

Edinburgh Napier University Research Funding Competition 2019/20 CASE FOR SUPPORT

NAME OF RESEARCHERS: PI: Dr Gemma Webster; researcher: Dr Bruce Ryan	
1.	Title of proposal: Information Avoidance and diabetes – a preliminary empirical study
2.	<p>Description of proposed research</p> <p>The aim of this work is to conduct an empirical study on Information Avoidance in healthcare, with a specific focus on diabetes, then publish the findings in a highly-rated Information Science journal. Information Avoidance is ‘any behaviour intended to prevent or delay the acquisition of available but potentially unwanted information’ (Sweeny, Melnyk, Miller, & Shepperd, 2010). Decreasing the impact of diabetes is important: around 6% of the UK population suffer from this condition (International Diabetes Foundation, 2017), while the cost of treating UK diabetics may reach £39.8 billion by 2035 (Hex, Bartlett, Wright, Taylor, & Varley, 2012). Hence the project’s immediate aims are to</p> <ol style="list-style-type: none"> 1. deliver a literature review on Information Avoidance by those who suffer chronic self-managed medical conditions, with a focus on diabetes 2. undertake an empirical study of Information Avoidance by diabetics in Scotland and Finland, focusing on research questions and themes raised by the literature review 3. hence deliver a high-quality paper in the under-researched (Golman, Hagmann, & Loewenstein, 2017) area of Information Avoidance 4. deliver a seminar on the findings to stakeholders such as the Edinburgh Centre for Endocrinology and Diabetes (ECED). <p>In addition, it will (1) <i>initiate a stream of research into Information Avoidance in healthcare</i>, in collaboration with healthcare professionals, particularly in chronic conditions where patients are responsible for their own day-to-day care; (2) <i>enhance research collaboration with Åbo Akademi University</i>, Finland. Collaboration with Finnish researchers and healthcare professionals is very desirable because there are proportionately more diabetics in Finland.</p> <p>Information research often focuses on active information seeking and use because it is assumed that information always aids decision-making. It is important to also look at avoidance as a part of information behaviour, to raise the awareness of such strategies as part of our understanding of information behaviour. Hence the <i>theoretical contribution</i> will be to bring passive/hidden/avoidance behaviour into research that most often focuses on active information-seeking (Sairanen & Savolainen, 2010). <i>Practical contributions</i> will include understanding causes of such Information Avoidance, and hence options for reducing its impact. At this stage it is assumed that diabetic Information Avoidance will provide a model of Information Avoidance in chronic self-managed diseases, and suggest further directions for research. The project is supported by Professor Strachan of ECED and support is anticipated from Diabetes UK and the Finnish Diabetes Association (FDA).</p>
3.	<p>Background of applicant and suitability to do the research</p> <p>Dr Gemma Webster will be PI. She conducts multidisciplinary research at Edinburgh Napier University within the Centre for Social Informatics. Her research interests and expertise include information behaviour and use in healthcare, and hence is ideal to lead this project.</p> <p>Dr Bruce Ryan will be the research assistant on this project. He well-placed to conduct the research as an information science researcher who has Type 1 diabetes.</p> <p>Professor Gunilla Widén and Dr Kristina Eriksson-Backa will undertake research in Finland, having a working relationship with the Finnish Diabetes Association. Professor Widén researches <i>inter alia</i> information behaviour and information literacy. Dr Eriksson-Backa’s researches health information behaviour and literacy, e-health and health communication.</p>
4.	<p>Motivation for the research</p> <p>The central motivation is to help reduce the human and financial costs of diabetes. It is estimated that 3 million people in the UK currently live with diabetes (International Diabetes Foundation, 2017). Diabetes currently accounts for <i>ca</i> 10% of UK total health expenditure,</p>

	<p>and is projected to account for around 17% in 2035/2036 (Hex et al., 2012). These authors state that complications account for a substantial proportion of the costs. Around 9% of the Finnish population has diabetes (Finnish Diabetes Association, 2009). This proportion is increasing rapidly (Hakkarainen et al., 2017), as are costs (Finnish Diabetes Association, 2009). The project will collect data in the UK and Finland, to begin to understand cultural and contextual factors around Information Avoidance in self-managed healthcare. These may include diet, personality, attitudes to self-healthcare, climate and provision of care.</p> <p>Diabetes management requires regular blood-sugar monitoring and control, and healthy lifestyles (International Diabetes Foundation, n.d.), while oral medication or insulin injections may also be needed. Blood-sugar monitoring and insulin injections are almost always done by the patients. Complications from poor management of diabetes can include heart disease, nerve damage, amputation, and blindness (International Diabetes Foundation, n.d.). Technology is being used to address the growing challenge of supporting self-management, through NHS projects such as My Diabetes My Way. Such technology has been shown to facilitate improved learning and education (Cunningham et al., 2019).</p> <p>However, despite the potentially severe effects of diabetes, major investments into facilitating self-management and limited research into Information Avoidance in health in general, e.g. (Ek & Heinström, 2011; Howell & Shepperd, 2013a) and in diabetes, e.g. (Howell & Shepperd, 2013b), it is not known why some people do not take advantage of the information provided. Not enough is known about the prevalence of this behaviour, or what can be done to help people become more involved in managing their conditions.</p> <p>Further motivations are</p> <ul style="list-style-type: none"> • to develop a new stream of information science research in the university, based in the Centre for Social Informatics (CSI) within the University’s School of Computing. This centre has international renown in Library and Information Science. Locating this new research stream within CSI will enable facile exchange of information science expertise. • to further the relationship between the University and Åbo Akademi University • to prepare the ground for a large international project in collaboration with Widén, Eriksson-Backa and colleagues at Åbo Akademi. The anticipated funding call is the ESRC ‘standard’ scheme. Grants from this call can allocate up to 30% of awarded funds to overseas research assistants, direct costs etc. <p>These motivations speak to Edinburgh Napier University’s values (being <i>professional</i>, <i>ambitious</i> and <i>innovative</i>) by applying underused theory to a major issue. They speak to the objectives <i>to grow our academic reputation; to build innovation, enterprise and citizenship; to internationalise our work</i> via a high-quality paper, engagement with diabetics and healthcare professionals, and collaboration with renowned international researchers.</p> <p>The project also clearly delivers in the Information Society and Wellbeing research themes, by focusing on the role of information in healthcare. The project has an interdisciplinary aspect by calling on team-members’ strengths in understanding ITC and its social aspects, information behaviour, information science, and on board-members’ healthcare strengths. The project also addresses the School of Computing Plan objective 1¹ for 2019/20.</p>
5.	<p>Objectives and methodology</p> <p>The project’s objectives are</p> <ul style="list-style-type: none"> • <i>Establish a project board</i> of senior colleagues for internal peer review of draft publications and external stakeholders (Proposed members: Professors H Kall and L Muir (Napier); Professors M Strachan and J McKnight of ECED, a Diabetes UK representative • <i>Review relevant literature</i>, primarily focusing on Information Avoidance by diabetics, with

¹ Objective 1: “Our new Research Groups will lead to more 4* papers, and an increased number of research funding applications [aligned to planning priority 9], building on a good miniREF.”

	<p>a secondary focus on Information Avoidance by sufferers of other chronic diseases</p> <ul style="list-style-type: none"> • <i>Establish research questions.</i> Currently it is anticipated that these will cover reasons for Information Avoidance, its effects on individuals, and potential ways to reduce its effects. Data will also be gathered on cultural and contextual factors as described above. • <i>Gather data</i> <ul style="list-style-type: none"> ○ Develop semi-structured interviews with information-avoiding diabetics. It is anticipated that, like Ryan, a significant number of diabetics attend health-checks but do little to understand and hence properly manage their conditions between checks. Hence, with due ethical approval, participants will be recruited and interviewed at diabetes clinics. Professor Strachan has already agreed this for Edinburgh clinics. ○ Triangulation via semi-structured interviews with specialist healthcare professionals. Such data-gathering will also be undertaken by Widén and Eriksson-Backa in Finland. • <i>Analyse and evaluate data</i> using qualitative coding and relevant software (e.g. NVivo) • <i>Draft an academic paper</i> for e.g. <i>Journal of the Association for Information Science and Technology</i> or <i>Journal of Documentation</i> (two of the top Information Science journals) • <i>Deliver a seminar</i> on the findings and implications to relevant healthcare professionals. It is anticipated that this will be video-recorded, to enable further dissemination. • <i>Deliver a report and poster</i> at the Edinburgh Napier University research conference <p>Throughout, research blog posts will be used to maximise impact, and amplified via Twitter.</p> <p>Post project activity (using Webster's research time allocation)</p> <ul style="list-style-type: none"> • <i>Revise academic paper</i> for final publication • <i>Publish stakeholder report</i>, and an article for Diabetes UK and FDA magazines etc. • Upload anonymised data (interview transcripts) to relevant research data repositories. • <i>Submit a large collaborative proposal</i> for e.g. MRC research grant, UKRI Future Leaders 																												
6.	<p>Timeline and outcomes of project</p> <p>Prior experience of healthcare-related projects suggests that participant-recruitment will take some time. Hence it is anticipated that the project will formally start in January 2020.</p> <table border="1" data-bbox="298 1129 1391 1877"> <thead> <tr> <th>Month</th> <th>Milestones</th> <th>Deliverables</th> <th>Ryan's days</th> </tr> </thead> <tbody> <tr> <td><i>Pre-project</i></td> <td> <ul style="list-style-type: none"> • Set up project board • Start participant-recruitment • Seek ethical approval • Write data-management plan </td> <td> <ul style="list-style-type: none"> • Project plans review • Stakeholder commitment • Ethical approval gained • Data management plan </td> <td>2</td> </tr> <tr> <td><i>Jan-Feb</i></td> <td> <ul style="list-style-type: none"> • Complete literature review • Define research questions </td> <td> <ul style="list-style-type: none"> • Literature review completed • Research questions defined </td> <td>10</td> </tr> <tr> <td><i>Mar to Apr</i></td> <td> <ul style="list-style-type: none"> • Develop, pilot and complete interviews with diabetics and healthcare professionals </td> <td> <ul style="list-style-type: none"> • Interview schedule prepared • Interview data is gathered </td> <td>10</td> </tr> <tr> <td><i>May</i></td> <td> <ul style="list-style-type: none"> • Evaluate and analyse data </td> <td> <ul style="list-style-type: none"> • Findings are ready for paper </td> <td>5</td> </tr> <tr> <td><i>June</i></td> <td> <ul style="list-style-type: none"> • Draft academic paper • Deliver seminar • Deliver conference report etc </td> <td> <ul style="list-style-type: none"> • Academic paper is ready for internal peer review • Dissemination is commenced </td> <td>4</td> </tr> <tr> <td><i>Post-project</i></td> <td> <ul style="list-style-type: none"> • Publish academic paper • Publish stakeholder report • Publish magazine article • Apply for funding for large follow-on project </td> <td> <ul style="list-style-type: none"> • Academic paper published • Stakeholder report published • Article published via diabetes associations • Preparations for further work. </td> <td>NA</td> </tr> </tbody> </table>	Month	Milestones	Deliverables	Ryan's days	<i>Pre-project</i>	<ul style="list-style-type: none"> • Set up project board • Start participant-recruitment • Seek ethical approval • Write data-management plan 	<ul style="list-style-type: none"> • Project plans review • Stakeholder commitment • Ethical approval gained • Data management plan 	2	<i>Jan-Feb</i>	<ul style="list-style-type: none"> • Complete literature review • Define research questions 	<ul style="list-style-type: none"> • Literature review completed • Research questions defined 	10	<i>Mar to Apr</i>	<ul style="list-style-type: none"> • Develop, pilot and complete interviews with diabetics and healthcare professionals 	<ul style="list-style-type: none"> • Interview schedule prepared • Interview data is gathered 	10	<i>May</i>	<ul style="list-style-type: none"> • Evaluate and analyse data 	<ul style="list-style-type: none"> • Findings are ready for paper 	5	<i>June</i>	<ul style="list-style-type: none"> • Draft academic paper • Deliver seminar • Deliver conference report etc 	<ul style="list-style-type: none"> • Academic paper is ready for internal peer review • Dissemination is commenced 	4	<i>Post-project</i>	<ul style="list-style-type: none"> • Publish academic paper • Publish stakeholder report • Publish magazine article • Apply for funding for large follow-on project 	<ul style="list-style-type: none"> • Academic paper published • Stakeholder report published • Article published via diabetes associations • Preparations for further work. 	NA
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7.	<p>Impact of project</p> <ul style="list-style-type: none"> • Healthcare: The project will contribute to understanding of Information Avoidance in 																												

	<p>chronic self-managed diseases, thus contributing to benefits around such conditions. It will specifically benefit diabetes patients and professionals by enabling reductions in the complications and costs of diabetes due to Information Avoidance. It may also aid healthcare decision-makers and service-developers. Because diabetes affects people all over the world, the project may have world-wide impact.</p> <ul style="list-style-type: none"> • Information Science/Health Informatics: The project will deliver findings and theory in Information Science, of direct relevance to health informatics researcher. • University: It will enhance Napier’s reputations in social informatics and healthcare. 										
8.	<p>Justification for resources</p> <p>The project will last from January 2019 to June 2020. There are no costs associated with colleague board-members, but external board-members may incur occasional travel costs. Professor Widén and Dr Eriksson-Backa have secured other funding for their work.</p> <table border="1"> <thead> <tr> <th>Payroll cost description</th> <th>Cost</th> </tr> </thead> <tbody> <tr> <td>RA (Dr Bruce Ryan): 31 days in total, working on: literature review, developing and running interviews; data-analysis; communications; writing.</td> <td>£6,860·21</td> </tr> <tr> <td>External board-member travel</td> <td>£50·00</td> </tr> <tr> <td>Refreshments for interview participants, and for seminar participants</td> <td>£50·00</td> </tr> <tr> <td>Total</td> <td>£6,960·21</td> </tr> </tbody> </table>	Payroll cost description	Cost	RA (Dr Bruce Ryan): 31 days in total, working on: literature review, developing and running interviews; data-analysis; communications; writing.	£6,860·21	External board-member travel	£50·00	Refreshments for interview participants, and for seminar participants	£50·00	Total	£6,960·21
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