

Involving people in e-health: results from a UK research study on the potential of ICTs to support weight management.

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This paper discusses Net.Weight, a research study which examined the potential of information and communication technologies (ICTs) to support people managing their weight. The context for Net.Weight was an acknowledgement that technology has a role to play in enabling wider engagement in the shaping of health care and services, but also that there is a need for more critical reflection about where and how technology can best be applied. It uses an existing three-level model of involvement, information, feedback and participation, to discuss the findings. It also makes use of the distinction, in the same model, between individual and group modes of involvement. It concludes that, with facilitation, people operate on a continuum, moving through the information, feedback and participation levels and that they operate in both individual and group modes. This has implications for health policy shaping as well as for an understanding of information and health literacy.

Keywords

health informatics, ICTs, involvement, policy shaping, weight management

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1. Context and Background

In the UK, as elsewhere, health policy agendas have tended to link the implementation of ICTs with the development of a patient-centred health service and the empowerment of patients, without the mechanisms by which this link works being fully explicated. For example, the development of health information services offered via the UK's NHS Direct and digital interactive television (DiTV) in the late 1990s were said to widen access to information in ways that support the development of self care and patient empowerment [1-2]. Other ICT applications mentioned in this regard include web-based health resources, the electronic care records service, electronic booking ('choose and book'), and email communications support for practitioner-patient consultations. More recent research has looked at the potential of Web 2.0 as an enabling technology in healthcare [3-5] and at how it is currently being used in self care through blogging [6] and online communities [7-8]. However, important research from both technology studies and health informatics reminds us that there is no necessary or straightforward correlation between the implementation and use of ICTs and improved services, health care experiences or health outcomes because social outcomes are not determined by technology alone. As early as 2000, a leading commentator in the field of consumer health informatics made it clear that, whilst computer-based informatics offer the *potential* to support patients help

themselves and make informed choices, there is still not enough known about consumer preferences, information needs and information use and how these might be better integrated into computer-based information systems [9]. This is as true in the Web 2.0 era as it was in 2000. Indeed with Web 2.0 offering the potential for patient and citizen feedback on health services, interesting new questions arise about the extent to which such technologies can be used to support new forms of governance, as well as individual choice.

One field in which debate about people's interaction with information and ICTs has been explored is that of information literacy, defined in the UK as "knowing when and why you need information, where to find it, and how to evaluate, use and communicate it in an ethical manner" [10]. Johnston and Webber [11] outline the role of information literacy as a way to support citizens in the information age while Williams [12] argues that those engaged in information literacy are "also concerned with the user-information interaction" and with making this interaction more effective. In the context of consumer health, the effectiveness of this user-information interaction is seen as vital for making "good health decisions" [13]. Conceptually, the Net.Weight study sat at the intersection of information and other literacy literatures, notably those associated with digital and health literacies, themselves complex constructs. For example, Norman and Skinner [14] argue that being health literate in an electronic world requires an expanded set of skills, incorporating six core skills or literacies: traditional literacy, health literacy, information literacy, scientific literacy, media literacy and computer literacy. Nutbeam [15], meanwhile, traces the development of two distinctly different approaches to health literacy, arguing that the clinical approach emphasises an individual's capacity to understand basic health information and service provision, while the public health approach focuses more on a set of skills which enable people to participate in their own health and well-being:

"Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health". [16]

This definition is notable for its incorporation of social, as well as cognitive, skills and proved a useful framework for the participative aspects of Net.Weight. The concept of motivation and the idea of individual ability also proved themselves to be relevant factors in the study.

The overall context for the Net.Weight study was an acknowledgement that technology has a role to play in enabling wider community engagement and greater user involvement in health agenda setting, but also that there is a need for more critical reflection about *where* and *how* technology can best be applied. In seeking to contribute to a better understanding of these important socio-technical factors, the project complemented work being carried out by Involve and the NHS Institute [17]. This research explored the potential of technologies to enable the public, patients and NHS staff to engage more effectively in NHS service delivery. Their report highlights the advantages and disadvantages associated with a range of 'developing technologies' from text and multimedia messaging, through video conferencing and digital interactive television, to user generated online content, social software, websites and mass media. Wilson and Casey's report [17] defines involvement as comprising of three levels. *Information* is the first level and is about effective information provision - getting the right information to the right people at the right time. *Feedback* is about providing opportunities for a response to information and service provision in a structured or conversational way. *Participation* is the most engaging and complex level of involvement and includes active participation in service provision in a more continuous and discursive way [17, p7]. The report also distinguishes between *Personal* and *Group* modes of involvement: the former concerned with an individual's relationship with the health service, the latter with the wider group or community who may be involved in the shaping of services [17, p7]. As will be discussed in this paper, the Net.Weight study is a good illustration of how the levels and modes of involvement identified by Wilson and Casey [17] can operate in a real life situation. It also demonstrates how critical reflection on information technologies for health can be successfully facilitated at community level and the implications of this for policy shaping and health literacy.

2. The Net.Weight Study

The Net.Weight study, formally entitled 'Supporting the Self Management of Obesity: The Role of Information and Communication Technologies', was funded by the Department of Health in the UK, under their Policy Research Programme: 'Technologies to Support Self Care, Chronic Disease Management and Healthy Living'. It examined the potential for increased, innovative and effective

uses of information and communication technologies (ICTs) to support people who are self-managing weight. It was located in the city of Brighton & Hove, on the south coast of England, and conducted by a multi-disciplinary team from the University of Brighton and Brighton and Sussex Medical School. Project participants were all either overweight or obese (using BMI measures) and 'trying to do something about it', in other words engaged in some form of self care.

The research had 5 key objectives:

- to map the 'information landscapes' of those involved in the self management of obesity from provider and user viewpoints
- to identify the opportunities and challenges posed by ICTs in the self management of obesity
- to identify the specific IT, information and health literacy skills and needs of those seeking to make use of ICTs in this context
- to design and run a series of participatory learning workshops to address skills needs and identify ways to better organise local health information to support obesity self management
- to evaluate the impact of participation in these workshops in terms of its ability to lead to increased, innovative and effective uses of ICTs to support the self management of obesity in one locality

The study had several inter-related research strands as illustrated in Figure 1.

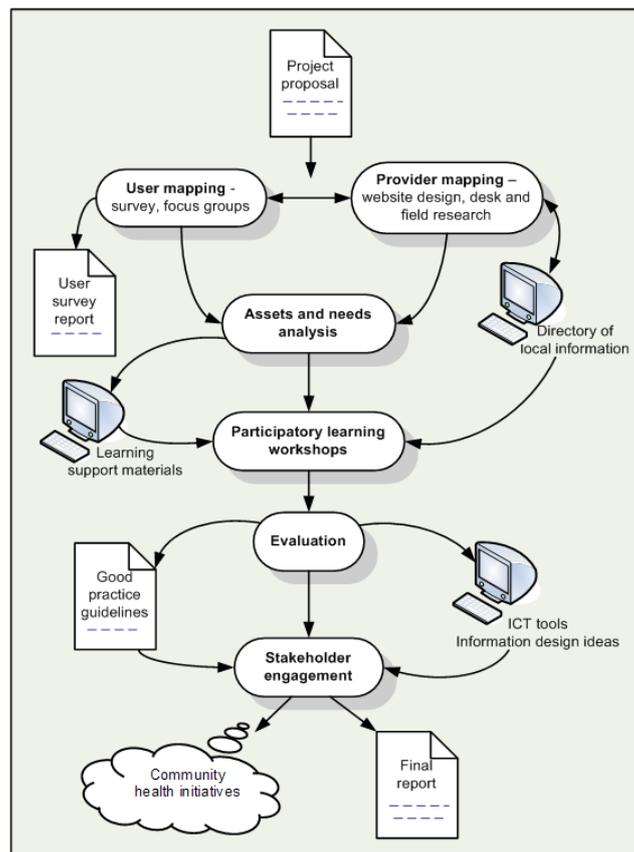


Figure 1: Flow diagram showing the inter-related research strands of the *Net.Weight* study

- provider mapping** identified key providers of information, advice and support for healthy living across the city and recoded data on these in a web-based, searchable directory, made available via the *Net.Weight Community* [18] website, designed to support the participatory learning workshops (see below), where these local resources were evaluated from a user perspective
- user mapping** (a questionnaire-based survey and 4 community-based focus groups) produced a detailed picture of users' 'information landscapes'. Data were collected on

respondents' current health status, their weight management goals and practises, their sources and needs with respect to information, advice and support for weight management and their use of the internet and other ICTs. Paper-based self-completion questionnaires were distributed throughout the city. An online version of the questionnaire was made available via some of the city's major employers (385 valid questionnaires)

- iii) **Assets and needs analysis** drew on the user mapping data to identify the existing skills, knowledge and needs of respondents in relation to health, information and IT use in the context of obesity self management. The Statistical Package for the Social Sciences (SPSS) and NVivo were used to support the analysis of the survey and focus group data. The findings fed directly into the design of the participatory learning workshops that formed the next stage of the study. Focus group participants were invited to take part in the design of workshops. A set of learning support materials, for use in the workshops, were also designed at this stage.
- iv) **Intervention stage** involved developing and running a series of participatory learning workshops (PLWs) to support and develop confidence, competence and critical skills in the relation to ICT, information and health literacy, in the context of obesity self management. 3 sets of 4 workshops were run, with a total of 39 participants attending at least one workshop. Content and timing of workshops was defined by users' needs according to the principles of participatory design.
- v) **Evaluation** captured data on participants' experiences of the workshops as they progressed and was used to feed back into the design process. Interviews were held with participants 6 months after the workshops to measure the success of workshops in terms of increasing participants' ability to engage effectively and critically with health information and ICTs in support of their self-defined health goals. Participants completed a short, pre-workshop questionnaire to assist with the reflection on change undertaken in post-workshop interviews. 16 of the 39 participants completed the pre-workshop questionnaire and 18 were interviewed.

3. Findings

This paper discusses the key findings using as a framework Wilson and Casey's [17] three-level approach to involvement: information, feedback and participation. It also addresses the *personal* and *group* mode distinctions identified by Wilson and Casey [17] as important to the understanding of health care.

3.1 Information

The range of information sources available to people wishing to manage weight is considerable and the Net.Weight user mapping survey [19] showed that people use a wide range of sources and a variety of media. However, information – and in particular generic health information - is not in itself the solution to the complex and intractable problem of weight management. The Net.Weight participants were largely knowledgeable about weight-related issues but they lacked information which was specific to their personal situation, often related to other health problems. One survey respondent, for example, wanted information about exercise for osteoarthritis and another wanted advice on foods that might help lower blood pressure. Survey respondents identified a need for the *right sort of information*, which fitted their own specific situations and the health conditions that were part of their weight management problem, supporting Wilson and Casey's [17] definition of information. In addition, the Net.Weight participants identified the importance of *local* information about weight management alongside information about *local* services. This was particularly valued and needed, although ironically local websites were rarely accessed or used in support of weight management, largely because they were not known about.

The user mapping survey [19] identified a real need to differentiate between *information*, *advice* and *support*, as people seek these inputs to different degrees and prefer to access them via different routes. As well as information, people need personalised advice and support for behaviour change. Health professional support continues to be sought but is often found lacking or too narrowly focused on weight alone. General practitioners are often thought less helpful than other members of the primary care team, such as practice nurses, and specialists such as nutritionists and dieticians. Family and friends are important sources of support, especially for women, as are slimming groups.

The results suggest that there may be over-emphasis, in policy and strategy, on generic healthy living information at the expense of other inputs necessary to support self care in this field. Key inputs identified as necessary included more tailored or 'personalised' information, whether from human or technological sources, and greater support from those with similar experiences. The study identified these as areas where the potential for innovative uses of ICTs could be further exploited. In particular greater use could be made of the potential for personalisation offered by of Web 2.0 technologies, especially in local health websites, where these were barely used.

3.2 Feedback

As noted above, the Net.Weight findings suggest that people engaged in weight management and healthy living want more than information; they want to find ways of sharing their knowledge and feeding their expertise into service and information design.

The main reasons given by participants for joining the workshops were to share their experience, to learn from other people with similar problems and to participate in a support network which, for some, would result in making friends. The workshops became a setting for mutual support and the informal exchange of information. This happened alongside the more formal or structured aspects of the workshop activities, particularly during practical hands-on and discussion sessions, when participants increasingly shared information about a wide range of subjects including local restaurants, favourite recipes, leisure activities and advice along 'what worked for me' lines. In their evaluative interviews participants spoke positively about this information sharing aspect of the workshops, as illustrated in the following reflection:

'I think collectively we had a lot of information and I think that was good. That was probably as big a part of it and as useful a part of it as any other. In that just people's... experiences are always really useful and interesting, aren't they?' (Interviewee)

The consumer health information literature, particularly through its focus over the last decade on the issues around health information quality and quality assessment [20-21] tends to imply a distinction between providers and users of information, largely ignoring the fact that people can be both. The interaction *between* users and *within* communities and the way in which this interaction itself generates information is largely ignored in this literature. An exception to this is Childs [22] who makes the point that in the context of sick children, support group workers are often themselves parents of such children and that both groups are equally knowledgeable about issues relating to their health conditions, with similar information needs and information-producing potential. The Net.Weight participants were certainly capable of generating as well as consuming information, adding a further dimension to the idea of effective user-information interaction explored by Williams [12], that of effective group-information interaction.

The workshops provided a physical space for people to meet and share experiences, which most felt was qualitatively better than meeting and sharing in a virtual space. However, it was recognised that online tools could play a role, mainly to complement support in the 'real' world. This suggests that if ICTs have a role to play with such groups it is in a 'blended' approach, where tools such as online social networks would help support real world groups rather than offer an alternative.

The research identified a wealth of expertise amongst those engaged in weight management. These people were found to be knowledgeable about both the individual and the more social and environmental causes of overweight and obesity. In the future, this expertise could be exploited to develop more user-centred interventions in this field. Again, this is an area where the potential for innovative uses of ICTs could be further developed, to complement real world support and information sharing.

3.3 Participation

The approach to the workshops adopted a similar philosophy to participatory design in the field of computing [23]. It was recognised that participants had a great deal of knowledge and expertise to contribute, particularly about the experience of self care of weight, but also about their current use of technology. Workshops were designed to reflect the needs and assets of the participants, as gauged by the user mapping survey and the pre-workshop skills questionnaire. Their skill levels ranged from being completely new to computers and ICTs to being extremely experienced. This encouraged

genuine peer support, where those with experience teamed up with and helped those who lacked skills and experience.

Participants' starting points in terms of ICT skills, experience in the use of the internet for weight management and confidence in evaluating information are important for determining the benefits of participation. Those who started from a relatively low base in any of these dimensions gained the most from the workshops, although most participants gained confidence in one or more dimensions. Over the longer term, other factors, primarily motivation and personal or health circumstances, shaped levels of engagement with ICTs in support of weight management. The workshops' evaluative exercises began to empower participants to make their own decisions regarding the appropriateness or otherwise of ICTs to support weight management and healthy living.

As confidence increased, participants were able to engage in re-designing a local healthy living website. They did this at the final workshop, working collectively and on paper, giving them the experience of acting as expert users, articulating and presenting their requirements and preferences and making them aware of their ability to act as co-designers in a user-centred design process. In the evaluative interviews, some participants articulated how this experience had increased awareness of the potential for becoming more involved in health service delivery more generally:

'I mean I wonder why they don't just invite people along to sort of discuss how as a Local Authority they could make the residents healthier. You know that does cross my mind that that really is you know a Local Authority sort of thing... I wonder why they don't sort of do any finding out about other things that people might want... Not necessarily costly things but just aiding the residents to get things underway. Maybe just to allow a room in their offices somewhere...' (Interviewee)

The research found that an intervention designed to encourage critical engagement with information and ICTs in the context of weight management can have very positive outcomes at an individual and at a group level. For some individual participants, the need to acquire basic skills and competence in ICTs was paramount, while for others the workshops provided a space where they could really reflect on the value of the ICT-based tools for supporting weight management. The intervention increased confidence across the board, with some participants using this increased confidence to make more use of ICTs in support of weight management and others using it to make an active decision not to do so. At a group level, participants' collective engagement in an exercise to re-design a local healthy living website demonstrated the potential of this model of community engagement for enhancing both digital inclusion and public engagement in health policy.

4. Approaches to literacy

Wilson and Casey's [17] distinction between personal and group involvement has been reflected in the findings discussed above. It is also reflected in the findings related to literacy. At an individual level, for example, some participants gained significant knowledge about relevant information sources on the internet:

'On the first workshop I was able to absorb all that information and... I went mad with the internet and the laptop for those first couple of workshops, trying to explore and extract all that information (Interviewee)

In the evaluative interviews the participants were asked if they had noticed any difference in the way they assessed information as a result of the workshops. Several said that the workshops had made a positive difference to their evaluation skills, in that they were more questioning, and some reported unequivocal gains, particularly with regard to confidence:

'I've learnt now which sites are better than the others, where it comes to help and advice... and it's given me a lot more confidence to look up and not always take a word for anything and everything.' (Interviewee)

However, most individuals reported little difference in their use of information sources, reinforcing the findings that information of itself is only part of the solution, or their ability to assess quality, citing a common sense approach: 'what an intelligent person would think anyway'.

On trust, an important criterion in assessing and evaluating information, there was both an individual and a group response. Findings from both the workshops and the post-workshop interviews

demonstrated the importance of organisational authority as an indicator of trust. The BBC, the UK's national television broadcast organisation, was cited a lot in this context, in part because of it being easily recognisable, a 'well-known name'. Of the NHS as a brand name, there was general agreement that '[...] anything with NHS on it or recommended by them' was trustworthy. While participants expressed those opinions individually, they also contributed to workshop discussions on the topic. There were heated debates on the notion of trust and authority, but also a coalescing of opinion leading to a kind of collective response:

'We feel confident with the NHS ... It's the same with the BBC.'

This insight into the collective response to trust, alongside the earlier findings around feedback, information generation and participative engagement, challenge those traditional definitions of information, health and e-health literacy, which either state or imply individual activity around locating, evaluating and using information. The CILIP definition [10] cited earlier *implies* individual activity while the Institute of Medicine [24], makes this explicit, defining health literacy as "the degree to which *individuals* have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" [24, p4, emphasis added]. In contrast, Johnston & Webber argue that information literacy must be seen as a "socialized activity" [11, p113]. Their re-conceptualisation of information literacy as a "soft applied discipline rather than...a set of personal attributes" [11, p109] echoes Nutbeam's [15] argument about the need to see health literacy as an asset which enables engagement in social action. Results from the Net.Weight study support this re-conceptualisation and suggest that a broad, social definition of information, health or digital literacy is most applicable in this context. Such an approach is more likely to lead to the types of collective empowerment needed to ensure a better 'fit' between the provision and use of information and ICTs in the field of weight management and healthy living.

5. Conclusions

Overall, the results of the Net.Weight project suggest that there is significant potential for increased, innovative and effective uses of ICTs in the self management of obesity, especially at a local level. With regard to Wilson and Casey's [17] levels of involvement it is also clear that, with support, people operate on a continuum, moving through information, feedback and participation levels as befits their own situations. People want the right kind of information but they also want to find ways of feeding back their experience and expertise into service and information design. With a longer timescale than was possible with Net.Weight, but with the kind of active facilitation the study provided, the participants' involvement could have developed into the 'continuous and discursive' participation suggested by Wilson and Casey as the most engaging [17]. Net.Weight also illustrated that there is scope for both individual and group modes of involvement in health care and that group involvement, in particular, offers valuable insights into the shaping of service delivery. Lastly, the success of *Net.Weight's* participative approach to critical engagement with health information and ICTs has implications for how we think about health, information and digital literacies. An approach to information literacy for health which incorporates a social as well as an individual perspective is likely to provide a more useful model for understanding the complexities of the processes involved and for improving health literacy levels.

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Glossary of Acronyms

BBC	British Broadcasting Corporation
BMI	Body mass index
CILIP	Chartered Institute of Library and Information Professionals
DiTV	Direct and digital interactive television
ICTs	Information and communication technologies
NHS	National Health Service
PLW	Participatory learning workshop