

Lincus: An Adaptation and Pilot Usability Study on Individuals with Learning Disabilities

L Gilbert, A Blanchard, J Barton and T Dawson

Abstract

Lincus is a tool that allows quantification of subjective and objective measures of health and wellbeing whilst also logging and correlating the impact of interventions and events. Pictorial surveys are provided, offering a range of focussed questions to enable a user to simply and effectively communicate their view of their wellbeing in certain areas of their lives. When completed regularly it provides a history of wellbeing and health over time, and stores details of both life events and interventions. As well as providing a detailed history for each user, this enables the measurement of the impact of such events and interventions on a user group or individual.

Lincus was adapted to the needs of people with severe learning disabilities by Rescon and Hft. This documents details the development phase and results of a 17 week trial performed from 14th April to 8th September 2014 by Hft in association with Rescon, to test its usefulness and usability by their service users and support providers.

A total of 313 surveys were completed by participants, with the assistance of support workers. The recorded (subjective) mental and emotional health scores of participants went up an average of approximately 20% through the course of the trial, indicating that the use of Lincus may have made them feel more supported. Interventions were not, however, captured during the trial, meaning that the effect of interventions on the participants could not be directly measured.

Introduction

Lincus is an individual or advocate operated picture and simple word based digital platform for quantifying and recording health and wellbeing information. Lincus surveys symptoms, signs, events, interventions and inputs them into a database where temporospatial relationships can be examined to inform decision-making including deterioration and pattern identification. Lincus has SSL certification, a choice of user interfaces, various data visualisation outputs, alerts, messaging and eCoaching capabilities. It captures the impact of interventions on individuals and their communities, and provides a way to take, store and visualise the histories of individuals, allowing them to chart their wellbeing through time. It provides a data analysis platform which can be used by organisations to analyse the impact of interventions that are performed on a combined user group, allows them to detect early deterioration of an individual as well as providing an objective measure of staff engagement.

Lincus was originally developed to overcome communication barriers between clinicians and patients that were identified during a US Veterans Affairs Type II diabetes project. It was further developed in collaboration with the Liverpool Clinical Commissioning Group, local government, industry and third sector partners to stratify risk in a more dynamic and responsive way than the current two-year epoch stratification models. The first pilot of Lincus was carried out to assess usability of the tool to assess the impact of interventions on subjective measures of wellbeing with the Liverpool YMCA ^[1], in a project supported by the Liverpool City Council. The pilot population were individuals with multiple and complex needs at risk of homelessness housed in temporary accommodation and supported by the YMCA. Staff from Rescon met with subject matter experts from the YMCA to develop the appropriate questionnaires for the target population before the trial started. The trial successfully demonstrated usability of the Lincus along with other findings including measurable impact of interventions, overall improvement in wellbeing and increased engagement between staff and service users. This resulting in Lincus gaining recognition by the National Institute of Clinical Excellence as a tool for behavioural change in 2013 ^[2].

The purpose of this pilot study was to assess the usability of Lincus in individuals with learning disabilities living within a supported environment. The study was performed in collaboration with Hft, a charity that supports those with learning disabilities. It investigated the effectiveness of using Lincus to improving the communication of users' perceived health and wellbeing to support workers, in addition to studying staff performance and stakeholder interaction.

Background

With increasing technological advances, there has been an increase in focus on the capabilities of software to enhance the monitoring and diagnostic processes in both health and social care settings. As the understanding of ongoing assessment increases, there has been an additional emphasis on providing targeted feedback based on data analysis as a tool for change both at a individual and an institutional level.

Sound knowledge of an individual's history is critical for accurate diagnosis and monitoring within clinical settings. This extends to social care settings, where perceived wellbeing is an important measure of effectiveness of care. A strong relationship between perception of health and mortality rate has been demonstrated ^[3]. It has also been shown that online assessments encourage individuals to disclose more information than they would using conventional methods, and their use has been demonstrated to encourage direct communication between individuals regarding factors

influencing health and wellbeing ^[4] ^[5] ^[6]. This may improve support organisation ability to identify appropriate interventions thus improving health and wellbeing of individuals ^[7] ^[8].

Recent advances in technology have allowed the development of novel methods of health and wellbeing evaluation. Such methods include providing individuals the opportunity to communicate and quantify their own symptoms. When changes are tracked over time this information can be used for the purposes of monitoring and evaluation. By taking into account this temporal change, information measured over several time points becomes more significant as a measure of wellbeing compared to “one-off” measures.

The positive impact of evaluation or observation in itself on wellbeing has been well documented ^[9]. Supporting this, self-reporting parameters of health and wellbeing has demonstrated significant improvement in general health and quality of life (QUAL) ^[10]. Feedback to end-users has been also specifically been shown to be influential in improving QUAL in participants with mental conditions ^[11].

Perceptual reporting as a tool for evaluation and intervention can be applied to numerous populations, including populations with reduced mental capacity ^[12]. Online assessment tools have been demonstrated to have useful application to individuals with complex individual needs, including high use by individuals diagnosed with epilepsy ^[13] ^[14]. Touch screen use is preferred for data entry by end users ^[15], and touchscreen use for QUAL assessment may also improve mental wellbeing in those displaying depressive symptoms after onset of a long-term condition ^[16].

Many self-reporting systems have interfaces that may be difficult to navigate, that rely on literacy, and that are available in a very small range of languages. This provides barriers to widespread use, especially in populations where they are most needed, such as in those with learning disabilities. Additionally, many of the available systems do not record and correlate life events and interventions with changes in the wellbeing status of individuals or groups, leading to a deficit of data that could indicate key causal relations and correlations.

To address these issues Lincus, a picture based and simple word descriptor tool with easily quantifiable inputs, was developed by UK technology company, Rescon. Lincus allows interventions and event to be inputted by the users or people associated with them. Subsequent analysis of this data over time can track improvement or decline in markers of wellbeing. As a consequence of the impact of events or interventions on wellbeing for individual users and groups of users can also be measured. All outputs are represented visually using interactive tools allowing further interrogation of results by the user.

Adaption and Pilot Protocol

A 17 week trial was used to assess the effectiveness of Lincus on the perceived health and wellbeing of end-users. Prior to adaption of Lincus, a meeting was held between subject matter experts from Hft and Rescon to develop survey questions and approach. Over the next 10 weeks Lincus for Hft was developed with Rescon’s researchers, graphic design team and developers.

Before the trial started launch Hft support workers attended a training day demonstrating how to use Lincus. Support workers were given the opportunity to raise any questions or concerns they had.

Eleven end users with learning disabilities participated in the trial, with the assistance of 16 support workers who assisted them in recording information in 4 key areas: general health; mental health, social life and emotional health. Each survey contained four or five questions. The questions are detailed in Table 1.

General Health	Mental Health	Social Life	Emotional Health
Wellbeing	Mood	Social Mood	Angry
Comfort	Stress	Home Situation	Excited
Tired	Engagement	Lonely	Supported
Hunger	Control	Family Time	Supported Spiritually
Thirst			

Table 1: Questions asked of end users in Hft trial, by survey category

Question wording was deliberately 1-2 words, as it was supported by pictorial representations. Each question was associated with a slider, matched to a range of icons for the user to measure how strongly they felt. A linear analogue non-numerical sliding scale was used. This prevents people fixating on specific numeric answers and encourages a more dynamic response. An example of the General Health survey page is shown in Figure 1. As well as quantifying the response it was also possible to enter any notes if their was a wish to expand on survey answers. An option to store the location at which the survey was answered was also available.

In order to facilitate focussing on individual questions and reduce the risk of users feeling overwhelmed, an additional “accessibility” view was created which showed one question at a time (Figure 2).



Support workers assisted end users to complete surveys on touch screen tablets, where end users were encouraged to input their response directly. For the first month support workers were asked to complete the surveys with the service users daily. After this first month surveys were completed as support workers felt necessary, or when end users asked to complete them. For tracability, the unique identifier of the support worker was also stored in each case.

Support workers were also encouraged to input events and interventions to further investigate the impact they had on perceived health and wellbeing. The events and interventions which were available were selected by Hft, and are listed in Table 2.



Events	Interventions
Seizure	Support Worker Intervention
Menopause	External Activity
Period	Internal Activity
Positive	Medical Visit
Negative	Change of Medication
	Lifestyle Advice
	Other

Table 2: HFT Events and Interventions


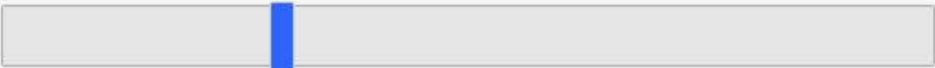
Wellbeing



Comfort


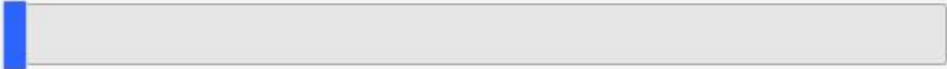
Tired





Hunger





Thirst



Enter any notes:



Edit date/time (default: now):



 (optional)

Figure 1: A full page version of the General Health Survey

The screenshot displays the 'Emotional Health Survey' interface. At the top, a blue header bar contains the title 'Emotional Health Survey'. Below this is a 'Full page Toggle' button. A progress bar consists of four numbered buttons: 1 (grey), 2 (orange), 3 (green), and 4 (grey). The main content area is titled 'Excited' and features three cartoon figures: a red figure sitting, a grey figure standing, and a green figure jumping. Below the figures is a horizontal slider bar with a blue vertical indicator. At the bottom of the main area are three buttons: a blue left-pointing arrow, a blue 'Save' button, and a blue right-pointing arrow. Below these is a grey 'Submit' button.

Figure 2: A question-by-question view of the Emotional Health Survey

User data was visualised as overall wellbeing over time, and also split into each of the 4 key areas for analysis. A simple, searchable data view was provided to show the history of each end user, with any events and interventions stored, as well as survey notes. An example is shown in Figure 3 (for privacy reasons this is not real data). The history could be viewed by the end user or by support workers with the appropriate permissions.

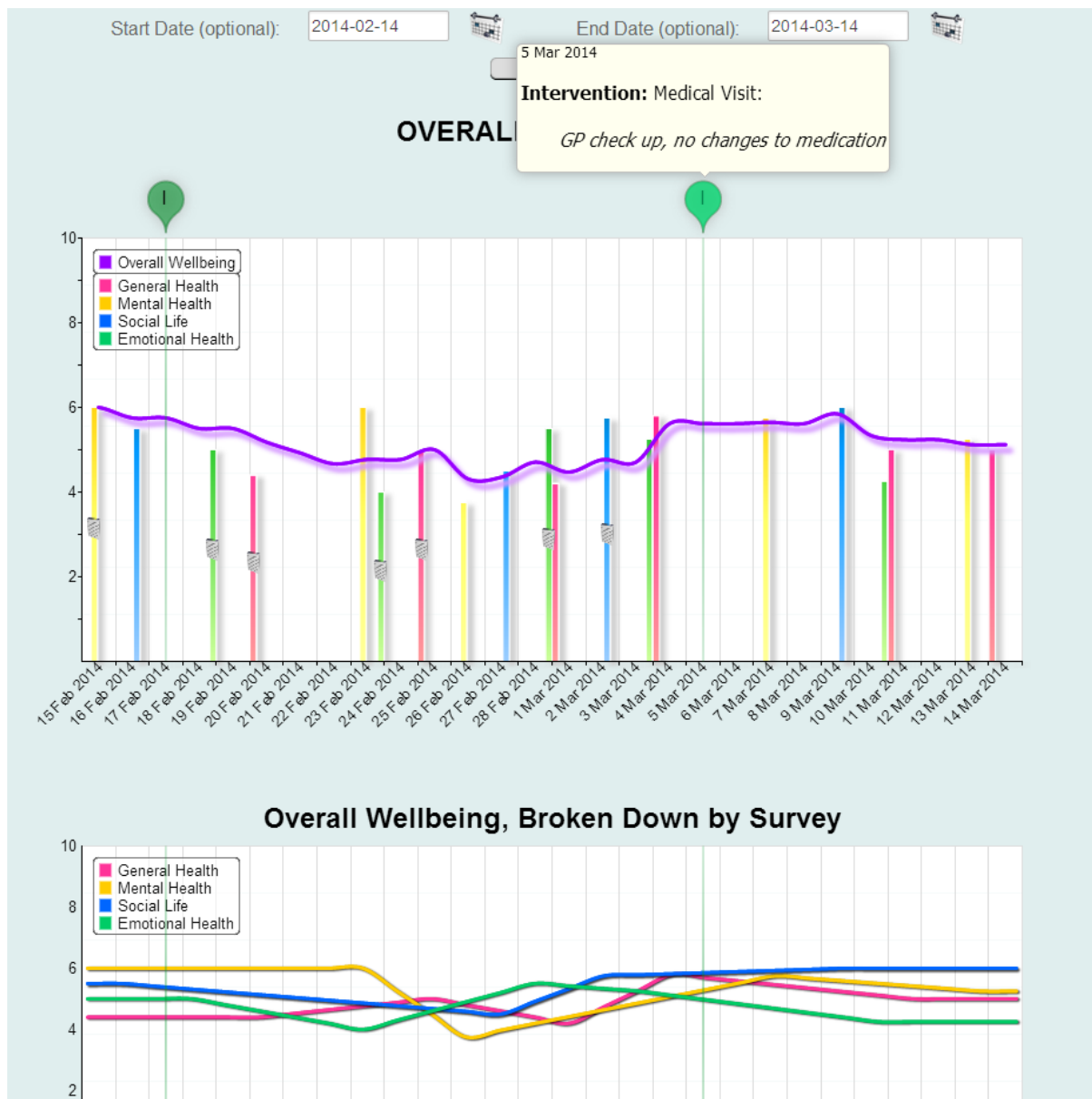


Figure 3: An example end user history

The program was run by a Centre Manager, who had a separate login with permissions that enabled her to assign support workers to different users, and perform simple data analysis. Figure 4 shows a Centre Manager view. There was a dashboard that allowed her to visualise and administer user accounts, and she was able to view the data as a whole or by cross section. In Figure 5 the administrator view shows the results of a “Date Search”, combining the data from all users over time to see how end users wellbeing scores might change over time (not real data).

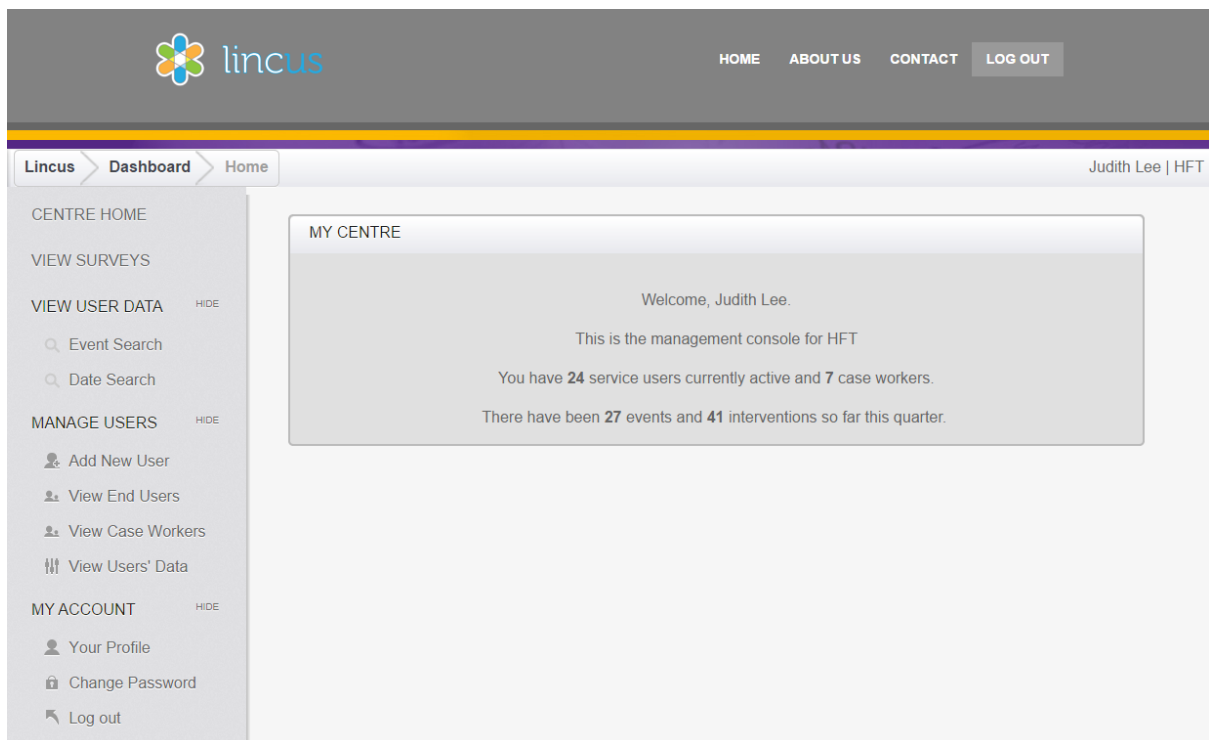


Figure 4: The Centre Manager dashboard (demonstration data).



Figure 5: The Centre Manager dashboard, showing the results of a search of the combined survey results of a group of end users over a time range (demonstration data)

Figure 6 demonstrates how the centre manager might look at the effects of a certain intervention on the group of users. This tool gathered survey data for all users before and after a specific type of intervention (in this case the “support worker intervention”, of which there are 13 events stored in

the database). The survey results from users who had received the intervention are combined such that they are all on the same time frame – the intervention point appears at “0” on the x-axis. The centre manager was able to see whether the wellbeing of end users rose or fell after the intervention, over a range of different time scales, with some basic statistics applied (demonstration data in Figure 6).

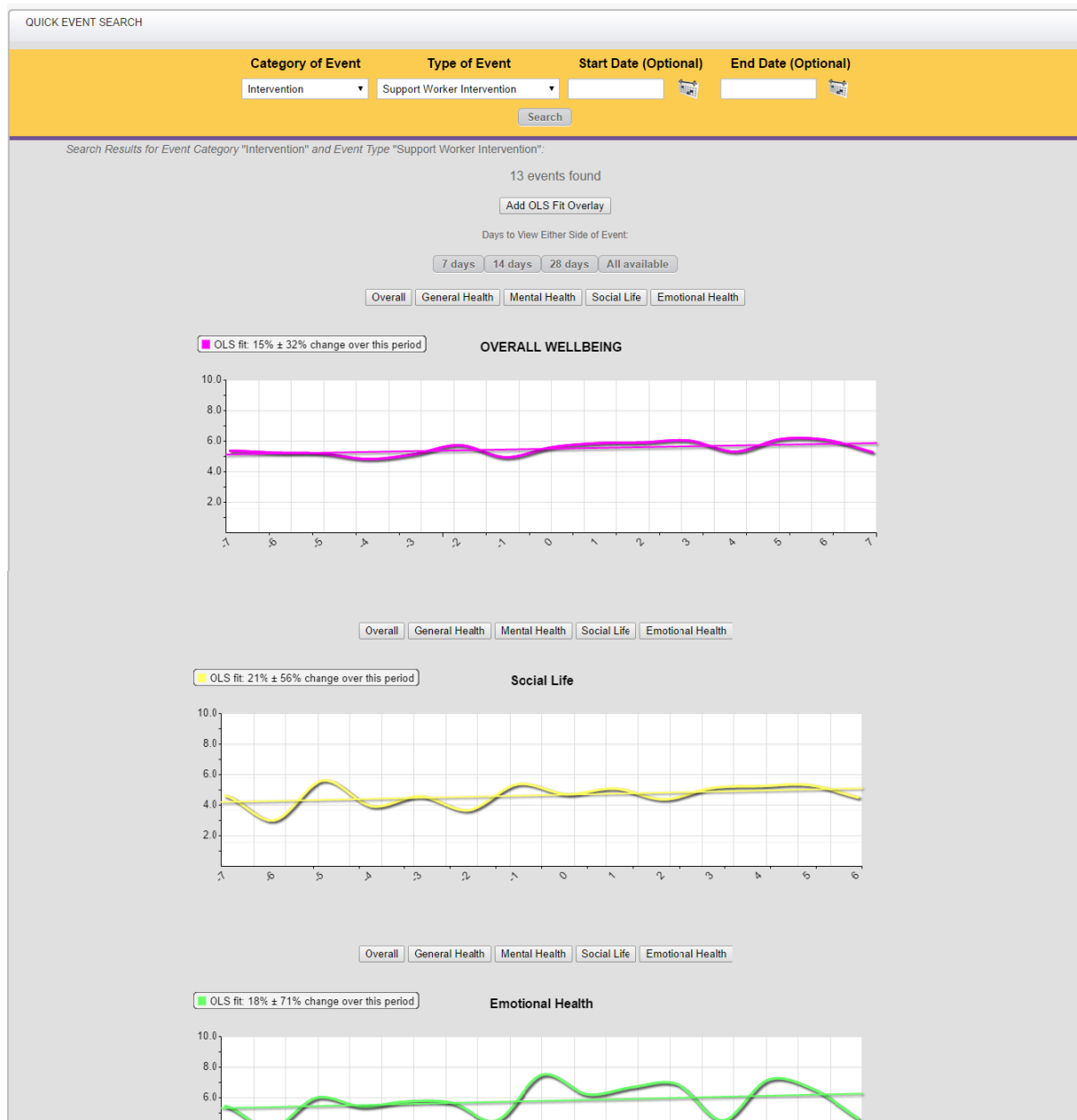


Figure 6: The results of a search of the combined survey results of all users who had recorded a certain type of intervention, normalised to the same time frame (demonstration data).

Support worker productivity and engagement was also identified throughout the study through frequency of survey completion, and the possibility to record interventions performed by the support workers.

Throughout the completion of the study research assistants contacted the support workers to ensure ongoing use and provide solution to any outlined problems. Support workers had the opportunity to contact the research team directly if they had any concerns, or if a problem arose.

Trial Outcomes

There were 313 surveys completed over the course of the trial. This averages to 1.7 surveys per week per user.

Support worker engagement was seen to drop off in the middle of the trial (see Figure 7) but recovered towards the end. Figure 8 shows the number of each different type of survey that was filled in. The emotional health survey was the most popular (111 surveys completed), and the mental health survey the least (58 surveys).

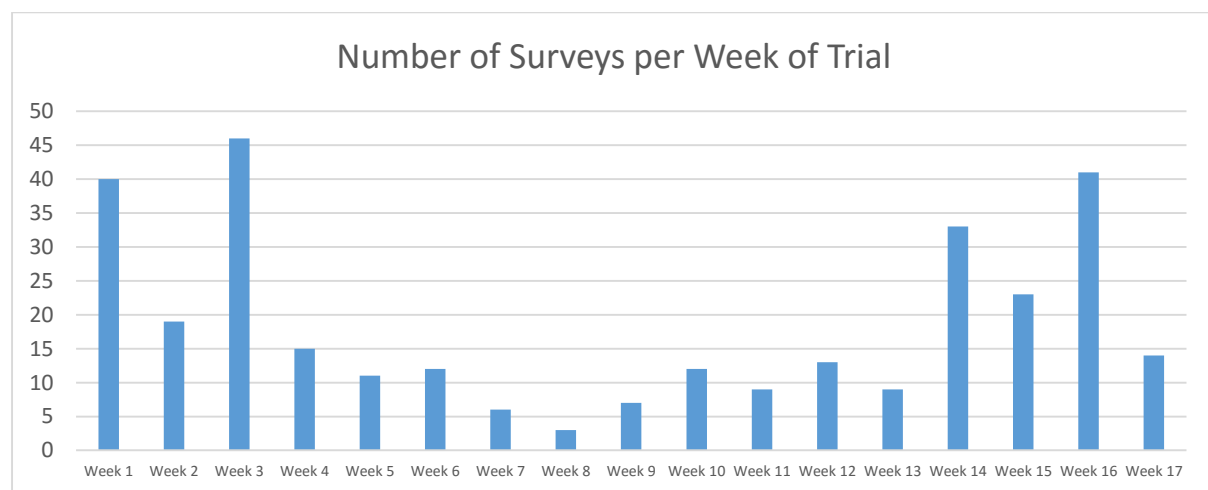


Figure 7: Number of surveys completed per week

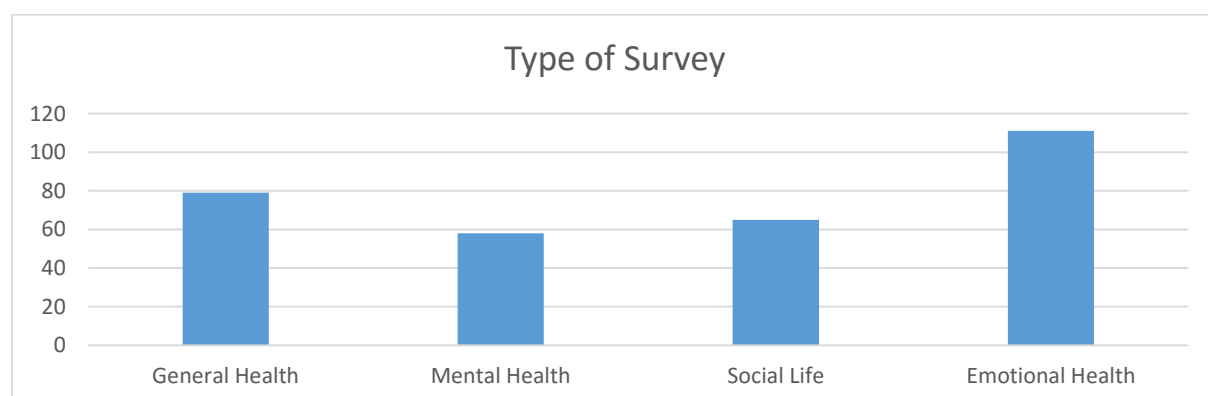


Figure 8: Number of each type of survey taken during the trial

The number of surveys enabled by each support worker varied widely. Support worker engagement with Lincus ranged from 2 to 82 surveys over the trial period (Figure 9). The spread of number of surveys taken by each end user was more uniform, ranging from 14 to 49 (Figure 10).

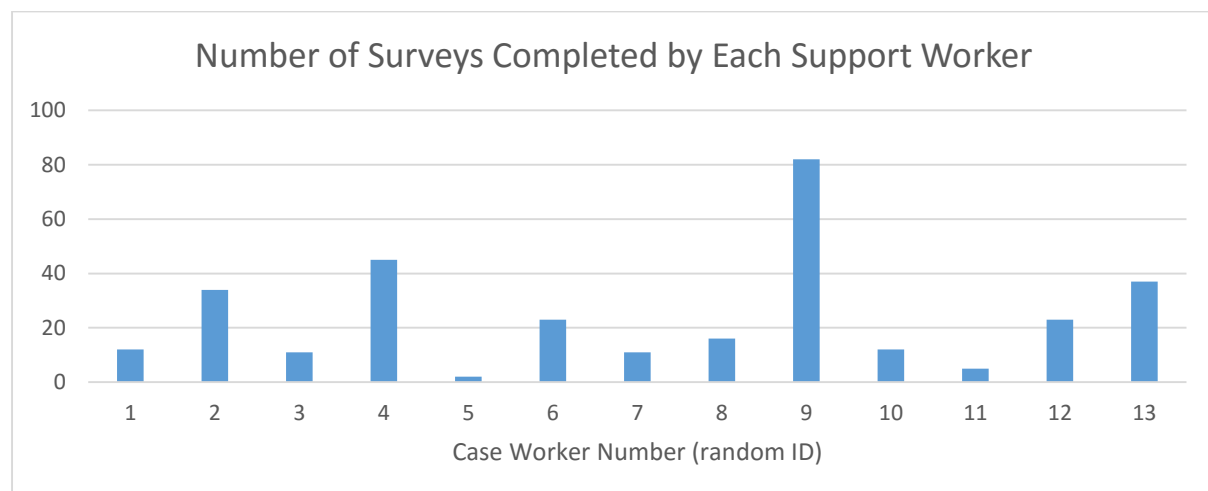


Figure 9: Number of surveys taken by each support worker over the course of the trial.

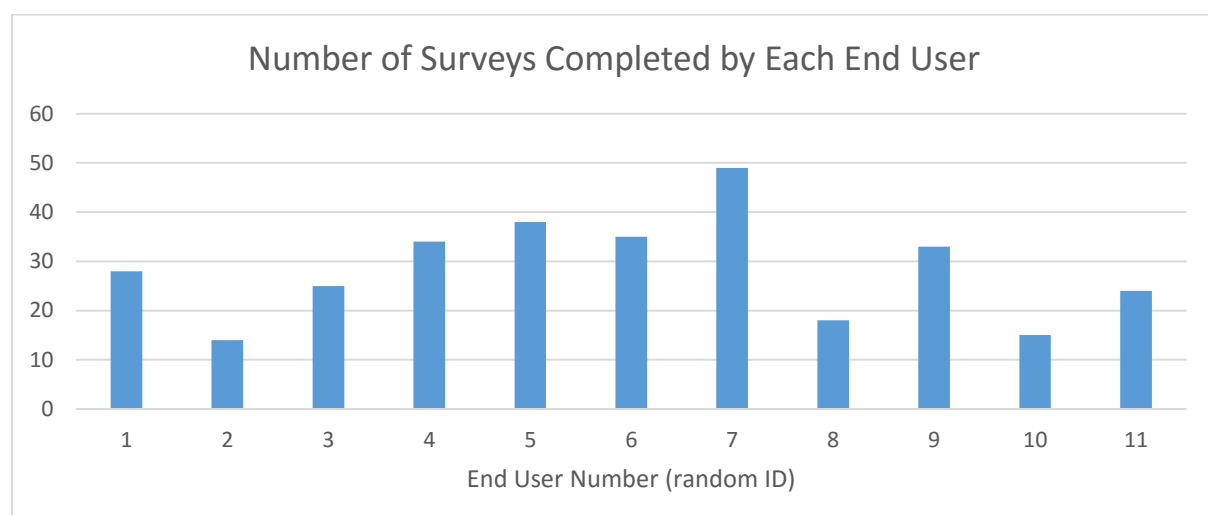


Figure 10: Number of surveys taken by each end user over the course of the trial.

No events or interventions were recorded by support workers despite the initial demonstration of the tool and regular follow up. Unfortunately this means that there is no event or intervention effect data to present. Refer to the results of the YMCA trial^[2] for the results of recording real events and interventions.

The average wellbeing of all participants was charted over time for the duration of the trial. The overall wellbeing of participants (Figure 11) was seen to improve by $8 \pm 4\%$, a small but measurable improvement. Mental Health and Emotional Health improved significantly, by $24 \pm 4\%$ and by $20 \pm 2\%$ respectively (Figures 12 and 13). General Health and Social Life showed no measureable changes (Figures 14 and 15).

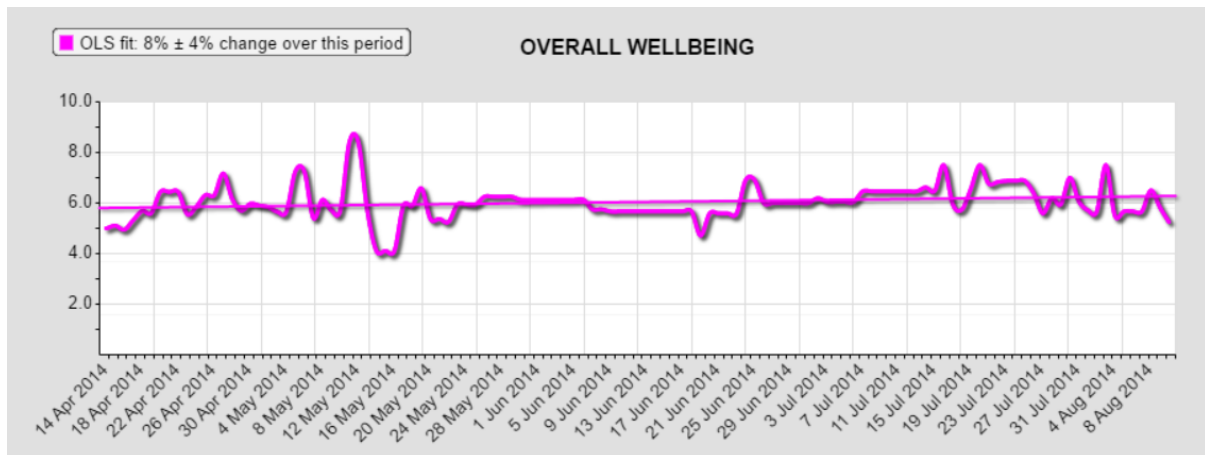


Figure 11: Average Overall Wellbeing scores for all participants through the trial

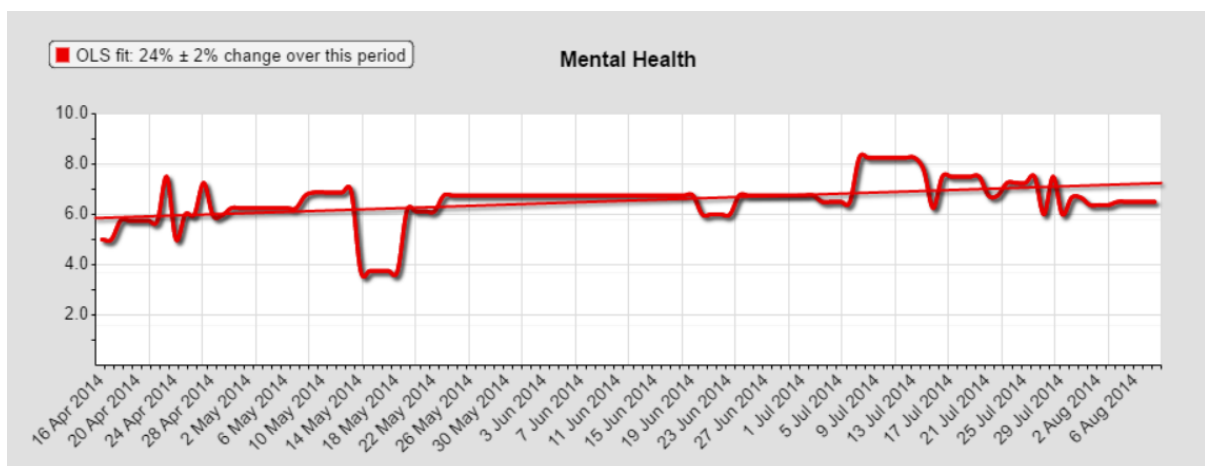


Figure 12: Average Mental Health scores for all participants through the trial

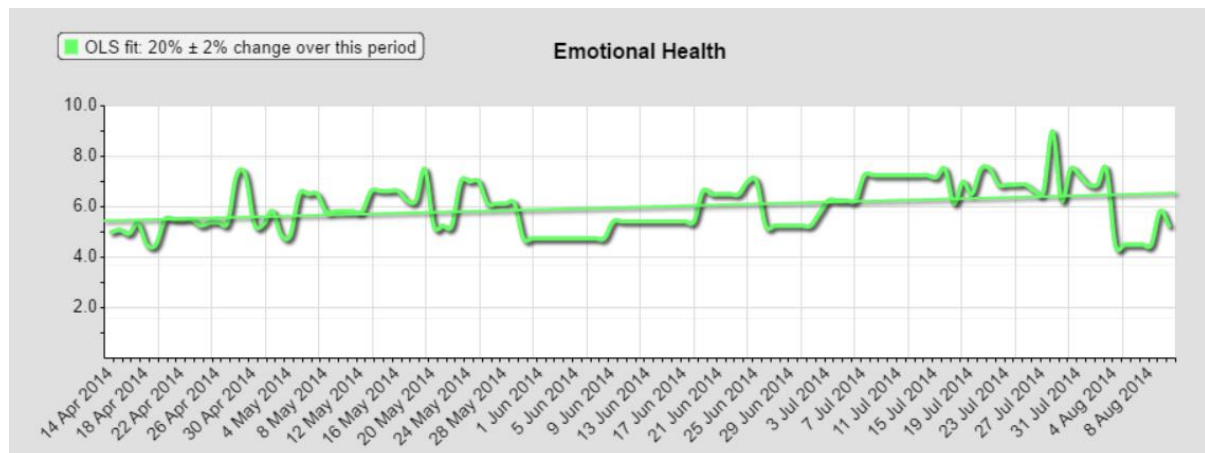


Figure 13: Average Emotional Health scores for all participants through the trial

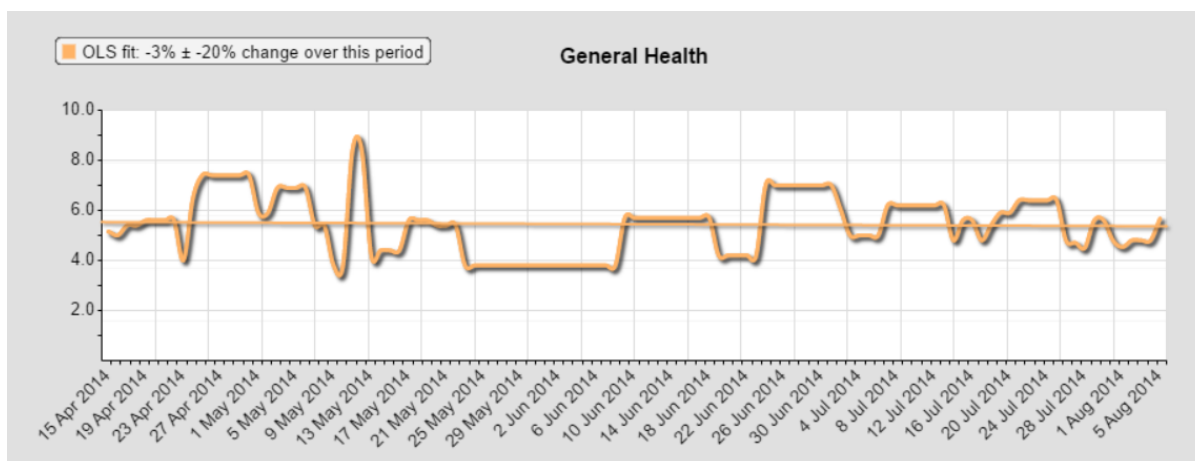


Figure 14: Average General Health scores for all participants through the trial

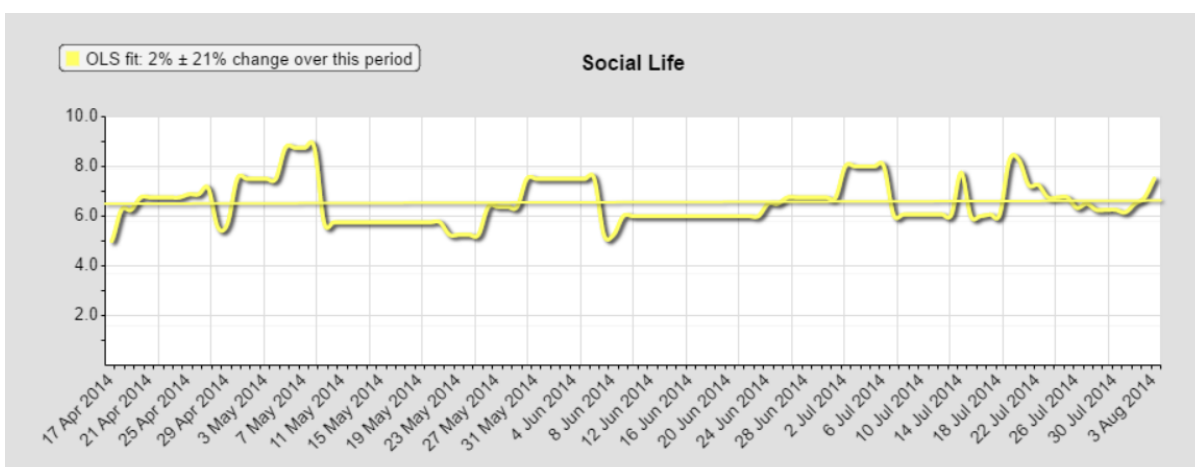


Figure 15: Average Social Life scores for all participants through the trial

Due to the small numbers of people in this trial, and inexperience with using this tool, these numbers cannot be relied upon as accurate. There are many factors that could have contributed to the improvement in health and wellbeing score. A much larger trial would be required to report results with any confidence.

Support workers reported that they found Lincus to be a positive tool for those with learning disabilities, with improved engagement noticeable with some end users.

Discussion

During the 17 week trial, the usability of Lincus was demonstrated. During the trial perceived mental and emotional health scores increased by around 20%, translating to small improvements seen in overall wellbeing. This could be due to directly or indirectly related to the use of Lincus, or completely unrelated. Larger studies would be required to test any relations.

No data was lost during the trial and the support workers involved in the trial found Lincus to be a positive tool, improving their interaction with end users (this is as expected from previous Lincus

trials, and literature supporting the idea that communication is enhanced by using an interactive assessment platform assessing QUAL ^[5] ^[6] ^[10].

Staff engagement dwindled towards the middle of the program. This may have been due to a reduced perception of observation, supported by research into the Hawthorne effect and its influence of staff performance ^[9], following the theory of reactivity stating that staff behaviour changes with the awareness of observation ^[17]. This effect is also demonstrated in healthcare settings, implicating emergency staff performance prior to hospital admission ^[18]. To address these issues more work on integrating Lincus into workflow through both service and technology redesign could be implemented.

Perceived improvements may have been attributed to improving weather throughout the trial period, particularly with reference to emotional health ^[19]. The improvement could have also been attributable to other factors such as the use of the Lincus tool through individuals feeling more supported or a Hawthorne-type effect.

Specifically Lincus may contribute towards improving emotional support, possibly through encouragement of staff interaction, as emotional health score increased after the implementation of Lincus. This may provide partial explanation for improvement in QUAL in individuals with mental conditions utilising assessment platforms ^[11], as well as improvements in depressive symptoms with implementation of touchscreen assessment ^[16].

Use and usability of Lincus varied within the group suggesting that Lincus may provide significantly greater benefit to certain subgroups. This was demonstrated by reports such as one suggesting an individual “asked to use Lincus when she was feeling anxious”, despite never previously identifying feelings of anxiety to support workers. This may provide a significant advantage for support workers, since understanding of emotional distress is key for quality of care. Similarly, another participant identified a desire to complete surveys when observing support workers using the platform. This enthusiasm may be partially due to the individual’s increased ability to engage in the platform, as opposed to with other individuals. Unsurprisingly, daily input did not suit everyone. There were also comments that five pictorial representations, as originally requested, could be confusing. As a result the tool was modified at the end of the trial to depict only the highest and lowest pictorial representation.

Whilst the trial was associated with positive findings, limitations included a lack of staff engagement. This meant event and intervention data was missed, and the impact of events and interventions on health and wellbeing could not be identified. Lack of engagement was also identified by reduced survey completion during the mid-stage of the trial. This highlights the use of Lincus’ functionality as a tool to assess staff engagement with the tool. As positive results were found relating to functionality of Lincus utilised by staff, it suggests that Lincus may have led to more extensive benefits if it was used to its full potential.

A further problem was identified with troubleshooting and computer literacy, where some staff had difficulties using the tablets and Lincus software. This is a barrier that was also brought up as being a potential issue in the YMCA study and the NICE report along with recommendations that staff are specifically trained and supported to use technologies that may be required for their work.

To address the issue of staff engagement and ease of use, more work will be done on integrating Lincus into workflow through both service and technology redesign. Future application of Lincus would ideally utilise more rigorous training and management of staff implementation, as well as emphasis in the use regular input of events and interventions.

Future work will focus on working with organisations to integrate Lincus more effectively into staff workflow along with service redesign. The provision of timesheets for organising the time of support workers, memos and reminders and an event calendar are practical ways to improve the usability of Lincus for support workers and improve cross organisation engagement.

Summary

Lincus was demonstrated to be a usable and useful tool in communicating (and possibly enhancing) perceived overall health and wellbeing in those with learning disabilities in supported accommodation. Lincus may have positively impacted emotional support and was noted to have improved interaction between support workers and end users. More rigorous implementation of the platform alongside making changes to the system to improve integration into workflow is likely to show more significant results. More research and development is needed to maximise the potential of Lincus in different populations. Meanwhile, Lincus is a tool that has been shown to have immediate benefit in its current form, in social care settings.

References

- [1] Gilbert, L., Pugh, D., Butler, S., Dowd, M & Dawson, T. (2013). Lincus Trial: YMCA Liverpool pilot study for individuals with multiple and complex needs.
- [2] NICE. (2013). *Lincus Trial: YMCA Liverpool pilot study for individuals with multiple and complex needs*. NICE.
- [3] Kaplan, G. A., & Camacho, T. (1983). Perceived health and mortality: a nine-year follow-up of the human population laboratory cohort. *American Journal of Epidemiology*, **117**(3), 292-304.
- [4] Lucas, G. M., Gratch, J., King, A., & Morency, L. P. (2014). It's only a computer: Virtual humans increase willingness to disclose. *Computers in Human Behavior*, **37**, 94-100.
- [5] Haverman, L., van Rossum, M. A., van Veenendaal, M., van den Berg, J. M., Dolman, K. M. *et al.* (2013). Effectiveness of a web-based application to monitor health-related quality of life. *Pediatrics*, **131**(2), e533-e543.
- [6] Velikova, G., Brown, J. M., Smith, A. B., & Selby, P. J. (2002). Computer-based quality of life questionnaires may contribute to doctor-patient interactions in oncology. *British Journal of Cancer*, **86**(1), 51-59.
- [7] Rubenstein, L. V., McCoy, J. M., Cope, D. W., Barrett, P. A., Hirsch, S. H. *et al.* (1995). Improving patient quality of life with feedback to physicians about functional status. *Journal of General Internal Medicine*, **10**(11), 607-614.
- [8] Taenzer, P., Bultz, B. D., Carlson, L. E., Specia, M., DeGagne, T. *et al.* (2000). Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. *Psycho-oncology*, **9**(3), 203-213.
- [9] Mayo, E. (1933). *The human problems of an industrial civilization*. New York: Macmillan Company. 194.
- [10] Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P. *et al.* (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *Journal of Clinical Oncology*, **22**(4), 714-724.

- [11] Boyer, L., Lançon, C., Baumstarck, K., Parola, N., Berbis, J. *et al.* (2013). Evaluating the impact of a quality of life assessment with feedback to clinicians in patients with schizophrenia: randomised controlled trial. *The British Journal of Psychiatry*, **202**(6), 447-453.
- [12] McCarney, R., Warner, J., Iliffe, S., van Haselen, R., Griffin, M. *et al.* (2007). 'The Hawthorne Effect: a randomised, controlled trial.' *BMC Medical Research Methodology*, **7**(1), 30.
- [13] Wagner, A. K., & Vickrey, B. G. (1995). The routine use of health-related quality of life measures in the care of patients with epilepsy: rationale and research agenda. *Quality of Life Research*, **4**(2), 169-177.
- [14] Wagner, A. K., Ehrenberg, B. L., Tran, T. A., Bungay, K. M., Cynn, D. J. *et al.* (1997). Patient-based health status measurement in clinical practice: a study of its impact on epilepsy patients' care. *Quality of Life Research*, **6**(4), 329-341.
- [15] Velikova, G., Wright, E. P., Smith, A. B., Cull, A., Gould, A. *et al.* (1999). Automated collection of quality-of-life data: a comparison of paper and computer touch-screen questionnaires. *Journal of Clinical Oncology*, **17**(3), 998-998.
- [16] McLachlan, S. A., Allenby, A., Matthews, J., Wirth, A., Kissane, D. *et al.* (2001). Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. *Journal of Clinical Oncology*, **19**(21), 4117-4125.
- [17] Kazdin, A. E. (1979). Unobtrusive measures in behavioral assessment. *Journal of Applied Behavior Analysis*, **12**(4), 713-724.
- [18] Campbell, J. P., Maxey, V. A., & Watson, W. A. (1995). Hawthorne effect: implications for prehospital research. *Annals of Emergency Medicine*, **26**(5), 590-594.
- [19] Kellerr, M. C., Fredrickson, B. L., Ybarra, O., Côté, S., Johnson, K. *et al.* (2005). A warm heart and a clear head the contingent effects of weather on mood and cognition. *Psychological Science*, **16**(9), 724-731.