

#### Overview

- Provide context
- Key influences on research & research nursing
- Our model of development at The Christie



### .....a little background

- Manchester Cancer Research Centre (MCRC)
   (The Christie, The University of Manchester & CR UK)
- North Of England
- Largest single site European cancer treatment centre
- Prestigious Academic University rich history of research
- CR UK Manchester Institute 1/5 funded by CR UK
- Major centre status 1/3 CRUK
- Brings together the core strengths of all three partners
- Basic Translation Clinical ("Bench to Beside")
- Serve a population of approx 3.2 million (network 5 million)
- 11 DGHs 1 Cancer Centre
- 14,000 new cases a year
- Treat 40,000 patients a year



#### Research in cancer care is essential

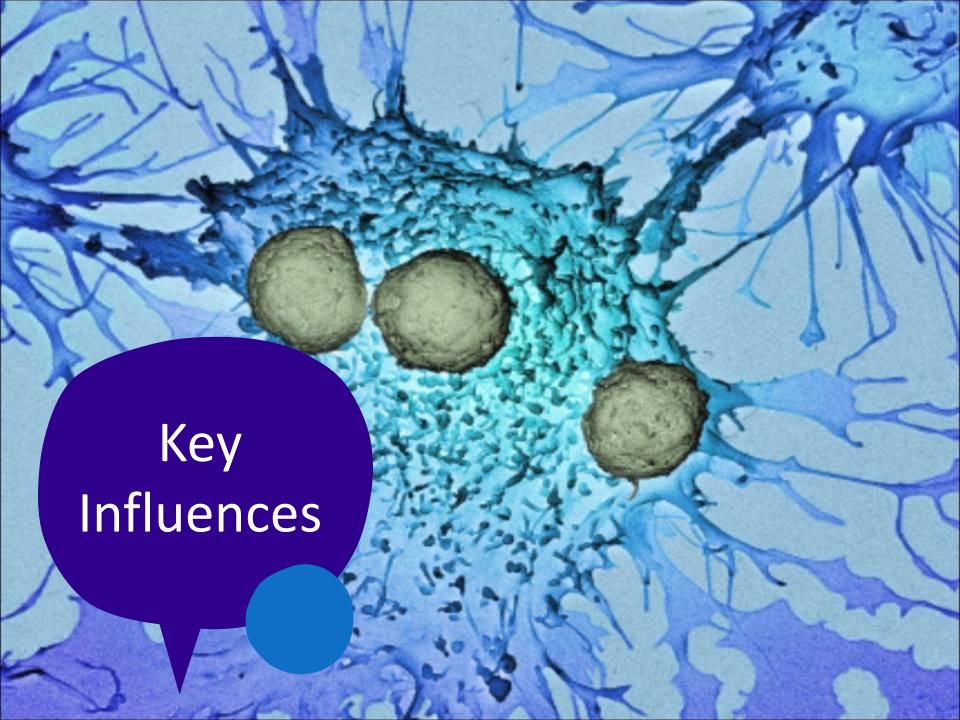
- Research provides the scientific information and theories for the explanation of the nature and the properties of our world
- Its makes practical applications possible, which is so very important in cancer care
- Some of the worst outcomes/survival rates in the UK
- Provides us with the evidence to improve patient outcomes



#### Definition - what is a Clinical Research Nurse?

- Clinical Research Nurse refers to anyone who is 'employed principally to undertake research within the clinical environment' United Kingdom Clinical Research Collaboration (UKCRC) 2007
- A variety of nursing roles all sharing the common feature that 'research' is a central part of their work
- Making a difference to our patients and their outcomes





#### Influences

#### **Political Organisation**

#### The NHS Operating Framework for the NHS England & Wales 2009/10

High quality care for all

#### NHS Constitution (2009):

• patients to be at the "heart " of everything & to be fully informed of all treatment options

#### **The white paper (2010):** 'Equity and excellence: Liberating the NHS'

The government is committed to the promotion and conduct of research as a core NHS role'

#### NHS Operating Framework (2010/11)

'All NHS organisations must play their full part in supporting health research

#### Health and social care act 2012

Promotion and use of research evidence



## Influences(2)

#### Financial influence

- Financial stringency in the NHS
- Pharmaceutical companies managing money carefully

(Research costs more)

#### **Charities**

Cancer Research UK, Macmillan, Breast Cancer Campaign have influenced the way cancer research is shaped

#### Social

Patients in the UK beginning to accept research as normal and are asking to be part of clinical trials

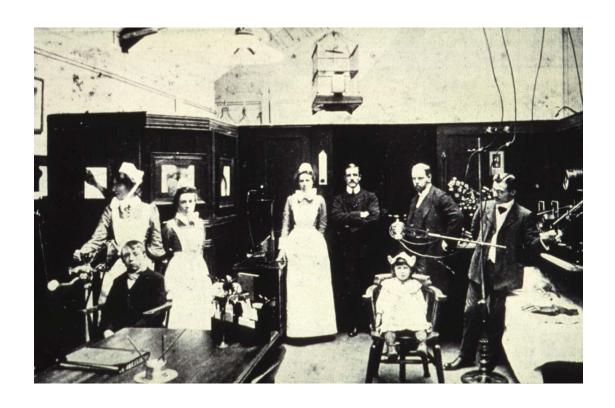
Clinical Research Networks has been created as part of the National Institute for Health Research (NIHR) infrastructure to organise and fund research across England

NIHR run Good Clinical Practice (GCP) Training for all Research Nurses and offer other educational courses





## How it felt ....





## ...but actually how it was

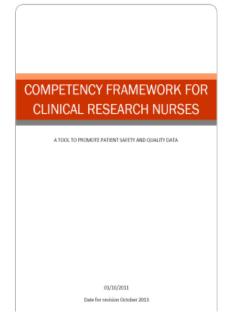
- Very small number of research nurses working in hospitals 1 research nurse to 1 consultant
- Paid in a variety of ways from the pharmaceutical industry funding, charities and university grants often limited
- Isolated from ward based clinical nurses
- Unclear management and governance
- Unclear career development
- We did everything.... recruitment, administered treatment, bloods, lab work, administration/paper work etc...



## How it is today.....Professional organisation

In 2001 Royal College of Nursing (RCN) commissioned work to examine and report on Nursing Career Pathways in Research.

Now have a Competency Framework for Clinical Research Nurses which gives clear guidance on how research nurses should practice, what pay banding they should be on and how they can develop their career (RCN 2011)





# RCN Core Competencies for Research Nurses (RCN 2011)

- To demonstrate and understand the historical background, political influence and strategy regarding clinical research in the UK
- Contributes to the preparation of submissions for regulatory review such as protocol design for submission to Research and Development, Ethics and the Integrated Research Application Service (IRAS)
- Understands and applies the principles and practice of obtaining valid informed consent from patients
- To apply professional knowledge and skills to facilitate efficient, safe participant focussed clinical research
- Contribute to effective and efficient use of resources
- Facilitate the delivery of clinical research
- Contribute to the safe collection and storage of data and accurate completion of study documentation



### Clinical Research @ MCRC /The Christie

- Research & Development Division
- Clinical Research Nurses 59 in total Band 6, 7 and 8
- Clinical Trial Co-ordinators 63 in total Bands 3, 4, and 5
- Disease specific teams 6 in total led by team leaders senior nurses
- Clear reporting structure within each team to ensure accountability & support
- Senior Research Nurses & Team Leaders manage these teams, with medical input & overview,
- Daily operate as small business units







#### Role of 'our' Clinical Research Nurse

- Project manage the trial from feasibility to archiving
- Oversight of trial set up/approvals
- Financial input and oversight
- Training role of trial/ non trial staff( core team)
- Extended roles. NMPS
- Recruit & support patients through the clinical trials process
- Meet performance indicators/National targets + metrics
- Work within NIHR competency framework
- Ensure GCP and UK research policy is implemented
- Respond, adapt & support to the changing needs of Sponsors, Principal Investigators & NHS
- Continually deliver high quality to ensure repeat business & 1st choice for Oncology Trials in UK.



#### To this I would add......Research Nurses...

- Have a comprehensive understanding of the study they are involved in
- Act as the patient's advocate and steering them through the additional tests and investigations
- Have fantastic organisational, teaching and communication skills
- Promote and explain research
- Work with the multidisciplinary team
- Influence the way future care is delivered



#### Manchester Cancer Research Centre

#### Scientists – Clinicians - Research Nurses - Patients

- Our goal to gain a greater understanding of the fundamental basis of how cancer develops and apply that knowledge to develop new diagnostic tests, new treatments and better ways to predict outcomes in order to optimise treatment options and care for cancer patients in the clinical setting
- Our Research Nurses are central to this



#### Manchester Cancer Research Centre





#### Thanks to CANCER RESEARCH ...

You are twice as likely to survive cancer today compared to 40 years ago (Cancer Research UK 2014)





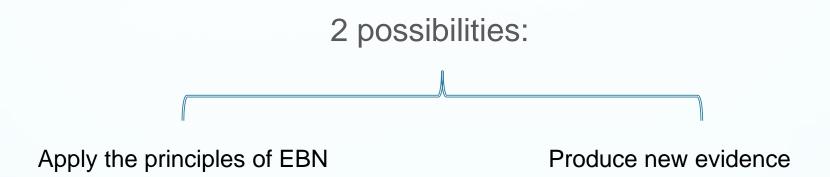


# Integration of research in the breast clinic

Antwerp, Feb 5 th, 2015

Stefano Terzoni, RN, PhD San Paolo teaching hospital, Milan - Italy

# Integration of research



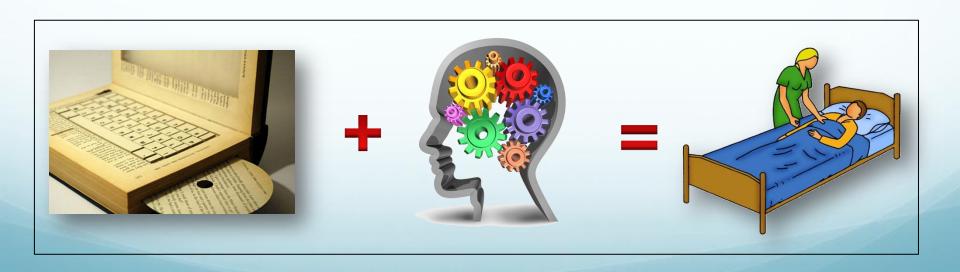
Several issues, reflected in the programme of our congress:

- Clinical aspects
- Ethics and patient expectations
- Organization (multidisciplinary approach, role of specialized nurses)

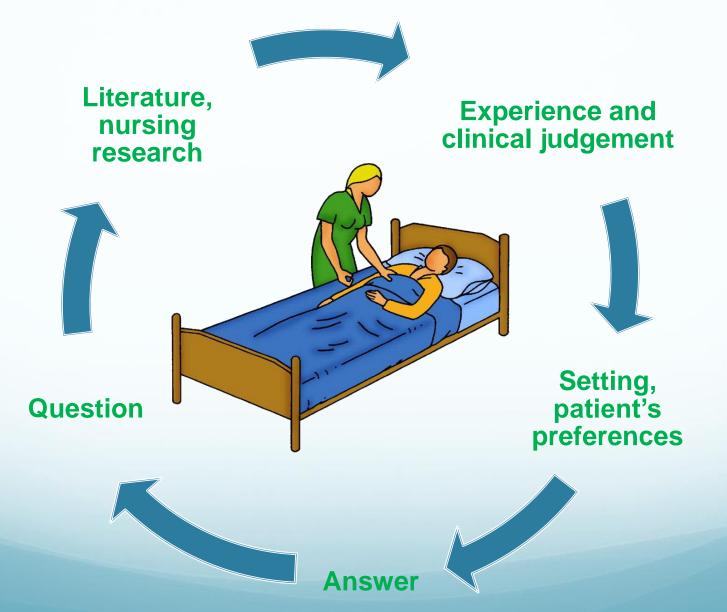
## It's not only about literature

EBN = process through which nurses take the best possible clinical decisions, using the best available evidence, their clinical **experience** and considering the **patients' preferences**, in a context of available **resources**.

Di Censo, Cullum, Ciliska 1998



# From practice to practice



# Research in clinical practice

- Methodology, statistics, literature search are only useful if applied in a circular process, FROM the bed TO the bed.
- If we get «lost in translation» during the process, it becomes time-consuming.



Plenty of evidence, but difficulties in integrating research into practice: why?

# Main point of strenght

- Continuous contact between breast nurses and patients, throughout the whole pathway
- Shared decision making fosters trust
- Explanation of evidence fosters trust
- Trust helps doing research

## **Barriers to EBN**

- Lack of time to search and read evidence
- Lack of literature search abilities (search strategy)
- Inability to understand statistical terms
- Inadequate understanding of the «jargon» in research papers

Majid S. J Med Libr Assoc 2011;99(3)

Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I prefer using more traditional methods instead of changing to new approaches.  I don't like people questioning my clinical practices, which are based on established methods.  Most research articles are not relevant to my daily practice.  I believe evidence-based practice (EBP) has only limited utility.  My workload is too high to keep up to date with all new evidence.	9.9%	54.4%	27.8%	5.4%	0.5%
	5.7%	47.1%	31.7%	12.7%	0.9%
	6.0%	46.1%	34.9%	10.5%	0.5%
	3.2%	35.1%	40.6%	18.0%	0.7%
	2.3%	23.7%	33.0%	32.4%	7.3%

## Points of weakness

- Different countries = different education,
   notwithstanding the Bologna process (1999)
- Lack of an internationally established definition of roles and functions of breast care nurses, lack of methodologically high quality studies
- EONS 2012, UK model, USA model, Australian model Some organizational models (e.g. nursing case management) are "young" in some Countries
- Eicher M. et al. (2012). EJC 48 1257-1262
- Yates P. et al. (2007). Collegian. 14(1):11-5.
- Royal College of Nursing (2007). Clinical standards for working in a breast speciality: RCN guidance for nursing staff

# Notwithstanding these limitations...

- Cruicckshank S et al. Specialist breast care nurses for supportive care of women with breast cancer. Cochrane Database of Systematic Reviews 2008, issue 1.
- Arving C et al. Satisfaction, Utilisation and perceived benefit of individual psychosocial support for breast cancer patients

   A randomised study of nurse versus psychologist interventions.
   Patient education and counseling 2006;62:235-43.
- Liebert B et al. National Breast Cancer Centre's Specialist Breast Nurse Project Team. An evidence-based specialist breast nurserole in practice: a multicentre implementation study. Eur J Cancer Care2003 Mar;12(1):91-7

# Research domains for BSN

Table 1 – Domains and content of the breast care nursing curriculum.								
The experience of breast cancer diagnosis	The experience of breast cancer treatments (including side-effects and their management)	Long term living after breast cancer	Practicing in the breast care nurse role					
1) The meaning of cancer  a) the cultural context of breast cancer; b) psychological reactions to diagnosis; c) social consequences of breast cancer (including partners, children, and the wider context of work and social role)  2) Diagnostic processes, including a) screening and early detection; b) understanding diagnosis, classification, staging and prognostic factors  3) Differences between benign and malignant breast disease 4) Causative processes, including a) genetics; b) epidemiology and risk factors  5) Risk reduction strategies a) healthy living; b) surgical and treatment options	1) Treatment options and decision making a) surgery, reconstruction and oncoplasty; b) systemic therapies (e.g. chemo, hormone and biological therapies); c) radiotherapy; d) complementary and alternative therapies; e) novel treatment approaches; f) management of advanced breast disease; g) principles of clinical trials  2) Recovery and rehabilitation a) wound care	1) Living with a changed sense of self a) altered body image; b) sexuality and fertility issues; c) premature menopause; d) prosthetics  2) Healthy living after breast cancer a) follow up and survivorship; b) bone health; c) sources of support/patient organisations  3) Living with the long termconsequences oftreatment for breast cancer a) lymphoedema; b) fatigue; c) chronic pain  4) Living with advanced disease a) recurrent and advanced breast cancer; b) fungating wound management; c) end of life care	1) Models of practice/role boundaries 2) Working within a multidisciplinary team 3) Clinical supervision 4) New models of care/future ways of working 5) Developing and implementing the role 6) Maintaining professionality 7) Awareness of local, national and international guidelines and standards of care 8) Utilisation of nursing research 9) Sharing good practice					

• Eicher M. et al. (2012). EJC 48 1257-1262

# Liebert et al.

 Almost all women had contactwith an SBN at five scheduled consultations and 67% of women in the intervention group requested at least one additional consultation with the SBN. Women in the intervention group were more likely to receive hospital fact sheets and to be told about and participate in clinical trials. Ninety-eight per cent of women reported that the availability of an SBN would affect their choice of hospital, with 48% indicating that they would recommend only a hospital with a SBN available. Health professionals reported that SBNs improved continuity of care, information and support for the women, and resulted in more appropriate referrals and useof the time of other members of the team.

# Proposals



 Schools of nursing: helping breast nurses to produce evidence-based, plain language summaries to answer questions suggested by hospital nurses



 Teacher nurses: practical courses on how to step from the bedside to literature search, and back. Making clinical sense of numbers in papers. Accreditation of courses inside hospitals

# Proposals



 Provide data to hospital managers: recognize the clinical and also economic value of EBP and research in breast units.
 Organizational support.

Gerrish K. J Nurs Manag; 2004(12): 114–123

 Some nurses perceive EBN as «questioning» their experience.
 What about the «good apples theory»?



## Conclusions

- Educational, organizational and ethical issues influence nursing research in breast units (what about multicentric studies?)
- Need to foster unification of educational programmes in all countries
- Nurses make a difference, but few whigh quality research paper are available to demonstrate this
- Shared decision making fosters patients' trust, and leads to better nurse-patient collaboration in research

# Thank you



stefano.terzoni@ao-sanpaolo.it