

Introducing PPI to the next generation of cancer researchers

Professor Valerie Speirs

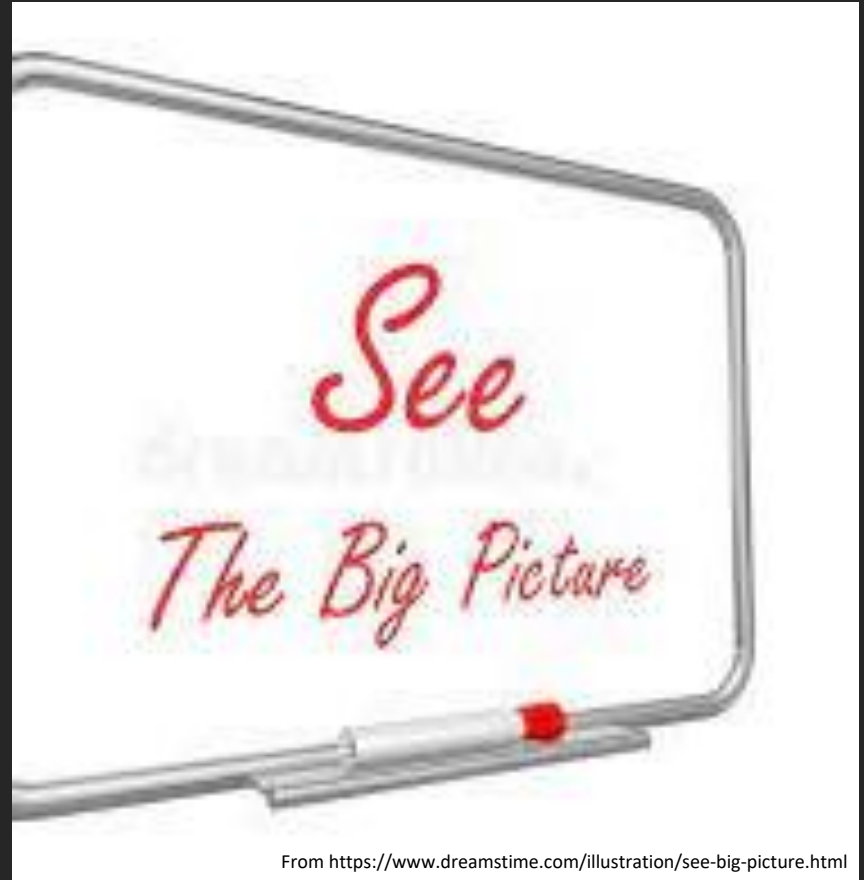
**School of Medicine, Medical Sciences and Nutrition,
University of Aberdeen**

valerie.speirs@abdn.ac.uk @ProfVals

NRS & CSO Patient and Public Involvement Event, Dundee 12 March 2024



From <https://www.dreamstime.com/photos-images/white-horse-blinders.html>



From <https://www.dreamstime.com/illustration/see-big-picture.html>

Adrienne Morgan

Maggie Wilcox

independent
cancer patients

voice

www.independentcancerpatientsvoice.org.uk

We are an independent patient
group led by patients for
patients bringing the views and
experience of cancer patients, their
family and carers to
research

I've spread the word
ICPV

ICPV

PPI – patient public involvement

Why should we include this in our research?

- Makes our research more relevant and useful to the end-users
- Influences the design, delivery and dissemination of research
- Involving people in research about a specific health condition or care situation who have (or have had) direct first-hand experience will demonstrably improve that research

ICPV study days

- Hosted the first ICPV study day (Leeds, 2009)
 - 23 participants
 - people affected by breast cancer, research nurses, scientists and clinicians
- 14 further study days
- VOICE
 - vision on information, confidence & engagement
- Science for patient advocates
 - A study week taking patient advocates from bedside to bench





In the Pathology lab, we see rogue cells for the first time.





MenGetBreastCancer.org

Men get breast cancer TOO!

Why Chest Check?

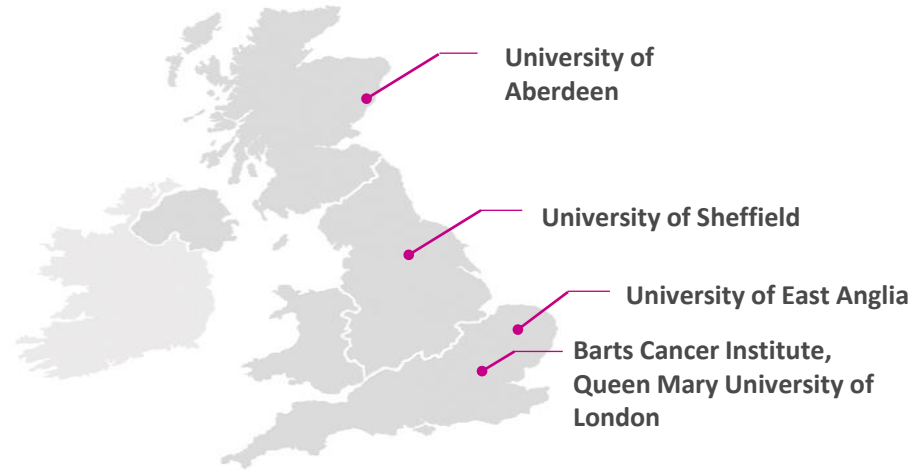
- With no routine screening, and currently little research, most male breast cancers are only found by **Checking the Chest!**
- WARNING SIGNS** are inverted nipples, a lump behind the nipple or any discharge, redness or skin dimpling.
- REASONS** 80% of lumps found are not cancerous.
- BUT** if you feel or see any changes, get checked by your doctor, if only to put your mind at rest!
- GO ON...** Save data each month - Check your Chest!

To find out how to do it - just visit walkthewalk.org/mengetbreastcancertoo

walk the walk
www.walkthewalk.org

Partners: The Royal Marsden, The Royal Free, FACT, MBO, Cancer Research UK, Breast Cancer Now, Breast Cancer Action, Breast Cancer Research Network, Breast Cancer Research Foundation, Breast Cancer Research Program, Breast Cancer Research Society, Breast Cancer Research Trust, Breast Cancer Research Unit, Breast Cancer Research Institute, Breast Cancer Research Center, Breast Cancer Research Group, Breast Cancer Research Team, Breast Cancer Research Unit, Breast Cancer Research Center, Breast Cancer Research Group, Breast Cancer Research Team, Breast Cancer Research Unit, Breast Cancer Research Center, Breast Cancer Research Group, Breast Cancer Research Team.

Breast Cancer Now Tissue Bank



www.breastcancertissuebank.org

Involving patient partners in
the Breast Cancer Now
Tissue Bank

Involving patient partners in the BCNTB

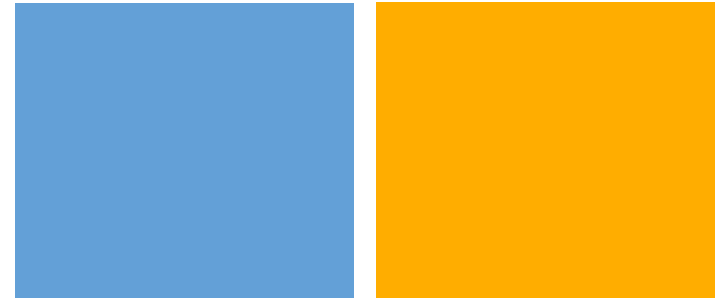
Assessing the initial applications to host the Tissue Bank



Tissue Bank Application



Involving patient partners in the BCNTB



- Members of Tissue Bank Advisory Council
 - Reviewing activity
 - Making recommendations
 - Shaping the future of the Tissue Bank



Involving patient partners in the BCNTB

- Member of Tissue Access Committee
 - Approval of Tissue Bank requests (lay reviewer questions)
- Is it a relevant topic?
- Does it have the potential to provide patient benefit?
- Does it cover an unmet need or hard to treat cancer e.g. triple negative or metastatic disease?
- **Is there a good lay summary?** – this is something that has improved greatly since I first started doing this (*anonymous patient partner*)

***The tissue is a precious gift
and needs to be treated as such***

Involving patient partners in the BCNTB

Co-authors on publications **AND** independent authorship

BREAST CANCER

Investment biobanking—increased returns from tissue samples

Valerie Speirs and Adrienne Morgan

Researchers now expect that samples obtained from biobanks are accompanied with well-annotated clinical data. Opened in 2010, the Breast Cancer Campaign Tissue Bank takes this criterion a step further: researchers obtaining tissues are required to return the data they generate from every sample back to the Tissue Bank.

Speirs, V. & Morgan, A. *Nat. Rev. Clin. Oncol.* advance online publication 5 February 2013; doi:10.1038/nrclinonc.2013.19

The Importance of Quality Patient Advocacy to Biobanks: A Lay Perspective from Independent Cancer Patients Voice (ICPV), Based in the United Kingdom

Maggie Wilcox, Margaret Grayson, Mairead MacKenzie, Hilary Stobart, Helen Bulbeck, and Robert Flavel

Abstract

Biobanking in the twentieth century will become of increasing importance in health research. Regulation and governance of biobanks must be open and transparent to ensure public trust and confidence and increase donation. Effective Lay Involvement all levels in biobank organisations should be standard practice helping ensure patient benefit remains the central aim and assisting the Promotion of Biobanks and Recruitment of Donors. Properly selected, educated and supported, they become valued members of the Biobank Team. This chapter is based on the work of Independent Cancer Patients' Voice (ICPV) in the UK and recognises that the National Health Service provides a framework which is not universal and neither is the model of patient advocacy which has been developed particularly in cancer research. However, although it has not been easy to find potential members for ICPV, nor to attract funding, we have earned the respect of our professional colleagues by our commitment in giving time and developing the skills necessary to provide effective involvement. These colleagues have enthusiastically mentored and supported us and have provided venues and tutoring for Educational Events. We are sure that patient advocates in other countries would welcome the opportunity for similar involvement and hope our experiences will be of interest.

M. Wilcox (✉) • M. Grayson • M. MacKenzie
H. Stobart • H. Bulbeck
Independent Cancer Patients' Voice (ICPV),
London, UK

© Springer International Publishing Switzerland 2015
F. Karimi-Busheri (ed.), *Biobanking in the 21st Century*, Advances in Experimental Medicine and Biology 864, DOI 10.1007/978-3-319-20579-3_14





Communication!

Trailblazers in cancer research: the next generation – the British Association of Cancer Research early-career conference



Home About Membership Awards & Bursaries Events News Jobs



other

earch

Patricia Fairbrother

The Value of Patient and Public Involvement to the Researcher

Reflections on my role as a Patient Advocate in Cancer Research



Patient delegates at UK Interdisciplinary Breast Cancer Symposium, 2024



Patients presenting posters: Interdisciplinary Breast Cancer Symposium, 2024



A UK study exploring the attitudes and experience of patients living with metastatic breast cancer with regard to clinical research: A patient advocate-academic collaborative study

Lucy Stepien¹, Janet Dunn², Claire Baines³, Sophie Scahill⁴, Narda Elshatari⁵, Ellen Casson⁶, Carie Palmer^{1,4}

¹Metastatic Breast Cancer Research Unit, University of Warwick, UK; ²Leamington Spa, UK; ³University of Warwick, UK; ⁴Leamington Spa, UK; ⁵University of Warwick, UK; ⁶Leamington Spa, UK

LAY SUMMARY

This study was co-designed by a patient and set out to gather attitudes and experiences of Metastatic Breast Cancer patients with regard to clinical research. Data were gathered by an online survey and additional interviews. There were 748 responses to the survey and 21 of these were also interviewed. Despite the majority of responses knowing about clinical trials, only 14% had been recruited into a trial and very few reported discussing trials at their clinical consultation.

Key messages include the importance of clinical staff in the provision of study information. There is a lack of patient facing trial databases but 87% would use one if it was available freely. There was a willingness to travel for participation in a trial, however more would travel, even worldwide, if there was financial support with travel costs.

INTRODUCTION

Clinical trials are key to improving outcomes in metastatic breast cancer (MBC). However, participation is low. Little data exists regarding the attitudes and experiences of patients in relation to clinical research. This study co-designed by a patient living with MBC and researchers aims to explore the experiences and issues related to accessing and participating in clinical research.

METHODS

This is a mixed methods study consisting of an online survey and qualitative interviews. Participants responded to an online questionnaire which contained closed and open questions, this was live between 17th May 2021 and 30th November 2021. Qualitative interviews from a sample of patients who gave their consent were carried out between 15th August 2021 and 20th November 2021. Descriptive statistical analysis of the quantitative results from the closed questions and thematic analysis of the qualitative data generated by the open-ended questions and interviews were utilised. Data were extracted on 17 December 2021.

RESPONDER CHARACTERISTICS

There were 748 responses to the survey.

- Median age was 55 years, 21% had Endocrine disease
- Majority found survey through social media/charity websites
- Sex: 745 females, 2 males & 1 not reported
- Employment status: 45% in work, 11% retired or off-sock
- Broad geographical spread across UK

QUALITATIVE INTERVIEWS

21 participants were interviewed for the qualitative sub study, with three complementary themes emerging from these surveys

Theme 1: Information about clinical trials/research

All participants called for more information. They wanted a 'patient friendly', 'all or one place' & accessible, so they didn't have to 'hunt' through the internet.

Lack of information led to misconceptions (e.g. 'research is more for people who have run out of options'), loss of confidence in staff and feelings of being unwell.

"I don't have a secondary breast cancer one, I have no one I can contact, I don't have anyone direct although do have a good team"

Theme 2: Barriers to participation

Having metastatic cancer was seen as a huge barrier. Participants felt discouraged (they know you're going to die) and flouted by rigid inclusion/exclusion criteria.

"I don't know what you mean by inclusion and exclusion criteria"

Occasionally they felt overprotected by very well-meaning but 'over-protective' staff. Medical jargon complicating understanding and a perceived slow/limited accessibility were also seen as barriers. Although the survey indicated that many were prepared to travel for treatment, this was discarded as another 'layer of exclusion'.

Theme 3: Research priorities

A dominant research priority for this group, was more participant involvement: 'why don't you get information on stage and we can have a clinical dialogue with the people that matter?'

"We need you as much as you need us and why don't you get some of us to come and give our perspective"

Thank you to all the participants who have responded to the survey and those who agreed to be interviewed

ACKNOWLEDGEMENT & DISCLAIMER

The views expressed in this paper are those of the authors and do not necessarily represent those of the funding bodies.



SURVEY RESULTS

Opportunities to enter a trial

Figure 1: Talking about clinical trials

Knowledge/Attitudes about trials

Figure 2: Benefits and barriers to joining a trial

Information needs

Figure 3: Information about trials

87% would search a database if it was patient friendly



CONCLUSIONS

- This large UK study provides insights into the experiences and attitudes of patients with MBC in relation to clinical research.
- It demonstrates that patients are keen to be involved in research but face barriers to inclusion.
- Key messages include the need to develop patient facing trial databases, the importance of clinical staff in the provision of study information and a willingness to travel for a trial but the need for financial support.
- Addressing issues identified in the survey are key to ensuring MBC patients not only have opportunities to participate in research but also the ability to take up these opportunities.

Male breast cancer

Virtual Men's Meetup



- Peer-led online group for men, ran by men who've had breast cancer
- Offers men a safe space to talk through their experiences with other men who just "get it"
- Occasional guest speakers; charity representatives, researchers, breast surgeons

When you think of breast cancer what immediately springs to mind?



How much do you about male breast cancer?



Type of research needed	Response
Prevention	✓
Risk factors	✓
New treatment	✓
Better support/information for men	✓
How to reduce gender stereotyping in breast cancer	✓
Better understanding of the biology of male breast cancer	✓



Lab tours

Reflections on the value of PPI engagement in my research

- Translational research aims to improve patient care. To do this well requires both the support of and interaction with patients
- Having patient voices behind all stages of the Breast Cancer Now Tissue Bank, has helped this flourish into the well-established biobank it is today
- Being able to speak with men who have received a, usually completely unexpected, breast cancer diagnosis and to listen and learn about their experiences has reshaped my thoughts on their needs and wishes from a research perspective
- Patients **will** ask the elephant in the room question - I'm convinced this has helped get me through some funding review panels

Working with patients emphasises the need to remember the reasons behind our work, the translational potential of our findings and, ultimately, how this can be life changing for patients.

Suggested reading

Staley *et al.* *Research Involvement and Engagement* (2021) 7:41
<https://doi.org/10.1186/s40900-021-00282-1>

Research Involvement
and Engagement

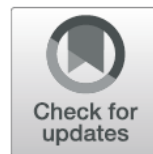
COMMENTARY

Open Access

Who should I involve in my research and why? Patients, carers or the public?

Kristina Staley^{1*} , Jim Elliott², Derek Stewart³ and Roger Wilson⁴

<https://pubmed.ncbi.nlm.nih.gov/34127074/>





Maggie Wilcox
1942-2021