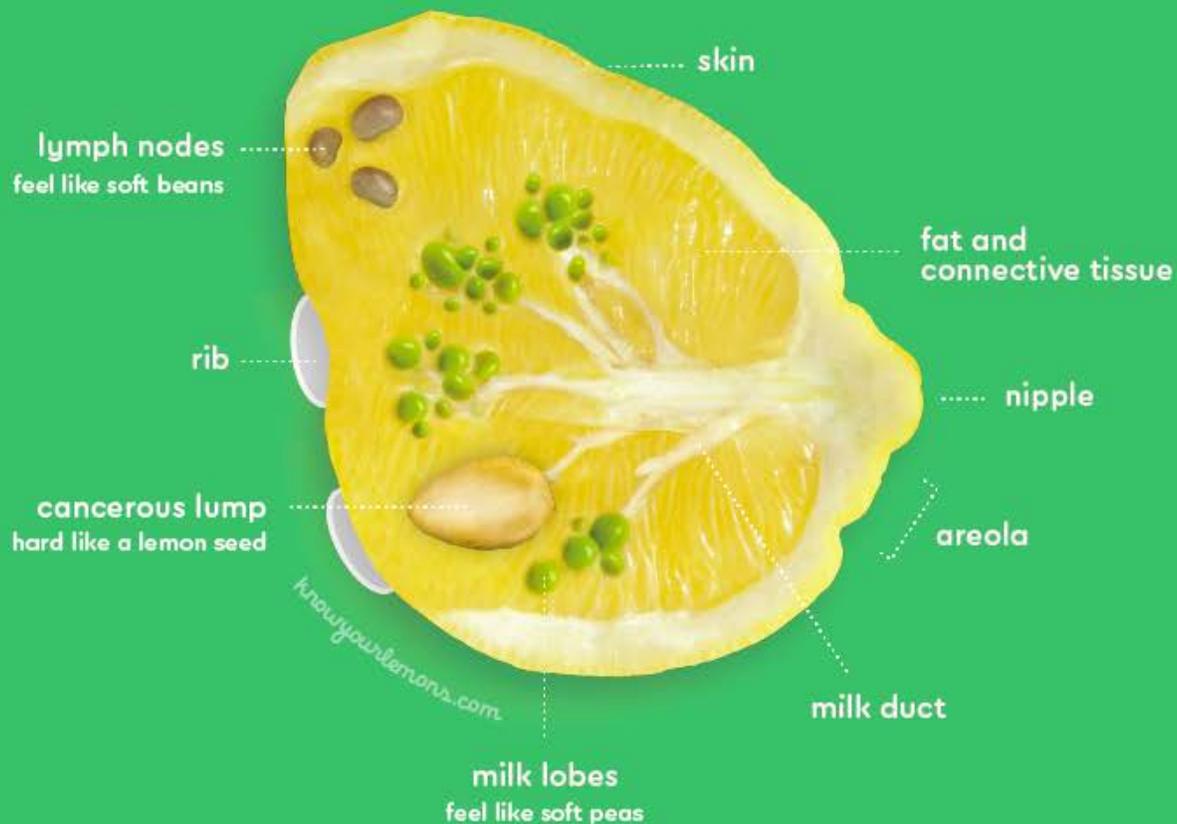
also explains lumps and anatomy



Half (49%) didn't know what a cancerous lump should typically feel like. (n=255)

WHAT TO FEEL FOR DURING A BREAST EXAM

Know what is normal for you between your regularly scheduled mammograms. A lump is not the only sign.



A cancerous lump
often feels hard and immovable
like a lemon seed.
(It can be any shape or size.)



Feel from your armpit to your collar bone
to the bottom of your rib cage.



Do you know when to self-exam and mammogram?



knowyourlemons.com

Feeling is just one part of detection.
Some symptoms are visible too.

knowyourlemons.com

feeling a
thick area

dimple

nipple crust

red or hot

unexpected fluid

skin sores



bump

hard lump

growing vein

sunken nipple

new shape/size

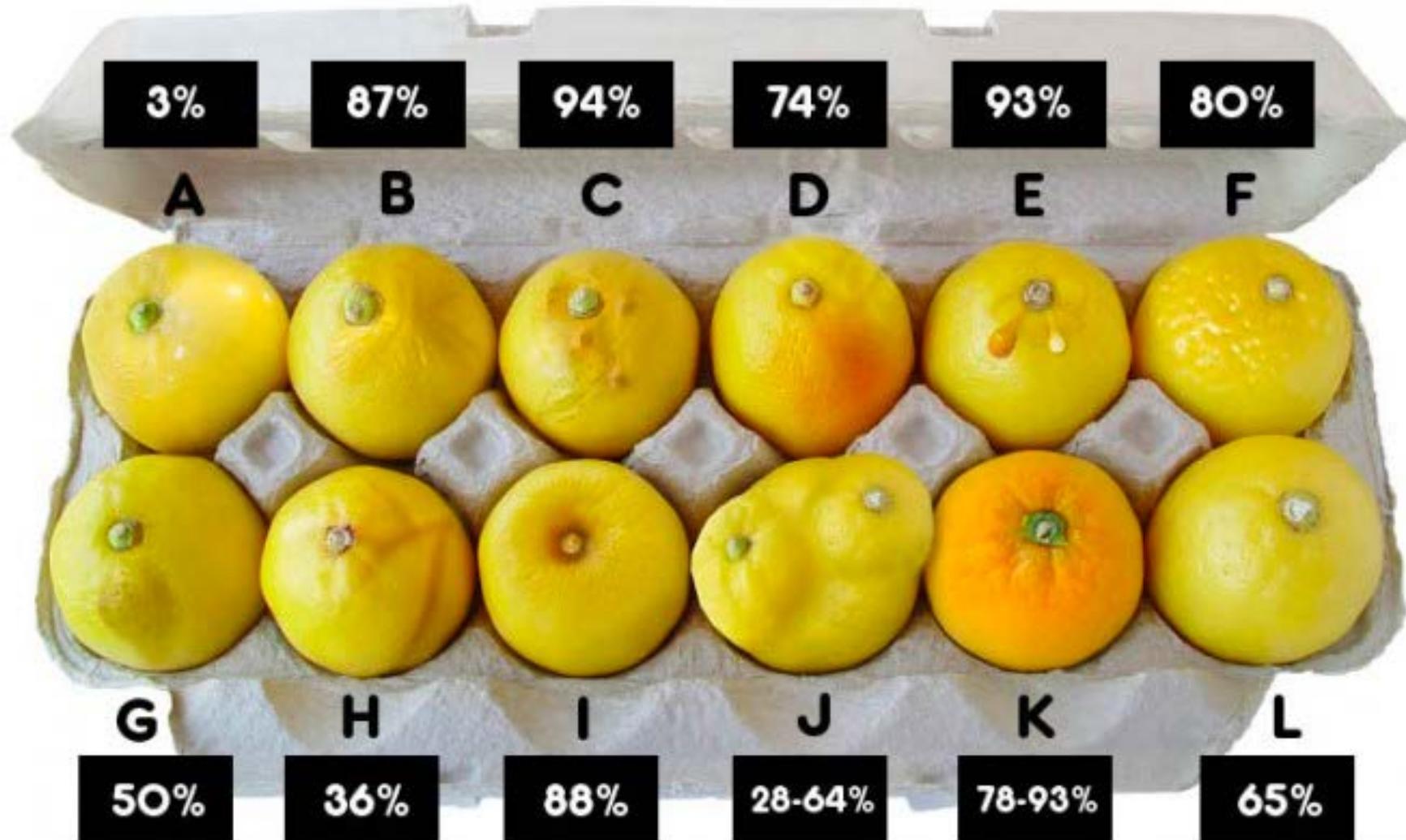
orange peel skin

knowyourlemons.com

worldwide
breast cancer

Early testing: which symptoms communicate with no words?

n=67 (UK)



70% of patients felt more knowledgeable about breast cancer (n=248)

89% of patients felt more confident in their ability to recognize breast cancer symptoms (n=77)

knowyourlemons.com

feeling a
thick area

dimple

nipple crust

red or hot

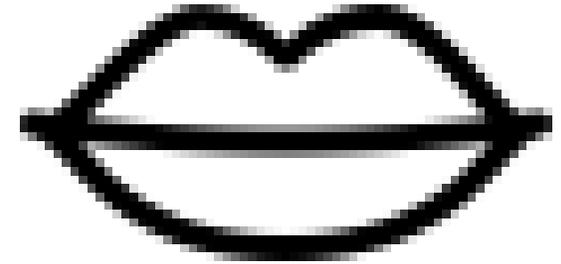
unexpected fluid

skin sores



knowyourlemons.com

worldwide
breast cancer



Now we can educate on a broader scale than ever before.



19 languages. 93 countries. 200 million people.



Recent study: Nigeria

(summer 2018, n=1061)

The Problem

- In Nigeria, 50% of women are diagnosed at Stage IV when it is unsurvivable.¹
- It's unclear why symptoms are presented so late, but taboo, fear and lack of health literacy are likely contributing factors.²
- Without a population screening program, breast cancer symptom awareness and reporting changes are key to early detection.

1. Adisa, et. al, 2011; Eke, Ojo, Akaa, Ahachi, Soo, & Adekwu, 2017; Osaro, 2016)

2. Agba et al., 2012; American Cancer Society, 2011; Cancer Today, 2012; Osaro, 2016; Prevalence of Breast Cancer, 2015



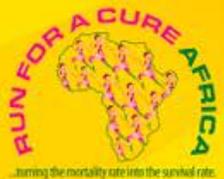
WHAT BREAST CANCER CAN LOOK AND FEEL LIKE

Recognise something? Don't panic, some changes are normal. But if it stays around be smart—show your doctor.



In Nigeria, lemons are green.

The female spokesmodel was styled to represent the audience.



A cancerous lump often feels hard and immovable like a lemon seed. It can be any shape or size.

Breast change? Call Run for a Cure Africa: 0818 000 1298



knowyourlemons.com /nigeria



worldwide
breast cancer

Screening and Education Sessions

Lagos: June - Aug 2018 n=1061

96% now feel confident in recognizing a sign of breast cancer.

98% say they will go to a doctor if they see a possible symptom.

92% will share the lemon image with family/friends.

Tactile knowledge of a cancerous lump increased from 27% to 70% (n=427)

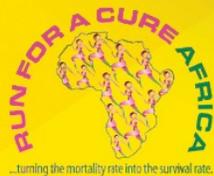


Breast change?  Give us a call.

0818 000 1298



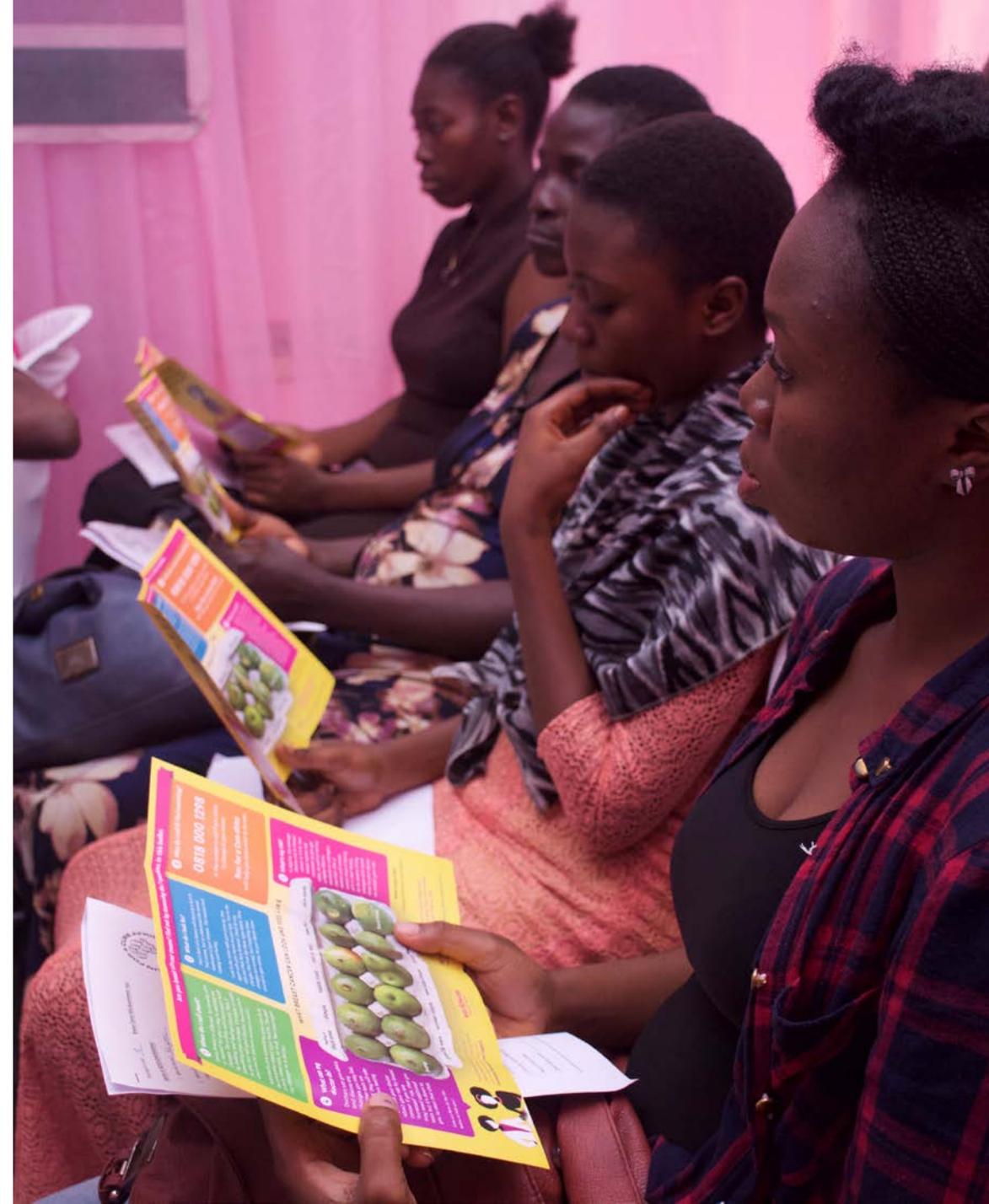
Learn about each symptom at: knowyourlemons.com



worldwide
breast cancer

Future Study

Longitudinal Study:
Magnets and leaflets were distributed to every woman who attended the sessions. Included in this is a dedicated phone number to call Run for a Cure Africa if they notice a breast change. We will record the outcome of the patient referrals and track the stages of the diagnosis against baseline data.



Future Study

Reasons for late presentation need to further explored (n=427):

- 72% said nothing would keep them from telling a doctor.
- 17% said worry about getting a positive diagnosis would keep them from investigating.
- 9% said worries of the cost of seeing a doctor would be prohibitive.

55% said they would have treatment if they were diagnosed:

- Only 3% believed treatment would be unsuccessful.
- 25% said costs would prevent them.
- 11% were concerned about appearance changes with treatment.



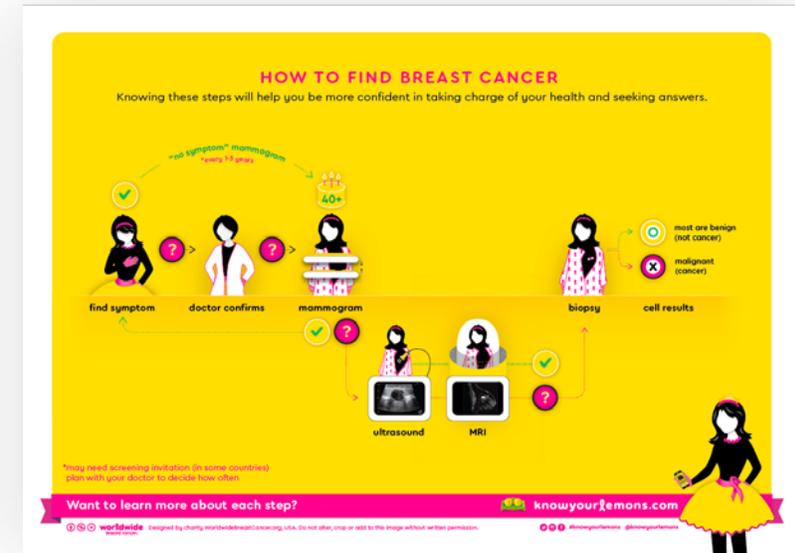
self-exam + anatomy



12 symptoms



diagnostic pathway



Our educational materials are available in 19 languages, 93 countries.

We partner with NGOs and companies who share our goal of educating every woman.



Print & Social Media Campaign



Educator Certification & Teaching Kit



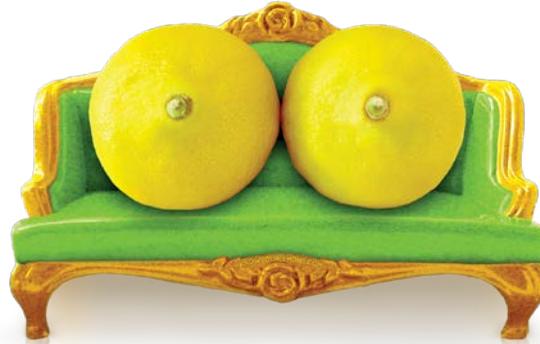
Know Your Lemons App

knowyourlemons.com

We have several tools available.

worldwide
breast cancer

Thank you.



Corrine Ellsworth-Beaumont, PhD
knowyourlemons.com
corrine@worldwidebreastcancer.org

worldwide
breast cancer



**UNIVERSITY
OF MALAYA**

The Leader in Research & Innovation

Mitigating breast cancer late presentation in Malaysia: A community psycho-educational approach

Prof Nur Aishah Taib

Department of Surgery, Faculty of Medicine, University of Malaya



World Cancer Congress
Kuala Lumpur, Malaysia
1–4 Oct 2018

Strengthen
Inspire
Deliver



Track 4 - Maximising quality of life and death.
Empowering patients and care givers

Disclosure of interest: None declared

BREAST CANCER IN ASIA

The challenge and response

Once largely confined to Western countries and Australasia, breast cancer is now a major healthcare issue across Asia-Pacific. Already it is the most common form of cancer for women in nine of the ten Asia-Pacific jurisdictions covered in *Breast cancer in Asia: The challenge and response*, an Economist Intelligence Unit study commissioned by Pfizer.

WHERE BREAST CANCER IS MOST COMMON

Incidence per 100,000

There is substantial variation in the incidence of breast cancer between countries in the region. The age-standardised rate (ASR) of incidence in China, for example, is about one-quarter that in Australia. Based on recent trends, however, the burden of breast cancer looks set to grow, as lifestyles change and especially as populations age.

25.8
India

22.1
China

51.5
Japan

52.1
South Korea

61.2
Hong Kong

64.3
Taiwan

29.3
Thailand

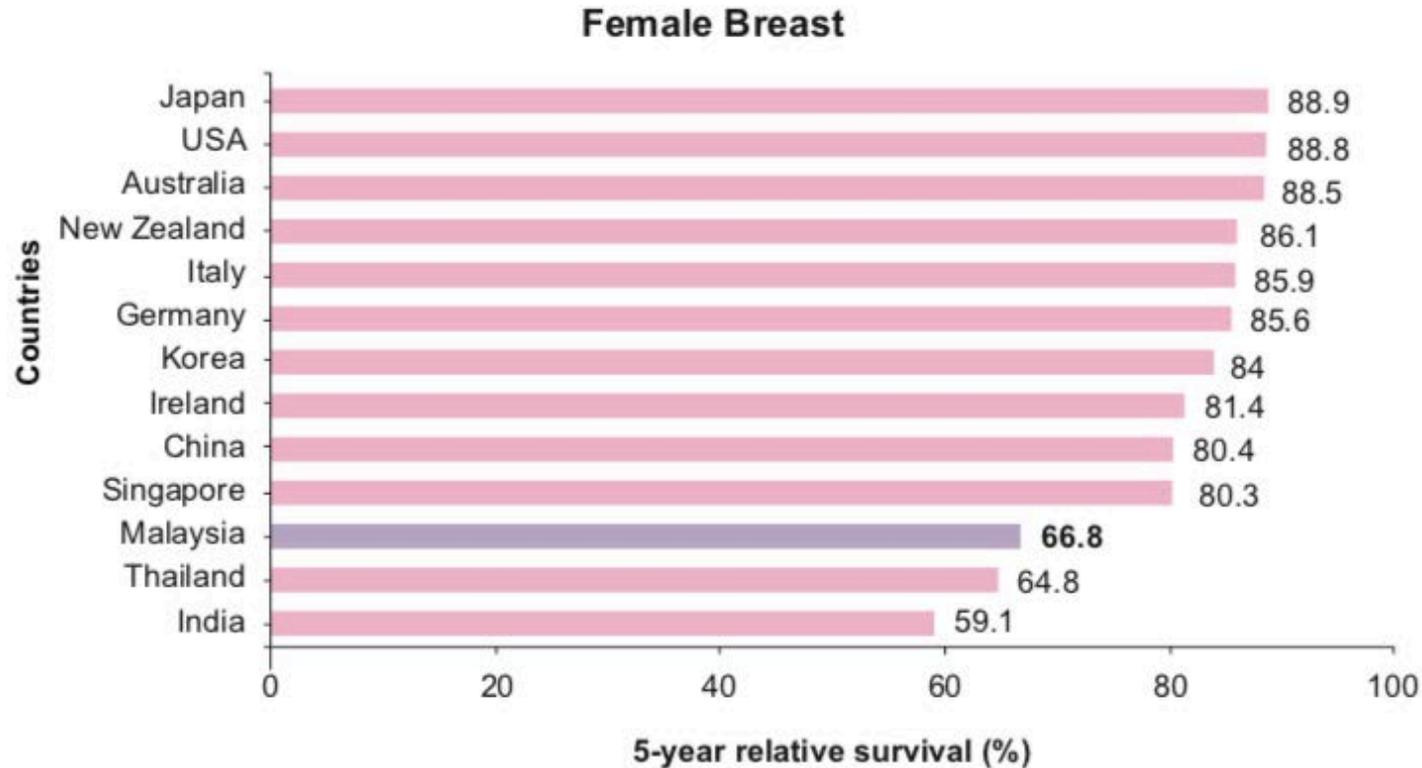
38.7
Malaysia

65.7
Singapore

86.0
Australia



Relative Survival Rates Comparison



*Source of the International data: CONCORD-3 study, 2005-2009 (C. Allemani et al, 2018) Malaysia: MyScan, 2018

Figure 13. Female Breast: International comparison of 5-year relative survival



Author's personal copy

World J Surg
DOI 10.1007/s00268-013-2339-4

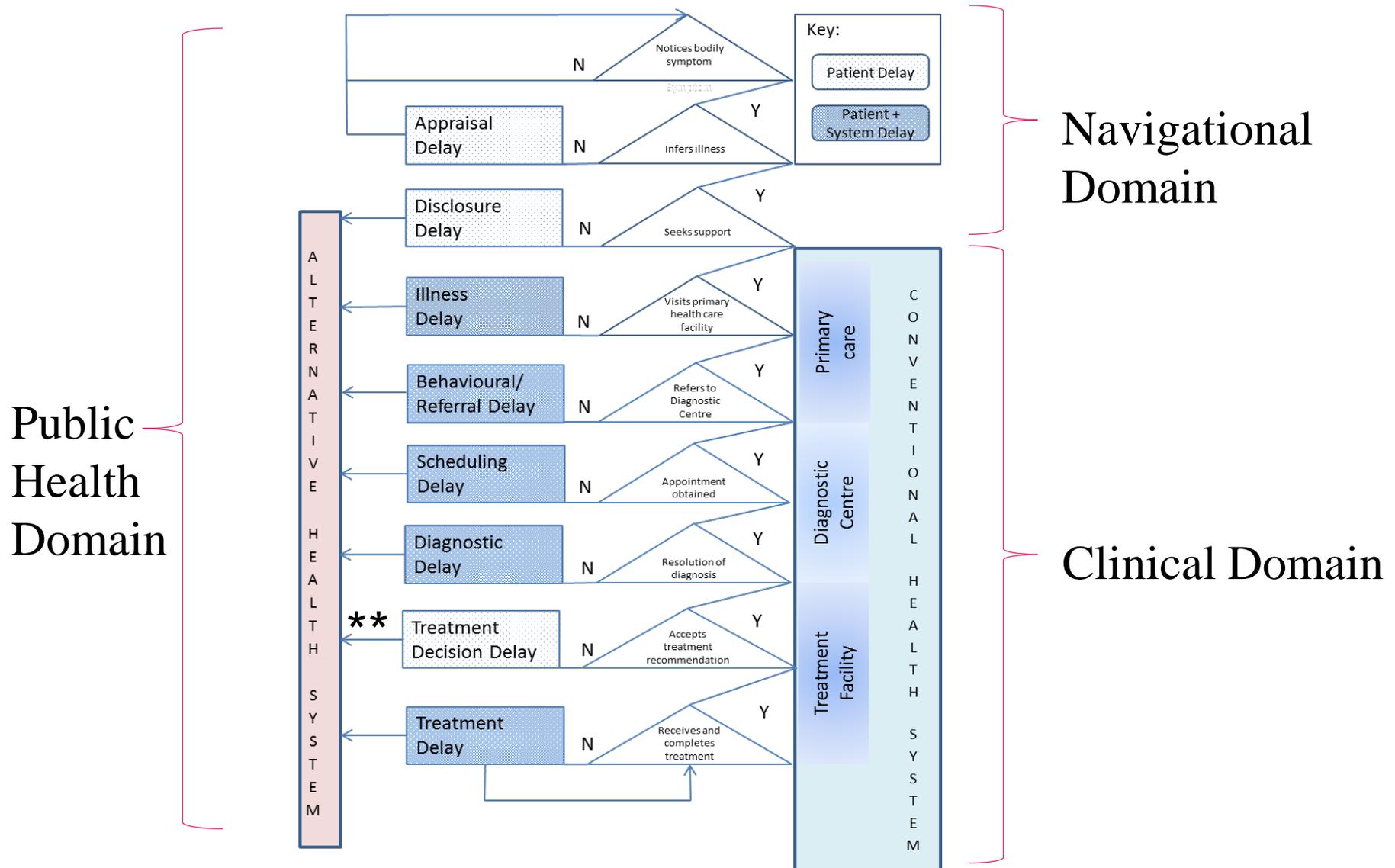


A Grounded Explanation of Why Women Present with Advanced Breast Cancer

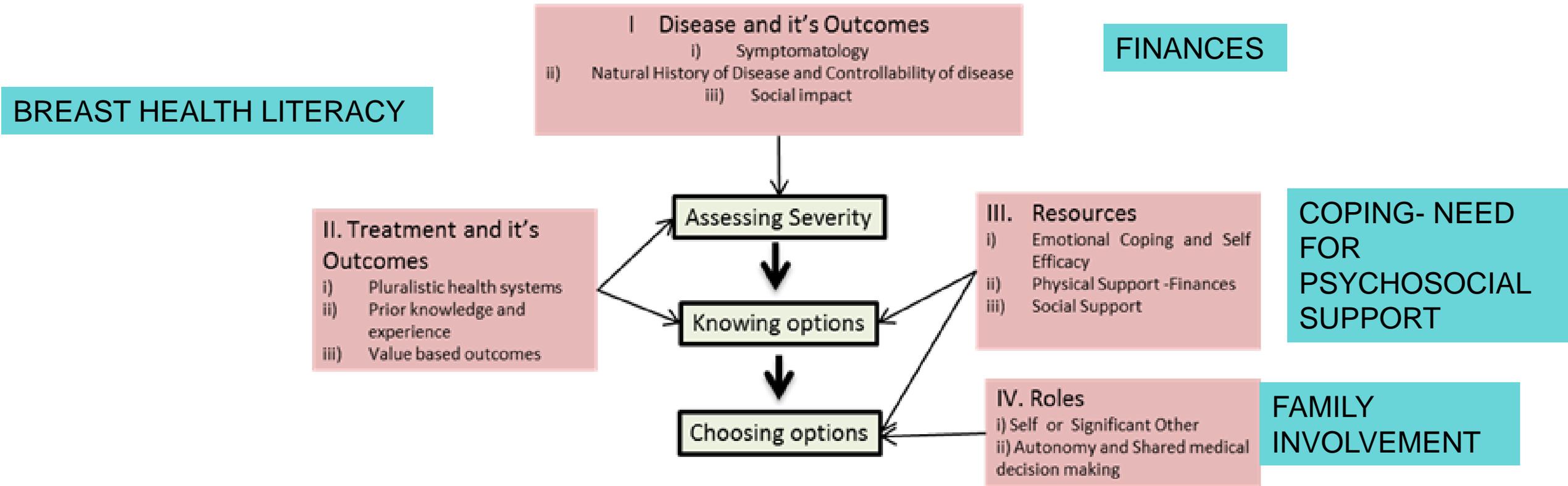
**Nur Aishah Taib · Cheng Har Yip ·
Wah Yun Low**

© Société Internationale de Chirurgie 2013

The Points of BC Delay Model

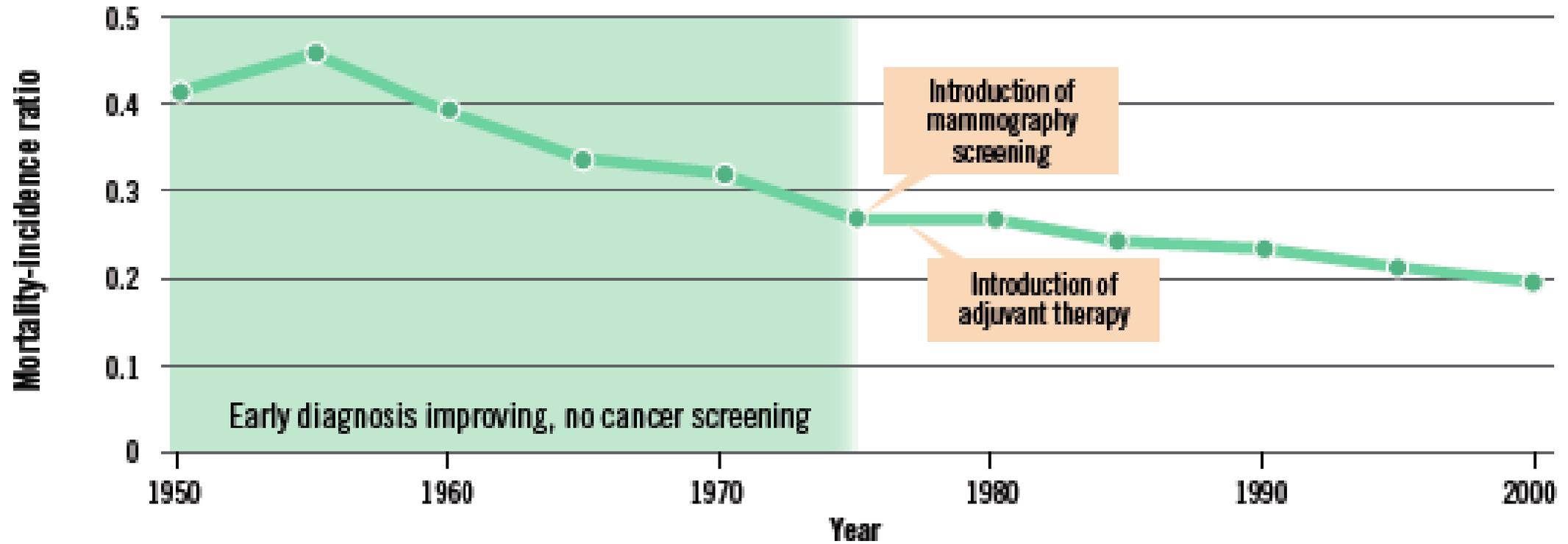


BCDE Model: Decisions to disclose/ seek help/diagnosis/treatment



Essential Component: Patient Centred Care

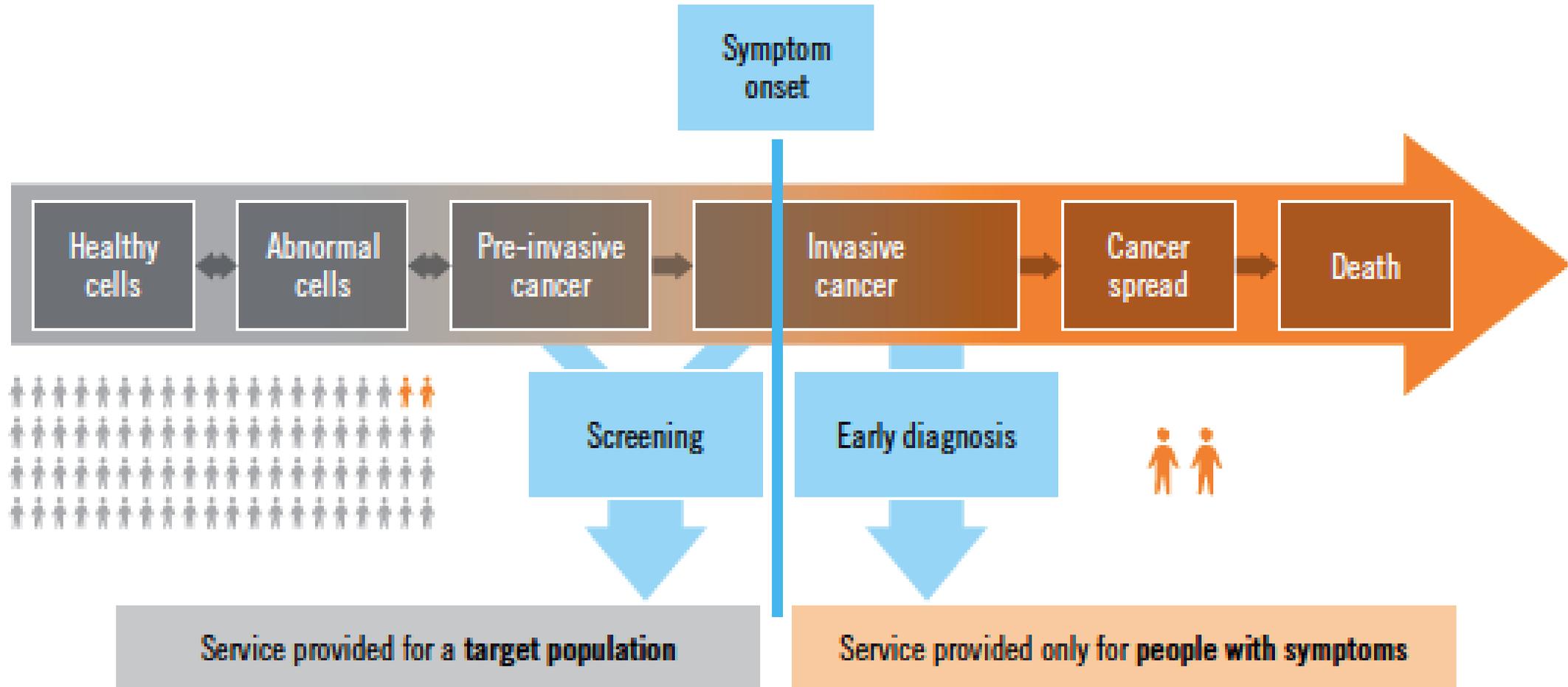
Figure 4. Example of early diagnosis impact from the United States



Notes: Impact of improved awareness on reduction in breast cancer mortality in the United States as measured by the mortality-to-incidence ratio. A high mortality-to-incidence ratio is a general estimate that a high proportion of people diagnosed with cancer are dying from it. Before the introduction of mammography and adjuvant therapy, there was a significant improvement in breast cancer survival due to early diagnosis.

Source: Shulman et al. 2010 (15).

Figure 2. Distinguishing screening from early diagnosis according to symptom onset



Gejala – ketulan yang tidak sakit (Painless breast lump)



HOW DO YOU DETECT BREAST CANCER

BAGAIMANA MENGESAN KANSER PAYUDARA

Langkah-langkah ini akan meyakinkan anda dalam mengendali dan mencari penyelesaian masalah kesihatan anda.



*mungkin memerlukan jemputan saringan mamogram (di sesetengah negara) rancang dengan doktor anda kekerapan yang diperlukan

Anda mahu tahu tentang setiap langkah?

 knowyourlemons.com



Improving Breast Health Literacy through an Innovative Breast Cancer Awareness Campaign using the Know Your Lemons materials in Malaysia

A total of 679 participants

96.2% stated that the language used in the "KYL" poster or leaflets was clear and understandable;

95.3% thought materials were attractive and able to draw attention; and acceptable (89.2%) in Malaysian culture.

IMPROVING BREAST HEALTH LITERACY THROUGH AN INNOVATIVE BREAST CANCER AWARENESS CAMPAIGN USING THE KNOW YOUR LEMONS (KYL) MATERIALS IN MALAYSIA

METHODOLOGY

✓ "Show You Care, Be Aware" campaign was organized in **University of Malaya campus**

[8 - 20 October, 2017]

✓ The "KYL" materials were translated for Malaysian audience

✓ 679 participants were interviewed using questionnaire during 6 events in UM, after educational intervention sessions

✓ Discussion on leaflets and questions and answers, and practical demonstrations of breast self examination on dummy were also done at the booths



BAGAIMANA RUPA DAN RASA KANSER PAYUDARA
Kesan sesuatu? Jangan risau, perubahan itu mungkin normal. Sekiranya tidak hilang, jadilah orang yang bijak—tunjukkan kepada doktor.

knowyourlemons.com

berasa tebal dan keras lesung pipit puting berkerak kemerahan atau panas lelehan luar biasa luka di kulit

benjolan ketulan keras

urat menonjol puting ke dalam saiz/bentuk bar kulit buah limau

"Ketulan kanser selalunya berasa keras dan sukar digerak seperti biji benih lemon. Lanya boleh dalam pelbagai bentuk dan saiz."

Anda hendak tahu tentang setiap simptom atau tanda-tanda? knowyourlemons.com

worldwide breast cancer Dirkabentuk oleh badan amal WorldwideBreastCancer.org, USA. Tidak dibenarkan untuk mengutip, mengambil atau menyalin pada inang tanpa kebenaran bertulis. @knowyourlemons #knowyourlemons

IMPROVING BREAST HEALTH LITERACY THROUGH AN INNOVATIVE BREAST CANCER AWARENESS CAMPAIGN USING THE KNOW YOUR LEMONS(KYL) MATERIALS IN MALAYSIA

RESULTS

Table 1: Socio-demographic Characteristics of the respondents

Variables		N (%)
Age	30 years or below	414 (61%)
	30 -49 years	151 (22.2%)
	50 and above	114 (16.8%)
Ethnicity	Malay	492 (72.5%)
	Chinese	119 (17.5%)
	Indian	68 (10.0%)
Education	Primary or below	24 (3.5%)
	Secondary	73 (10.8%)
	College/University	582 (85.7%)

Fig 2 : Feeling confident in recognizing the signs and symptoms of breast cancer

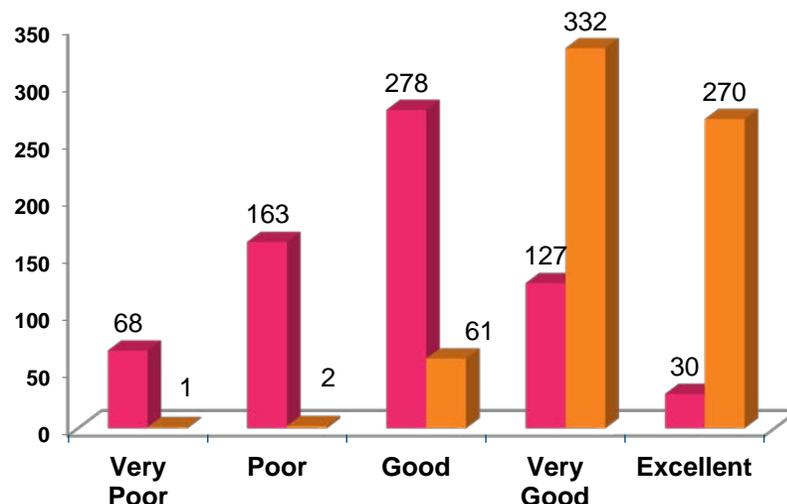
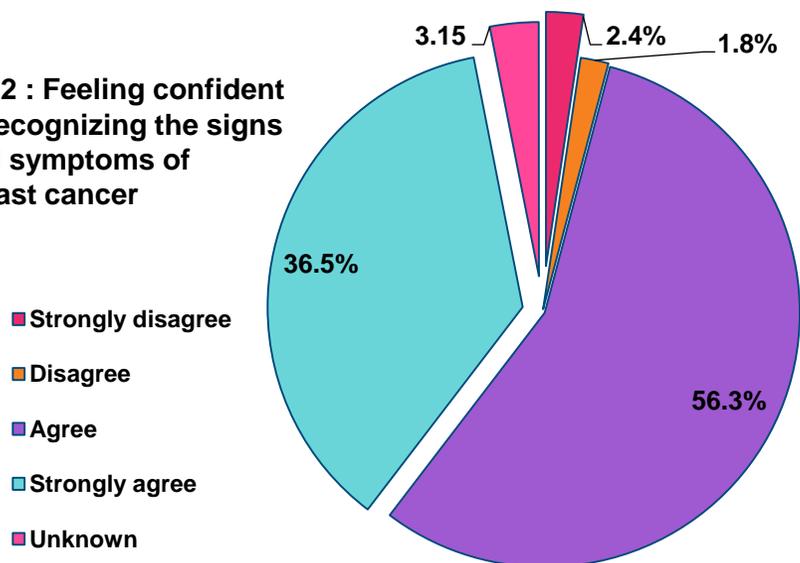


Fig 1: Self rated knowledge of BC before and after campaign

Before Campaign Mean (SD)	After Campaign Mean (SD)	Z	p value
2.83 (0.999)	4.30 (0.657)	-21.06	<.001

Fig 3: Improved perceived knowledge on the process of detecting cancer

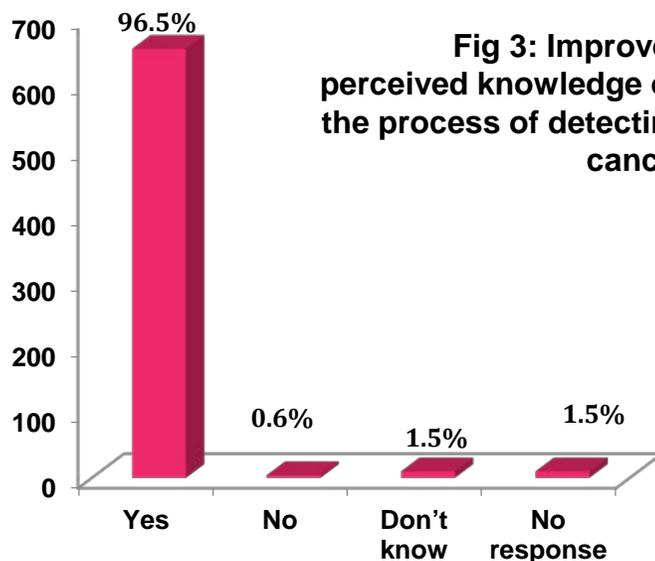
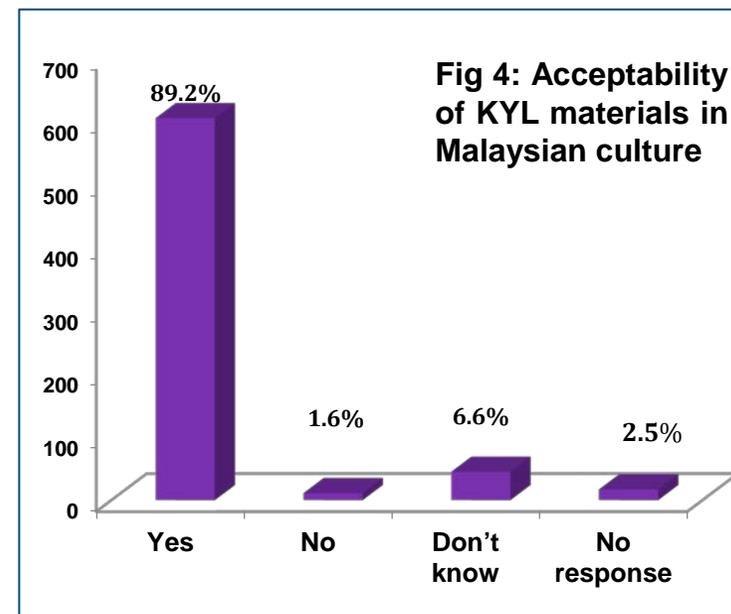


Fig 4: Acceptability of KYL materials in Malaysian culture



IMPROVING BREAST HEALTH LITERACY THROUGH AN INNOVATIVE BREAST CANCER AWARENESS CAMPAIGN USING THE KNOW YOUR LEMONS MATERIALS IN MALAYSIA

Conclusion

- ❑ Health education using KYL materials improve breast health literacy
- ❑ KYL Materials were acceptable amongst urban and educated community.
- ❑ KYL materials can enhance confidence among Malaysian public towards early detection of breast cancer.

Further plan

- ❑ Qualitative study
- ❑ Community based KYL programme in low income urban observatory

Acknowledgement

worldwidebreastcancer.org

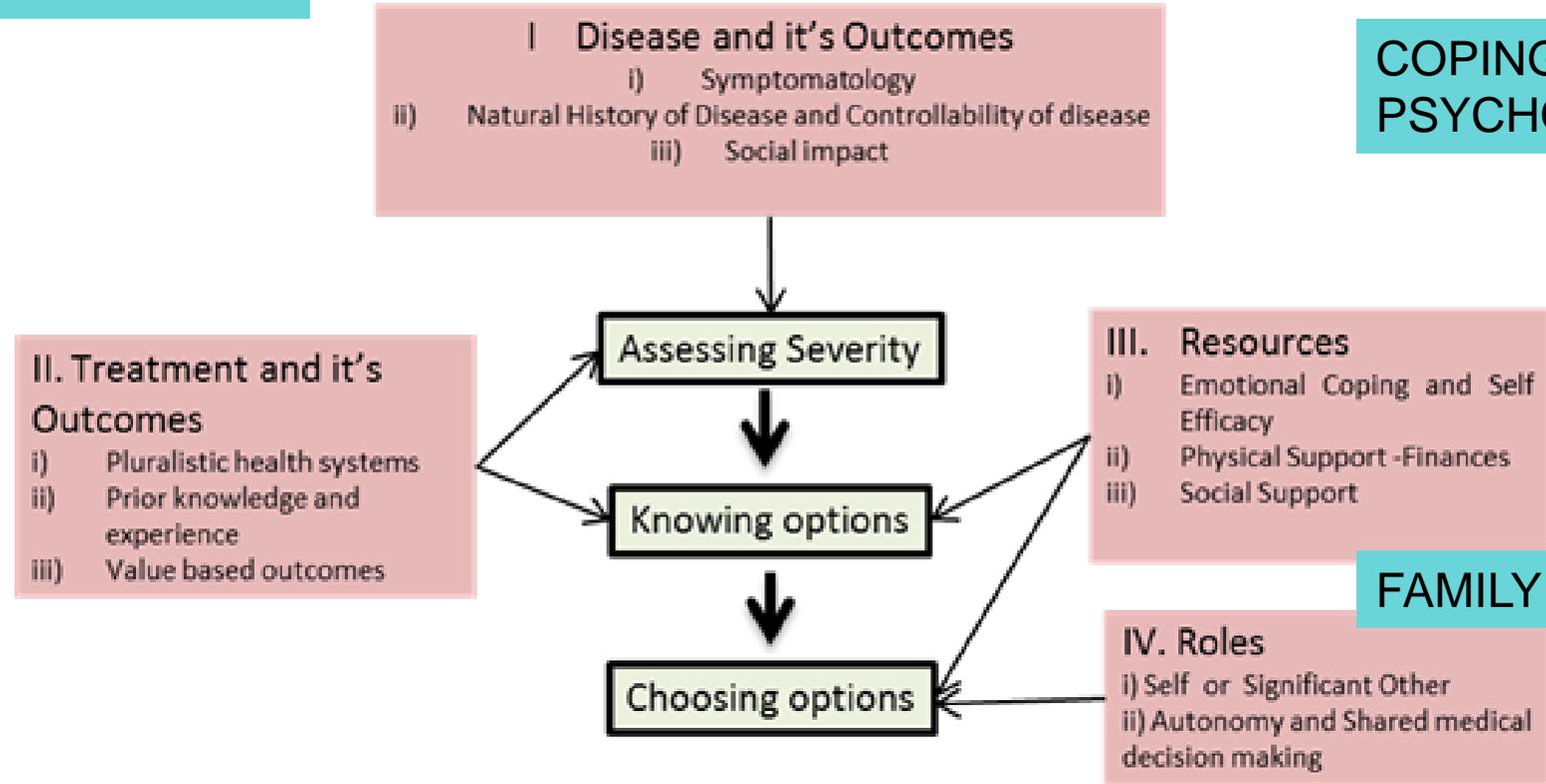


BCDE Model: Decisions to disclose/ seek help/diagnosis/treatment

BREAST HEALTH LITERACY

FINANCES

COPING- NEED FOR PSYCHOSOCIAL SUPPORT



Essential Component: Patient Centred Care

Conclusion



- Need a community psychoeducational approach to breast health literacy
- Educational materials are acceptable, increase confidence to detect breast cancer symptoms.

Contact details: naisha@um.edu.my