

Institution: University of Cambridge		
Unit of Assessment: Mathematical Sciences		
Title of case study: Improving medical risk communication for cancer patients, clinicians and the general public during the covid-19 pandemic		
Period when the underpinning research was undertaken: Jan 2014 – Dec 2020		
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:
David Spiegelhalter	Chairman, Winton Centre for Risk & Evidence	October 2007-December 2018 (Emeritus since 2018)
Alexandra Freeman	Communication Executive	August 2016-date
Gabriel Recchia	Director, Winton Centre	July 2018-date
George Farmer	Research Associate	January 2017– April 2018
Period when the claimed impact occurred: 2017-2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact (indicative maximum 100 words) <p>The Winton Centre researches ways to communicate quantitative evidence transparently and without bias. The aim is to make potential risks and benefits clear through communication, tools and training, to increase decision-making confidence. This has led to greater understanding and supporting decision making by improving the ways that medical data is presented and communicated to patients, the general public and health professionals.</p> <p>I1) Communication of possible outcomes of cancer treatment options in NHS Predict websites. Used around 35,000 times per month worldwide by clinicians in consultation with people diagnosed with early-stage breast and prostate cancers to inform their choice of therapy.</p> <p>I2) Communicating COVID-19 evidence, statistics and risks to the public, patients and policymakers.</p> <p>I3) eLearning courses in Risk Communication for healthcare professionals and students. Assessed and endorsed by Royal Colleges and with over 4,500 module completions.</p>		
2. Underpinning research (indicative maximum 500 words) <p>To make informed decisions about treatments or policies, the public, patients, clinicians and policymakers need clear information about potential harms and benefits of different options, and to know the quality of the evidence underlying this information. The Winton Centre at the University of Cambridge researches methods of communicating quantitative evidence to inform these decisions. The work combines qualitative interviews & quantitative studies, measuring objective comprehension, decision satisfaction, risk perception, trust, and weighting of information in decision-making.</p> <p>Research underpinning NHS Predict (Figure 1). Predict is an algorithm that calculates the likely benefits from different cancer treatment options (developed by Professor Paul Pharoah at the University of Cambridge, 2010). The original website was designed for clinicians and the results were presented in a 'stacked bar chart' format. However, the 2015 Montgomery legal ruling demands that <i>patients</i> are given information that allows them to understand the personal outcomes of treatment options well enough to be involved in their own healthcare decisions.</p>		

Hence, the Winton Centre carried out qualitative work with both clinicians and past patients, and quantitative work with members of the public, to test their information needs and comprehension of different representations of the statistics (R1). Specific difficulties were discovered with the comprehension of the original format, and further studies carried out to improve it (R2). New ways to represent the data were developed, aiming to give patients and clinicians a well-rounded view of the statistics. The research was also applied to a new Predict:Prostate site and the visualisation software released Open Source.

Research into communicating COVID-19 risks, statistics and evidence

Communicating quantitative evidence

around COVID-19 has been a focus since March 2020. Spiegelhalter was part of the team that developed the QCovid risk stratification model (R3) which calculates a personalised score for people based on their risk factors for COVID-19, especially the importance of age, to inform political decision-making (R4).

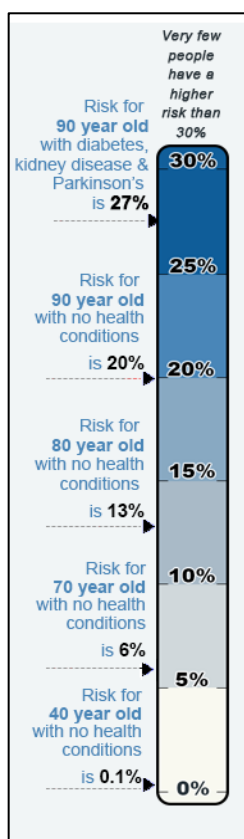


Figure 2: Winton's COVID-19 risk

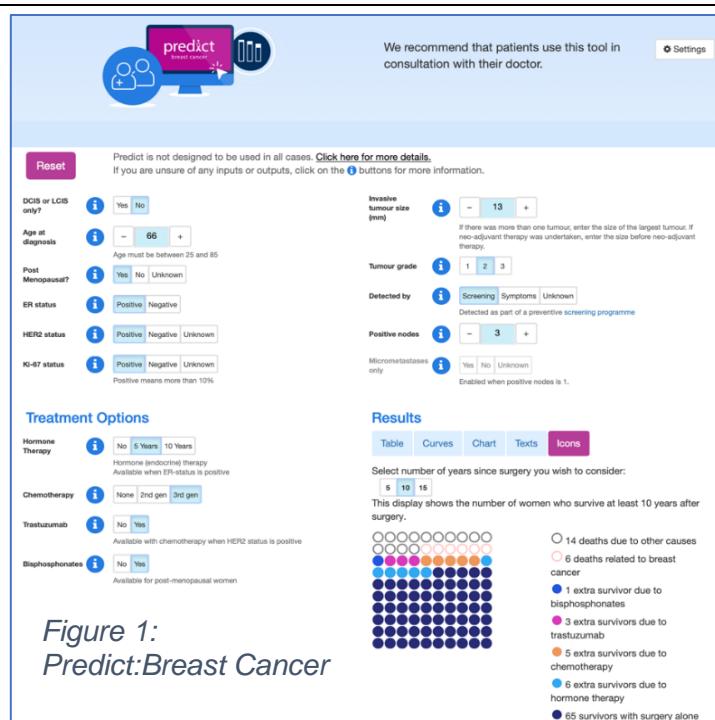


Figure 1: Predict:Breast Cancer

The Centre undertook rapid, mixed methods research to produce guidelines on communicating a personalised score to the public (R5). The findings showed that when communicating risk numbers, percentages appear to be the clearest format (having the smallest variance in responses). They also make the risk seem lowest, with chances expressed as 'x out of 100', 'x out of 1000' or '1 in x' conveying increasingly higher likelihoods. People shown 'the number likely to survive' rather than 'the number likely to die' perceived a lower and less worrying risk, but with some compromise in comprehension. A visual, linear 'risk ladder' (Figure 2) with a well-chosen and well-explained maximum point helped give context to absolute risks. Participants found that the most useful comparators were the absolute risks faced by individuals of defined ages and risk factors, from very low to very high-risk individuals i.e. putting numbers against a series of 'personas' that are their natural mental models. Giving context in the form of non-COVID risks appeared less helpful, as was choosing personas that weren't easily imagined (e.g., 'an average person of this age').

Research underpinning the eLearning courses in Risk Communication

The eLearning courses for healthcare professionals were developed from the Centre's body of work. Explicitly the research into communicating uncertainty (showing that using a numerical range did not undermine people's trust in the numbers or the communicator (R6)) and the research on communicating medical information in fact boxes (R7)

(demonstrating that laying harms and benefits out in a tabular form enhanced people's understanding and memory of the information regardless of their numeracy levels).

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

- R1.** G.D. Farmer, G.M. Pearson, W.J. Skylark, A.L.J. Freeman and D.J. Spiegelhalter. Making prognostic algorithms useful in shared decision-making: Patients and clinicians' requirements for the Predict:Breast Cancer interface, *medRxiv*, 2020, DOI: 10.1101/2020.11.16.20232348.
- R2.** Recchia, G. L.; Bles, A. M. V. and Freeman, A. L. (2020). PREDICT: the potential pitfalls of visualisations of risk. *Breast Cancer Research and Treatment* 180 (2): 577-578. DOI: 10.1007/s10549-019-05514-3.
- R3.** Clift, A.K.; Coupland, C.A.; Keogh, R.H.; Diaz-Ordaz, K.; Williamson, E.; Harrison, E.M.; Hayward, A.; Hemingway, H.; Horby, P.; Mehta, N.; Benger, J.; Khunti, K.; Spiegelhalter, D.; Sheikh, A.; Valabhji, J.; Lyons, R.A.; Robson, J.; Semple, M.G.; Kee, F.; Johnson, P.; Jebb, S.; Williams, T.; Hippisley-Cox, J. Living risk prediction algorithm (QCOVID) for risk of hospital admission and mortality from coronavirus 19 in adults: national derivation and validation cohort study. *BMJ*. 2020, 371, m3731. DOI: 10.1136/bmj.m3731.
- R4.** Spiegelhalter, D. Use of "normal" risk to improve understanding of dangers of covid-19. *BMJ*. 2020, 370, m3259. DOI: 10.1136/bmj.m3259.
- R5.** A.L.J. Freeman, J. Kerr, G. Recchia, C.R. Schneider, A.C.E. Lawrence, L. Finikarides, G. Luoni, S. Dryhurst and D.J. Spiegelhalter. Communicating personalised risks from COVID-19: guidelines from an empirical study, *medRxiv*, 2020, DOI: 10.1101/2020.10.05.20206961.
- R6.** Van Der Bles, A.M.; van der Linden, S.; Freeman, A. L. and Spiegelhalter, D. J. (2020). The effects of communicating uncertainty on public trust in facts and numbers. *Proceedings of the National Academy of Sciences*, 117(14), 7672-76. DOI: 10.1073/pnas.1913678117.
- R7.** Brick, C.; McDowell, M. and Freeman, A.L. (2020). Risk communication in tables versus text: a registered report randomized trial on 'fact boxes'. *Royal Society Open Science*, 7(3), 190876. DOI: 10.1098/rsos.190876.

Outputs published in peer-reviewed journals.

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

This research described in section 2 has provided a greater understanding in decision making by improving the ways of presenting and communicating medical risk to patients, the general public and health professionals.

11) Improving patients' access to and understanding of medical data via NHS Predict

Before the interface redesign, Predict:Breast Cancer (launched in 2010) usage was around 20,000 times per month. The desire from patients for information that would allow them to be involved in their treatment options was evident from the Centre's qualitative interviews and in posts to patient forums such as Breast Cancer Now (forum.breastcancernow.org):

"If I were being offered alternatives, I would want to take ownership of that".

"I would want to know information to have a better conversation the next time I see my doctor".

The new interface, incorporating the research findings, was launched in 2018 and allowed the site to be used directly with patients in clinic. Usage rose to over 30,000 times per month worldwide (**E1**) and won national awards, including the 2018 Office for National Statistics Research Excellence People's Choice Award and the 2019 National Cancer Research Institute Research Excellence Impact Award. Monthly Google Analytics 'sessions' in October 2019 show worldwide use (Figure 3): UK 7,900; US 4,400; Australia; the Netherlands, Japan 2,000-2,500 each; Canada, Brazil, 1000-1800 each. As a freely available tool, the uptake in low- and middle-income countries has been high. A 2019 online survey of 100 breast cancer oncologists in India found that 58% reported using Predict online (**E2**). Some feedback from users on the impact of Predict:Breast Cancer is given (**E3**) e.g.

"Well done to the Predict team for developing this crucial tool which has a daily impact in patients' lives." Consultant Oncologist, Charing Cross and Chelsea & Westminster Hospitals.

"Thank you, you have made my decision easier" Anonymous patient feedback.

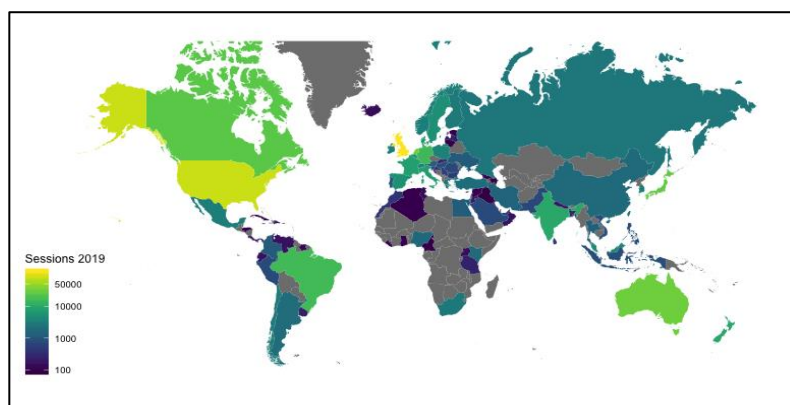


Figure 3: Predict: Breast Cancer website usage worldwide (by Google)

In 2019, the same research was applied to produce the brother site Predict:Prostate, with a constant usage between 300-500 sessions by users with cookies enabled during 2020. Actual usage likely at least 3 times higher: December 2020 data capturing all users showed around 1700 sessions, with fewer than a third having cookies enabled (E4). A multi-centre, in-clinic randomised, controlled evaluation of Predict:Prostate during 2019-2020 demonstrated 26% lower decisional conflict scores in consultations randomised to use Predict compared to standard care. The Predict patients also gave better ratings for 'effective decision', 'uncertainty' and 'value clarity'. 90% of patients said they found Predict helpful, and 94% would recommend it to others (E4). Both versions of Predict were approved in March 2020 as medical devices under EU Directive 93/42/EEC (E5).

I2) Communication of evidence and quality of evidence around COVID-19 to the public and policy-makers

Throughout the first wave of the pandemic, Spiegelhalter gave weekly briefings to the press via the Science Media Centre (SMC) about the COVID-19 statistics and how they should be interpreted, to improve the public understanding of the evidence. These were attended by journalists from 23 national and international media outlets, resulting in more accurate coverage of the statistics in around 130 articles, reaching millions of people. He also responded to 38 queries from journalists via the SMC (E6) and many more directly. Spiegelhalter's inbox is consistently full of queries and comments from the public on how much his contribution has helped them make personal choices based on the evidence (E7).

"Thanks for your great article on communicating evidence, rather than trying to persuade people. Probably one of the best of the (many) I read in my life – congratulations!"

"Thank you so much for the only thoroughly clear analysis you provided on BBC Television this morning. A 94-year old in isolation I had been seeking, without success, some specific guidance from Government as it applies to people in the same circumstances as myself."

As stated by the Chief Executive of the Science Media Centre *"Professor David Spiegelhalter has made a dramatic difference to the media coverage of Covid-19. [...] His sole motive is to improve the quality of the debate which he achieves on a daily basis."* (E6)

Professor Spiegelhalter was awarded the 2020 Royal Society Michael Faraday Prize and Lecture *"For bringing key insights from the disciplines of statistics and probability vividly home to the public at large, and to key decision-makers, in entertaining and accessible ways, most recently through the COVID-19 pandemic."* (E8).

The Centre's work on the risk stratification and personalised risk communication programmes was used as the basis for the NHS's clinical COVID-19 risk communication tool, rolled out across all UK GP surgeries in December 2020, with a public release planned in January 2021.

Statements from the Interim Chief Medical Officer, NHS Digital (E9) [text removed for publication] confirm the impact of this research:

“The supporting research that has been completed by the Winton Centre.....has been immensely valuable in shaping and guiding our work as we move towards national implementation of a new tool for the clinical stratification of COVID-19 risk.” (E9)

[text removed for publication]

[text removed for publication].

I3) Improving the communication of medical evidence and risks by healthcare professionals to patients

The Winton Centre's work has been included in six eLearning courses on Risk Communication for health professionals and medical students - produced in collaboration with Bond University and the Academy of Medical Royal Colleges in the UK (Figure 4). The courses were endorsed by the Royal College of GPs and the Royal Colleges of Surgeons in England and Edinburgh. From 2018 to 2020, the two host platforms have recorded over 4,500 elearning module completions. An evaluation study showed that the 366 participants who completed one of the courses (and consented for their data to be analysed), displayed highly significant improvements in confidence in their skills and in the proportion of correct answers for most knowledge questions (E11). The courses are freely available on the NHS's eLearning for Healthcare platform (3,500 of the 4,500 module completions were *via* this). Hence, the Centre's training has enabled many NHS staff to increase their knowledge and confidence in evidence and risk communication.

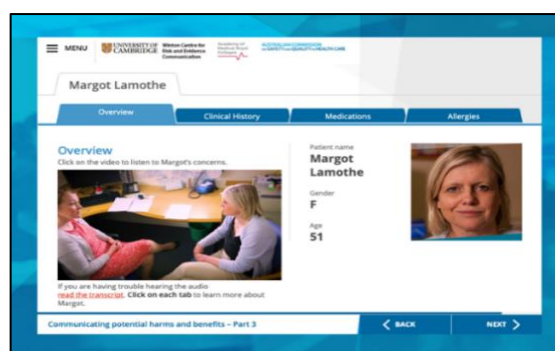


Figure 4: Page from the eLearning course

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

E1. Google analytics

E2. Batra A, Patel A, Gupta VG, et al. Oncotype DX: Where Does It Stand in India? *J Glob Oncol*. 2019;5:1-2. <https://doi.org/10.1200/jgo.19.00151>

E3. Testimonials from (anonymous) patients and clinicians as to the benefits of the Winton Centre's work on Predict:Breast Cancer.

E4. Thurtle, D, Jenkins, V, Freeman, A, Pearson, GM, Recchia, G, Tamer, P, Leonard, K, Pharoah, P, Gnanapragasam V. Clinical impact of the Predict *Prostate* tool in men newly diagnosed with non-metastatic prostate cancer: a randomised controlled trial. *medRxiv*, 2020, DOI: 10.1101/2021.01.24.21249948. Usage data.

E5. Medical Device certificates for Predict:Breast Cancer and Predict:Prostate

E6. Letter and data from the Science Media Centre

E7. Example emails from the public to Professor David Spiegelhalter

E8. Royal Society Michael Faraday Prize Lecture

E9. Testimonial from CMO of NHS Digital

E10. [text removed for publication]

E11. Hoffmann, T. C.; Del Mar, C.; Santhirapala, R. and Freeman, A. (2020). Teaching clinicians shared decision making and risk communication online: an evaluation study. *BMJ evidence-based medicine*. DOI: 10.1136/bmjebm-2020-111521. Modules completed.