

Institution: University of the Highlands and Islands (UHI)		
Unit of Assessment: 3		
Title of case study: Improving education, awareness, help-seeking, and early detection in teenage cancer		
Period when the underpinning research was undertaken: 2012 to 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Gill Hubbard	Role(s) (e.g. job title): Professor of Health Services Research	Period(s) employed by submitting HEI: University of Stirling 2004 to 2017, UHI August 2017 onwards (after transition of nursing from Stirling to UHI, approval granted in line with para 321 Guidance on submissions)
Period when the claimed impact occurred: 2013 to 2020		
Is this case study continued from a case study submitted in 2014? No		
<p>1. Summary of the impact</p> <p>Nearly 2,500 teenagers are diagnosed with cancer each year in the UK. Raising awareness about cancer and its risk factors helps teenagers detect cancer sooner during adolescence and into early adulthood. University of the Highlands & Islands (UHI) research has found that as many as half of all teenagers cannot identify cancer warning signs or cancer risk factors and are at increased risk of melanoma because of sunburn. The research team partnered with Teenage Cancer Trust (TCT) to develop and evaluate programmes to improve understanding and change risky behaviour. Pupil and teacher testimonials suggest these programmes help teenagers detect cancer earlier, with life-saving implications. In 2018, TCT reported its education and cancer awareness programme reached 25% of UK secondary schools and over 300,000 teenagers. As a result of this success, both Westminster and Scottish governments have ramped up education and cancer awareness programmes as part of their national strategies to tackle this cluster of diseases, and the Department of Health has made cancer education part of the National Curriculum in England. CanTeen, a teenage cancer charity in Australia, is rolling out an equivalent education cancer awareness programme across Australia, modelled on the research conducted in the UK.</p>		
<p>2. Underpinning research</p> <p>A key step in the early detection of cancer is awareness of cancer warning signs and risk factors, but initial research led by Hubbard showed significant problems in this regard among UK teenagers. In national studies carried out in 2012, half of teenagers were unable to identify cancer warning signs [3.1] and, with the exception of smoking, teenage awareness of cancer risk factors was low [3.2]. A further national study found that half of teenagers are at increased risk of skin cancer during their lifetime because of poor application of sun protection behaviours and high rates of sunburn [3.3]. In response to this research demonstrating poor cancer awareness, TCT partnered with the research team to undertake three research projects:</p> <ol style="list-style-type: none"> 1. In 2012, a quasi-experimental study of TCT's existing education and cancer awareness programme that they delivered in secondary schools throughout the UK. The evaluation found that recognition of nine common cancer warning signs significantly increased two weeks after the programme and was maintained at six-month follow-up [3.4]. 2. In 2013, the research team used the findings of the above study to revise TCT's education and cancer awareness programme by drawing on behaviour change theory and behaviour change techniques (the revisions based on the research are described in output 3.5). The revised programme – What is cancer? – placed greater emphasis on increasing adolescents' communicative self-efficacy by including role-play and addressing barriers to seeking help from a doctor by including a short film. The Scottish government programme <i>Detect Cancer Early</i> then funded TCT and the research team to conduct a full-scale cluster randomised controlled trial of the revised education and cancer awareness programme. <i>Detect Cancer Early</i> was formally launched by the Scottish Government in February 2012 to raise the public's awareness of early signs and symptoms of cancer to encourage them to seek 		

help earlier. The trial across 20 schools (10 intervention and 10 control) and more than 2,000 students found that the education and cancer awareness programme improved teenage awareness of cancer risk factors and cancer warning signs [3.5]. The trial also found that teenagers in intervention schools were almost three times more likely to discuss cancer with a parent at a two-week follow-up, compared with the control group [3.5]. This is important because talking about cancer is associated with detecting cancer earlier.

3. In 2015, the research team developed and evaluated a skin cancer education and awareness programme for TCT, [Shunburn](#). The quasi-experimental study showed favourable improvements in cognitions relating to sun-safety behaviour, skin cancer recognition, and communication of skin cancer related health concerns [3.6].

In response to this UK research, in 2016 the Australian equivalent of TCT, CanTeen, approached Hubbard to inform the development and piloting of a comprehensive education and cancer awareness programme in Australia, [When Cancer Comes Along](#). The Australian programme uses behaviour change theory and behaviour change techniques developed and tested in the UK by Hubbard's team. A pilot study found that around 90% of Australian teenagers reported that the programme gave them a better understanding of cancer risk factors and felt more comfortable about asking a doctor for help if faced with cancer [3.7]. The programme continues to be delivered by CanTeen and a larger national evaluation is underway.

3. References to the research

- 3.1. Hubbard G, MacMillan I, Canny A, Forbat L, Neal RD, O'Carroll RE, Haw S and Kyle RG, Cancer symptom awareness and barriers to medical help-seeking in Scottish adolescents: a cross-sectional study *BMC Public Health* 2014, 14:1117
 - 3.2. Kyle, RG, Nicoll, A, Forbat, L, Hubbard, G (2013), Adolescents' awareness of cancer risk factors and associations with health-related behaviours, *Health Education Research*. doi: 10.1093/her/cyt055
 - 3.3. Kyle RG, MacMillan I, Forbat L, Neal RD, O'Carroll RE, Haw S, Hubbard G, Scottish adolescents' sun-related behaviours, tanning attitudes and associations with skin cancer awareness: a cross-sectional study. *BMJ Open* 2014;4:e005137. doi:10.1136/bmjopen-2014-005137
 - 3.4. Kyle, RG, Forbat, L, Rauchhaus P, Hubbard, G, (2013), Increased cancer awareness among British adolescents after a school-based educational intervention: a controlled before-and-after study with 6-month follow-up, *BMC Public Health*, 13, 190
 - 3.5. Hubbard G, Stoddart I, Forbat L, Neal RD, O'Carroll RE, Haw S, Kyle RG, School-based brief psychoeducational intervention to raise adolescent cancer awareness and address barriers to medical help-seeking about cancer: a cluster randomised controlled trial, *Psycho-oncology* 2016, 25,7, 7600-771 <https://doi.org/10.1002/pon.v25.7>
 - 3.6. Dombrowski SU, Quigley J, Skinner R, O'Carroll R, Stoddard I, Kyle RG, Hubbard G, (2016). Acceptability and feasibility of a brief school-based psychoeducational intervention to promote sun-safe behaviours and skin cancer awareness in Scottish adolescents. Report to Teenage Cancer Trust.
 - 3.7. Wright, A, Patterson, P, McDonald, F & Hubbard, G 2019, 'Development and piloting of 'When Cancer Comes Along': A cancer awareness program for Australian secondary school students', *Health Promotion Journal of Australia*, pp. 1-7. <https://doi.org/10.1002/hpja.314>
- Note:** the underpinning research and subsequent outputs were carried out by the following team of researchers at the University of Stirling: Hubbard (now at UHI) was the Principal Investigator and Kyle was the Research Fellow; Skinner, Quigley, Canny, Nicoll were PhD students and Research Assistants; Forbat, O'Carroll, and Dombrowski provided advice about behavioural theory and behaviour change techniques; and, Haw provided advice about evaluating interventions. Other contributors included Neal at the University of Bangor (now at University of Leeds) who provided advice on early cancer detection; and Stoddart (née Macmillan) represented TCT.

4. Details of the impact

The formative evaluation research by the team led to changes in TCT's education and cancer awareness programme in 2013. An email from Iona Stoddart (née Macmillan) who was the Scotland lead for Teenage Cancer Trust's education and cancer awareness programme states: "Following the first evaluation of Teenage Cancer Trust's cancer awareness and education programme by your research team in 2012 and based on your recommendations, we changed the programme by placing more emphasis on increasing adolescents' communicative self-efficacy by including role-play and we addressed barriers to seeking help from a doctor by including a short film. The revised programme was then successfully evaluated by your team and the results were then published" [5.1]

Since 2013 (and all within the eligible REF period August 2013 - 2020), using the education and cancer awareness programme (*What is cancer?*) that was revised based on Hubbard's research, a large number of teenagers have been educated about warning signs of cancer and cancer risk factors, with positive outcomes for their wellbeing. In addition, new national policy in Scotland and England has ensured enhanced take-up of these education and cancer awareness programmes in legislation for national curricula.

4.1 More than 300,000 teenagers have benefitted; 25% of UK secondary schools reached

TCT has delivered *What is cancer?* in schools each academic year. In 2015/16 for instance, TCT reported that 76,743 students had received the education and cancer awareness programme [5.2, p4]. According to an official TCT report published in July 2016, over 300,000 teenagers have benefitted from the programme [5.3, p2]. In July 2018, TCT announced that they had reached 25% of UK secondary schools with the programme [5.4, p4]. Benefits to students include increases in knowledge about warning signs of cancer and cancer risk factors. For example, awareness of unexplained weight loss as a potential sign of cancer rose by 36%, changes to a mole as a potential sign rose by 30%, getting sunburnt as a risk rose by 26%, and being overweight as a cancer risk also rose by 26% [5.3, p4]. In addition, 100% teachers said that the education and cancer awareness programme increased students' awareness of cancer [5.2, p5].

4.2 Cancer is detected earlier with potentially life-saving implications

Testimonials from pupils and teachers [5.3; 5.5] suggest that TCT's education and cancer awareness programme has helped young people detect cancer earlier with potentially life-saving implications. A TCT report published in 2016 cited a teacher who said: "A boy who has been worried about a testicular lump for the last two years has decided to tell his mum because he listened to your talk and decided to act on your advice" [5.3, p7]. A young female who had been diagnosed with ovarian cancer said: "I had been back and forth to the doctors who kept saying it was nothing to worry about. I remembered the cancer lesson we'd had about being persistent if things didn't feel right and so I kept going back and I was eventually referred and diagnosed. If I hadn't had the lesson I think I would have just left things until they got a lot worse. After my operation I was told if I'd been diagnosed any later I might have died." [5.5]

4.3 Government take up and roll out education and cancer awareness programmes

The partnership between the research team and TCT led to both the Scottish and Westminster Government Cancer Strategies endorsing TCT's education and cancer awareness programmes. Scotland's *Beating Cancer: Ambition and Action* strategy, published in March 2016, demonstrates a commitment to roll out TCT's education and cancer awareness programmes in Scotland [5.6: page 5 and 18]. The strategy states: "Through our Detect Cancer Early programme we will continue to work in partnership with Teenage Cancer Trust to roll out their schools based education and awareness programmes. This will help ensure young people across Scotland have access to cancer prevention and early detection messages. We will highlight in particular the links between unsafe tanning and cancer to help protect those who are most vulnerable - the young and impressionable" [5.6, p18].

This strategy was a culmination of an announcement in summer 2013 by the Scottish Government to allocate £70,000 towards TCT's education and cancer awareness programme,

two parliamentary motions passed in 2013 in support of Teenage Cancer Trust's education and cancer awareness programme, a parliamentary question in 2014 by a Member of the Scottish Parliament who referred to the research team's published research about sun safety, and the Health Minister's response endorsing education and cancer awareness programmes in schools [5.7].

According to a letter written by the Chief Executive of TCT, the research played a critical part in being able to influence both England and Scotland government policy. On 21 March 2016, the CEO wrote: "As a result of the study, we have been able to present our findings to policy makers and have been successful in gaining their support. In 2015 Teenage Cancer Trust's education and awareness programme was endorsed by being included in *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020* and more recently in March 2016 we were included in Scotland's *Beating Cancer: Ambition and Action* strategy ... Without the evidence, we wouldn't have been able to illustrate the impact of our education and awareness programme and promote it so widely" [5.8].

The impact on policy in England that the Chief Executive refers to in the letter is *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020* [5.9, p15]. The strategy refers to the research being undertaken and recommends that Public Health England consider all evidence for national roll out of education and cancer awareness programmes: "Subject to evaluation of pilots being undertaken by Teenage Cancer Trust and others, NHS England and Public Health England should consider the evidence base for rolling out a cancer education programme to all secondary schools to raise awareness of healthy lifestyles and cancer symptoms" [5.9, p15].

4.4 Cancer education forms part of the National Curriculum in England from 2020

A major achievement for TCT and the research team is that cancer awareness and education is now part of the national curriculum. In 2019, the Department of Health made health education compulsory in all state-funded secondary schools and published statutory guidance [5.10, p37]. This guidance makes education and cancer awareness – including sun safety – an integral part of the National Curriculum in England from 2020. In preparation for this change, the Personal, Social, Health and Economics (PSHE) Association relaunched the TCT's education and cancer awareness programme for England and awarded it the PSHE quality mark in 2019 [5.11]. In Scotland, since 2019 the Association has recommended TCT's education and cancer awareness programme within the Health and Wellbeing strand of the Scottish curriculum, available for download from its website [5.12]. These education and cancer awareness programme materials are also available from TCT's own website. TCT reported that there had been 642 unique downloads of *What is cancer?* from 7 November to 2 December 2019 and also reported that, from November 2018 to November 2019, there had been 3,853 unique downloads of *Shunburn* [5.13].

4.5 International impact

In response to the published UK research [3.1-3.5], CanTeen in Australia approached Hubbard to advise the development and evaluation of a cancer education and awareness programme in Australia, *When Cancer Comes Along*. Australia has the higher cancer rate (including non-melanoma skin cancer) in the world. The Australian programme is modelled on the UHI/TCT research and uses behaviour change theory and behaviour change techniques that were developed and tested in the UK. In an October 2018 letter to Hubbard, CanTeen's General Manager of Research and Youth Cancer Services wrote: "Based on your research and partnership with Teenage Cancer Trust, we developed *When Cancer Comes Along*, CanTeen's high school cancer awareness program. We successfully piloted the program in four schools, and are now running a full scale evaluation across Australia. To date, as part of the piloting and evaluation, we have delivered the cancer awareness program in ten high schools to at least 250

students. Based on these figures, we estimate that in over a decade we will reach 3,000-5,000 adolescents' [5.14].

5. Sources to corroborate the impact

5.1. Email from Iona Stoddart (nee Macmillan) formerly Scotland lead for Teenager Cancer Trust's education and cancer awareness programme 4th February 2020

5.2. Teenage Cancer Trust. Making a difference for young people with cancer: Achievements Report 2015-16

<https://www.teenagecancertrust.org/sites/default/files/teenage%20cancer%20trust%202016%20achievements%20report.pdf>

5.3. Teenage Cancer Trust, Transforming Cancer Knowledge in the Classroom and Beyond, July 2016 https://issuu.com/teenagecancertrust/docs/a4_transforming_cancer_knowledge_do

5.4. Teenage Cancer Trust responds to UK government health education plans, July 2018

<https://www.teenagecancertrust.org/about-us/news/teenage-cancer-trust-responds-uk-government-health-education-plans>

5.5. BBC news report, 18 June 2013

<https://www.bbc.co.uk/news/uk-scotland-scotland-politics-22944400>

5.6. Scottish Government. Beating Cancer: Ambition and Action, 2016

<https://www2.gov.scot/Resource/0049/00496709.pdf>

5.7. Scottish Parliamentary motions and questions

<https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S4M-07055&ResultsPerPage=10>

<https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S4M-07630&ResultsPerPage=10>

<https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S4W-23186&ResultsPerPage=10>

5.8. Letter from Teenage Cancer Trust's Chief Executive March 2016.

5.9. Independent Cancer Taskforce, Achieving world class cancer outcomes: A strategy for England 2015-2020. July 2015.

https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

5.10. Department for Education. Relationships Education, Relationships and Sex Education (RSE) and Health Education. 2019.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/805781/Relationships_Education_Relationships_and_Sex_Education_RSE_and_Health_Education.pdf

5.11. Association for Personal, Social, Health and Economics (PSHE) resources

<https://www.pshe-association.org.uk/curriculum-and-resources/resources/what-cancer-lesson-plans-teenage-cancer-trust>

5.12. PSHE Health and Wellbeing education in Scotland

<https://www.pshe-association.org.uk/curriculum-and-resources/resources/health-and-wellbeing-education-scotland>

5.13. Teenage Cancer Trust google analytic data for 'What is Cancer?' and for 'Shunburn.'

5.14. Letter to Gill Hubbard from CanTeen