Institution:
University of Central Lancashire

Unit of Assessment:
3 – Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study:
Changing the way follow-up services are delivered to benefit cancer survivors

Period when the underpinning research was undertaken:
2010-2018

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Kinta Beaver	Professor of Cancer Care	2010 - 2020
Susan Williamson	Senior Research Fellow	2010 - 2020
Chris Sutton	Reader in Clinical Trials	1988 - 2018

Period when the claimed impact occurred:
2014-Present

Is this case study continued from a case study submitted in 2014? Y/N
N

1. Summary of the impact (indicative maximum 100 words)

Beaver's research has benefitted the NHS by demonstrating that Telephone Follow-Up is equally effective, and as beneficial to patients treated for cancer, as hospital-based follow-up. It has impacted on policy and clinical practice guidelines for the British Gynaecological Society, Cancer Australia and Cancer Care Ontario in Canada. By demonstrating that Telephone Follow-Up is clinically cost effective with high levels of patient satisfaction we have changed the way these services are delivered. Both patients and practitioners have expressed their satisfaction with Telephone Follow-Up, with one Gynaecology Oncologist commenting "***This is the preferred choice by patients as it is delivered at home… by specialist nurses who know the patients and can spend more time discussing their holistic needs"*** A recent on-line consensus meeting of 121 global participants made recommendations to implement Telephone Follow-Up to lower the risk of COVID-19 transmission during cancer treatment. Beaver's research with both breast and endometrial cancer patients was referenced, demonstrating international impact, as face to face hospital appointments get replaced with alternative forms of follow-up, including Telephone Follow-Up.

2. Underpinning research (indicative maximum 500 words)

There are 2,500,000 cancer survivors in the UK. As the number of cancer survivors continues to increase, Hospital-Based Follow-Up, involving regular face to face outpatient appointments over several years, has become increasingly unsustainable practically and economically. Over the last 16 years Beaver and colleagues have designed and evaluated an innovative strategy to shift the format of follow-up care from a hospital-based approach to one targeted at meeting the individual needs of patients. Harnessing the skills of clinical nurse specialists, Beaver designed and adapted a telephone intervention process to provide appropriate and timely information for patients treated for different types of cancer. Randomised controlled trials (RCT) were carried out to evaluate the clinical and cost effectiveness of nurse-led telephone follow-up. Previous research (pre-University of Central Lancashire employment) with breast and colorectal cancer patients has impacted on national policy guidelines and has featured in recommendations from Macmillan Cancer Support for cancer patient follow-up.

Between 2011 and 2014 a large RCT was carried out comparing hospital and specialist nurse-led Telephone Follow-Up for women diagnosed and treated for endometrial cancer known as the ENDCAT trial. ENDCAT was the first clinical trial on endometrial cancer follow-up in the world to report its findings to the clinical and academic community. Beaver and colleagues worked collaboratively with NHS gynaecology oncologists, clinical nurse specialists, and with seven clinical nurse specialists responsible for the delivery of telephone follow-up across five NHS hospital Trusts in North West England. The trial recruited 259 women; 129 were randomised to telephone follow-up and 130 to hospital follow-up. The research demonstrated that patients were highly satisfied with Telephone Follow-Up, were not more anxious than with face-to-face hospital-based appointments or clinical examinations, and their welfare was unaffected by the

shift to an equally effective service [1]. The trial included an economic evaluation to examine the cost effectiveness of Telephone Follow-Up and found that this approach was cost neutral to the NHS even though nurses spent longer on the telephone than doctors providing Hospital-based Follow-Up appointments [2]. Although cost savings for the NHS could not be demonstrated, there were opportunity costs for the NHS in freeing up consultant time and clinic space. Qualitative interviews with patients and clinical nurse specialists identified that Telephone Follow-Up was viewed very positively. Patients found this approach to be convenient, discrete and personal, enhancing confidence and providing reassurance. The clinical nurse specialists found the structured format of the telephone intervention enabled them to utilise their skills and knowledge to identify and meet patients' holistic needs [3].

On completion of the ENDCAT trial, patients were asked to score and comment on their satisfaction with the service using a survey design [4]. 211 (89.4%) patients returned the questionnaire; 105 in the telephone group and 106 in the hospital group. The telephone group were more likely to indicate that appointments were on time and were more likely to report that their appointments were thorough. Based on a scale of 1 (very unsatisfied) to 10 (very satisfied), the telephone group reported a mean score of 9.48 for satisfaction with telephone follow-up and a mean score of 9.40 for overall satisfaction with information received.

3. References to the research (indicative maximum of six references)

1. Beaver K, Williamson S, Sutton C, Hollingworth W, Gardner A, Allton B, Abdel-Aty M, Blackwood K, Burns S, Curwen D, Ghani R, Keating P, Murray S, Tomlinson A, Walker B, Willett M, Wood N, Martin-Hirsch P (2017). Comparing hospital and telephone follow-up for patients treated for Stage I endometrial cancer (ENDCAT Trial): a randomised, multicentre, non-inferiority trial. *BJOG: An International Journal of Obstetrics and Gynaecology*. 124(1), 150-160 DOI: http://doi.org/10.1111/1471-0528.14000
2. Dixon P, Beaver K, Williamson S, Sutton C, Martin-Hirsch P, Hollingworth W (2018). Economic evaluation alongside a randomized controlled trial of hospital versus telephone follow-up after treatment for endometrial cancer. *Applied Health Economics and Health Policy.* Published On-Line 12.04.18. DOI: http://doi.org/10.1007/s40258-018-0378-6 (Open Access)
3. Williamson S, Beaver K, Gardner A, Martin-Hirsch P (2018). Telephone follow-up after treatment for endometrial cancer: a qualitative study of patients' and clinical nurse specialists' experiences in the ENDCAT Trial. *European Journal of Oncology Nursing*. 34; 61-67 DOI: https://doi.org/10.1016/j.ejon.2018.02.005
4. Beaver K, Williamson S, Sutton CJ, Gardner A, Martin-Hirsch P. Endometrial cancer patients' preferences for follow-up after treatment: a cross-sectional survey. *European Journal of Oncology Nursing*. Published on-line 31st January 2020. Vol 45. DOI: https://doi.org/10.1016/j.ejon.2020.101722

4. Details of the impact (indicative maximum 750 words)

Beaver's work impacts on patients and health care staff in the North West of England, it has a national impact on policy and clinical guidelines, and an international impact in relation to the COVID-19 pandemic.

Patient Benefit

Endometrial cancer is the fourth most common cancer in women and has increased by 57% over the last 30 years, directly linked to obesity. According to Cancer Research UK 2019, between 2014 and 2016 there were approximately 9,300 new diagnoses in the UK every year. Providing adequate support and follow-up for cancer survivors continues to stretch NHS resources. Beaver's innovative approach to follow-up care for patients treated for endometrial cancer aimed to provide patients with the information they need to self-manage and to reduce the burden on hospital outpatient clinics. Patients receiving Telephone Follow-Up from specialist nurses were highly satisfied with the care and information received, and the service provided [1]. 78% reported receiving all the information they needed. The time to detection of recurrent disease was similar with five in each group. For the telephone group – there was a median of

seven days and for the hospital group a median of nine days. Patients receiving Telephone Follow-Up saved time, money and had less time off work. The estimated return journey costs per patient for hospital consultations were GBP11.47, whilst productivity costs were approximately twice as high under Hospital Follow-Up [2]. Patients indicated that they preferred telephone to face to face hospital follow-up [3]. Telephone follow-up was convenient for patients, reassuring and promoted self-management [3]. Comments on the telephone service were overwhelmingly positive, primarily related to the convenience of the service, knowing who to contact if a problem arose, and being reassured by the consultation.

"Very happy with the follow-up care. Preferred telephone appointments as long trips to the hospital weren't necessary." Patient ID 24 [4, A]

"*Overall very satisfied with telephone consultations. I have a contact number and am assured I can ring at any time with any queries I might have. This is something I would highly recommend."* Patient ID 06 [4, A]

Health Care Professional Benefit

Clinical nurse specialists gained satisfaction from fully utilising their skills and providing patients with the information they needed to self-manage. To date, specialist nurses have conducted hundreds of telephone appointments with patients and continue to receive positive feedback with high levels of patient satisfaction with the service. On trial completion, five hospitals in the North West region continued to provide nurse-led Telephone Follow-Up for patients treated for endometrial cancer (Lancaster, Barrow, Preston, Burnley, Blackpool) and report an intention to extend the service to other patients.

"I love it…, I think it's really, really good I, I really enjoy [it] and I look forward to doing the clinic and once the trials finished I certainly will carry on with it and I will see other patients as well so I will be extending the clinic [telephone] to suit all gynae patients rather than just endometrial." (Clinical Nurse Specialist 02) [J]

"The service is seeing more and more ladies with gynaecological cancers and more time is able to be allotted to these ladies due to the phone clinic … I find the clinic (telephone) efficient, less time consuming but as thorough as face to face and easy to perform." Barbara Allton testimonial, Gynaecology Oncology Clinical Nurse Specialist, [B1]

Benefit to the NHS:

Currently, findings from the ENDCAT trial are referenced nationally as high-level evidence, Grade A [C]. It guides clinicians in follow-up service provision for patients diagnosed and treated for endometrial cancer. The British Gynaecology Cancer Society (BGCS) published national clinical guidelines in 2018 stating: **'Alternative modes of follow-up such as telephone follow-up do not appear to be inferior to hospital-based follow-up, in terms of quality of life for stage I endometrial cancer'** [C, p36]. More recently, in 2019, Beaver was invited on to an expert panel meeting on gynaecological cancer follow-up. The panel recommended implementation of remote monitoring including Telephone Follow-Up for intermediate and high-risk endometrial cancer patients, thus extending our inclusion criteria. Furthermore, Telephone Follow-Up was also extended to the new patient group of ovarian cancer patients. These recommendations will inform revised national clinical guidelines for the follow-up care of gynaecological cancer patients [D].

Testimonials from senior clinical staff indicate the reach and significance of our work:

"Telephone follow-up is now delivered across the UK and beyond with the evidence base delivered by UCLAN's department of oncology nursing. This mode of cancer care is supported by Macmillan and other patient focused organisations. This is the preferred choice by patients as it is delivered at home and delivered by specialist nurses who know

the patients and can spend more time discussing their holistic needs…Professor Beaver's work has changed the landscape of follow-up care in the UK and provided the robust evidence to support this." Dr Pierre Martin-Hirsch, Gynaecology Oncologist, President of the British Society of Colposcopy and Cervical Pathology. [B2]

We received recognition of the importance of our work in the field of nursing, the largest health care workforce in the NHS, when the ENDCAT research and clinical team were shortlisted for the prestigious RCNi awards [E].

International reach

Patients with cancer can be in an immunosuppressed state due to treatment. As such, they are high risk in terms of morbidity and mortality during the COVID-19 pandemic. As hospitals globally are considered a source for contracting the virus, face to face appointments have been cancelled or replaced with alternative forms of follow-up, including Telephone Follow-Up. Hence, our work on Telephone Follow-Up is now likely to have an even greater impact, providing evidence on the effectiveness of this approach. Academic papers and reports are already being published that reference our work (Simcock et al 2020, Kang et al 2020); [F, G]. Simcock et al (2020) describe a consensus meeting of 121 global participants with recommendations to implement Telephone Follow-Up to lower the risk of COVID 19 transmission during cancer treatment and follow-up [F]. A paper published in the United States, referencing our work, reports on the importance of telemedicine during the COVID-19 pandemic for head and neck cancer patients [G]. A report published by the Australian government defining a policy framework for the management of patients with cancer during the pandemic [H] makes repeated reference to the Simcock et al. (2020) paper. Although only recently published, the findings from the ENDCAT trial have been referenced as supporting evidence in the Cancer Care Ontario (Canada) guidelines for Follow-up after Primary Therapy for Endometrial Cancer [I].

One practitioner commented that Beaver's research was ***"…making a difference to women effected by breast cancer in this pandemic as we've adapted to offer information, support and the opportunity to discuss their needs using experience and knowledge from your research."*** [B3]

5. Sources to corroborate the impact (indicative maximum of 10 references)

A. Survey data from a questionnaire submitted to ENDCAT trial participants on completion of the trial. Beaver K et al (2020). Endometrial cancer patients' preferences for follow-up after treatment: a cross-sectional survey. *European Journal of Oncology Nursing*. Published on-line 31st January 2020. Vol 45. DOI: 10.1016/j.ejon.2020.101722.
B. Testimonials from senior clinical staff:
   B1 – Testimonial from Barbara Allston, Gynaecology Oncology Clinical Nurse Specialist
   B2 – Testimonial from Dr Pierre Martin-Hirsch, Gynaecology Oncologist, President of the British Society of Colposcopy and Cervical Pathology
   B3 – Testimonial from Macmillan Lead Breast Care Nurse Specialist
C. Sundar, Balega, Crosbie et al (2018), *Uterine Cancer Guidelines: Recommendations for Practice*. British Gynaecology Cancer Society, London UK. Pages 36,37,38 55 https://www.bgcs.org.uk/wp-content/uploads/2019/05/BGCS-Endometrial-Guidelines-2017.pdf (Accessed 18 March 2021)
D. Outcome from an expert panel meeting organised by the British Gynaecological Cancer Society, held in London in March 2019. Newton C et al (2020) British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU). *Journal of Gynaecological Cancer*. DOI: 10.1136/ijgc-2019-001176.
E. The ENDCAT trial team were shortlisted for the RCNi annual nursing awards.
   E1 – YouTube clip: https://www.youtube.com/watch?v=I6UwRN_5jQY (Accessed 18 March 2021).
   E2 – Featured article in Nursing Standard March 2017. Nursing Standard is the UK's highest circulating nursing publication and reaches over 96,000 nurses every week.

F. Report on a global consensus meeting to determine recommendations for working practices for oncology practitioners during the COVID-19 pandemic. Simcock R, Thomas TV, Estes C, Filippi AR, Katz MS, Pereira IJ, Saeed H (2020) COVID-19: Global radiation oncology's targeted response for pandemic preparedness. Clinical and Translational Radiation Oncology. 22; 55–68
G. An academic paper from the United States reporting on the importance of telemedicine during the COVID-19 pandemic for head and neck cancer patients. Kang et al (2020). The 3 Bs of Cancer Care Amid the COVID-19 Pandemic Crisis: "Be Safe, Be Smart, Be Kind"—A Multidisciplinary Approach Increasing the Use of Radiation and Embracing Telemedicine for Head and Neck Cancer. *Cancer*. DOI: 10.1002/cncr.33031
H. Cancer care in the time of COVID-19: A conceptual framework for the management of cancer during a pandemic (May 2020). Australian Government and Cancer Australia. https://apo.org.au/node/305841 (Accessed 18 March 2021)
I. The ENDCAT trial was referenced as supporting evidence in the Cancer Care Ontario, Canada, clinical practice guideline on Follow-up after Primary Therapy for Endometrial cancer (2017).
J. Williamson S, Beaver K, Gardner A, Martin-Hirsch P (2018). Telephone follow-up after treatment for endometrial cancer: a qualitative study of patients' and clinical nurse specialists' experiences in the ENDCAT Trial. *European Journal of Oncology Nursing*. 34; 61-67