

This file contains supplemental material for the following paper:
Wallace, L.M. , Brown, K. and Hilton, S. (2014) Planning for, implementing and assessing the impact of health promotion and behaviour change interventions: a way forward for health psychologists. Health Psychology Review, volume 8 (1): 8-33. <http://dx.doi.org/10.1080/17437199.2013.775629>

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CASE STUDY- ANNEXE

Case study in planning for impact: Mums and MS

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We describe next the application of the framework to a current intervention, a web hosted educational intervention for pregnant and new mothers who have Multiple Sclerosis (MS)

(<http://www.mumsandms.org.uk>). The programme was developed using intervention mapping (IM) (Bartholomew, 2006). It aimed to increase self efficacy to make decisions about healthcare options (such whether to have normal vaginal delivery or opt for a planned caesarean section in childbirth as a precaution against relapse of MS symptoms, or to opt to restart MS medications that would require breastfeeding to cease early, or not to breastfeed at all) (Kosmala-Anderson, Wallace, & Turner, 2012). The intervention is currently the subject of funding applications for an efficacy trial. While it is simpler to illustrate the framework with a fully completed intervention, we have selected this because it shows the way impact management can be built in from the outset.

- 1) The genesis of the intervention and identifying partner engagement in research and impact activities

The idea for the intervention was an example of researcher “push”. The research team became aware of the need for an intervention through discussion with pregnant women with MS and their clinicians. While they did not conceptualise the solution as an intervention, they provided evidence of need. The researchers responded to this by investigating available interventions and the evidence for need from research studies. The needs analysis is the first stage of intervention mapping IM. The outputs were evidence that there were no resources tailored specifically to this sub group of women with MS, and some studies showing the unmet needs of these women for evidence based information related either to decisions they would face or of self care interventions related to pregnancy and childbirth for these women. By establishing who the beneficiaries would be of the intervention we were able to engage women with MS, clinicians and funders to contribute to the impact management process. The next stage of intervention development followed the IM framework, whereby we established the

determinants of expected behavioural and environmental outcomes of the intervention which could be addressed by such an intervention, using an e-Delphi method (Iqbal & Pison-Young, 2009).

Importantly for our impact plan, we found we needed to include topics relevant to self management as well as decision-making and to include sections to be shared with partners, who were an impact audience we had not initially considered. The third IM stage involved selecting intervention methods and practical strategies, with the expert panel of beneficiaries (clinicians, users and funders) established in stage 1. The next stage of IM involved planning the assessment methods for process and outcomes evaluation, which again made use of the beneficiaries' views, as well as expertise in self management and decision-making assessment methods. In IM there is a stage of planning for implementation, which at the prototype phase was confined to designing a public access website, where we built in measures of impact as described below. Planning for wider adoption, implementation and sustainability was revisited once we had evaluated the prototype and made adjustments based on our process measures.

2) Who are the research and impact partners and what engagement in the research and impact activities should they have?

In this project, the partners were found to be very willing to participate in impact activities, for example by giving comments in the web forums in response to requests for feedback on usability and on ways to involve the target group in using the intervention. General Practitioners (GPs) involved in interviews about their patients' use of the website were also interested in the sustainability of the intervention for future users.

The partners were women with MS and their partners, the MS Society charity in the UK and clinicians from secondary care reproductive health and neurology services and from primary care. The potential other interested parties, if there were to be cost savings in healthcare use, would be health service managers and commissioners. As this was a researcher push and end user "interest" rather than push, the subsequent proposal and protocol was researcher-led, and designed to fit a funding call of primary research for the needs analysis, and the MS charity subsequently gave a research grant to

build and pilot test a prototype. We therefore had wide scope to choose the partners most likely to engage with the initial research and maintain an input into shaping the impact activities.

3) Identifying expertise in impact management

We identified in-house expertise in research dissemination beyond academic writing to include writing for public and practitioner audiences, and used our research centre's panel of lay members as a further resource to consult on the readability of outputs. We identified expertise in maximising the uptake, accessibility and measurement of these impacts for web interventions from Coventry University's Serious Games Institute.

4) Plan the key messages

We illustrate the refinement of impact messages with some examples of specific messages that arose from the evaluation of the prototype, (IM stage 6), and how we anticipate refining these in next stages of intervention development, evaluation and implementation.

At the current stage of research, having conducted a full cycle of IM to build and evaluate the prototype, we have made the following predictions of the messages for our impact plan: The impact messages for patients are likely to be the positive impact on self efficacy for informed decision making and reduced anxiety about childbirth. Underpinning these outcomes are messages that the intervention uses research and expert opinion to keep the content credible and legitimate. In addition to the messages for women with MS and their partners, we identified the particular messages relevant for clinicians. It is also important that the strength of evidence is highlighted if there is an area where little is yet known. A comment from a clinician from illustrates this:

The easily [accessible] information is clear and concise - the inclusion of references also allowed me to find out more information if I wanted to. – Women with MS. And please confirm that you will be keeping the scientific paper section under review and up to date. It would be fantastic to know that I can come to this site and be sure that I am getting the up to date information that I need.

The messages for clinicians and service managers engaged in the use of the intervention as an adjunct to their services derive benefits from supporting patients to make informed decisions. Clinicians anticipated the benefits could include having patients make fewer demands for consultations to seek advice they could access from the website. Service benefits could include fewer consultations with secondary care clinicians, lower interventional delivery rates and shorter length of in patient stay post partum.

The next stage of the intervention development was to repeat the IM cycle, and making changes to the intervention, planning the efficacy trial and processes for adaptation during the trial. We anticipate that, depending on the results of the trial, we will move towards implementation in routine use. The next stages of this work will enable us to refine the key messages in the impact plan as an integral part of this work. For example, we will inform the messages in the plan through the process evaluation to create the plan for adoption and sustainability (IM stage 5). This will involve conducting interviews with clinicians involved in the trial to ascertain the perceived ease of implementation for different circumstances of types of patient, as well as ease with referring patients to the site and engaging with patients who were using the site while in their care. A further example of how the initial prototype study has already informed the impact plan's messages to health service and research funders, are estimates of the cost of maintaining the intervention in use. However the pilot did not elaborate the costs to end users of using the intervention, nor did the pilot compare the costs of use compared to the equivalent costs of alternatives or no intervention. These questions are to be addressed in the evaluation plan of the efficacy trial, and will form an essential part of the plan for implementation into routine use.

6) Identifying the goals of impact management

The main goals of the impact management of the intervention are to *raise awareness and interest* among women with MS to enable women to be more confident in making key decisions about their pregnancy and childbirth, including type of delivery and infant feeding. A further goal is *behaviour*

change in clinicians to support the promotion of the intervention as an adjunct to their services. A further goal is *commercialisation* to enable an income stream to support the on going updating of the website.

7) Designing an impact communication plan

At the prototype intervention stage, we established goals, intended strategies for action, target groups and means of monitoring progress. The impact communication plan is informed by McGuire's Persuasive Communication Matrix (McGuire, 1969, 2001) from which we intend to make testable predictions about what action strategies may be the most effective within the impact plan. The Communication Persuasion Matrix is derived from the early work of McGuire (1968) and the persuasive communication or input/output model (Bull, Holt, Kreuter, Clark, & Scharf, 2001). It provides a method of identifying main and interaction effects involving input (independent variables) and output (dependent variables) in the process of persuasion (McGuire 1968). The inputs are the source (e.g. person or agency), message (e.g. arguments), channel (e.g. verbal or nonverbal) receiver (e.g. what type of person or agency) and target (e.g. changed attitude). The matrix has helped us to focus on the source (credibility of the evidence and trustworthiness such as the endorsement by known clinicians), and the social characteristics of the communicator (attractiveness and familiarity, and similarity to the recipient, (McGuire, 1985). The matrix has led us to focus on these features in selecting role models of other users and clinicians when communicating to these different target groups. Whether these input/output relationships underpin the effectiveness of the communications we design could also be evaluated.

8) Impact management strategies

The two types of knowledge translation processes we have used so far are *distribution* of material about the website to the public and via clinicians and the funder charity. The intervention has been recommended by clinicians from Cambridge University Hospitals NHS Foundation Trust Neurology Department and is also advertised on MS Society website. A next stage will be to develop impact via *capacity building* of clinicians to refer and support their patients while using the site. This will itself

be a form of intervention (possibly an e-learning resource) and will be subject to the systematic development processes used for the patient focussed website.

9) Impact indicators

The impact indicators for this intervention are the extent to which the intervention *reached* the target group within the 20,000 women of childbearing age with MS in the UK who may be considering pregnancy each year (Lee & O'Brien, 2008), compared to the number who are aware of and who access the intervention. While difficult to gain national figures, a local partner tertiary obstetric service estimates it has 170 potential users per year, so an indicator would be based on this figure as the denominator. Since the website was launched on March 1st 2011 to 31st December 2011, 1195 people visited it at least once, and making 1595 visits in total in 10 months. Of all the visitors 75% were new visitors and remaining 25% were returning ones. Within a month after launching the website was visited on average by 10 people every day (including returning users), currently it has on average 4 views per day (source: Google analytics).

Usefulness as determined by partners might include “unintended” positive or negative impacts, such as the readiness of participants to try other web based interventions for MS related conditions such as fatigue (Morris, 2008). We have monitored the use of the intervention to date by the number of users, the website use statistics including the length of time a person is logged on for website page hits.

9) Impact resources and costs.

The expertise and manpower to conduct impact activities have been borne by the research team and by the funder through offering publicity links and press releases. Data collection has been built into each stage of the research project as the process evaluation, but establishing usability will require also asking questions of people who do and who do not access or continue to continue access the website. The costs of running and updating the site in routine use will need to be built into cost recovery from end user purchase of access to the website, or through income from licenses to use the site if it is bought by an organisation such as a women’s health charity. Data collection about the impact of the intervention on how many patient consultations are triggered or avoided by the use of the website may

require access to either personal records or access to anonymised health care use data by diagnostic group, which will require healthcare data analyst time to extract and analyse.

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